WHEN CHILDREN DIE

IMPROVING PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES

Committee on Palliative and End-of-Life Care for
Children and Their Families
Board on Health Sciences Policy

Marilyn J. Field and Richard E. Behrman, Editors

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"Knowing is not enough; we must apply.
Willing is not enough; we must do."
—Goethe

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DEDICATION

To all the children and families whose lives and whose stories
have helped us to learn and to advocate for changes that will
benefit other children and families

CONTENTS

APPENDICES

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*Appendices B through H are available only online at http://www.nap.edu/catalog/10390.html

BOXES, FIGURES, AND TABLES

Boxes

Figures

Tables

PREFACE

When a child dies, it is always out of season. When a child dies, dreams die and we are all diminished by the loss of human potential. Although dying is a part of life, a child's death, in a very real sense, is unnatural and has a devastating and enduring impact. Over the past century such deaths have been significantly reduced by socioeconomic, public health, and medical advances in developed countries such as the United States. Although with our current knowledge, we could do much more to decrease mortality among children and youth, even our best efforts will not prevent some children from dying. Nevertheless, we all have a mandate to ensure that their young lives do not end in preventable fear, pain and distress and that grieving families are comforted.

This report argues that we can and should do more than we are currently doing to prevent and relieve the physical and emotional suffering of dying children and the psychic pain of their families, to respect the personal dignity of the dying child and grieving family, and to allow all who are affected by a child's death the opportunity to address their feelings and concerns. Although there are many unanswered questions about optimal care in these tragic situations, a great deal is known about what should be done *now* to improve the care of dying children and their families. We can and must reduce the number of those who fail to receive consistent, competent care that meets not only their physical needs, but their emotional, spiritual, and cultural ones as well.

The report also emphasizes the need to improve the professional education of a broad spectrum of groups, develop appropriate supporting public health policies, and provide high quality end-of-life and bereavement services for children and their families. Addressing these needs will require more scientific knowledge and data about the care of children with life-threatening medical conditions, including those of sudden unexpected onset. Behavioral changes by health providers and administrators, government officials, religious leaders, police and others will be required. Changes in policies at the federal, state, and local level are also critical if systems change in health care is to occur.

By definition, children cannot advocate for themselves. When they are dying, an attuned listener can learn from them, but they are essentially voiceless in the public domain. Add to this the fact that in an end-of-life situation, their families, their most natural advocates, are often paralyzed by grief, and we can perhaps see why their plight has received so little attention.

Although the number of children who die is, thankfully, relatively small, the event can devastate a family. While we cannot relieve all suffering, we can help prepare these children and families for what comes. It is hard to imagine a situation that has a greater imperative for humane caregiving, yet, far too often today, it is not provided. It is time to correct this situation. We hope this report will serve as a call to action.

Richard E. Behrman, M.D., J.D.
Committee Chair

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In developing its report, the committee benefited greatly from the assistance of many individuals and groups. Important information and insights came from a public meeting during which the committee heard from many organizations and from individuals with personal experiences that added an invaluable human dimension to our understanding. The committee also learned much from a smaller meeting with families and gives its special thanks to Rosario and Salvador Avila, Gary and Rose Conlan, Deborah Dokken, Winona Kittiko, Tina Heyl-Martineau, and Les Weil for their willingness to discuss their experiences and perspectives. Appendix A includes the meeting agendas and participant lists and also cites the organizations that provided written statements to the committee.

The consultants to the committee, Mildred Solomon, Joanne Wolfe, and Cynda Rushton, provided valuable guidance at many points during the course of the committee's work. The committee appreciates the contributions of the authors of background papers included in the appendixes to the report; Bruce Himelstein often provided help beyond his role as background paper author.

Our project officer at the National Institute of Nursing Research, Anne Knebel, was unfailingly helpful in answering questions about the palliative care research agenda at the National Institutes of Health. Donna Hoyert, Joyce Martini, and others at the National Center for Health Statistics provided guidance on government mortality data. Melissa Harris, Theresa Pratt, and Tammi Levy-Cantor at the Center for Medicare and Medicaid Services helped with the intricacies of Medicaid policies, including those governing demonstration projects.

Nancy Contro, Harvey Cohen, and others at the Lucile Packard Children's Hospital at Stanford University generously shared the knowledge and insights they gained in developing their pediatric palliative care

program, and Murray Pollack and his colleagues in the Pediatric Intensive Care Unit at Children's National Medical Center in Washington, D.C., also provided insights into the day-to-day reality of caring for seriously ill children. Joan Teno and Sherry Weitzen of Brown University analyzed and provided data on the site of death for children.

Anne-Armstrong Dailey, Kay Scanlon, and others at Children's Hospice International were helpful on many matters and provided extensive information about the Medicaid hospice demonstration projects to test new models of all-inclusive care for children and their families. Among many others who provided information and answered questions are Stephen Connor at the National Hospice and Palliative Care Organization; Elaine Vining and Janis Guerney at the American Academy of Pediatrics; Susan Dull at the National Association of Children's Hospitals and Related Institutions; Stacy Orloff at the Hospice of the Florida Suncoast; and Susan Huff at the Center for Hospice and Palliative Care in Buffalo, New York.

Many within the Institute of Medicine were, as usual, helpful to the study staff. We would especially like to thank Alden Chang, Carlos Gabriel, Francesca Moghari, Sally Stanfield, Christine Stencel, and Bronwyn Schrecker.

REVIEWERS

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's (NRC) Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published reports as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **R. DON BLIM**, appointed by the Institute of Medicine, and **ELAINE L. LARSON**, Professor of Pharmaceutical and Therapeutic Research, Columbia University School of Nursing, New York, NY. Appointed by the NRC Report Review Committee, these individuals were responsible for making certain that an independent examination of this report was carried out in accordance with the institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

WHEN CHILDREN DIE

SUMMARY

> *We are in need of medicine with a heart. . . . The endless physical, emotional, and financial burdens that a family carries when their child dies . . . makes you totally incapable of dealing with incompetence and insensitivity.*
>
> Salvador Avila, parent, 2001

The death of a child is a special sorrow, an enduring loss for surviving mothers, fathers, brothers, sisters, other family members and close friends. No matter the circumstances, a child's death is a life-altering experience.

Except when death comes suddenly and without forewarning, physicians, nurses, social workers and other health care personnel usually play a central role in the lives of children who die and of their families. At best, these professionals will exemplify "medicine with a heart," helping all involved to feel that they did everything they could to help, that preventable suffering was indeed prevented, and that the parents were good parents. At worst, families' encounters with the health care system will leave them with painful memories of their child's unnecessary suffering, bitter recollections of careless and wounding words, and lifelong regrets about their own choices. In between these poles of medicine, families will often experience both excellent care and incompetence, compassion mixed with insensitivity, and choices made and then later doubted.

Moving the typical experience of children and families toward the best care and entirely eliminating the worst care is an achievable goal. It is a goal that will depend on shifts in attitudes, policies, and practices involving not only health care professionals but also those who manage, finance, and regulate health care. That is, it will require system changes, not just individual changes. Improvement will also require more clinical and health services research to fill gaps in our knowledge of what constitutes the "best" palliative, end-of-life, and bereavement care for children and families with differing needs, values, and circumstances.

Viewed broadly, *palliative care* seeks to prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decisionmaking. Such care and assistance is not limited to people thought to be dying and can be provided concurrently with curative or life-prolonging treatments. *End-of-life care* focuses on preparing for an anticipated death (e.g., discussing in advance the use of life-support technologies in case of cardiac arrest or other crises or arranging a last family trip) and managing the end stage of a fatal medical condition (e.g., removing a breathing tube or adjusting symptom management to reflect changing physiology as death approaches). Together, palliative and end-of-life care also promote clear, culturally sensitive communication that assists patients and families in understanding the diagnosis, prognosis, and treatment options, including their potential benefits and burdens.

The death of a child will never be easy to accept, but health care professionals, insurers, educators, policymakers, and others can do more to spare children and families from preventable suffering. Although research is needed to assess systematically the strengths and limitations of different care strategies, promising models exist now in programs being undertaken by children's hospitals, hospices, educational institutions, and other organizations. Some of these programs focus on better preparing pediatricians and other child health specialists to understand and routinely apply the principles of palliative and end-of-life care in their practice. For example, some pediatric residency review committees have added requirements for training in aspects of palliative, end-of-life, and bereavement care. Other innovative programs aim to identify and reform specific clinical, organizational, and financing policies and practices that contribute to care that is ineffective, unreliable, fragmented, or financially out of reach. The federal government is sponsoring several demonstration projects to test modifications in current Medicaid policies to improve care coordination and access, and some private health plans are also making coverage of hospice and palliative care for children more flexible.

This report builds on two earlier Institute of Medicine (IOM) reports—*Approaching Death: Improving Care at the End of Life* (1997) and *Improving Palliative Care for Cancer* (2001). It continues their arguments that medical and other support for people with fatal or potentially fatal conditions often falls short of what is reasonably, if not simply, attainable. Specifically, this report stresses the following themes:

- The death of a child has a devastating and enduring impact.
- Too often, children with fatal or potentially fatal conditions and their families fail to receive competent, compassionate, and consistent care that meets their physical, emotional, and spiritual needs.
- Better care is possible now, but current methods of organizing and financing palliative, end-of-life, and bereavement care complicate the provision and coordination of services to help children and families and sometimes require families to choose between curative or life-prolonging care and palliative services, in particular, hospice care.
- Inadequate data and scientific knowledge impede efforts to deliver effective care, educate professionals to provide such care, and design supportive public policies.
- Integrating effective palliative care from the time a child's life-threatening medical problem is diagnosed will improve care for children who survive as well as children who die—and will help the families of all these children.

The report recognizes that while much can be done now to support children and families, much more needs to be learned. The analysis and recommendations reflect current knowledge and judgments, but new research and insights will undoubtedly suggest modifications and shifts in emphasis in future years.

CONTEXT AND CHALLENGES

In the United States and other developed countries, many infants who once would have died from prematurity, complications of childbirth, and congenital anomalies (birth defects) now survive. Likewise, children who previously would have perished from an array of childhood infections today live healthy and long lives, thanks to sanitation improvements, vaccines, and antibiotics. In the space of a century, the proportion of all deaths in the United States occurring in children under age 5 dropped from 30 percent in 1900 to just 1.4 percent in 1999. Infant mortality dropped from approximately 100 deaths per 1,000 live births in 1915 to 7.1 per 1,000 in 1999. Nonetheless, children still die. Approximately 55,000 children ages 0 to 19 died in 1999.

Patterns of child mortality differ considerably from patterns for adults, especially elderly adults who die primarily from chronic conditions such as heart disease and cancer. Palliative, end-of-life, and bereavement care must take these differences into account. As shown in Figure S.1, about half of all child deaths occur during infancy. Most of these deaths occur soon after birth from congenital abnormalities or complications associated with pre-

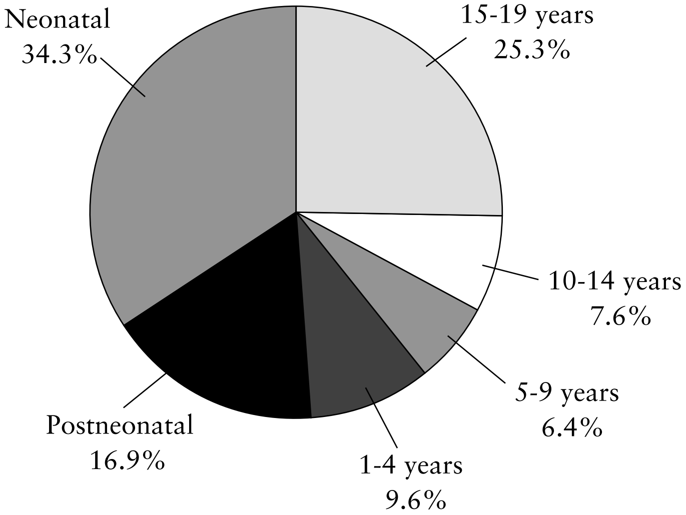

FIGURE S.1 Percentage of total childhood deaths by age group (1999).

maturity, pregnancy, or childbirth. For older infants, sudden infant death syndrome (SIDS) is an important cause of death.

For older children and teenagers, unintentional and intentional injuries are the leading causes of death. Overall, injuries account for approximately 30 percent of child deaths (Figure S.2). Given the importance of sudden and unexpected deaths from injuries and SIDS, efforts to improve care for children and to provide support for bereaved families must extend to emergency first-response personnel, including police, emergency department staff, and staff of medical examiners' offices. Among fatal chronic conditions, the most important are cancers, diseases of the heart, and lower respiratory conditions.

Common Problems Experienced by Both Children and Adults

Some deficits in palliative and end-of-life care for children parallel those experienced by adults. For example, frightened and upset patients and families may receive confusing or misleading explanations of diagnosis, prognosis, and treatment options. They may likewise be provided too little opportunity to absorb shocking information, ask questions, and reflect on goals and decisions, even when no immediate crisis drives decisionmaking. Patients at all ages suffer from inadequate assessment and management of pain and other distress, despite the ready availability of therapies known to help most patients. For both children and adults, physicians may advise and

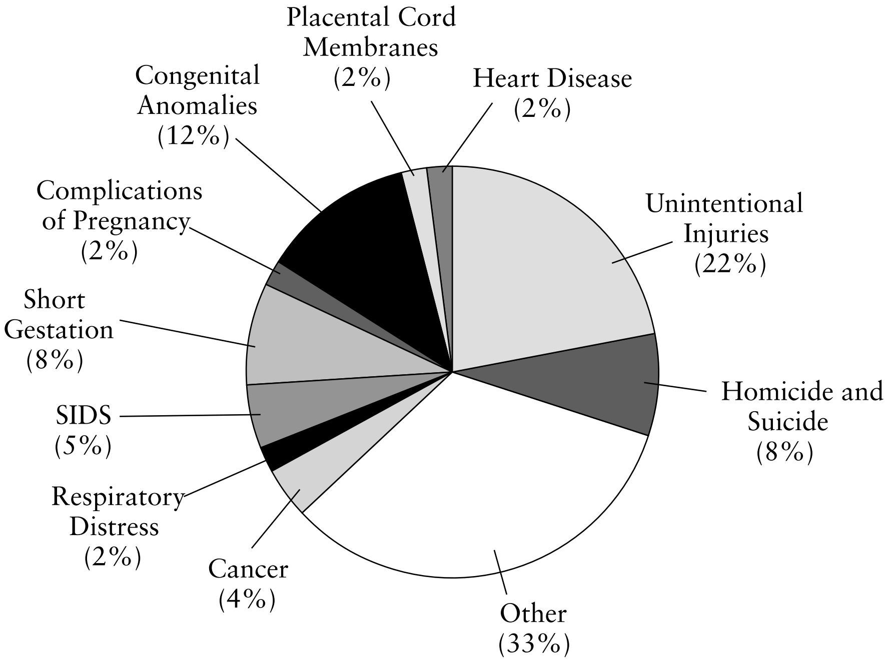

FIGURE S.2 Percentage of total childhood deaths by major causes (1999).

initiate treatments without adequate consideration or explanation of their potential to cause additional suffering while offering no or virtually no potential for benefit. Because clinicians, patients, and families are reluctant to discuss death and dying, opportunities are routinely missed to plan responses for the reasonably predictable crises associated with many fatal medical problems. Failures to prepare for death may deprive families of the chance to cherish their last time with a loved one and say their final goodbyes.

Further, if children or adults require complex care from multiple providers of medical and other services, they and their families may find this country's fragmented health and social services systems to be confusing, unreliable, incomplete, and exhausting to negotiate. Even experienced physicians, social workers, and others are frequently frustrated and stymied by these systems. At the same time, patients, families, and providers may feel that they are in a constant battle with health plans over coverage and payment policies that favor invasive medical and surgical procedures, discourage interdisciplinary care, and undervalue palliative services, including the time needed to fully and effectively inform and counsel patients and families facing fatal or potentially fatal conditions. Other children and adults suffer because they lack health insurance altogether.

Issues Unique to or Particularly Evident with Children

Notwithstanding these common problems, certain concerns in palliative, end-of-life, and bereavement care are unique to or particularly evident with children. As is often emphasized, children are not small adults. Clinicians, parents, and others working with ill or injured children must consider developmental differences among infants, children, and adolescents that may affect diagnosis, prognosis, treatment strategies, communication, and decisionmaking processes.

Many children who die are born with rarely seen medical conditions, which creates substantial uncertainty in diagnosis, prognosis, and medical management. Even for common medical problems, children's general physiologic resiliency complicates predictions about their future. In situations laden with fear, anxiety, and desperation, this greater uncertainty adds to the burdens on physicians and families as they try to assess the potential benefits and harms of treatment options and make hard decisions. Further, many communities will not have enough cases of various life-threatening medical conditions in children to generate much local experience and clinical expertise in their evaluation and management, including end-of-life care. As a result, seriously ill children and their families must often travel far from home for treatment, which removes them from their usual sources of emotional support and may disrupt parents' employment and strain family relationships and finances.

While still mentally competent, adults can create advance directives and other binding documents to guide their care if they later suffer significant loss of decisionmaking capacity. In contrast, states, almost without exception, will not recognize a formal advance directive signed by a minor, even a minor living independently. In most situations, parents have legal authority to make decisions about medical treatments for their child.

Many problems facing children with life-threatening medical conditions and their families and many shortcomings in end-of-life care are embedded in broader social, economic, and cultural problems. Unlike virtually all elderly adults, who are covered by Medicare, approximately 15 percent of children lack public or private health insurance. Children with insurance are covered by myriad private and state programs that have widely differing but poorly documented policies and practices for covering palliative, end-of-life, and bereavement services. On the one hand, this diversity of insurance sources could encourage innovation; on the other hand, it makes it extraordinarily difficult to identify and correct deficiencies in any comprehensive way.

In addition, children and young families are disproportionately represented among immigrants and thus are especially vulnerable to misunderstandings related to differences in language, cultural experiences, and values about life, illness, death, and medical or nonmedical therapies. Millions of children, both immigrants and native born, live with their families in unsafe environments that put them at high risk of injury. Such environments can also make it a challenge to get a child to the doctor, pick up a prescription, or persuade a home care provider to come into the neighborhood. These broader problems are not the subject of this report, but their contribution to deficits in care for children and their families should be recognized in strategies to improve pediatric palliative, end-of-life, and bereavement care.

WORKING PRINCIPLES

In general, the basic working principles and starting points set forth in the 1997 IOM report apply to children as well as adults. Some details differ, however, and certain additional values apply either uniquely or with special emphasis to children. Of the principles adopted by this committee (Box S.1), the first three are specific to children; the other four restate earlier principles from the 1997 report in terms of children.

Box S.1
Working Principles for Pediatric Palliative, End-of-Life, and Bereavement Care

1. Appropriate care for children with life-threatening medical conditions and their families is designed to fit each child's physical, cognitive, emotional, and spiritual level of development.
2. Good care involves and respects both the child and the family.
3. Families are part of the care team.
4. Effective and compassionate care for children with life-threatening conditions and for their families is an integral and important part of care from diagnosis through death and bereavement.
5. Professionals caring for children have special responsibilities for educating themselves and others about the identification, management, and discussion of the last phase of a child's fatal medical problem.
6. Both individual change and organizational change are needed to provide consistently excellent palliative, end-of-life, and bereavement care for children and their families.
7. More and better research is needed to increase our understanding of clinical, cultural, organizational, and other practices or perspectives that can improve palliative, end-of-life, and bereavement care for children and families.

PROVIDING AND ORGANIZING CHILD- AND FAMILY-CENTERED CARE

Palliative, end-of-life, and bereavement care for children with life-threatening conditions and their families has many objectives and dimensions that relate to the physical, emotional, and spiritual well-being of each child and family and to their frequent need for practical help with coordinating care, preparing for the future, and maintaining as normal a life as possible. Depending on a child's medical condition, his or her plan of care may include a mix of preventive measures, curative or life-prolonging interventions, and rehabilitative services in addition to palliative care. The mix can be expected to change over time as a disease progresses, the goals of care are reconsidered and changed, and the benefits and burdens of therapies are re-evaluated based on guidance and counseling from physicians and others.

When first confronted with the news that their child has a fatal or potentially fatal condition, parents will usually be shocked, perhaps uncomprehending. Initially and thereafter, they may be profoundly reluctant to accept that their child will die and will want to feel that they have tried everything possible to save their child. At the same time, they will want to protect their child from pain and other suffering. Thus, they may simultaneously hold multiple, possibly conflicting goals. This puts an exceptional premium on clear and timely information and sensitive counseling about the potential benefits and harms of different courses of care. Such communication requires not only technical and intellectual skills but also empathy, education, experience, teamwork, time, and reflection—as well as supportive administrative and financing systems.

As parents and clinicians determinedly pursue curative and life-prolonging interventions for an infant, child, or adolescent, they may sometimes fail to appreciate fully the suffering that these interventions may inflict. Not all suffering caused by the pursuit of cure or prolonged life can be prevented, but if the potential sources of distress are not adequately considered, opportunities to prevent or relieve distress will certainly be missed. Care plans should always include steps to assess and prevent physical, emotional, and spiritual suffering. As described by the American Academy of Pediatrics, the goal of palliative care is "to add life to the child's years, not simply years to the child's life."

Formal clinical and administrative protocols are one means of defining expectations and responsibilities for the quality of care provided by health care professionals and institutions. Depending on the aspect of care in question, clinical practice guidelines and institutional protocols may include or be supplemented by ethical guidance, model conversations, checklists, documentation standards, and evaluation plans. They should be based on the best available scientific evidence and expert judgment, including sound guidelines developed by professional societies and other national groups. Careful local review and adaptation may help meet local needs and win support from those who must implement the guidelines and protocols.

> **Recommendation: Pediatric professionals, children's hospitals, hospices, home health agencies, professional societies, family advocacy groups, government agencies, and others should work together to develop and implement clinical practice guidelines and institutional protocols and procedures for palliative, end-of-life, and bereavement care that meet the needs of children and families for**
>
> - **complete, timely, understandable information about diagnosis, prognosis, treatments (including their potential benefits and burdens), and palliative care options;**
> - **early and continuing discussion of goals and preferences for care that will be honored wherever care is provided;**
> - **effective and timely prevention, assessment, and treatment of physical and psychological symptoms and other distress, whatever the goals of care and wherever care is provided; and**
> - **competent, fair, and compassionate clinical management of end-of-life decisions about such interventions as resuscitation and mechanical ventilation.**

Parents repeatedly cite the frustrations they have experienced in coordinating the care needed by a very ill child. The twin tasks of reducing the burdens of care coordination and improving the continuity of care present formidable challenges. This is especially true for children with complex, chronic problems that require inpatient, home, and community-based services from many different professionals and organizations that may be separated geographically, institutionally, and even culturally from each other and that may be subject to different insurance rules and procedures.

Interdisciplinary care teams (including hospice or palliative care teams), case managers, disease management programs, and "medical homes" for children with special health care needs all have a role to play in improving care coordination and continuity. In addition, those caring for children with life-threatening medical conditions need to collaborate in establishing procedures that support coordination, continuity, and timely transmission of information within and across sites of care. They also should assign specific responsibility to individuals and groups for implementing all policies and procedures related to palliative, end-of-life, and bereavement care.

Recommendation: Children's hospitals, hospices, home health agencies, and other organizations that care for seriously ill or injured children should collaborate to assign specific responsibilities for implementing clinical and administrative protocols and procedures for palliative, end-of-life, and bereavement care. In addition to supporting competent clinical services, protocols should promote the coordination and continuity of care and the timely flow of information among caregivers and within and among care sites including hospitals, family homes, residential care facilities, and injury scenes.

Children with life-threatening medical conditions are often referred to specialized centers for treatment. Some need little follow-up care, but others require considerable attention after they return home. Especially in more rural areas, these children, their families, and the local health care professionals, community hospitals, and other organizations that serve them need additional support. This support may include proven Internet and interactive telemedicine applications as well as telephone consultations and written guidelines and care plans.

Recommendation: Children's hospitals, hospices with established pediatric programs, and other institutions that care for children with fatal or potentially fatal medical conditions should work with professional societies, state agencies, and other organizations to develop regional information programs and other resources to assist clinicians and families in local and outlying communities and rural areas. These resources should include the following:

- **consultative services to advise a child's primary physician or local hospice staff on all aspects of care for the child and the family from diagnosis through death and bereavement;**
- **clinical, organizational, and other guides and information resources to help families to advocate for appropriate care for their children and themselves; and**
- **professional education and other programs to support palliative, end-of-life, and bereavement care that is competent, continuous, and coordinated across settings, among providers, and over time (regardless of duration of illness).**

Parents (or guardians or other designated adults) will, in most cases, have legal authority to make decisions about a child's medical care. Nonetheless, excluding children and, particularly, adolescents from conversations about their diagnosis, prognosis, and treatment strategies can isolate these patients emotionally and prevent parents and clinicians from truly appreciating a child's values, goals, and experience of his or her disease and its treatment.

> **Recommendation: Children's hospitals, hospices, and other institutions that care for seriously ill or injured children should work with physicians, parents, child patients, psychologists, and other relevant experts to create policies and procedures for involving children in discussions and decisions about their medical condition and its treatment. These policies and procedures—and their application—should be sensitive to children's intellectual and emotional maturity and preferences and to families' cultural backgrounds and values.**

After a child dies, friends, neighbors, spiritual advisers, hospice personnel, grief counselors, and others in the local community may provide most of the bereavement and practical support for a family. Parents or siblings may also seek care from their personal physicians or a psychotherapist. Still, the physicians, nurses, social workers, and others who cared for the child can meaningfully "be with" the family in a variety of ways in the days and months following the child's death. An abrupt end to contact can feel like—and be—a kind of abandonment.

> **Recommendation: Children's hospitals and other hospitals that care for children who die should work with hospices and other relevant community organizations to develop and implement protocols and procedures for**
>
> - **identifying and coordinating culturally sensitive bereavement services for parents, siblings, and other survivors, whether the child dies after a prolonged illness or after a sudden event;**
> - **defining bereavement support roles for hospital-based and out-of-hospital personnel, including emergency medical services providers, law enforcement officers, hospital pathologists, and staff in medical examiners' offices; and**
> - **responding to the bereavement needs and stresses of professionals, including emergency services and law enforcement personnel, who assist dying children and their families.**

FINANCING

Approximately two-thirds of children are covered by employment-based or other private health insurance. About one-fifth are covered by state Medicaid or other public programs, but some 14 to 15 percent of children under age 19 have no health insurance. In this latter group, some children will receive care paid for or provided by "safety-net" providers, private philanthropies, and other sources, but some will go without needed services. The diverse sources of payment for children's health care make it difficult to obtain a comprehensive picture of coverage, reimbursement, and other problem areas, but certain general problems are evident.

For insured children and families, coverage limitations, provider payment methods and rules, and administrative practices can discourage timely and full communication between clinicians and families and may restrict access to effective palliative and end-of-life care. Low levels of payment to providers can make it difficult for health care professionals, hospitals, and hospices to provide certain treatments or even accept some high-cost patients. At the same time, financing policies can promote excessive use of advanced medical technologies and inappropriate transitions between settings of care. In addition, as employers or states restructure their health insurance programs, families are often subject to changes in health plans, provider networks, or terms of coverage (e.g., reduction in home health care benefits). These changes may disrupt continuity of care, including relationships with trusted providers.

Most private health plans, particularly those sponsored by large employers, appear to cover hospice care to some extent, as do nearly all state Medicaid programs. Medicaid programs and some private health plans follow Medicare in limiting hospice care to patients who are certified to have a life expectancy of six months or less and are willing to forgo further curative or life-prolonging care. Such requirements are particularly troublesome for children whose life expectancy is uncertain or whose parents cannot face relinquishing efforts to save or extend their child's life.

Recommendation: Public and private insurers should restructure hospice benefits for children to

- **add hospice care to the services required by Congress in Medicaid and other public insurance programs for children and to the services covered for children under private health plans;**
- **eliminate eligibility restrictions related to life expectancy, substitute criteria based on a child's diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care (possibly in a case management framework); and**
- **include outlier payments for exceptionally costly hospice patients.**

In addition to targeting restrictive hospice coverage, this recommendation also is directed at limitations in the current hospice per diem payment method. Research and experience suggest that patients with particularly high-cost needs are often denied hospice or are accepted on the condition that certain expensive services will not be provided by the hospice. An outlier payment system (similar to that adopted by Medicare for inpatient hospital care) for exceptionally high-cost hospice patients should help to reduce access problems by protecting hospices from some financial losses associated with serving these patients.

Even with these changes, additional reforms are needed to promote the integration of palliative care from the time of diagnosis through death and into bereavement and to make palliative care expertise more widely available. If enrollment in hospice is not possible or appropriate for a child, palliative care consultations and counseling for families should be covered.

Further, to recognize the required role of parents in decisionmaking for children, physician reimbursements should be adequate to cover intensive communication and counseling of parents, whether or not the child is present. In addition, bereavement care should be covered as such, whether or not part of a hospice's services. Otherwise, insured parents or siblings who seek counseling generally will be covered only under diagnoses such as depression, which could result in later problems in securing health insurance. Although the committee does not believe that adding these services will be expensive because the number of children who die after extended illnesses is relatively small, it recognizes the cost pressures on private health plans and state Medicaid programs. Thus, the Centers for Medicare and Medicaid Services (CMS) should develop estimates of the cost of adopting these recommendations in Medicaid. As the results of several hospice demonstration projects become available, other adjustments in Medicaid policies may be identified.

Recommendation: In addition to modifying hospice benefits, Medicaid and private insurers should modify policies restricting benefits for other palliative services related to a child's life-threatening medical condition. Such modifications should

- **reimburse the time necessary for fully informing and counseling parents (whether or not the child is present) about their child's (1) diagnosis and prognosis, (2) options for care, including potential benefits and harms, and (3) plan of care, including end-of-life decisions and care for which the family is responsible;**
- **make the expertise of palliative care experts and hospice personnel more widely available by covering palliative care consultations;**
- **reimburse bereavement services for parents and surviving siblings of children who die;**
- **specify coverage and eligibility criteria for palliative inpatient, home health, and professional services based on diagnosis (and, for**

certain services, severity of illness) to guide specialized case managers and others involved in administering the benefits; and

- **provide for the Centers for Medicare and Medicaid Services to develop estimates of the potential cost of implementing these modifications for Medicaid.**

To implement the recommendations related to improved access to hospice and palliative care, child health professionals, insurers, and researchers will have to work together to define eligibility criteria related to diagnosis and, as appropriate, severity of illness. On a more general level, CMS should take the lead in examining the appropriateness of diagnostic, procedure, and other classification schemes that were originally developed for adult services and are now used by many Medicaid programs and private health plans that cover children. These schemes include diagnosis-related groups (DRGs) for hospital payment and the resource-based relative value scale (RVRBS) for physician payment. Also, given the confusion about billing for palliative care services and the frequent denials of payment for improper coding or documentation, children's access to care may also be improved by providing clearer guidance about accurate coding and documentation of covered palliative services.

Recommendation: Federal and state Medicaid agencies, pediatric organizations, and private insurers should cooperate to (1) define diagnosis and, as appropriate, severity criteria for eligibility for expanded benefits for palliative, hospice, and bereavement services; (2) examine the appropriateness for reimbursing pediatric palliative and end-of-life care of diagnostic, procedure, and other classification systems that were developed for reimbursement of adult services; and (3) develop guidance for practitioners and administrative staff about accurate, consistent coding and documenting of palliative, end-of-life, and bereavement services.

LEGAL AND ETHICAL ISSUES

Questions and disagreements about what constitutes appropriate medical treatment for infants and children with severe and often fatal medical problems are frequent topics in the bioethics literature and occasionally in high-profile litigation. One goal of palliative care is to minimize avoidable conflicts that can arise as a result of failures in communication, insufficient attention to goal setting and care planning, and inappropriate clinical care. Continued efforts at the individual and the organizational level can contribute to the prevention and resolution of conflicts about clinical care, for example, by defining procedures for identifying and managing situations that pose high risks for conflict, developing and testing communication protocols to prevent or defuse conflict, establishing procedures for ethics consultations (or, in some cases, psychological counseling), and developing evidence-based practice guidelines that clarify the benefits and burdens of medical interventions in different clinical situations.

EDUCATION OF HEALTH PROFESSIONALS

Whether the issue is inattention to pain or other symptoms, poor communication, or a clinician's own anxieties about death, children and families suffer when they encounter pediatricians and other professionals who are ill-prepared to provide competent and compassionate palliative, end-of-life, and bereavement care. By itself, education cannot ensure such care or guarantee desired changes in attitudes or behaviors, but it must provide the essential foundation of scientific knowledge, skills, and ethical understanding for all professionals who treat infants, children, and adolescents.

In addition to supporting changes in pediatric generalist and specialist education and consistent with the 1997 IOM report, this committee strongly supports the continued evolution of palliative care as a defined and accepted area of teaching, research, and patient care expertise. The development of a group of specialists in pediatric palliative care has begun, often with support from the larger group of palliative care specialists who care for adults. The numbers of such specialists are still small, but they have a central role not only in providing care but also in enlisting other clinicians, educators, professional societies, research funders, managers, and policymakers to support improvements in pediatric palliative care. Although improved reimbursement will help sustain and expand the ranks of specialists in pediatric palliative care, relevant academic leaders and medical center administrators must also recognize such expertise as essential to meeting their institution's educational and service missions.

Recommendation: Medical, nursing, and other health professions schools or programs should collaborate with professional societies to improve the care provided to seriously ill and injured children by creating and testing curricula and experiences that

- **prepare all health care professionals who work with children and families to have relevant basic competence in palliative, end-of-life, and bereavement care;**
- **prepare specialists, subspecialists, and others who routinely care for children with life-threatening conditions to have advanced competence in the technical and psychosocial aspects of palliative, end-of-life, and bereavement care in their respective fields; and**

- **prepare a group of pediatric palliative care specialists to take lead responsibility for acting as clinical role models, educating other professionals, and conducting research that extends the knowledge base for palliative, end-of-life, and bereavement care.**

Even for medical conditions that are invariably or often fatal, classroom lectures, clinical rotations, and medical textbooks focus almost exclusively on the pathophysiology of disease and the conventional or experimental interventions that might prolong life—often with little regard for the likelihood of success and with little attention to the burdens experienced by dying patients and their families. In one recent survey of pediatric oncologists, respondents reported that the most common way they learned about end-of-life care was "trial and error." Experience in practice is an important and necessary teacher, but relying on such unstructured and unguided experience puts children and families at risk of much preventable suffering. Even in the crowded undergraduate medical curriculum, opportunities exist to use palliative care and end-of-life issues as powerful illustrations in didactic and clinical teaching.

Recommendation: To provide instruction and experiences appropriate for all health care professionals who care for children, experts in general and specialty fields of pediatric health care and education should collaborate with experts in adult and pediatric palliative care and education to develop and implement

- **model curricula that provide a basic foundation of knowledge about palliative, end-of-life, and bereavement care that is appropriate for undergraduate health professions education in areas including but not limited to medicine, nursing, social work, psychology, and pastoral care;**
- **residency program requirements that provide more extensive preparation as appropriate for each category of pediatric specialists and subspecialists who care for children with life-threatening medical conditions;**
- **pediatric palliative care fellowships and similar training opportunities;**
- **introductory and advanced continuing education programs and requirements for both generalist and specialist pediatric professionals; and**
- **practical, fundable strategies to evaluate selected techniques or tools for educating health professionals in palliative, end-of-life, and bereavement care.**

DIRECTIONS FOR RESEARCH

Among the most common phrases in this report are "research is limited" and "systematic data are not available." Research to support improvements in palliative, end-of-life, and bereavement care constitutes only a tiny fraction of research involving children. Likewise, research involving children and their families occupies a small niche in the world of research on palliative and end-of-life care, which itself is small in comparison to other areas of clinical and health services research. Thus, clinicians and parents must often make decisions about the care of children with little guidance from clinical or health services research.

> **Recommendation: The National Center for Health Statistics, the National Institutes of Health, and other relevant public and private organizations, including philanthropic organizations, should collaborate to improve the collection of descriptive data—epidemiological, clinical, organizational, and financial—to guide the provision, funding, and evaluation of palliative, end-of-life, and bereavement care for children and families.**

In the 2001 report *Improving Palliative Care for Cancer*, the IOM's National Cancer Policy Board included two recommendations aimed at stimulating palliative care research in "centers of excellence" designated by the National Institutes of Health and encouraging such centers to take a lead role as agents of national policy in promoting palliative care. This report endorses a similar strategy to use federally funded pediatric oncology centers, neonatal networks, and similar structures to promote attention to palliative, end-of-life, and bereavement care in both pediatric clinical trials and regular patient care. By organizing multiple sites to investigate a common problem using a common methodology, such a strategy should increase the numbers of children involved in studies and increase the credibility of the findings. It should also stimulate the development of investigator expertise in pediatric palliative care research and encourage the formulation and successful completion of more high-quality research projects.

> **Recommendation: Units of the National Institutes of Health and other organizations that fund pediatric oncology, neonatal, and similar clinical and research centers or networks should define priorities for research in pediatric palliative, end-of-life, and bereavement care. Research should focus on infants, children, adolescents, and their families, including siblings, and should cover care from the time of diagnosis**

through death and bereavement. Priorities for research include but are not limited to the effectiveness of

- **clinical interventions, including symptom management;**
- **methods for improving communication and decisionmaking;**
- **innovative arrangements for delivering, coordinating, and evaluating care, including interdisciplinary care teams and quality improvement strategies; and**
- **different approaches to bereavement care.**

This report also suggests more specific directions for research in a number of areas including symptom control, financing, service organization and delivery, perinatal loss, emergency medical services, and education. Some research in these and other areas will focus narrowly on children who have died or who are expected to die. Other research will include children who have survived or may survive life-threatening medical problems. Both kinds of research should provide knowledge that informs and improves the care of children who survive as well as those who do not. It should likewise help every family that suffers with a seriously ill or injured child. Indeed, all of the recommendations in this report, if implemented, should help create a care system that all children and families can trust to provide capable, compassionate, and reliable care when they are in need.

CHAPTER 1

INTRODUCTION

We are the parents of three premature babies—Abigail who died after five and a half months, Jonathan who died soon after being born, and Jeremy who is now 12, tall, athletic, and good in school. . . . I go back to the journals I kept while Abby was in intensive care. . . . It was hard to feel like parents in the ICU. Sometimes there was no room for us, both literally and figuratively. There was no place for parents to hang their coats. The family room closed during the Christmas holidays because of a holiday decorating contest. . . .

No one really talked to us about the possibility that Abigail would die, except in her first week. Even then it was couched in euphemisms that were easy to misunderstand or ignore. I remember being asked one evening, "How far do you live from the hospital?" That was the extent of the inquiry. When Abby coded and died, I was scared and lonely, standing outside, unable to be with her. No one had time to tell me what was happening.

We spent so much time fighting for Abby, getting information, and so forth. Could we have better spent our time just being with her? If we had known better what to expect, would we have just held her? Our second child, Jonathan, died a couple of hours after his birth, largely because we knew some things to ask for after our experience with Abigail.

Looking back, we were professionals, we had contacts, we were used to speaking up for ourselves. What about parents without that?

Deborah Dokken, parent, 2001

The death of a child is a special sorrow, a lifelong loss for surviving mothers, fathers, brothers, sisters, grandparents, and other family members. Some children die after an extended illness; others die suddenly with no forewarning. No matter the circumstances, a child's death is a life-altering experience.

At best, the physicians, nurses, and others who care for a child who dies and for the surviving family will help all involved feel that they did everything they could, that the parents were good parents, that the child and family spent their time together—however limited—forging or reinforcing bonds of love. At worst, families live with memories of possibly needless suffering and with enduring regrets or doubts about their own choices. In between are experiences like that of Abby's family—experiences of good care alternating with unwittingly inflicted pain, of compassion mixed with insensitivity, of choices made and then doubted. Health care professionals may also feel anguished and unsure that they did what was best.

The goal of palliative, end-of-life, and bereavement care for children and their families is to provide them with the best care and support possible and to do so reliably and consistently, no matter how or where a child is cared for. Despite good intentions, that goal is too often not met. Omissions and missteps in care may not be recognized. If they are, health care professionals and organizations may not systematically learn from experience as Abby's and Jonathan's parents did.

Because children are resilient, because they are so cherished, and because advances in medicine and public health have greatly reduced child mortality in the United States, those caring for children with life-threatening medical problems are usually committed to pursuing all curative and life-prolonging options until death is at hand. This intensive but limited focus can expose children and families to unnecessary suffering, particularly if inadequate attention is paid to the potential burdens as well as benefits of these options and to children's physical and emotional distress.

A more comprehensive approach to care is needed. Regardless of the decisions made about curative or life-prolonging treatments, children with life-threatening medical problems and their families should have access to accurate information and excellent supportive care that offers physical, emotional, and spiritual comfort from the time of diagnosis through death and into bereavement—if death is the outcome. Good palliative care should benefit children who survive a life-threatening medical problem as well as those who do not—and should support the families of children in both groups. When they look back, families should feel that everyone did their best to help their child and family.

In recent years, health care professionals, policymakers, researchers, faith communities, and others have paid increasing attention to the needs of people approaching death and those close to them. Because approximately

70 percent of Americans who die each year are elderly adults, most of this attention understandably focuses on their circumstances and needs.

Nonetheless, even in affluent countries, children still die—approximately 55,000 in the United States in 1999. Each of these deaths brings loss, change, and enduring grief to the family. Each death also affects a broader circle of friends, neighbors, schoolmates, and others in the community who may feel distress and a sense of kinship, even if they do not personally know the child or family.

Care for children necessarily differs from care for adults, reflecting children's developing physiological, psychological, and cognitive characteristics and their legal, ethical, and social status. These differences are reflected in the development of pediatric specialties in medicine and other health professions, the creation of pediatric hospitals and other care settings, and the growth of educational programs and research dedicated to improving care for children. Professionals in the evolving fields of palliative and end-of-life care are understanding the need to apply their principles to children and considering how to train palliative care specialists as well as others who regularly care for children and families facing medical problems that are likely to end in the child's death. The importance of such efforts is increasingly being recognized (see, e.g., Armstrong-Dailey and Goltzer, 1993; Armstrong-Dailey and Zarbock, 2002; ChIPPS, 2001; Goldman, 1996; Hilden et al., 2001b; Levetown, 2001; Linke, 2002; Rushton, 2001; Trafford, 2001).

This report examines what is known about the needs of children with life-threatening medical problems and their families and the extent to which these needs are being met. It also presents suggestions and recommendations for strategies to provide more effective, compassionate, and reliable palliative, end-of-life, and bereavement care.

PROBLEMS AND CHALLENGES

> *When Rosario Maria was born with severe brain injury, she was given two days to live. She survived eight years. . . . It was noticeable that when we finally decided to take the inevitable steps that would lead to her death, the medical staff stopped considering her as a priority.*
>
> Rosario Avila, parent, 2001

Many physicians, nurses, social workers, and others provide excellent, sensitive palliative, end-of-life, and bereavement care to children and their families. Nonetheless, as later chapters in this report describe in more depth, shortcomings in care can too frequently be found. Effective, compassionate, reliable palliative and end-of-life care has not usually been a priority for health care providers, managers, researchers, policymakers, or the general public.

Some of the deficits in palliative and end-of-life care for children that are described in this report are similar to those experienced by adults (IOM, 1997). For example, frightened and upset patients and families may receive confusing or misleading explanations of diagnosis, prognosis, and care options. They may likewise be provided too little opportunity to absorb shocking information, ask questions, and reflect on goals and decisions, even when no immediate crisis is driving decisionmaking. Patients of all ages suffer from inadequate assessment and management of pain and other distress, despite the availability of therapies known to help most patients. For both children and adults, physicians may advise and initiate treatments without adequate consideration of their potential to cause additional suffering while offering no or virtually no potential for benefit. Opportunities are routinely missed to plan responses in advance for the reasonably predictable crises associated with many ultimately fatal medical problems.

Certain issues in palliative and end-of-life care are unique to or particularly evident with children. For example, despite 1997 legislation (renewed in 2001, P.L.107-109) that has stimulated increased pediatric drug testing, some drugs used to treat pain, nausea, and other symptoms in adults have yet to be tested or labeled for use in infants, children, or adolescents. Pediatricians thus may have inadequate information to guide their choices of drugs and minimize dangerous side effects, and some may choose not to treat certain children rather than risk such complications and associated liability. To cite another example, although legal issues related to decisionmaking may be somewhat parallel for intellectually and emotionally immature children and for adults who suffer from progressive dementia, the real-life situations may unfold quite differently, particularly in cases of child–parent conflict. While still mentally competent, adults can create advance directives and other binding documents to guide their care if they suffer significant loss of decisionmaking capacity. As discussed in Chapter 8, only one state will recognize an advance directive signed by a minor, although pediatric professionals agree that children should be informed and involved in discussions about their care, consistent with their developmental status.

Many children are born with rarely seen medical conditions, which creates uncertainty in diagnosis, prognosis, and medical management. Even for common medical problems, children's general physiologic resiliency complicates predictions about survival and other outcomes. In situations laden with fear, anxiety, and desperation, this greater uncertainty complicates the physician's and family's efforts to assess and weigh the potential harms and benefits of treatment options.

Further, many communities will not have enough children with life-threatening medical conditions to generate much local experience and clinical expertise. Seriously ill children and their families may, therefore, be more likely than adults to have to travel far from home for treatment. This may remove them from their usual sources of emotional and social support, disrupt parents' employment, and strain family relationships and finances.

Various programs for children with serious disabilities and other special needs help many families obtain and coordinate care for their child. These programs do not, however, cover all such children, especially in middle-income families, and they often require parents to understand and negotiate complicated eligibility and service requirements. Providers likewise may be frustrated by such requirements and by payment methods and levels that favor invasive medical and surgical procedures, discourage multidisciplinary care, and undervalue the time spent assessing children with grave problems, evaluating care strategies, and counseling and assisting their families.

Many problems facing children with life-threatening medical conditions and their families and many shortcomings in palliative and end-of-life care are embedded in broader social, economic, and cultural problems. Large numbers of children and families lack public or private health insurance and have limited access to health services. Even when a child is covered through private or public insurance; some important services may not be reimbursed. If a child requires care from multiple providers of medical and other services, families may find this country's fragmented health and social services systems to be confusing, unreliable, incomplete, and exhausting to negotiate. Even physicians, social workers, and others experienced with sick children and programs to serve them are frequently frustrated and stymied by these systems.

In addition, children and young families are disproportionately represented among immigrants and thus are especially vulnerable to misunderstandings related to differences in cultural experiences and values about life, illness, death, and medical or nonmedical therapies. Many families lack the education or English-language skills that make communication and understanding of clinical and other information easier. Even in communities with large immigrant populations, skilled translators and translated materials tend to be scarce, putting the children and families at greater risk of inadequate or inappropriate care. Many immigrants also lack access to Medicaid or job-based health insurance.

Millions of children, immigrants and native born, live with their families in unsafe environments that put them at high risk of intentional injury and certain kinds of unintentional injury. Such environments also can make it a challenge to get a child to the doctor, pick up a prescription, or persuade a home care provider to come into the neighborhood. These broader problems are not the focus of this report, but those seeking to improve pediatric palliative, end-of-life, and bereavement care must take them into account.

IMPROVING PALLIATIVE, END-OF-LIFE, AND BEREAVEMENT CARE FOR CHILDREN AND THEIR FAMILIES

> *We took a trip to Florida. It turned out to be just two weeks before Eric died, and he was on multiple medications. And the home health company UPS'd those supplies to Florida so they were waiting for us when we arrived . . . [The very ill mother of] a friend of mine . . . was told that if she left the home, she would lose her home health benefit. . . . I felt very blessed.*
>
> Winona Kittiko, parent, 2001

The death of a child will never be easy to accept, and families may resist early explorations or discussions of hospice care, advance decisions about the use of life-support interventions, or other preparations for a child's anticipated death. Nonetheless, health care professionals, insurers, policymakers, and others can do much to save children and families from preventable suffering. Although more research is needed to document the strengths and limitations of different care strategies, the last decade has seen a wide range of initiatives to improve palliative and end-of-life care and focus public attention on the need for individuals and communities to support changes in attitudes, policies, and practices that cause avoidable physical, emotional, and spiritual distress. Some recent initiatives focus specifically on understanding and improving care for children who die and their families and making it easier for families to obtain—and accept—palliative care without forgoing curative or life-prolonging treatments. Many of these projects are at an early stage and have not yet been fully implemented or evaluated.

As discussed in Chapter 6, children's hospitals play a major role in caring for children with medical conditions that are invariably or often fatal. Recognizing this, the Education Development Center in Massachusetts and several children's hospitals—with funding from the Nathan Cummings Foundation, the Open Society Institute, and several other groups—have begun a collaborative project to help improve the quality and consistency of care provided by these specialized institutions to children and their families following the diagnosis of a life-threatening condition (Solomon et al., 2002; see http://www.ippcweb.org). This Initiative for Pediatric Palliative Care promotes the integration of family-centered palliative care with curative or life-prolonging treatments. Related objectives include the development of explicit policies and protocols for symptom management, communication, and decisionmaking and the assessment of performance through routine data collection. Other elements of this project include the development of quality indicators for family-centered pediatric palliative care and the creation of curriculum materials and learning strategies to improve practitioner competence.

As wider use of sonograms and other diagnostic technologies has expanded the number of families who receive a prenatal diagnosis of a lethal or potentially lethal congenital anomaly, several organizations have developed perinatal hospice programs for parents who choose to or have no option but to continue the pregnancy (Sumner, 2001). For example, in 1995, the Madigan Army Medical Center began a program of support for families from the time of diagnosis through fetal death, stillbirth, or infant death and into bereavement (Calhoun and Hoeldke, 2000; see also Sumner, 2001).

The American Academy of Pediatrics recently issued its first explicit policy statement and recommendations on palliative and end-of-life care for children (AAP, 2000g). The American Academy of Hospice and Palliative Medicine has designed a series of self-study modules for physicians who care for dying patients and their families that can be used in undergraduate and medical as well as continuing medical education (AAHPM, 2000). A new module will focus specifically on children. In 2001, the National Hospice and Palliative Care Organization began distributing a compendium of educational and practical resource materials on pediatric palliative care intended for clinicians and others in both hospices and hospitals (ChIPPS, 2001). A recent Institute of Medicine (IOM) report on palliative care for cancer included a chapter on children and families (IOM, 2001c). Several hospices and children's hospitals have begun or are starting palliative care programs.

One recent initiative comes as the result of congressional action directing the Centers for Medicare and Medicaid Services (CMS; formerly the Health Care Financing Administration) to support several demonstration projects to help Medicaid programs, hospices, and other organizations in five specified states develop and evaluate a Program for All-Inclusive Care for Children and their Families (PACC). The program is administered by Children's Hospice International (CHI, 2002; see also http://www.chionline.org). These projects focus on children living with life-threatening medical conditions and their families. The idea is to develop and test models of continuous, integrated, and comprehensive pediatric palliative and end-of-life care similar to the Program of All-Inclusive Care for Elders (PACE) program, which was pioneered for older adults by OnLok Senior Health Services in California. As explained in Chapter 7, waivers of certain federal or state Medicaid requirements for the projects will remove some of the financial and regulatory barriers to such comprehensive care.

A number of public and private organizations including the National Institute of Nursing Research, the National Cancer Institute, the Open Society Institute, and the Robert Wood Johnson Foundation are supporting various efforts by individuals and research coalitions (e.g., the Children's Oncology Group) to strengthen the research base for palliative and end-of-life care for children and their families. These efforts involve clinical research as well as policy, organizational, educational, and behavioral research. For example, three studies have helped clarify the extent and limitation of Medicaid and private insurance coverage for palliative and end-of-life care (e.g., Gabel et al., 1998; Huskamp et al., 2001; Tilly and Wiener, 2001). Other research has assessed clinicians' knowledge and effective use of therapies for children's pain and other distress (see Chapter 3). Congress has substantially increased the incentives for research by pharmaceutical companies to tests drugs in children so that pediatricians, families, and child patients will have better information on which to base therapy decisions (see Chapter 10).

STUDY ORIGINS AND REPORT OVERVIEW

In 1993, the Institute of Medicine convened a small group to discuss the value and content of a study of end-of-life care. That group recommended that the IOM undertake to stimulate discussion and encourage consensus on directions for change in the care of dying patients (IOM, 1993). The IOM launched the study in 1995. The resulting report, *Approaching Death: Improving Care at the End of Life* (IOM, 1997), assessed the knowledge base for providing effective and compassionate end-of-life care and recommended steps that clinicians, educators, researchers, policymakers, and others could take to improve such care.

Although the 1997 report was intended to address care across the age spectrum, this proved difficult in practice given that the overwhelming majority of deaths occur in adults, primarily those age 65 and over. Those under age 20 account for approximately 2 percent of deaths each year. Thus, most of the programs, policies, and research cited in the earlier report focused on older adults.

This second study, which began late in 2000, examines the special needs and circumstances of children and their families and, again, suggests steps that clinicians, educators, researchers, policymakers, and others can take to improve care. The IOM, which is the health policy arm of the National Academy of Sciences, appointed an expert committee of 14 members to prepare this report. Their charge was to

- describe the major causes and settings of death for children;
- review what is known about (1) the medical and other services

provided to dying children and their families and (2) the education of physicians and other professionals who care for gravely ill children;

- assess the state of knowledge about clinical, behavioral, cultural, organizational, legal, and other important aspects of palliative and end-of-life care for children and their families;
- examine methods for communicating information, determining family and child/ patient preferences, resolving conflicts, and evaluating the quality of palliative and end-of-life care as experienced by children and their families; and
- propose a research and action agenda to strengthen the scope and application of the knowledge base for providing effective and compassionate palliative and end-of-life care for children and their families.

This report presents the committee's analysis and recommendations. The committee recognizes that while much can be done now to support children and families, much more needs to be learned. The analysis and recommendations included here reflect current knowledge and judgments, but new research and insights will undoubtedly suggest modifications and shifts in emphasis in future years.

Appendix A describes the committee's information-gathering strategies, which included a public meeting at which interested professional, family, and advocacy groups presented statements and a smaller meeting with families of children who had died or were living with life-threatening medical conditions. The remainder of this chapter describes some of the basic principles that guided the committee's work and reviews a number of concepts important in an examination of palliative and end-of-life care for children and their families.

Chapter 2 presents a profile of death in childhood. That profile and the concepts and principles discussed in this chapter provide a foundation for subsequent examination of the clinical, social, financial, and other practices and policies needed to support effective, flexible, and compassionate palliative and end-of-life care for children and their families.

To underscore the variability in the pathways followed by children who die and their families and set the stage for the discussion in Chapters 4, 5, and 6, Chapter 3 reviews several prototypical trajectories of death in childhood. It also presents a number of case histories that further illustrate this variability and the challenges it presents for families, health care providers, policymakers, and others. The last part of the chapter reviews the limited research investigating the nature and adequacy of palliative and end-of-life care for children and their families.

Chapter 4 considers several questions of concern to children and families faced with a child's serious medical problem: What is happening to me?

What is happening to my child? What are our choices? How will you help us? Chapter 5 considers the basic dimensions of palliative and end-of-life care: physical, emotional, spiritual, and practical as they should engage all those who regularly care for children with life-threatening medical problems and their families. The chapter also discusses bereavement care. In Chapter 6, the focus is on caregivers and care settings. The availability and elements of palliative and end-of-life care in the hospital and at home are reviewed as are strategies for reducing the burdens that families experience in coordinating care for their child within this country's fragmented health care system.

Chapter 7 examines the financing of palliative and end-of-life care for children and their families. It discusses how financing policies and their implementation can create obstacles to effective and compassionate care. Chapter 8 presents an overview of ethical and legal issues that health care professionals, administrators, policymakers, and families may confront in deciding about care for children with life-threatening medical conditions. Chapter 9 discusses what is known about how health care professionals are or can be educated to care for children and families living with a child's life-threatening medical condition. Because the knowledge base for effective pediatric palliative and end-of-life care is so limited, Chapter 10 describes directions for clinical and health services research and examines some of the ethical and practical issues in involving children, especially seriously ill children, in research.

In addition, the report includes several appendixes that explore certain issues in greater detail. Appendix B discusses efforts to develop quantitative tools that provide more accurate estimates of prognosis, especially for infants. The challenge of measuring quality of life for seriously ill or dying children is examined in Appendix C. Appendix D reviews issues of cultural sensitivity in palliative, end-of-life, and bereavement care for children and families, and Appendix E discusses bereavement following the death of a child. A large fraction of children's deaths result from sudden and unexpected events, and Appendix F discusses the role of emergency medical services providers in caring for these children and their families. Appendix G reviews the current state of education in pediatric palliative care. Appendix H describes the planning for one of the PACC projects mentioned earlier. These appendices are available only online (http://www.nap.edu/catalog/10390.html).

GUIDING PRINCIPLES

Early in the course of this study, the committee concluded that the basic working principles or starting points set forth early in the 1997 IOM report applied to children as well as adults, although the specifics sometimes

Box 1.1
Working Principles for Pediatric Palliative, End-of-Life, and Bereavement Care

1. Appropriate care for children with life-threatening medical conditions and their families is designed to fit each child's physical, cognitive, emotional, and spiritual level of development.
2. Good care involves and respects both the child and the family.
3. Families are part of the care team.
4. Effective and compassionate care for children with life-threatening conditions and for their families is an integral and important part of care from diagnosis through death and bereavement.
5. Professionals caring for children have special responsibilities for educating themselves and others about the identification, management, and discussion of the last phase of a child's fatal medical problem.
6. Both individual change and organizational change are needed to provide consistently excellent palliative, end-of-life, and bereavement care for children and their families.
7. More and better research is needed to increase our understanding of clinical, cultural, organizational, and other practices or perspectives that can improve palliative, end-of-life, and bereavement care for children and families.

differ. The committee also recognized additional values that apply either uniquely or with special emphasis to children. The working principles that guided this committee are summarized in Box 1.1 and discussed below. The first three are specific to children; the remainder restate the earlier principles from the 1997 report in terms of children.

Appropriate care for children with life-threatening medical conditions and their families is designed to fit each child's physical, cognitive, emotional, and spiritual level of development. As is often emphasized, children are not small adults. From birth to adulthood, their physical, intellectual, spiritual, and emotional characteristics, needs, and capacities change in relatively predictable ways, although individual children may vary in the pace and details of their development. For children and families living with life-threatening medical problems, developmental science should guide both the formulation and adaptation of care plans appropriate for the individual child and the information and support provided to the family.

Good care involves and respects both the child and the family. For clinicians who care for children, it is a norm of practice to consider the family as the unit of care. *Family* most commonly means parents, siblings, and other close relatives, but it may be used more broadly to include legal guardians as well as close friends such as godparents, neighbors, and schoolmates. For families, respect means being sensitive to their culture, values, and resources. It also means understanding and supporting the need of mothers and fathers to be "good parents" as they provide and make decisions about medical care for their child. For children, respect means being sensitive to their goals and values, their suffering, their maturity and desire to participate in decisions about their care, and the ways in which different care strategies may help them live as normally as possible given their circumstances.

Families are part of the care team and need full information and support to perform well. Parents are key decision makers and usually are key providers of physical and emotional care for their child, not only at home but also in hospitals. Like other caregivers, parents need appropriate training and information to function effectively. At the same time, for physicians and the rest of the health care team, parents are also part of the unit of care—along with their child. Although parents may cherish every minute of care they provide to an ill child, other caregivers should be alert to excessive strain on parents from a physically, emotionally, or technically demanding regimen of caregiving.

Competent, consistent, and compassionate palliative, end-of-life, and bereavement care is an integral and important part of pediatric care in all settings, from diagnosis of a child's life-threatening medical problem through death and bereavement—if death is the outcome. As stated in the 1997 IOM report, those who are dying "deserve attention that is as thorough, active, and conscientious as that provided to those for whom disease prevention, diagnosis, cure, or rehabilitation are still dominant goals. Individual and system failures to care humanely for dying patients—including failures to use existing knowledge to prevent and relieve distress—should be viewed as clinical and ethical failures" (IOM, 1997, p. 22). All those who care for children who may die should examine their own practices and their institutional context to identify areas for improvement. To guide their own judgments and those of the families that depend on them, clinicians must have a solid scientific and clinical understanding of appropriate symptom assessment and management and of the potential benefits and harms of life-prolonging technologies. They then must help families develop the understanding of these issues that they need to make informed decisions.

Good communication skills and compassion are critical. Parents of children with life-threatening medical conditions are unusually vulnerable to misunderstanding communication that is not attentive to their shock, fear, numbness, confusion, grief, and need for hope. Children's ability to understand their situation and their interest in participating in care decisions will vary depending on their intellectual and emotional maturity and personal characteristics.

Professionals caring for children have special responsibilities for educating themselves and others about the identification, management, and *discussion of the last phase of a child's fatal medical condition.* Much of the emotional, practical, spiritual and other support needed by children who die and their families will come from within the family. Friends and neighbors, members of their faith community or other social groups, schoolmates and teachers, coworkers, and others outside the medical world may also offer significant support. Nonetheless, perhaps more than for aged adults, physicians, nurses, and other medical personnel play a central role for children who die, in part because parents usually want every medical option to save or extend the life of their child. Clinicians have a moral responsibility to educate themselves about what constitutes good physical and emotional care for dying children and appropriate and sensitive support for their families.

Both individual change and organizational change are needed to provide more effective and consistent palliative, end-of-life, and bereavement care. The commitment of clinicians, researchers, and policymakers to saving children's lives and restoring them to health is powerful and beneficial. Acceptance that cure or meaningfully prolonged life is not possible is painful and difficult—so difficult that some clinicians and parents may not recognize that they are pursuing treatments that bring suffering without benefit. Physicians and other professionals may not commit themselves fully to understanding, assessing, preventing, and relieving pain and other distress. They may even draw away from children and families when death is inevitable and fail to support grieving family members after a child's death. Efforts to change individual attitudes, knowledge, and behavior are essential, but they are unlikely to succeed without supportive organizational, professional, legal, and financial structures. It should not be so difficult—as it is today—to provide timely, coordinated, reliable, effective, and compassionate palliative care for children and adults alike.

More and better research is needed to improve palliative, end-of-life, and bereavement care for children and families. For children even more than for adults, the knowledge base for good palliative and end-of-life care is limited in all areas including physiological, psychosocial, and policy research. Research involving infants, children, and adolescents often involves particular practical and ethical challenges. Still, researchers and research funders have a responsibility to identify questions important to improving pediatric palliative and end-of-life care that can be feasibly and ethically studied. Although protection of children and close oversight of potential risks and burdens are essential, research involving children is also essential and can be undertaken ethically and responsibly. Such research is critical to fill gaps in clinicians' understanding of steps that can help prevent or relieve the suffering of children and their families and also to provide them with tested medications and other strategies for doing so.

CONCEPTS AND DEFINITIONS

This section considers a number of terms widely used in discussions of childhood and in discussions of death. Other concepts are defined and discussed in later chapters (e.g., child- and family-centered care in Chapter 6).

Child

This report uses the terms *child* and *children* very generally to cover the age spectrum from birth through the teenage years. Without taking a position in the moral and legal debate over what constitutes personhood, the report also considers efforts to support families facing a prenatal diagnosis of a lethal congenital condition. Further, although it is not the focus of this report, the committee recognizes the grief of parents who suffer the death of an adult daughter or son.

As they move from birth into adulthood, children are constantly changing and developing physiologically, intellectually, and emotionally. Chronological age is often less important than an understanding of a child's physical, cognitive, emotional, and spiritual development and the medical, social, and other support appropriate to different stages of development.

Definitions of the periods of childhood vary somewhat and reflect a mix of biological and social considerations (see, e.g., Needlman, 2000). In general, a *neonate* is a child from birth through 4 weeks of age (under 28 days). An *infant* is a child from 4 weeks of age through the end of the first year of life. (See Chapter 2 for more terminology related to infants and fetuses.) A *toddler* is often described as a 1 to 3-year old. Preschool children—ages 2 or 3 through 4 or 5 years—are often distinguished from school-age children. An adolescent is sometimes described as a child from 13 through 17 or 19 years of age, but children 10 through 14 may be described as pre- and early adolescents and those 15 through 19 as middle and late adolescents.[1] At 18, a person may make his or her own decisions about matters such as health care and advance directives without parental consent. The need for clarity in the definition of age groupings is obvious for statistical comparisons and analyses involving, for example, leading causes of death among different demographic groups.

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[1] Some of those involved with adolescent health services identify the transition period to adulthood as extending into the third decade of life (SAM, 1995; Stepp, 2002). The spectrum of pediatric or adolescent care may also be stretched to cover the situation of children with conditions such as congenital heart disease or cystic fibrosis who survive into adulthood and continue to benefit from care and support provided by their pediatric care team.

Family

As noted earlier, *family* generally refers to parents (or legal guardians), siblings, grandparents, and other close relatives. It sometimes is used more broadly to include godparents, playmates, girlfriends or boyfriends, and others close to the child or immediate family. In certain contexts, particularly those involving decisionmaking, family may occasionally be used as a synonym—when the meaning is clear—for parents or legal guardians. As noted earlier, even people who have no personal tie to a child who dies or to the surviving family may experience a sense of loss when they learn of a child's death and feel a strong connection with the family's grief.

Palliative Care, End-of-Life, and Hospice Care

Although some use palliative care and hospice or end-of-life care interchangeably, the committee views *palliative care* more broadly as care that seeks to prevent, relieve, reduce, or soothe the symptoms produced by serious medical conditions or their treatment and to maintain patients' quality of life.[2] The benefits of such care are not limited to people thought to be dying or those enrolled in hospice programs. Rather, "palliative care is a model of caring for patients and their families who suffer from life-threatening illnesses" (AAP, 2000g, p. 351). As used in this report, palliative care also considers the needs of patients and families for timely, accurate, and compassionate provision of information about their diagnosis, prognosis, and treatment options, including the benefits and burdens of treatments. Such information assists patients and families in making decisions.

Palliative care does not itself focus on cure, but it can be provided concurrently with curative or life-prolonging care. Effective anticipation,

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[2] See, for example, *American Heritage Dictionary* (1992); *Stedman's Medical Dictionary* (1995). In contrast, the World Health Organization defines palliative care more narrowly as "the active total care of patients whose disease is not responsive to curative treatment . . . [when] control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount" (WHO, 1990, p.11). Another source refers to the "appropriate medical care of patients with advanced and progressive disease for whom the focus of care is quality of life and in whom prognosis is limited (although sometimes it may be several years)" (Association of Palliative Medicine of Great Britain and Ireland, cited in ABIM, 1996a). Similarly, the definition prepared in Great Britain in 1987 when palliative care was first recognized as a specialty defines palliative medicine as the "study and management of patients with active, aggressive, far-advanced disease for which prognosis is limited and the focus of care is quality of life" (Doyle et al., 1998, p.3). Billings defines palliative care as an interdisciplinary approach to the comprehensive management of physical, psychological, social and spiritual needs for patients who have progressive incurable illnesses (Billings, 1998).

prevention, and relief of pain and other physical and emotional distress may, in fact, be essential for patients to tolerate demanding treatment regimens. For children who live into adulthood with difficult chronic conditions and experience periodic medical crises, palliative care is also important to prevent unnecessary physical and emotional suffering. In sum, good palliative care following the diagnosis of fatal or potentially fatal condition should help children who survive as well as children who die. All those regularly involved in caring for patients with life-threatening medical problems have roles to play in the delivery of palliative care as defined here.

In addition to the meticulous management of pain and other physical symptoms, palliative care emphasizes the emotional, spiritual, and practical needs of patients and those close to them—from the time of diagnosis through death and bereavement. Helping people live well in the presence of life-threatening medical conditions (and their treatments) requires both compassion and sophisticated strategies and tools for measuring, preventing, and reducing the physical, psychological, and other burdens often associated with such conditions and their treatment.

End-of-life care has no precise meaning (see the discussion below of end-of-life, dying, and death). The term is used in this report to describe care that focuses on preparing for an anticipated death (e.g., advance discussion about using life-support technologies in case of cardiac arrest or other crises, arranging a last family trip, notifying relatives and friends) and managing the end stage of a fatal medical condition (e.g., removing a breathing tube, adjusting symptom management to reflect changing physiology as death approaches).

The term *hospice* may be used to describe a philosophy, a program of care, or a site of care (e.g., a unit in a hospital or other facility). Most commonly, and in this report, hospice refers to an organization or program that provides, arranges, coordinates, and advises on a wide range of medical and supportive services for dying patients and those close to them. The great majority of hospice care is provided at home to elderly adults with chronic conditions, although hospices also provide care for residents of nursing homes and, less commonly, assist with hospitalized patients.

Most hospice services that are provided to elderly people are financed by Medicare. For this reason, hospice care and the Medicare hospice benefit are often, but incorrectly, considered synonymous. As discussed in Chapter 7, the Medicaid hospice benefit follows the Medicare model, but private insurance coverage sometimes is more flexible. Hospice care may also be covered by philanthropy or direct payments from families.

Terms such as *comfort care* or *supportive care* are sometimes used as synonyms for palliative or hospice care by those who believe that they are more understandable and acceptable to patients and their families. Because hospice is so closely associated with end-of-life care and because a child's death is especially hard to accept, hospices may similarly devise different names for their pediatric programs as well as rethink their models of care. As noted later in this report, parents may dread—even hate the thought of—hospice care and may be reluctant to participate in explicit discussions about their child's prognosis, recognize the burdens of certain treatments, or prepare for their child's death.

The broad principles of palliative and end-of-life care apply to children as well as adults. Nonetheless, differences in children's anatomy, physiology, psychosocial and cognitive development, and social and legal status require that assessment, treatment, communication, prognostic, and decisionmaking strategies be adapted to each child's level of development.

Grief and Bereavement

Grief is the term usually used to describe people's feelings and behaviors in response to death. Sadness, numbness, anger, sleep disturbances, inability to concentrate, fatigue, and similar feelings and behaviors are normal responses to a loved one's death. Research suggests that the death of a child prompts more intense grief than the death of a parent or spouse. (See Appendix E.)

Anticipatory grief often occurs in advance of an expected loss. Such losses may include not only death but also losses of expectations for a "normal" life, for example, following diagnosis of a child's serious physical or cognitive disability. Anticipatory grief may be experienced by children with potentially fatal medical problems as well as by those close to them.

Bereavement describes the situation or fact of having experienced loss through death rather than to the emotional content of the experience. *Mourning* sometimes refers to the social rituals and expressions of grief (IOM, 1984) and sometimes to the psychological process of adapting to loss (Silverman, 2000). Rather than talk of recovery or closure following bereavement, experts in grief and bereavement prefer the concepts of emotional reconstruction or reconstitution. *Complicated grief or bereavement* refers to a response to loss that is more intense and longer in duration than usual (Prigerson and Jacobs, 2001).

Although bereavement is a term usually applied to family members, feelings of grief may be shared by many others who have known the child or who feel close to the family. The physicians, nurses, and others who care for a child who dies may grieve, whether or not they feel able to express it. Families may feel comforted and supported when these caregivers communicate that they too grieve the child's death, even as they also offer other support including follow-up information about the child's death (e.g., after a pathologist's or medical examiner's report), referrals to bereavement support groups, and inquiries about the physical and emotional status of parents, siblings, and other family members. Increasingly, researchers and others are considering the grief experienced by those who care for children who die and their families (see, e.g., Rushton, in press; Browning, in press).

The End of Life, Dying, and Death

The end of life can come at any age, including infancy. Nonetheless, because death now typically comes in old age, it is natural for Americans to think of that time as life's end. Today, life ended in childhood seems an affront to the natural order of things, different from the sad but commonplace fate of children in earlier times or distant places.

The IOM's 1997 report noted that *dying* is not a precise descriptive or diagnostic term. Usually, people referred to as dying have a condition from which they are likely to die within a few days to several months. Nonetheless, concern also extends to people with progressive conditions expected to end in death but perhaps not for years.

The definition of *death* is less important for this report than the identification of clinically, ethically, and legally appropriate ways to make decisions and manage care at the end of life. Nonetheless, some concerns do surround the definition of death and application of criteria for declaring death—in particular, brain death (or death by brain criteria). Today, there is widespread but not complete consensus that death occurs either with the irreversible cessation of circulatory and respiratory functions or with the irreversible cessation of all functions of the brain, including the brain stem (see, e.g., President's Commission, 1981; Capron, 2001). Generally accepted criteria for determining brain death require a series of neurological and other assessments, although some jurisdictional and institutional differences exist in details such as who can determine brain death and how long a patient must be observed (Wijdicks, 2001). For children, special guidelines apply. They generally specify two assessments separated by an interval of at least 48 hours for those 1 week to 2 months of age, 24 hours for those ages 2 months to 1 year, and 12 hours for older children; additional confirmatory tests may also be advisable under some circumstances. (Brain death criteria are normally not applied to infants less than 7 days old.[3]) Researchers have found inconsistencies in the application of pediatric brain death criteria (Lynch and Eldadah, 1992; Mejia and Pollack,

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[3] Because of the unique physiologic changes of brain blood flow during the period of transition from fetus to newborn infant, the brain death criteria developed for adults and older infants and children have not proven useful for infants less than a week old. Currently, no clinically applicable criteria for brain death for newborn infants less than 1 week of age are available.

1995), and professional and parental confusion about the concept has been documented (see, e.g., Harrison and Botkin, 1999). Declaration of brain death, particularly following traumatic injuries, often permits organ donation, an option that allows many parents to feel that some good will come from their tragic loss. Sometimes, the declaration of death may be somewhat delayed beyond the period required by protocols to provide families more time to understand their child's situation and to say their good-byes.

Life-Threatening and Fatal Conditions

The term *life-threatening* condition has no common definition. For purposes of this report, life-threatening conditions are those that (1) carry a substantial probability of death in childhood, although treatment may succeed in curing the condition or substantially prolonging life, and (2) are *perceived* as potentially having a fatal outcome. For example, children with Down syndrome have lower-than-average life expectancy, but the condition is not usually viewed as life threatening unless a child has associated anomalies likely to prove fatal in infancy or childhood.

As used in this report, a *life-shortening or fatal medical condition* is one that is not curable and will end in premature death, especially during childhood.[4] Although such a prognosis for some medical problems may be very clear to clinicians, parents may not accept that their child will die, even when death is very near.

Determination of prognosis is not, however, a precise science, and it is often not possible to identify far in advance which children with life-threatening problems will die. (See Appendix B.) For example, although the fatality rate is high for extreme prematurity, many infants survive after being near death. Whether or not the eventual outcome of a child's medical problem is death, the needs of children and their families for physical, emotional, spiritual, and practical support and for accurate information will often be similar and substantial during much of the time following diagnosis of a life-threatening medical problem. The combination of medical uncertainty and families' need to maintain hope reinforces the principle that palliative care should be integrated with curative and life-prolonging care from the time a life-threatening problem is diagnosed.

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[4] Some use the term *life limiting* to refer to these conditions (see, e.g., ACT, 1997). This term is potentially confusing because various nonfatal conditions can be life limiting in the sense that they limit people's quality of life or limit their ability to undertake activities of daily living.

Pathways or Trajectories of Dying

Chapter 2, which reviews mortality data for children, makes clear that death comes to children in many different ways, although certain pathways are more common than others. For many infants born very prematurely or with lethal birth defects, death usually comes soon after birth. For many other children, death comes suddenly and with no forewarning following intentional or unintentional injuries. (Even for children with progressive fatal conditions who experience and survive several medical crises, death from a final crisis may still be regarded by parents as unexpected.) Some children die of serious but potentially curable illnesses such as cancer, perhaps after an extended period of apparent recovery. The demands on physicians and others will vary for each of these and other pathways. Chapter 3 includes case histories that further illustrate this point.

For an increasing number of conditions, technologies such as bone marrow and organ transplantation have blurred the pathways of dying. They offer a last chance, possibly very small, of significantly prolonged survival, often with a diminished but—for many—still acceptable quality of life. For inherited genetic conditions such as cystic fibrosis or neurodegenerative disorders, parents may hope their child will live long enough to benefit from gene therapy or some other as yet unproven or undiscovered treatment. These hopes affect discussions with physicians about treatment goals and sometimes interfere with preparations for death, including decisions about resuscitation in the event of cardiopulmonary arrest.

Extending Life, Prolonging Death

Life-extending or *life-prolonging* interventions can add decades, years, months, weeks, days, or minutes of life for a child with a serious medical problem. At some point, the balance of the expected benefits and burdens of efforts to cure or prolong life may shift decisively. The intervention cannot meaningfully extend life but can only prolong dying and suffering. As discussed later in this report, both clinicians and parents may be reluctant to recognize or accept such a shift in the balance of benefits and burdens and may continue nonbeneficial treatments, sometimes to their later regret. Differences in understanding or perceptions of benefits and harms are at the heart of many difficult discussions among family members, clinicians, and others involved in decisions about end-of-life care.

This report uses the terms *life support* and *life-sustaining treatment* to describe interventions or technologies such as cardiopulmonary resuscitation or mechanical ventilation that can maintain vital functions temporarily during and after major surgery or following medical crises. In some situations, these interventions may only prolong a patient's dying. Antibiotics, artificial hydration, and other common therapies may likewise, in some situations, merely prolong dying and suffering.

Quality of Life, Quality of Dying

Many clinicians, researchers and policymakers are now familiar with the concept of health-related *quality of life*, which emphasizes health as perceived and valued by people for themselves (or, in some cases, for those close to them) rather than as seen by experts (see, e.g., Cohen and Mount, 1992; Patrick and Erickson, 1993; Gold et al., 1996). Measures of health-related quality of life include physical, mental, social, and role functioning; sense of well-being; freedom from bodily pain and other physical distress; satisfaction with health care; and overall sense of general health. Many people who have medical problems that are likely to cause their death can spend months or years living well despite the boundaries posed by their condition and its treatment. Increasingly, those who are working to improve palliative and end-of-life care for children and adults emphasize the goal of living as fully or normally as possible in the face of death.

The still-evolving concept of the *quality of dying* focuses on a person's experience of living as death comes near (Wallston et al., 1988; Byock, 1997; Patrick et al., 2001). In the special world of the dying patient, some physical outcomes become increasingly less possible, while other outcomes, such as a sense of peace or spiritual transcendence, may become more meaningful. The world of the dying child is less understood, particularly the ways in which goals, concerns, and perceptions relate to developmental changes. Nonetheless, as discussed in this report, even young children may have spiritual and existential concerns, seek meaning in their short lives, and have goals to achieve before they die.

Efforts to measure these concepts present many challenges. As Appendix C describes, measuring quality of life for children, especially very young or developmentally delayed children, presents special difficulties related to their ability to communicate their needs or feelings. Regardless of age, measuring the quality of dying is difficult because it is often unclear when someone is "dying" and because patients may be unable to respond to questions as a result of their condition or medications. Researchers and others frequently rely on reports from parents, especially through after-death interviews, but family members and patients may diverge in their ratings of a patient's pain, anxiety, and other physical or psychological distress.

Good and Bad Deaths

References to “good” deaths appear less commonly in discussions of children who die than in recollections of the deaths of elderly family members or friends. This undoubtedly reflects, in part, the different cultural perception of death at a young age that has come with the last century’s sharp reductions in child mortality in this country. Nonetheless, the committee believes that, in general, an earlier IOM committee’s characterizations of “good” and “bad” deaths apply when death comes to a child (IOM, 1997, p. 24):

> A *decent or good death* is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards. A *bad death*, in turn, is characterized by needless suffering, dishonoring of patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended.

As noted by the earlier committee, notions of a good death may reflect values of a dominant culture that some may not share. Thus, it proposed that “a humane care system is one that people can trust to serve them well as they die, even if their needs and beliefs call for departures from routine practices or idealized expectations of caregivers” (IOM, 1997, p. 24). This kind of trustworthiness—and the competence, sensitivity, and flexibility it demands—is integral to good palliative, end-of-life, and bereavement care for both children and adults.

CHAPTER 2

PATTERNS OF CHILDHOOD DEATH IN AMERICA

> *A simple child, that lightly draws its breath, And feels its life in every limb, What should it know of death?*
>
> William Wordsworth, 1798

In 1999, children aged 0 to 19 accounted for 29 percent, or 77.8 million, of the U.S. population of 272.7 million (U.S. Census, 2001). Reflecting their generally good health, children accounted for only 2 percent of all deaths—about 55,000 compared to more than a half million deaths for adults aged 20 to 64 and 1.8 million for those age 65 and over (NCHS, 2001a).[1] Wordsworth's implicit hope is far more a reality today than during the time 200 years past when the poet's two youngest children died.

This chapter summarizes information about the death rates and leading causes of death for children of different ages. It also reviews information about where children die. The discussion begins, however, by briefly putting life-threatening illness and death during childhood in the broader context of child health and illness in the United States. The chapter ends with a short discussion of conclusions and implications for health care providers and policymakers.

CHILDHOOD DEATH IN THE CONTEXT OF IMPROVED CHILD HEALTH

Any discussion of death in childhood and the experience of children

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[1] Unless otherwise indicated, data are from the National Center for Health Statistics report *Deaths: Final Data 1999* (NCHS, 2001a).

and families living with life-threatening medical problems has to be put in the context of child health as it has improved during the last century. First, in the United States, death in childhood is now rare rather than commonplace. Second, causes of death in childhood have changed. Third, children have different patterns of mortality than adults. Fourth, although most children are now healthy, a significant fraction lives with serious health problems.

Death in Childhood Is No Longer Expected

In 1900, 30 percent of all deaths in the United States occurred in children less than 5 years of age compared to just 1.4 percent in 1999 (CDC, 1999a; NCHS, 2001a). Infant mortality dropped from approximately 100 deaths per 1,000 live births in 1915 (the first year for which data to calculate an infant mortality rate were available) to 29.2 deaths per 1,000 births in 1950 and 7.1 per 1,000 in 1999 (CDC, 1999b; NCHS, 2001a).[2]

This decrease in mortality reflects a century's worth of advances in public health, living standards, medical science and technology, and clinical practice. Many infants who once would have died from prematurity, complications of childbirth, and congenital anomalies (birth defects) now survive. Children who previously would have perished from an array of childhood infections today live healthy and long lives thanks to sanitation improvements, vaccines, and antibiotics. In the United States, the average life expectancy at birth rose from less than 50 years in 1900 to more than 76 years in 1999, due in considerable measure to continuing reductions in infant and child mortality (NCHS, 2001c).

Nonetheless, each year in this country, thousands of parents lose their children to conditions such as prematurity, congenital anomalies, injuries, and diseases such as cancer and heart disease. Thousands more siblings, grandparents, other family members, friends, neighbors, schoolmates, and professional caregivers are touched by these deaths. Instead of being a sad but common family experience, death in childhood now stands out as a particular tragedy, at least in developed nations such as the United States.

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[2] Despite such progress, the United States ranked twenty-seventh in infant mortality among 38 countries in 1997, lower than such nations as the Czech Republic and Portugal and tied with Cuba (NCHS, 2001c). The relatively high infant mortality rate in the United States has been attributed in part to this country's large number of low birth weight infants, which in turn, reflects underlying social and economic problems and disparities (see, e.g., Guyer et al., 2000; Hoyert et al., 2001).

Leading Causes of Death in Childhood Have Changed

In 1900, pneumonia and influenza, tuberculosis, and enteritis with diarrhea were the three leading causes of death in the United States, and children under 5 accounted for 40 percent of all deaths from these infections (CDC, 1999a). Today, only pneumonia (in combination with influenza) is among the top 10 causes of death overall or for children. Substantial declines in mortality have continued in recent decades. During the past 40 years, infant deaths due to pneumonia and influenza fell from 314 per 100,000 live births in 1960 to 8 per 100,000 in 1999 (Singh and Yu, 1995; NCHS, 2001b). As infectious disease mortality has declined in significance, unintentional and intentional injuries have emerged as leading causes of death, especially for children past infancy.

In 1960, infant deaths from short gestation/low birth weight and congenital anomalies (described in federal reports as "congenital malformations, deformations, and chromosomal abnormalities") occurred at rates of 457 and 361 per 100,000 live births, respectively (Singh and Yu, 1995). By 1999, these rates had dropped to 111 and 138 per 100,000, respectively (NCHS, 2001b).

More recently, mortality from sudden infant death syndrome (SIDS), which was first reported as a separate cause of death in 1973, has dropped substantially—by more than a third between 1992 and 1996, with continuing decreases since then (Willinger et al., 1998; NCHS, 2000b). SIDS is still, however, the third leading cause of infant death in this country.

Children Have Different Patterns of Mortality Than Adults

As shown in Table 2.1 (which uses broader age categories than those used later in this chapter) the leading causes of death differ considerably for children compared to adults, especially elderly adults. For infants, the leading causes of death include congenital anomalies (a highly diverse group of malformations and other conditions), disorders related to short gestation and low birth weight, and sudden infant death syndrome. For older children and teenagers, mortality from unintentional and intentional injuries grows in importance. Among adults, as age increases, the relative contribution of injuries decreases, and death rates related to chronic conditions such as heart disease increase sharply. Beginning in adolescence, increasing age also brings increases in causes of death linked to individual behaviors involving diet, exercise, smoking, alcohol use, and similar factors.

Figure 2.1 shows the percentages of all deaths in childhood accounted for by leading causes of child mortality. Table 2.2 shows the proportion of all deaths for given age groups accounted for by the top five leading causes of death. For most age groups, a few causes of death account for two-thirds

TABLE 2.1 Top Ten Causes of Death, Numbers of Deaths by Cause and Total, and Total Death Rates, by Age Group (1999)

	Age Group (years)			
Rank	Infant (<1)	1–4	5–14	15–24
1	Congenital anomalies[a] 5,473	Accidents[b] 1,898	Accidents 3,091	Accidents 13,656
2	Short gestation and LBW[c] 4,392	Congenital anomalies 549	Malignant neoplasms 1,012	Homicide 4,998
3	SIDS 2,648	Malignant neoplasms 418	Homicide 432	Suicide 3,901
4	Complications of pregnancy 1,399	Homicide 376	Congenital anomalies 428	Malignant neoplasms 1,724
5	Respiratory distress syndrome 1,110	Diseases of the heart 183[4]	Diseases of the heart 277	Diseases o the heart 1,069
6	Placental cord membranes 1,025	Pneumonia and influenza 130	Suicide 242	Congenita anomalies 434
7	Accidents 845	Perinatal period[e] 92	Chronic lower respiratory diseases 139	Chronic lo respirator 209
8	Newborn Sepsis 691	Septicemia 63	Benign neoplasms 101	HIV 198
9	Diseases of the circulatory system 667	Benign neoplasms 63	Pneumonia and influenza 93	Stroke 182
10	Atelectasis[f] 647	Chronic lower respiratory diseases 54	Septicemia 77	Pneumoni and influe 179

ause and

	15–24	25–44	45–64	>65
	Accidents 13,656	Accidents 27,121	Malignant neoplasms 135,748	Diseases of the heart 607,265
t s	Homicide 4,998	Malignant neoplasms 20,737	Diseases of the heart 99,161	Malignant neoplasms 390,122
	Suicide 3,901	Diseases of the heart 16,666	Accidents 18,924	Stroke 148,599
l	Malignant neoplasms 1,724	Suicide 11,572	Stroke 15,215	Chronic lower respiratory disease 108,112
of	Diseases of the heart 1,069	HIV infection 8,961	Chronic lower respiratory diseases 14,407	Pneumonia and influenza 57,282
	Congenital anomalies 434	Homicide 7,437	Diabetes mellitus 13,832	Diabetes mellitus 51,843
ower y diseases	Chronic lower respiratory diseases 209	Diseases of the liver 3,709	Diseases of the liver 12,005	Alzheimer's Disease 44,020
oplasms	HIV 198	Stroke 3,154	Suicide 7,977	Accidents 32,219
a enza	Stroke 182	Diabetes mellitus 2,524	HIV 5,056	Nephritis 29,938
a	Pneumonia and influenza 179	Pneumonia and influenza 1,402	Septicemia 4,399	Septicemia 24,626

continued next page

TABLE 2.1 Continued

	Age Group (years)			
Rank	Infant (<1)	1–4	5–14	15–24
Total deaths (all causes)	27,937	5,249	7,595	30,656
Death rate per 100,000 (all causes)	705.6[g]	34.7	19.2	81.2

NOTE: The rank order of leading causes of death changed somewhat between 1998 and 1999, reflecting in part changes in the coding rules for selecting underlying cause of death between the ninth and tenth editions of the International Classification of Diseases.

[a] Congenital malformations, deformations, and chromosomal abnormalities.

[b] Most vital statistics reports now use the term "unintentional injury" rather than accidents.

[c] LBW = low birth weight.

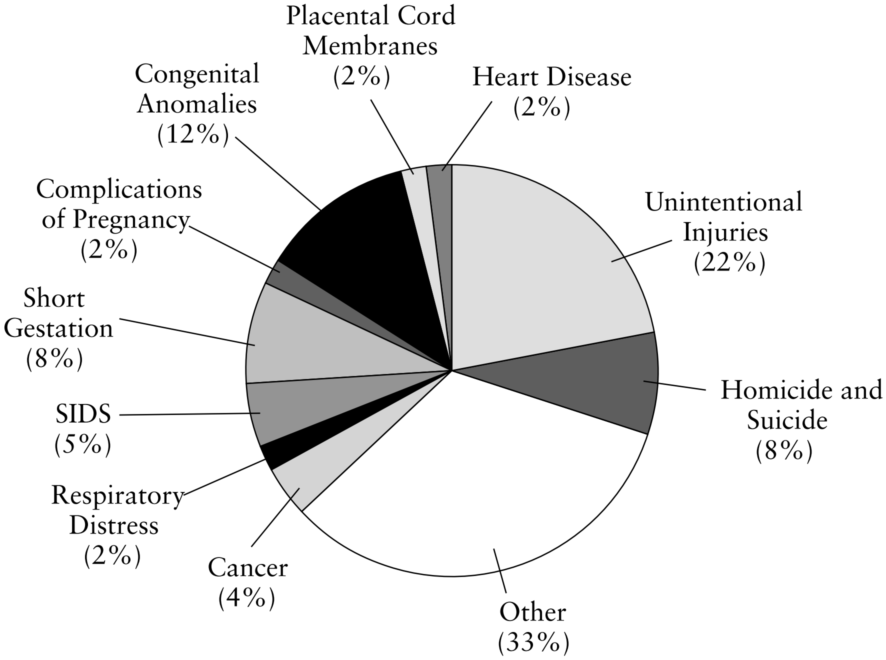

FIGURE 2.1 Percentage of total childhood by major causes (1999).
SOURCE: NCHS, 2001a.

15–24	25–44	45–64	>65
30,656	130,322	391,953	1,797,331
81.2	157.5	662.2	5,203.6

[d] Deaths related to congenital malformations of the heart are included with congenital anomalies.

[e] Certain conditions originating in the perinatal period.

[f] Pulmonary collapse or, more generally, absence of gas from part or all of the lung.

[g] Death rate calculated per 100,000 population (under 1 year) rather than per 1,000 live births, which is the infant mortality rate (see Table 2.4)

SOURCE: NCHS, 2001a, b.

to three-quarters of all deaths. The major exception involves infants who die from a broader array of medical problems, as discussed in more detail below.

Most Children Are Healthy, but Many Live with Serious Health Problems

Although experts worry about the long-term health consequences of common problems such as juvenile obesity and lack of exercise, most children are healthy. Nonetheless, many children live with special health care needs, in part because medical and clinical advances make it possible to save and prolong the lives of children who in earlier times would have died from prematurity, congenital anomalies, injuries, and other problems.

As defined by the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services, children with special health care needs "have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and . . . also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138).[3] These conditions include cerebral palsy,

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[3] The definition is not yet consistently used, even by the government. For example, one federal government web site (www.childstats.gov) uses the term to describe children who are "limited in their activities because of one or more chronic health conditions."

TABLE 2.2 Percentage of All Deaths Due to Top Five Leading Causes, by Age (1999)

Age (years)	Percentage of Total
<1	53
1–4	65
5–9	71
10–14	69
15–19	84
20–24	81
25–44	66
45–64	74
>65	73

SOURCE: NCHS, 2001a,b.

vision loss, sickle cell anemia, asthma, mental retardation, autism, and serious learning disorders (NRC, 1996; Newacheck et al., 1998).

Newacheck (2000) has estimated that some 18 percent of children (more than 12 million) have special health care needs, which range from modest to extraordinary. Most have conditions that are not expected to lead to death in childhood. Of the estimated 12.8 million individuals with needs for long-term care at home or elsewhere, approximately 384,000 were children (National Academy on Aging, 1997).

A study by Feudtner and colleagues (2001) found that complex chronic conditions such as cancer and cardiovascular problems accounted for nearly 15,200 deaths among individuals 0 to 24 years of age in 1997. (Note that this estimate spans an additional five years beyond the 0 to 19 age range discussed in this chapter.) The researchers estimated that on any given day, about 5,000 of these individuals were in their last six months of life and potentially could have benefited from hospice care based on restrictive Medicaid eligibility criteria.

A working group on pediatric palliative care has estimated that about 8,600 children would benefit on any given day from palliative care services because of their limited life expectancy and serious needs (ChIPPS, 2001). This estimate did not link the potential for benefit to an assumed life expectancy of six months or less, a criterion for Medicare or Medicaid hospice benefits.

Some children who die from critical acute problems might need intensive palliative or hospice services for a few days or even hours, whereas children with complex chronic problems might need mostly intermittent services over a period of months or years. A substantial percentage of children would not benefit from palliative or hospice services because they die suddenly and unexpectedly, leaving caregivers to tend to the bereaved family.

The next three sections of this chapter review death rates and major causes of death for children by broad age groups. Later sections consider socioeconomic and other disparities in death rates and causes of death.

INFANT, FETAL, AND PERINATAL DEATHS

Because so many deaths occur during pregnancy and in the first year after birth and because understanding the causes of such deaths is of particular interest, a number of terms have been developed to describe and differentiate these deaths. Table 2.3 lists the most widely used terms and their definitions and also includes other common terms and definitions relating to this period.

Death Rates and Numbers

Table 2.4, which shows trends in infant, fetal, and perinatal mortality rates since 1950, reveals continuing mortality decreases in the last half-century. In 1999, the infant mortality rate in the United States reached a low of 7.1 infant deaths per 1,000 live births, or 28,371 total infant deaths. After infancy, the mortality rate drops significantly and does not rise again to similar rates until people reach their mid-50s.

More children die in the first year of life than in all other years of childhood combined (27,937 infants compared to 26,622 children aged 1 to 19 years in 1999) (see Figure 2.2). Two-thirds of infant deaths occur in the neonatal period (18,728 of 27,937 deaths).

Of some 6.2 million pregnancies each year, about 63 percent result in a live birth, 20 percent in an induced abortion, and 15 percent in a fetal death (Martin and Hoyert, 2001). Ninety percent of spontaneous fetal losses occur within the first 20 weeks of pregnancy. A large percentage of these end so early that the pregnancy is unrecognized. Most of the decline in fetal death rates in recent decades has occurred in the late fetal period.

Leading Causes of Infant Death

Understanding the common causes of infant death is important in understanding the potential role of supportive care for these children and their families. Table 2.5 reports the five leading causes of infant, neonatal, and postneonatal death. These causes account for approximately 54 percent of all infant deaths. In contrast, the next five causes (complications of placenta, cord, and membranes; infections; unintentional injuries; intrauterine

TABLE 2.3 Terminology Relating to Infants and Fetuses

Term	Definition
Infant	Child less than 1 year of age
Full-term infant	Infant born between 37 and 42 weeks' gestation
Premature infant	Infant born before 37 weeks of gestation
Neonatal period	First 27 days of life[a]
Early neonatal period	First 6 days of life[a]
Postneonatal period	Days 28–365 of life[a]
Low birth weight	Birth weight less than 2,500 grams (5.5 pounds) at birth
Very low birth weight	Birth weight less than 1,500 grams (3.3 pounds) at birth
Extremely low birth weight	Birth weight less than 1,000 grams (2.2 pounds) at birth
Miscarriage or spontaneous abortion	Naturally occurring, spontaneous expulsion of a human fetus, especially between the twelfth and twenty-seventh weeks of gestation
Antepartum fetal death	Death of a fetus before labor begins
Intrapartum fetal death	Death of a fetus during labor
Fetal death	Death of fetus prior to complete expulsion or extraction from the mother of a product of human conception (irrespective of duration of pregnancy) that is not an induced termination of pregnancy.[b] Some states use the term "stillbirth" for such fetal deaths
Late fetal deaths	Fetal deaths of 28 weeks' or more gestation[b]
Perinatal mortality	Late fetal deaths plus infant deaths within 7 days of birth. (definitions of perinatal mortality vary and sometimes include fetal and infant deaths from the twentieth or the twenty-eighth week of gestation through the seventh or twenty-seventh day of life)
Infant mortality rate	Number of infant deaths per 1,000 live births

[a] NCHS, 2001c, Table 23.

[b] NCHS, 1997. The federal government recommends that state governments, for vital statistics reporting purposes, report fetal deaths of 350 grams or more or, if the weight is unknown, 20 weeks' or more gestation; 13 U.S. jurisdictions follow this recommendation, but the majority (25) use only the 20 weeks' gestation criterion. Fetal mortality rates are based on deaths of 20 or more weeks' gestation.

hypoxia and birth asphyxia; and pneumonia and influenza) account for approximately 14 percent of deaths.

Congenital anomalies and disorders relating to short gestation and unspecified low birth weight dominate as causes of neonatal deaths. During the postneonatal period, SIDS and unintentional injuries and intentional

TABLE 2.4 Infant, Fetal, and Perinatal Mortality Rates, Selected Years 1950–1999

		Neonatal					
Year	Infant(All)	<28 Days	< 7 Days	Post-neonatal	Fetal	Late Fetal	Perinatal
1950	29.2	20.5	17.8	8.7	18.4	14.9	32.5
1970	20.0	15.1	13.6	4.9	14.0	9.5	23.0
1990	9.2	5.8	4.8	3.4	7.5	4.3	9.1
1999	7.1	4.8	3.8	2.4	6.7	3.4	7.2

NOTES: Infant, neonatal, and postneonatal rates are based on deaths per 1,000 live births.
Fetal mortality rate = number of fetal deaths of 20 weeks or more gestation per 1,000 live births plus fetal deaths (at 20 weeks or more). Fetal deaths are sometimes called stillbirths, but terms and criteria (e.g., gestation period, weight) vary among jurisdictions (NCHS, 1997). Late fetal mortality rate = number of fetal deaths of 28 weeks' or more gestation per 1,000 live births plus late fetal deaths. Perinatal mortality rate = number of late fetal deaths plus infant deaths within 7 days of birth per 1,000 live births.
SOURCE: NCHS, 2001c.

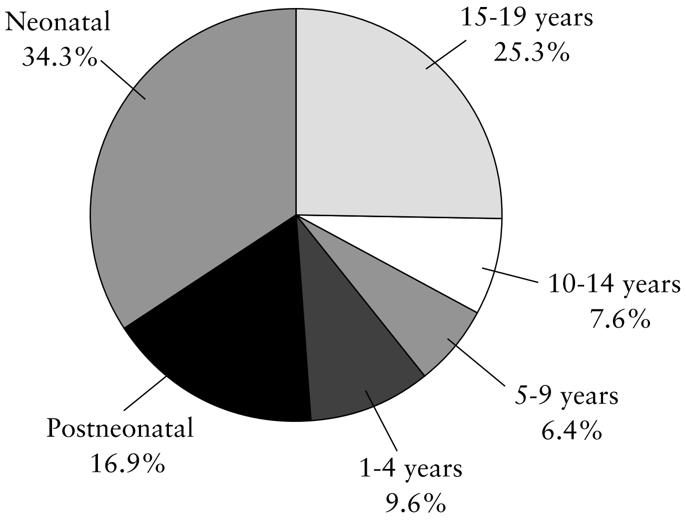

FIGURE 2.2 Percentage of total childhood deaths by age group (1999).
SOURCE: NCHS, 2001b.

injuries increase in relative importance, although the mortality rate overall is substantially lower. Congenital anomalies also cause deaths among children past infancy, but they do so to a lesser extent because most children with problems likely to prove fatal have already died.

Feudtner and colleagues (2001) reported that about one-quarter of all infant deaths in Washington state during 1980 to 1998 were linked to complex chronic conditions such as cardiac, brain, and spinal malformations, with the rest relatively evenly divided between injuries and other acute events (e.g., extreme prematurity, SIDS, respiratory distress syndrome). For the entire group of children, approximately one-fifth of all deaths were linked to chronic complex conditions.

Congenital Anomalies

Congenital anomalies, whether detected before or after birth, can involve any part of an infant. (Federal mortality reports refer to "congenital malformations, deformations, and chromosomal abnormalities" [NCHS, 2001b, p. 71].) Definitions vary. For example, one source defines them as "structural defects present at birth" (*Merck Manual,* 2001, Chapter 261). Another definition is "existing at birth, referring to certain mental or physical traits, anomalies, malformations, diseases, etc. which may be either

TABLE 2.5 Top Five Causes of Infant, Neonatal, and Postneonatal Mortality and Total Deaths (1999)

Rank	Infant Mortality	No.	Neonatal Mortality	No.	Postneonatal Mortality	No.
1	Congenital anomalies	5,473	Short gestation and LBW	4,320	SIDS	2,440
2	Short gestation and LBW	4,392	Congenital anomalies	3,892	Congenital anomalies	1,581
3	SIDS	2,648	Complications of pregnancy	1,391	Accidents and adverse effects	743
4	Complications of pregnancy	1,399	Respiratory distress syndrome	1,050	Pneumonia and influenza	399
5	Respiratory distress syndrome	1,110	Complications of placenta, cord, membrane	1,010	Homicide	288
Total (all causes)		27,937		18,728		9,209

SOURCE: NCHS, 2001b.

hereditary or due to an influence occurring during gestation up to the moment of birth" (*Stedman's Medical Dictionary,* 1995). Congenital anomalies may be inherited or sporadic (for example, arising de novo during embryonic development). Some are readily evident during physical examination at birth, whereas others are detectable only by radiologic, genetic, or other testing. Many defects may be detected before birth by ultrasound examination or examination of fluid or tissue samples.

Congenital anomalies can arise from fetal environmental causes (e.g., drug exposure, infection, maternal nutritional deficiencies, injury) or from chromosomal or genetic abnormalities (which may be inherited or spontaneous). About one newborn in 100 has a hereditary malformation, and about 1 in 200 has an inherited metabolic disorder or an abnormality of the sex chromosomes (Shapiro, 2000). Most anomalies are not lethal, and most (for example, an extra finger, toe, or nipple) have little effect on infant health. The most serious structural anomalies affect the formation of the heart, brain, or other vital organs, and many fatal inherited disorders involve neuromuscular or metabolic functions.

Congenital heart disease is the major cause of death in children with congenital anomalies, but it still occurs in only 0.5 to 0.8 percent of live births. The incidence of cardiac anomalies is higher in fetal deaths (10 to 25 percent) and premature infants (about 2 percent, excluding patent ductus arteriosis, a common heart problem that results from the persistence of a fetal circulatory pattern, not from a malformation) (Bernstein, 2000). Advances in surgical procedures, in particular, have significantly improved outcomes for infants with congenital heart problems, but survival is still limited for infants with uncorrectable malformations or coexisting defects in other vital organs.

Congenital disorders of the nervous system that are often or always fatal include anencephaly (absence of all or a major part of the brain) and severe spina bifida (especially rachischisis, a completely open spine) among others. Anencephaly and spina bifida (all degrees of severity) each occur in approximately 1 in 1,000 live births. Virtually all children with anencephaly die within days after birth. The overall risk of mortality for children with spina bifida is 10 to 15 percent, and death usually occurs within the first 4 years of life. Children with severe spinal cord defects who survive often have major chronic care needs (e.g., assistance in eating, bathing, toileting, and dressing). Even with surgical repair of the spinal opening, the spinal cord injury is permanent. The extent of paralysis or mental retardation depends on the location and extent of the defect (Haslam, 2000). Congenital anomalies can also affect the gastrointestinal tract, skeletal system, genitourinary system, circulatory system, and pulmonary system, with varying prognoses depending on the severity of the anomaly and its susceptibility to surgical correction.

Genetic abnormalities may be inherited or arise sporadically. For example, trisomy 13 (Pateau syndrome), trisomy 18 (Edward's syndrome), and trisomy 21 (Down syndrome), conditions in which an extra chromosome is present, are typically not inherited in the usual sense but tend to arise from age-linked errors in the division of ova. Trisomy 13 and 18 are almost always fatal, with less than 10 percent of children surviving more than one year (*Merck Manual,* 2001, Chapter 261). In contrast, trisomy 21 (Down syndrome) rarely leads to death in childhood, but associated problems (e.g., cardiac and skeletal anomalies and a propensity to leukemia) generally cause death by middle age. Duchenne muscular dystrophy and Tay-Sachs disease are among a number of nonchromosomal genetic disorders that are inherited and usually or always lead to death in childhood.

Low Birth Weight and Prematurity

Short gestation and low birth weight are the leading causes of neonatal mortality and handicaps in infants (Stoll and Kliegman, 2000b; see also Sowards, 1999). Most very low birth weight infants are premature, rather than simply small for their gestational age. Only 20 percent of infants weighing 500 to 600 grams at birth survive, compared to 85 to 90 percent of those weighing between 1,250 and 1,500 grams. Similarly, very few infants born at 22 weeks' gestation survive, but more than 95 percent of those born at 30 weeks do.

Most extremely low birth weight (<1,000 grams at birth) infants who die do so within a few days of birth, although some survive for weeks or months before dying (see, e.g., Meadow et al., 1996; Lemons et al., 2001; Tommiska et al., 2001). A study by Meadow and colleagues (1996) reported that the survival rate at birth for these infants was 47 percent but rose to 81 percent by the fourth day of life. After the fourth day of life, an infant's overall severity of illness was a more important factor in survival than the original birth weight. Mortality for premature infants results primarily from conditions associated with immature organs (e.g., respiratory distress related to immature lungs and intraventricular hemorrhage, bleeding into the brain related to underdeveloped cerebral blood vessels) or infection (e.g., sepsis [infection of the blood], necrotizing enterocolitis [an inflammation that causes injury to the bowel], pneumonia) that are complicated by an insufficiently developed immune system.

Sudden Infant Death Syndrome

SIDS is the most common cause of death in infants after 1 month of age. It is a diagnosis of exclusion when a postmortem examination, death scene investigation, and review of case records fail to reveal a specific cause of death. Deaths typically occur between 2 and 4 months of age, and 90 percent of SIDS deaths occur before the child is 6 months old (AAP, 2001c). Environmental factors such as the baby's sleeping position, soft bedding, and cigarette smoke have been implicated as risk factors. An immaturity of the infant's innate ability to control his or her breathing, heartbeat, blood pressure, or arousal level may also contribute to these deaths (AAP, 2001c). Educational programs encouraging parents to put infants to sleep on their backs (the "Back to Sleep" campaign) have been credited as an important factor in the reduction of SIDS rates (Willinger et al., 1998; AAP, 2000b).

The vast majority of unexpected and unexplained infant deaths are caused by SIDS. Experts estimate, however, that between 1 and 5 percent of deaths that are diagnosed as SIDS may actually result from intentional suffocation or other abuse (AAP, 2001c). For this reason and, more generally, to learn more about sudden unexplained infant deaths, death scene investigations of all such deaths are recommended (AAP, 1999c), although no uniformly accepted standards for such investigations now exist (NMRP, 1999). Autopsies are performed in approximately 90 percent of sudden infant deaths that occur without evident explanation (Iverson, 1999). In addition, although the details vary, an increasing number of jurisdictions routinely require an assessment of child deaths by multidisciplinary child fatality review teams that attempt to determine the circumstances surrounding child deaths and identify preventable causes of death, including child abuse and neglect. As discussed later, police investigations, although necessary when the cause of a child's death is unexplained, add extra stress for parents and warrant extra sensitivity by investigators who meet parents.

MORTALITY FOR CHILDREN AGED 1 TO 4 AND 5 TO 9

Death Rates and Numbers

Children in these age groups are much less likely to die than infants. The death rate for infants is more than 751 per 100,000 population (and 7.2 per 1,000 live births) whereas the death rate for children aged 1 to 4 is 34.6 per 100,000 and for children aged 5 to 9 is 17.7 per 100,000 (Tables 2.2 and 2.6). Of the age groups reviewed in this chapter, children aged 5 to 9 have the lowest death rate, with lower rates of death from most leading causes including unintentional and intentional injuries.

TABLE 2.6 Top Five Causes of Death in Children Aged 1–4 and 5–9 Years, Death Rates, and Total Deaths (1999)

Rank	Mortality Ages 1–4	No.	Rate[a]	Mortality Ages 5–9	No.	Rate[a]
1	Unintentional injury	1,898	12.6	Unintentional injury	1,459	7.3
2	Congenital anomalies	549	3.6	Malignant neoplasms	509	2.6
3	Malignant neoplasms	418	2.8	Congenital anomalies	207	1.0
4	Homicide	376	2.5	Homicide	186	0.9
5	Diseases of the heart	183	1.2	Diseases of the heart	116	0.6
Total (all causes)		5,249	34.7		3,474	17.4

[a] Per 100,000 population in age group.

SOURCE: NCHS, 2001a.

Leading Causes of Death for Children 1 to 4 and 5 to 9

Not only death rates but also causes of death differ significantly for children who survive their first year. In particular, unintentional and intentional injuries become more important. The diseases that kill so many older adults—heart disease and cancer—kill relatively few children in these age groups. As shown in Table 2.6, more children aged 1 to 4 were murdered in 1999 than died of heart disease.

Unintentional Injuries

Unintentional injuries are the leading cause of death in children ages 1 to 9. In 1999, they accounted for 36 percent of deaths in the 1 to 4 age group and 42 percent of deaths in the 5 to 9 age group.

Among children aged 1 to 4, motor vehicle occupant injury is the leading cause of unintentional injury-related death, followed by drowning, fire and burns, airway obstruction injuries (choking and suffocation), and motor vehicle pedestrian injuries. Among children aged 5 to 9, motor vehicle occupant injury is again the leading cause of unintentional injury-related death, followed by drowning, fire and burns, airway obstruction injuries, and other transportation fatalities (NCHS, 2001b). Failure to wear seat belts is an important factor in motor vehicle deaths. Nearly 6 out of 10 children under the age of 15 killed in a motor vehicle crash in 2000 were not restrained by a seat belt or child safety seat (NHTSA, 2000).

Congenital Anomalies

Congenital anomalies continue to be a leading cause of death for children in the 1 to 4 age group and, to a lesser extent, the 5 to 9 age group. The total deaths from this cause were, however, slightly more than 800 in 1999 for both age groups combined compared to more than 5,000 for the infant group.

Malignant Neoplasms

Cancer is the leading disease-related cause of death for children more than 1 year of age.[4] In 1999, 2,244 children aged 0 to 19 died of malignant neoplasms (NCHS, 2001a). Analyses by the National Cancer Institute show

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[4] Cancer is not a leading cause of infant death (see Table 2.1). Nonetheless, although it causes only 0.2 percent of infant deaths, the peak incidence of childhood cancer occurs in the first year of life. Infants fare worse than older children for some diagnoses (e.g., acute lymphoblastic leukemia) but better for others (e.g., neuroblastoma) (Ries et al., 1999, 2001).

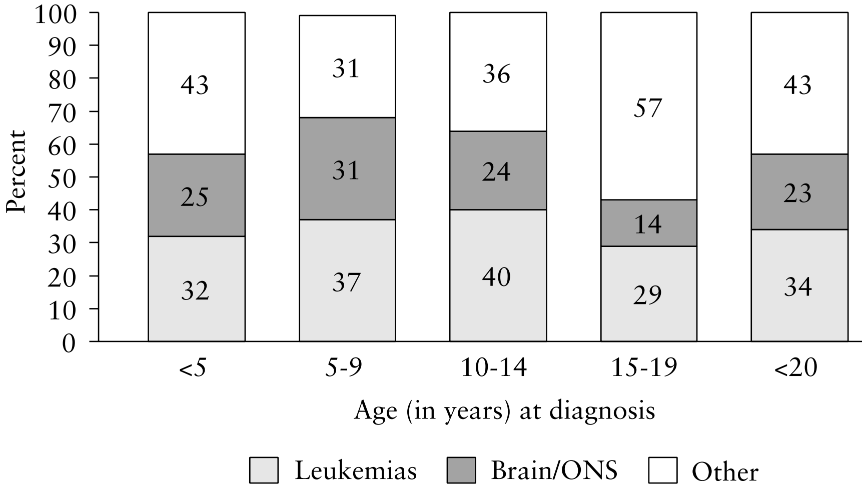

FIGURE 2.3 Percentage distribution of childhood cancer mortality by type and age group, age <20 (1995).
NOTE: ONS = other nervous system.
SOURCE: Ries et al., 1999.

that leukemias and cancers of the brain and central nervous system are the most frequent causes of cancer-related deaths in those under age 20 (Figure 2.3) (Ries et al., 1999, 2001). For adults, lung cancer, breast cancer, and prostate cancer dominate as cancer-related causes of death (Reis et al., 2001).

Survival rates for most childhood cancers have improved dramatically over the past three decades. Age-adjusted mortality dropped by nearly 44 percent from 1975 to 1998 (Ries, 2001). For leukemias in childhood, the decrease was more than 55 percent, but for brain and other nervous system tumors, it was considerably smaller, 24 percent.

According to the National Cancer Institute, the death rate between 1994 and 1998 from all cancers was 2.7 per 100,000 for children aged 0 to 4 and 5 to 9 years (Ries, 2001). Leukemias and brain and other nervous system cancers were the most common types of cancer in these two age groups (as well as in the 10- to 14-year group). They also accounted for more than half the cancer mortality for these age groups. Five-year relative survival rates for children in all age groups for these cancers were fairly similar—between 76 and 79 percent—for the period 1992 to 1997.

Intentional Injuries

In 1990 to 1995, the homicide rate for children aged 1 to 14 in the United States was five times the rate in other industrialized countries (CDC, 1997). The rate of suicide was twice as high for the United States. Although the overall death rate for children decreased substantially during 1950 to 1993, homicide rates tripled and suicide rates quadrupled. More recently, child deaths due to homicide have been declining (NCHS, 2001c). Firearms are the major cause of homicide deaths among children in the United States. Gunshot wounds account for 5 percent of pediatric injuries seen in emergency departments and produce the highest death rate due to injury (NPTR, 2001).[5]

In 1999, homicide was the fourth leading cause of death for children aged 1 to 4 years and was also the fourth leading cause for 5- to 9-year-olds, who had the lowest rate among children. Homicide mortality was nearly threefold higher (2.5 deaths per 100,000, or 376 deaths) for children aged 1 to 4 years than for the 5 to 9 age group (0.9 per 100,000, or 186 deaths). As discussed below, homicide mortality rates vary not only by age but by sex and other characteristics.

Although young children are less likely to be victims of violence than are adolescents, when they are victims, parents and other caretakers are more likely than acquaintances and strangers to have inflicted the abuse, especially for children aged 1 to 4. Within the category of parents and other caretakers, analyses of data from the Federal Bureau of Investigation indicate that parents accounted for 60 percent of the abuse reported to the police, and stepparents and boyfriends or girlfriends of parents accounted for 19 percent (Finkelhor and Ormrod, 2001). As discussed in Chapter 8, such abusive situations present ethical and legal problems related to normal parental responsibilities for decisions about children's medical care.

MORTALITY FOR CHILDREN AGED 10 TO 14 AND 15 TO 19

Death Rates and Numbers

The age groups 10 to 14 and 15 to 19 include the adolescent years. Adolescents can, however, be categorized differently based on social, biological, or developmental criteria. For example, those age 18 and older are legally adults. In most states, they can obtain a driver's license at age 16. Still, pediatricians may continue to care for patients with complex chronic conditions even after they have entered early adulthood.

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[5] The National Pediatric Trauma Registry is a multicenter nationwide registry established in 1985 to study the etiology of pediatric trauma and its consequences.

TABLE 2.7 Top Five Causes of Death for Adolescents (1999)

Rank	Mortality Ages 10–14	No.	Rate[a]	Mortality Ages 15–19	No.	Rate[a]
1	Unintentional injury	1,632	8.3	Unintentional injury	6,688	33.9
2	Malignant neoplasms	503	2.6	Homicide	2,093	10.6
3	Homicide	246	1.3	Suicide	1,615	8.2
4	Suicide	242	1.2	Malignant neoplasms	745	3.8
5	Congenital anomalies	221	1.1	Heart Disease	463	2.3
Total (all causes)		4,121	21.1	Total (all causes)	13,778	69.8

[a] Per 100,000 population in the age group.

SOURCE: NCHS, 2001b.

Leading Causes of Death for Children 10 to 14 and 15 to 19

Table 2.7 reports the leading causes of death for children aged 10 to 14 and 15 to 19. Overall, 10- to 14-year-olds have death rates similar those of 5- to 9-year-olds. For older teenagers, however, death rates rise sharply—more than tripling compared to the 10 to 14 age group. This increased mortality reflects developmental changes, including increased risk-taking behaviors as adolescents accelerate their independence from their parents.

Unintentional Injuries

Unintentional injuries are the leading cause of death for both younger and older adolescents, but the rate for older adolescents is almost four times that of the younger group. Not surprisingly, given that younger children are not legally allowed to drive, the rate of unintentional deaths involving motor vehicles increases dramatically with age, from 5.0 deaths per 100,000 children aged 10 to 14 to 26.3 deaths per 100,000 in those aged 15 to 19 in 1999 (NCHS, 2001e). Almost three-quarters of all unintentional traumatic deaths in the older adolescent group involved motor vehicle crashes, including collisions between vehicles, single-car crashes, collisions with fixed objects (e.g., telephone poles, trees), pedestrians, and trains. Older teens also have higher death rates for other kinds of injuries (7.3 per 100,000 for those aged 15 to 19 compared to 3.5 per 100,000 for those aged 10 to 14 in 1998) (NCHS, 2001e).

The teens who die in motor vehicle crashes are passengers 86 percent of the time, but in 68 percent of those crashes, the driver is also a teenager. Alcohol is a significant factor when teens are killed in motor vehicle crashes, with more than half of the teenaged victims found to have blood alcohol levels 0.1 mg/dL or greater (Jones et al. 1992).

Intentional Injuries

Homicide and suicide mortality rates increase as children move through adolescence, with greater than an eight-fold difference between the younger and older adolescent groups for homicide and about seven-fold difference for suicide. Among 10- to 14-year-olds, homicide was the third leading cause of death in 1999, and suicide ranked fourth. For those aged 15 to 19, homicide was the second leading cause of death with suicide ranking third. The majority of suicide and homicide deaths in both age groups were linked to firearms (NCHS, 2001e).

Malignant Neoplasms

Adolescents tend to suffer from different types of cancers than younger children (Ries et al., 1999). Embryonal cancers (e.g., neuroblastoma, Wilms' tumor) are uncommon cancer diagnoses in this age group; germ cell cancers (e.g., testicular cancer) are more common. In 1995, the top four causes of cancer mortality in 10- to 14-year-olds were leukemia, brain and central nervous system (CNS) tumors, bone and joint tumors, and non-Hodgkin's lymphoma (Ries et al., 1999). In 15- to 19-year-olds, the top causes of mortality due to malignant neoplasm were brain and CNS tumors, leukemia, bone and joint tumors, sarcomas, and non-Hodgkin's lymphoma.

Overall, malignant neoplasms are the second leading cause of death in 10- to 14-year-olds and the fourth leading cause of death in 15- to 19-year-olds. The cancer death rate is, however, slightly higher in the older teens than in the younger group (3.8 per 100,000 versus 2.6 per 100,000 in 1999) (NCHS, 2001b). Between 1973 and 1992, the incidence of cancer rose the most and the death rate decreased the least in the 15- to 19-year age category compared to any other child or adult age group (Bleyer et al. 1997).

GENDER, SOCIOECONOMIC, AND OTHER DIFFERENCES AND DISPARITIES IN CHILD MORTALITY

Whether the objective is preventing deaths or planning programs to improve palliative and end-of-life care for children and their families, one useful step is examining demographic and other data for risk factors or variables associated with different rates or causes of child death. Variables typically examined include geographic location, age, sex, socioeconomic and ethnocultural characteristics, and community characteristics such as density, average income or income inequality, and rates of violence.[6]

Differences and Disparities by Region

Reflecting social, economic, physical, and other differences, states and regions show considerable variation in child mortality by cause. One stark contrast involves infant mortality. In 1999, the District of Colombia had the highest infant mortality rate (15.0 per 1,000 live births), followed by South Carolina (10.2 per 1,000 live births). Maine and Utah had the lowest rate in 1999 at 4.8 deaths per 1,000 live births (NCHS, 2001e).

In 1999, for those aged 0 to 19, Wyoming led the nation in motor vehicle fatality rates (23.5 per 100,000), followed by Mississippi (20.9 per 100,000). The lowest fatality rates were for Hawaii (3.6 per 100,000) and Rhode Island (3.8 per 100,000) (NCHS, 2001e). For motor vehicle fatalities involving all ages, factors contributing to differences in rates appear to include population density, proportions of light and heavy trucks in use, alcohol use, and delayed medical care (see, e.g., Muelleman and Mueller, 1996). Two single-state studies, one in Colorado (Hwang et al., 1997) and one in Alabama (King et al. 1994), reported higher death rates from motor vehicle crashes and unintentional injuries for children in rural areas. Another study reported that rural children ages 1 to 19 had a 44 percent higher death rate from injuries than their urban counterparts in 1992, with the greatest differences found in the 15 to 19 age group (Ricketts, 2000). (Reported differences in urban and rural death rates may vary depending on how rural and urban are defined [Farmer et al., 1993]).

Juvenile homicide rates also differ substantially among states. Maryland led the nation in 1999 with a homicide rate of 7.8 per 100,000, followed by Illinois at 7.25 per 100,000. Hawaii and Utah had the lowest

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[6] Reporting categories for published information from various data sets that include mortality are not completely standardized. For example, the federal government's primary mortality report provides information by Hispanic origin and by race (white and black non-Hispanics (NCHS, 2001a). In contrast, published information from the NCHS linked data set of births and infant deaths subdivides infants by Hispanic origin (black and white) and by race (white, black, American Indian, and Asian or Pacific Islander (NCHS, 2000b). Because death information is linked to information collected at birth, the latter data set also includes more detailed individual data such as the mother's age, educational attainment, marital status, place of birth (U.S. or foreign), and smoking during pregnancy. Information about the infant includes birth order, birth weight, period of gestation, and trimester when prenatal care began.

TABLE 2.8 Death Rates for Selected Causes by Geographic Region (1999)

Region	Infant Mortality	Motor Vehicle (ages 15–19)	Suicide (ages 15–19)	Homicide (ages 15–19)
Northeast	13.6	19.0	5.9	8.0
South	32.8	33.3	8.5	11.8
Midwest	30.8	26.3	8.7	10.7
West	23.5	30.0	8.8	11.0

NOTE: Infant mortality rate is per 1,000 live births. Other death rates are per 100,000 children aged 15 to 19. Homicide deaths include deaths from homicides and legal interventions.

Regions: Northeast (Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont); South (Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia); Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin); and West (Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming).

SOURCE: NCHS, 2001e.

rates at 0.6 and 0.75 per 100,000, respectively[7] (NCHS, 2001e). For homicide rates across all age groups, factors contributing to variations appear to include level of urbanization and socioeconomic conditions (see, e.g., Cubbin et al., 2000).

On a regional basis (Table 2.8), the South led the nation in infant mortality, homicides, and motor vehicle-related mortality rates for ages 15 to 19. The West Coast led in suicide rates for this age group. The Northeast region had the lowest death rates for all categories reported here.

Gender Differences

Across all age ranges and for most causes of death, boys have a higher death rate than girls. The disparity increases with age and ranges from a 20 percent higher death rate for male children less than 5 to a 130 percent greater death rate for older adolescent boys compared to girls (NCHS, 2001a).

Male gender is a major risk factor for all injury-related deaths (NPTR, 2001; Hussey, 1997). The most dramatic gender difference is seen in the homicide rate for older adolescents. Boys are more than five times as likely

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[7] Rates are based on fewer than 20 deaths throughout the year.

to be victims of homicide than girls (1,748 boys aged 15 to 19 were killed compared to 345 teen girls in 1999 aged 15 to 19). Thus, homicide prevention efforts typically focus on young males. For those concerned about support for survivors, special attention to the psychological impact on young male siblings and friends of teen homicide victims may serve dual goals of support for the grieving and preventing further violence.

Socioeconomic and Ethnocultural Differences

A number of studies have examined the association between socioeconomic variables—including income, education, and social status—and variations in mortality among geographic areas and population subgroups (see, e.g., IOM, 2002). Nonetheless, the validity of racial categories and their relevance in clinical and health care research and decisionmaking are sometimes controversial.[8] Concerns about the appropriate use of such categories without adequate attention to underlying differences in access to health care, poverty, and other factors are reasonable. Nonetheless, racial and ethnic disparities in health outcomes and health care access are troubling and cannot be ignored in health care research, planning, and delivery. For example, in addition to considering underlying sources of disparities and developing programs to counter them, advocates of palliative care must consider disparities in the help available to and desired by families for themselves and their children.

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[8] For example, a recent editorial in the *New England Journal of Medicine* argues that race is a social not a scientific construct and that "attributing differences in a biological end point to race is not only imprecise but also of no proven value in treating an individual patient," although it may be important in the formulation of "just and impartial public policies" (Schwartz, 2001, p. 1392). A second editorial argues that "racial differences . . . have practical importance for the choice and dose of drugs" but emphasizes the clinical importance of identifying and understanding "the genetic determinants of the reported racial differences" rather than relying on self or other reports (Wood, 2001, p. 1395). In the same issue, authors of an article reporting outcomes by racial categories note that such categories may be "only a surrogate marker for genetic or other factors" (Exner et al., 2001, p. 1355). Brosco (1999) suggests that the American habit of separating statistics based on race, especially infant mortality statistics, has led to a policy in children's health that focuses on welfare and reducing poverty rather than on improving all children's health. He argues that such policy allows for bias against certain races, or moral character judgments against socioeconomically disadvantaged groups, and may contribute to resistance to policies that would benefit all children, such as universal health care coverage for children. Others argue that the collection of information on race, ethnicity, and primary language is necessary to guide social policy to reduce racial and ethnic disparities in health status (Perot and Youdelman, 2001). The AAP (2000h) has concluded that it "is no longer sufficient to use [racial, gender, and socioeconomic] categories as explanatory. If data relevant to the underlying social mechanisms have not been collected and are otherwise unavailable, researchers should discuss this as a limitation of the possible conclusions of the presented research."

At all ages, the death rate for black children is higher than for white or Hispanic children. Even before birth, black fetuses have higher mortality rates than white fetuses. In 1998, the fetal mortality rate was more than twice as high for blacks as for whites (12.3 versus 5.7 per 1,000)[9] (NCHS, 2001, Table 23).

In the United States, disparities in infant mortality rate are related to maternal variables such as the mother's age, level of education, amount of prenatal care, marital status, or smoking habits and also differ depending on the infant's age at death, sex, birth weight, or period of gestation. Nonetheless, even when adjusted for these risk factors, racial disparities in mortality remain (Guyer, 2000).

Black infants have a 150 percent higher mortality rate than white infants (1,456 compared to 577 deaths per 100,000 live births, respectively) (NCHS, 2001b). Puerto Rican, Hawaiian, and American Indian infants also experienced higher mortality rates than white infants (26, 33, and 55 percent higher, respectively) (Singh, 1995). In contrast, Chinese, Japanese, and Filipino infants had 30 percent, 23 percent, and 16 percent lower infant mortality rates, respectively, than white infants. Cuban, Central and South American, and Mexican infants had mortality rates that were 12 percent, 10 percent, and 6 percent lower, respectively, than those of whites (Singh, 1995).

Low birth weight is the primary cause of infant mortality in black infants and occurs at a rate of 280.9 per 100,000 live births compared to 72 per 100,000 for white infants.[10] Infants born to black American women are more likely to have low birth weights than those born to either white American women or African-born black women in the United States, which suggests the role that social and cultural factors may play in this difference (Stoll and Kliegman, 2000a,b).

Over the past 50 years, infant mortality has declined at a relatively lower rate for black than for white infants (2.9 percent per year for the former compared to 3.2 percent per year for the latter [Singh and Yu, 1995]). The result is lower rates for both but a greater relative difference. Between 1964 and 1987, racial disparity in infant mortality generally increased across all levels of education and was wider at the highest levels of education (Singh, 1995).

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[9] Race determined by using the race of the mother.

[10] The number of low birth weight infants, however, increased in white, American Indian, and Asian or Pacific Islander women between 1990 and 1999. Guyer suggests that this increase, for white women in particular, is likely due to the increased use of in vitro fertilization leading to more multiple births, which have a higher likelihood of premature delivery and low birth weights (Martin and Parks, 1999; Guyer et al., 2000).

A study of injury-related mortality attempted to identify socioeconomic factors linked to racial differences in injury rates (Hussey, 1997). When compared to white children, black children were twice as likely to live with a head of household who had not completed high school, more than four times as likely to live in a household in the lowest income bracket, almost four times as likely to live in a female-headed household, and almost three times as likely to live in an inner city. Of these socioeconomic factors, however, the educational attainment of the head of household was the single independent factor related to mortality of children related to injuries. When the head of household had less than a high school diploma, the injury-related death rate of children in the family was 3.5 times greater than for children living with a college-educated head of household. Income and other disparities interact to account statistically for almost two-thirds of the overall difference in injury-related death rates.

Older black children have higher death rates than whites for both injury-related and other causes of death (Table 2.9). For other causes of death, in 1999, HIV/AIDS was not among the top 10 among white children, but it ranked tenth among causes of death for black children 1 to 4 years old, seventh for those aged 5 to 14, and sixth for ages 15 to 24 (NCHS, 2001e).

The greatest disparity in death rates between races is seen in the adolescent homicide rate. Black adolescents between the ages of 15 and 19 years are killed at six times the rate for white adolescents (37.5 per 100,000 versus 5.7 per 100,000). In contrast, suicide and motor vehicle death rates are almost half again as high among white adolescents, ages 15 to 19, compared to black adolescents in this age group (8.6 per 100,000 versus 5.9 per 100,000 for suicide and 28.4 versus 18.2 per 100,000 for motor vehicle deaths) (NCHS, 2001e).

A number of factors appear to underlie racial differences in homicide rates including socioeconomic disparities and age structure of racial subgroups. For example, in a study of domestic homicides in black and white neighborhoods in New Orleans and Atlanta, Centerwall (1995) reported that differences in relative risk of homicide essentially disappeared when controlled for socioeconomic variables such as household crowding. As noted earlier, the United States has substantially higher homicide mortality for children than other developed countries, and explanations for this difference (and similar differences across all age groups) generally focus on handgun availability (CDC, 1997).

WHERE CHILDREN DIE

Based on analysis of 1997 national mortality data, more than 56 percent of child deaths (under age 19) occurred in inpatient hospital settings

TABLE 2.9 Deaths Due to Injury Compared to Other Conditions, by Age and Race (1999)

	Injury Rate (number) [a]			Other Conditions Rate (number) [b]		
Age (years)	Black	White	Black/White Ratio	Black	White	Black/White Ratio
1–4	27.4 (609)	13.4 (1,605)	2.0	30.6 (693)	16.1 (1,936)	1.9
5–9	14.8 (465)	7.2 (1,129)	2.1	13.2 (418)	8.2 (1,278)	1.6
10–14	13.8 (426)	10.7 (1,650)	1.3	13.9 (416)	9.1 (1,385)	1.5
15–19	69.6 (2,119)	51.2 (8,009)	1.4	22.9 (692)	13.9 (2,156)	1.6

[a] Unintentional and intentional injuries.
[b] All noninjury causes.

SOURCE: NCHS, 2001e.

and another 16 percent in outpatient hospital sites (primarily the emergency department).[11] Approximately 5 percent of children were declared dead on arrival at a hospital. Almost 11 percent of children died in home, and the site of death was unknown for a similar percentage. Only a tiny fraction of children (0.36 percent) died in nursing homes. For the population overall, an estimated 52 percent of deaths occurred in hospitals, 22 percent at home, and 21 percent in nursing homes. The percentage of those dying in nursing homes rises steeply with age, increasing from 11 percent among those aged 65 to 74 to 43 percent among those aged 85 or older.

For children who died of cancer in 1997, about 58 percent of deaths occurred in hospital inpatient units, about 36 percent occurred at home, and 2.8 percent occurred in hospital outpatient settings (see footnote 11). In contrast to these national data, a study at Boston Children's Hospital and Dana-Farber Cancer Center found that of 103 child patients who died of cancer during the period September 1997 to August 1998, about half (49 percent) died in the hospital and about half died at home (Wolfe et. al., 2000b). Of those who died in the hospital, nearly half died in the pediatric intensive care unit (PICU) and an additional third in the oncology ward. Regional variations in medical practice, health care resources, urban or rural place of residence, and other factors could account for the different pattern in the national data.

A recent analysis of deaths of individuals less than 25 years old in Washington state from 1980 to 1998 found that 52 percent occurred in the hospital, 17 percent at home, 8 percent in the emergency department or during transport, and 22 percent at other sites (Feudtner et al., 2002). When only deaths from complex chronic conditions and only individuals between ages 1 and 24 were considered, the picture changes. Between 1980 and 1998, the proportion of these deaths occurring at home rose from 21 to 43 percent. Although those who resided in more affluent areas and those with congenital, genetic, neuromuscular, and metabolic conditions were more likely to die at home, considerable regional variation in site of death remained unexplained.

Nearly all SIDS deaths occur in the home. In contrast, most babies who die during the neonatal period never leave the hospital. Some die in the delivery suite shortly after birth; others die within hours to months after being transferred to the neonatal or pediatric intensive care unit. A few

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[11] This information was provided by Joan Teno, M.D., and Sherry Weitzen, M.H.A., Center for Gerontology and Health Care Research, Brown University, based on an analysis of a database of all deaths in 1997 reported to the National Center for Health Statistics. For more detailed information on site of death data, see http://www.chcr.brown.edu/dying/siteofdeath.htm.

hospitals and hospices have worked together so that families, if they wish and the infant survives long enough after birth, can take infants with fatal conditions home, if only for a day or two before the child's expected death (Sumner, 2001).

According to the National Pediatric Trauma Registry, the most common sites for injuries to children are the road (41 percent) and the home (31 percent). One study of children who died of injuries in an urban county during 1995 and 1996 found that most were pronounced dead at hospitals (although some of these deaths actually occurred outside the hospital) (Bowen and Marshall, 1998), but 10 percent of the children were pronounced dead at home and 4 percent on roads.

Although data are limited, children who die of complex chronic conditions such as AIDS, cystic fibrosis, and muscular dystrophy usually die in the hospital, typically following several earlier hospitalizations for crises that they survived. One multicenter study of children with AIDS who died reported that nearly 65 percent died in the hospital and almost one-quarter died at home (Langston et al., 2001). Another study of children with AIDS reported that nearly three-quarters died in the hospital, either in the pediatric ward (38 percent), the PICU (29 percent), or the emergency department (7 percent) (Oleske and Czarniecki, 1999). Forty percent of these children were orphans living in foster care, adoptive care, or with extended families prior to their deaths.

Clinicians from cystic fibrosis centers in Canada and the United States have reported that the majority of their patients with cystic fibrosis died in the hospital. Of the 45 patients who were reported to have died of the disease in Canada in 1995, 82 percent died in the hospital (Mitchell et al., 2000). A U.S. study, which examined 44 deaths over a 10-year period (1984–1993) in a children's hospital, found that 43 of the children died in the hospital (5 in intensive care) and 1 died at home under hospice care (Robinson et al., 1997). The typical length of stay in the hospital prior to death was two to three weeks, with a range of several hours to several months.

Very few studies describe the deaths of children who suffer from other congenital or genetic conditions. Records of patients admitted to Helen House, the first pediatric hospice in England, between 1982 and 1993 indicate that the largest group of child patients (127 children, 41 percent) had a neurodegenerative disease. By the end of the study period, 77 (58 percent) of the children had died: 49 percent at home, 23 percent at Helen House, and 20 percent in the hospital (8 percent died in "other situations") (Hunt and Burne, 1995). A very small Australian study indicated that six of the nine patients who died from muscular dystrophy and spinal muscular atrophy died in the hospital, some in the emergency department (Parker et al., 1999). The majority of children with congenital heart disorders die in an intensive care setting, often after or while awaiting a heart transplant (Rees in Goldman, 1999).

Regardless of the specific cause of death, many patients who die in the hospital die in the PICU after a short hospitalization for an acute problem. In a study of a diverse set of 16 pediatric intensive care units, Levetown and colleagues (1994) found that of 5,415 consecutive admissions to the PICUs, 265 (5 percent) of the patients died. Of the group that died, 248 (94 percent) died in the PICU. The average length of stay in the PICU before death was 3 days (range 0 to 82 days), and the average total length of stay in the hospital prior to death was only 4 days (range 0 to 305 days). The majority (61 percent) of children who died in the PICU suffered from an acute condition such as brain damage due to lack of oxygen (for instance, in drowning), infection, and trauma. Thirty-five percent of the children who died in the PICU had chronic conditions such as congenital malformations, acquired neurologic problems, cancer, metabolic disease, immune deficiency, and respiratory disease. A recent Canadian study, which examined end-of-life care for children who died anticipated deaths (77 of 236 deaths) following admission to one hospital, reported that more than 80 percent died in intensive care (McCallum et al., 2000).

IMPLICATIONS

The profile of childhood death presented in this chapter has a number of implications for those providing or supporting care for children who die and their families. First, children who die and their families are clearly a diverse group. Many children die suddenly and unexpectedly from injuries. Many others die in infancy from complications of prematurity or congenital defects. Some children need care for a few days, whereas others, particularly those with severe neurological deficits, require care for years before death. Further, some children have conditions that are inevitably fatal, whereas other children die from conditions that may be survivable. These differences suggest that palliative and end-of-life care must be flexible if it is to meet child and family needs. Chapter 3 further illustrates the differences in the paths that lead to death in childhood and the different challenges presented by these varied pathways.

Second, unintentional and intentional injuries are important contributors to death in childhood. Emergency medical services dominate in these situations, but many children die before care arrives or without awareness of care. They leave shocked and bereft parents, siblings, grandparents, and others needing support in their bereavement.

Third, particularly for infants and very young children, a varied array of rare, fatal disorders generates a relatively small number of deaths individually, although collectively their impact is more significant. The combination of diversity and small numbers adds to the complexity of determining prognosis, recognizing the end stage of illness, assessing the appropriateness of shifts in the emphasis and goals of care, and helping children and their families prepare for death. Small numbers and diversity can also complicate the development of successful programs to provide and fund palliative and end-of-life care for children and their families. Further, the combination of these characteristics with children's changing developmental needs suggests that palliative care and hospice programs designed for adults will require significant modifications to help children and their families.

Fourth, many important causes of death in childhood—including those due to injuries, low birth weight, and SIDS—are linked to socioeconomic disparities. In addition to encouraging preventive health services and other policies and programs to counter or reduce socioeconomic inequalities, advocates of pediatric palliative care need to consider how their programs can best serve disadvantaged and troubled families and how they can best identify the kinds of support desired by these families for themselves and their children.

Fifth, hospitals, especially their neonatal and pediatric intensive care units, play a particularly important role in care for children who die of complex chronic problems. Discussions of end-of-life care for older adults tend to emphasize practices and policies intended to allow more people to die at home without unwanted "rescue" efforts. Although similar efforts adapted to children and their families may be desirable, more flexible attitudes about the role of hospital care including intensive care at the end of life may be appropriate for this young population.

Sixth, no single protocol for palliative and end-of-life care will fit the varied needs of children who die and their families, and no single focus of research will build the knowledge base to guide such care. The diversity of circumstances and the relatively small numbers of child deaths will challenge researchers and policymakers as well as clinicians.

Chapter 3 builds on this chapter's epidemiologic and quantitative focus by adding a more qualitative perspective on the pathways to death in childhood. It reinforces the conclusion that care for children who die and their families must be adjusted to their specific circumstances and needs, although the fundamental principles outlined in Chapter 1 will broadly apply.

CHAPTER 3

PATHWAYS TO A CHILD'S DEATH

. . . I ran downstairs . . . out into the pouring rain. . . . "For God's sake, where is the ambulance?" . . . [At the hospital,] Dr. Stillman came back looking devastated, and utterly drained. . . . He said that Alexander had died of SIDS. . . . The whole thing was sick. I would know if Alexander was dead. Wasn't I his mother?
Esmeralda Williamson-Noble, parent, no date

My twenty-year-old brother died 8 months ago from cancer. When he became ill, our whole family changed, and my parents didn't have time to think of anything else. . . . It still seems as if Michael's death is all my mother thinks about.
High school junior (Paulson, 2001)

Since birth [our son's] medical needs have increased, and his health has deteriorated. . . . Our goal has been to try to provide him with the best quality of life he could have. . . . We live every day not knowing when will be our son's last. . . . [For emergencies] we carry around a sheaf of papers—about 12 pages—that detail all of our wishes as we know them to this point, because we don't know what every situation will bring.
Tina Heyl-Martineau, parent, 2001

Children who die follow many different pathways to death. Their families accompany them and then follow their own pathways of grief beyond the child's death, even to the end of their own lives. Understanding the similarities and differences in pathways to a child's death and in the experiences of their families is a helpful foundation for considering the range of palliative, end-of-life, and bereavement services needed to assist children and families. In addition, it is important to keep in mind that for life-threatening conditions that are not invariably fatal, children who eventually die and children who survive often cannot be predictably distinguished at the time of diagnosis, during initial treatment, or sometimes even after initial treatments have failed. This unpredictability increases the challenges and the importance of understanding how to integrate aspects of palliative care from the time of diagnosis.

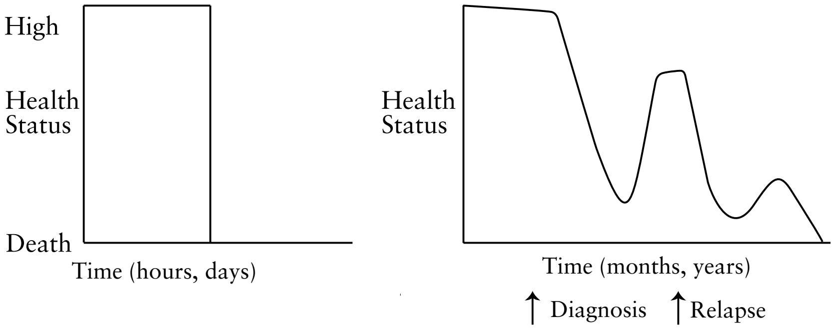
The first section of this chapter discusses prototypical trajectories of dying that depict in graphic form the different ways that death may come to children. The second section presents illustrative stories or vignettes that attempt to represent—in ways that epidemiologic data and charts cannot—the human dimensions of death in childhood. These stories, although they inevitably and greatly simplify real life, suggest how the varied circumstances that surround the deaths of children may affect the child, the family, and the health professionals who care for them.

The third section discusses prototypical patterns of care that illustrate traditional and newer perspectives on the relationship between curative or life-prolonging care and palliative and end-of-life care. The newer perspective, stressed in this report, encourages the integration of certain aspects of palliative care from the time a child is diagnosed with a fatal or potentially fatal medical condition. The section also discusses how the emphasis of care may vary depending on the medical circumstances and may, given similar medical "facts," be affected by differences in family values and circumstances as well as differences in the resources available to them.

Documentation of the focus and adequacy of pediatric palliative and end-of-life care is very limited. The final section of the chapter reviews this small literature.

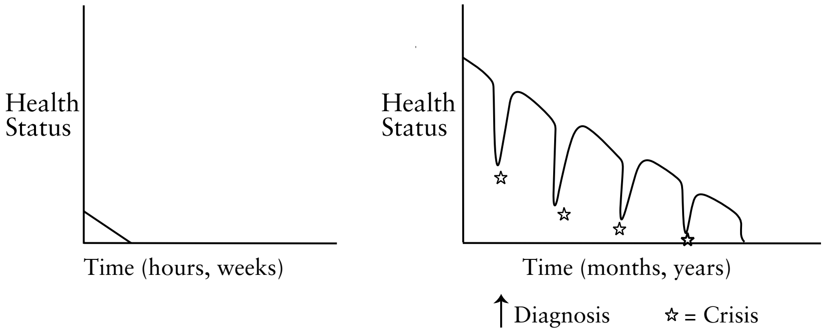
TRAJECTORIES OF DYING

To help illuminate differences in the paths that people follow to death, Glaser and Straus introduced the concept of a trajectory of dying. They proposed that "the dying trajectory of each patient has at least two outstanding [and variable] properties . . . duration and shape" (Glaser and Straus, 1965, p. 6). The shape of the trajectory depends on time and on the person's level of functioning or health status. Figure 3.1 presents four simplified trajectories of death in childhood that depict time along the horizontal axis and health status along the vertical axis. These trajectories underscore the reality that no single model of care and support will apply to all dying children and their families. The trajectories do not, however, necessarily map in a straightforward fashion to specific models of palliative care.



a. Sudden, unexpected death

b. Death from potentially curable disease (e.g., brain cancer)



c. Death from lethal congenital anomaly

d. Death from progressive condition with intermittent crises (e.g., muscular dystrophy)

FIGURE 3.1 Prototypical trajectories of child death.
SOURCE: Adapted from IOM, 1997.

The most abrupt trajectory, Figure 3.1a, represents the unexpected, sudden death—for example, that of a child killed instantly in a car crash or discovered dead in his crib at home. Such events account for more than a third of childhood deaths. Although children who have died can themselves experience no medical or supportive care, first-response emergency medical personnel commonly follow protocols that require efforts at resuscitation. When a child is involved, only rarely is death actually declared "in the field" rather than in the hospital. If the declaration is based on criteria for brain death, protocols require a period of assessments and observation that may take from 12 to 48 hours or longer (see Chapter 1).

Figure 3.1b depicts the experience of children who respond positively to initial, sometimes difficult and possibly life-threatening treatment for a potentially fatal condition, for example, certain brain cancers, but who eventually die of their disease or its further treatment. At diagnosis and during the early stages of initial treatment, these children may not be uniformly distinguished either from children who will not respond or from children who will eventually be cured. (Overall, 70 percent of children with cancer are cured.) Even when an initial positive response to treatment is followed by a return of the disease, determining prognosis is not automatic. From a palliative care perspective, at least three tasks follow diagnosis—each adapted to the situation of the individual child and family. One task is to provide the family—and the child, as appropriate—with accurate and timely information on diagnosis, prognosis, and treatment options and to help them make informed decisions and prepare for a future that includes the hope of cure. A second task is to provide comfort to the child (in particular, by preventing or relieving symptoms of the disease or its treatment) and support to the family. If initial or subsequent treatment fails the child, families will need information about the benefits and burdens of remaining treatment options and about prognosis. When further curative or life-prolonging interventions fail, the additional task for the care team is to help the child and family through the dying phase of the child's illness and then support the family at death and after.

Figure 3.1c depicts the brief trajectory of an infant born with problems incompatible with extended life. As described in Chapter 2, extreme prematurity, severe congenital anomalies, and other life-threatening conditions affecting infants account for a significant fraction of child deaths. With modern prenatal care, some families know in advance that their child will not survive, and some know that they are at significant risk of premature delivery. Extremely premature infants and infants with severe congenital anomalies have produced high-profile disagreements about appropriate care, but care to comfort the infant and the family is always appropriate. As illustrated later in this chapter and discussed further in Chapters 4 and 5, actual support for families may be very limited.

Figure 3.1d abstracts the experience of children who suffer from a fatal progressive illness—for example, muscular dystrophy—that is characterized by periods of slowly deteriorating health status that are interrupted by potentially fatal medical crises, which the child repeatedly survives until one crisis ends in death. In some situations, a child's past favorable response to treatment may leave parents and even clinicians unprepared for and surprised by a subsequent failure of treatment. In other situations, clinicians and parents recognize that the child has reached the final stage of his or her illness and focus on physical and emotional comfort, accepting that resuscitation and other life-sustaining interventions will be more burdensome than beneficial.

Various other trajectories for progressive conditions and for some chronic conditions could be mapped. For example, children with severe asthma and appropriate treatment may have mostly normal functioning without disease progression, but a sudden life-ending crisis may occur and be almost as unexpected as a death from injury.

The illustrative vignettes presented next describe experiences of a child's death that approximate the four trajectories presented above. In addition to the two dimensions of health status and time, they depict other dimensions of a child's death including the individuality of the child and family and the competence and compassion of health care professionals.

ILLUSTRATIVE STORIES OF CHILDREN AND THEIR FAMILIES

During the course of its work, the committee heard many compelling stories from parents whose child had died. In the details of their experiences and in their expectations, the families differed, but they made clear that parents long remember how health care professionals helped or hurt them.

Most parents reported a mix of good and bad experiences. Some told of exemplary care. Others reported insensitive and even cruel behavior from physicians, nurses, or others involved in their child's care. Some found that insurers or health plans were supportive; some had no insurance; others had continuing and exhausting difficulties trying to get care approved—and then suffered with their child when coverage of hospice or other supportive services was denied. Often faced with uncertainty about their child's prognosis and treatment options, some parents anguished over decisions about how far to pursue experimental treatments or whether and when mechanical ventilation or other life-support interventions should be withheld or withdrawn.

Beyond his or her medical condition, a child's experience of dying will depend on many factors, including the family's circumstances, values, and responses to the illness and the kind of medical and other services that are available to meet the child's physical, psychological, spiritual, and other needs. The brief stories presented below suggest how the complex interplay of these factors may affect the level of distress experienced by children and their families.

None of the following stories depicts a specific child and family exactly, although each is based on real experiences. Some are fairly typical of childhood deaths, whereas others represent more unusual or particularly challenging situations. The stories are clearly simplified, but they highlight differences in the needs of children and families and differences in the extent to which the care provided met these needs. Most depict deficits in some aspects of the care provided the child or family.

"Ana Rivera"

When death comes to children, it often is sudden and unexpected (Figure 3.1a). In this case, 3-month-old Ana's father finds her lifeless body in her crib one morning. Her parents' grief is complicated and intensified when they realize that a police officer's questions are probing the possibility of homicide. This story also illustrates the special difficulties facing immigrant parents whose language abilities and resources are limited.

Jorge and Maria Rivera had emigrated from El Salvador two years prior to Ana's birth, leaving their three children behind with Maria's mother and promising to send money to support the family. Maria's first husband and two older brothers had been killed during the war, but her cousin had escaped to the United States and urged Maria and her second husband Jorge to follow him. Jorge got a job at a fast-food restaurant and Maria cleaned houses, and they scrimped on everything so that they could send a little money back to their family in El Salvador. They felt isolated but were overjoyed when they learned that Maria was pregnant. A neighbor brought Maria to a clinic that provided prenatal care to poor women. The Riveras were proud to give this new baby—Ana—such a good start.

After an uneventful pregnancy, delivery, and first few months, Jorge found 3-month-old Ana cold, blue, and motionless in her crib one morning. The Riveras rushed Ana to the public hospital where she was immediately taken into a treatment room. In a short while, the Riveras were led into a small sitting room in the emergency department where a physician informed them, through a janitor who spoke both English and Spanish, that Ana had died. The janitor did not understand all of the words the physician said but assured the Riveras that everything had been done to help Ana. After the physician left, a police officer came into the room and began to ask Jorge questions about how he had found Ana, what he was doing prior to finding her, what her health had been like prior to that morning, and whether Jorge had ever hurt either Ana or Maria. Jorge remembered that he had been angry the night before and yelled at Ana when she wouldn't stop crying, but he was afraid to tell the police officer this information. No charges were brought against Jorge and Maria, but they lived in fear that they would be arrested and sent back to El Salvador. Both had intense feelings of loss for Ana and for their three other children who were still in El Salvador. A hospital social worker told the Riveras about bereavement support groups, but none was nearby and none had groups for Spanish speakers. The social worker really helped in one way. She helped make sure that the Riveras qualified for free care under a community program for the medically indigent, so at least they did not face medical bills that they could not possibly pay.

"Jimmy Marshall"

In this case, which involves another leading cause of child mortality, a car–bicycle collision set off a frantic effort to save an injured child's life. To the parents, the emergency department and intensive care unit are frightening and strange. Despite the help of several social workers, there is much they do not understand and that is never explained. They are unwittingly misled by one clinician who is satisfied with the technical success of a procedure but not focused on what is still a very grim, likely fatal situation. One result is a father's lifelong regret that he was not with his wife and son when the boy died.

While riding his bicycle with a friend, Jimmy Marshall, an 11-year-old boy, was struck by a car. Emergency personnel found him semiconscious with obvious head injuries and rushed him to the nearest trauma center, which treated but did not specialize in pediatric trauma. In the emergency department (ED), Jimmy was taken to a large, open resuscitation bay while the trauma team, including nurses, surgeons, neurosurgeons, emergency physicians, and pediatricians, cared for him. His condition was clearly very serious.

Friends rushed Jimmy's mother to the hospital. In a small, windowless room, the social worker provided some brief information and comforting words. Then, the ED "attending" came in to explain that Jimmy had suffered a serious brain injury and they were doing everything they could to help him. Later, a "pediatric resident" said that Jimmy was being taken to x-ray for special scans of his brain and that the team was very worried. Fighting tears and hysteria, Mrs. Marshall asked, "But he is going to be all right isn't he?" The resident appeared to almost shrug as she said, "I can't tell you that." The rest was a blur.

Just after Jimmy was taken to the intensive care unit, his father arrived. The attending physician gave a brief, grim update. Both Marshalls started to weep. The family would have welcomed the support of a hospital chaplain, but no one thought to see if someone was available. As they waited, the conversation around them sounded ominous, but the terminology was mysterious, and both parents were too bewildered or intimidated to ask many questions. Told that neurosurgeons needed to put a hole in their son's skull in order to monitor dangerous swelling, Mr. Marshall protested that this might injure Jimmy's brain. A doctor replied, "You have more important things to worry about right now."

After the procedure, the neurosurgeon approached, smiling and commenting that things went "great." For the first time, Jimmy's parents felt relieved and somewhat confident. The father, afraid that he would lose his job, then left to return to his construction work. However, when the doctor who appeared to be in charge returned, he told Mrs. Marshall that they needed to talk and that she should try to reach her husband.

In the interim, the doctor told Jimmy's mother that there had been increasing brain injury and that the task was to prevent the brain from swelling and "crushing itself." Her son might die. This seemed impossible given that only a few minutes earlier someone else had seemed so cheerfully pleased.

Suddenly, a nurse rushed in to say that the doctor was needed. Jimmy's heart had stopped and CPR (cardiopulmonary resuscitation) had been initiated. The doctors knew that the likelihood of resuscitating Jimmy was negligible but were obligated to try. The doctors subsequently had to tell the Marshalls that they had done everything, but Jimmy had died. Later, Mr. Marshall agonized that he hadn't been told enough to realize that he should stay with his wife and boy, and he sometimes felt angry at how the neurosurgeon misled them. He and his wife got a piece of paper with information about bereavement support, but it was laid aside and then lost in all the turmoil. There was no further contact from those who were with Jimmy when he died. At least, they had qualified for "free" hospital care.

"Melissa Devane"

As children mature, their intellectual and emotional understanding of serious illness and the prospect of death evolves. This story describes the complex relationships between a severely ill adolescent and her parents and physician and the different concerns she has as she moves from diagnosis and treatment, to recurrences and further treatment, to death (Figure 3.1b). The adolescent is in conflict with her parents and physician about undergoing burdensome experimental treatment but eventually persuades them to respect her wishes.

When Melissa was 13 years old, she was an excellent softball player who hoped some day to play on the Olympic softball team. Late one summer, her knee began to hurt severely and kept hurting. When Melissa's primary care physician thought an x-ray suggested a tumor, she referred her to Dr. Garcia, a pediatric oncologist. After a biopsy, Dr. Garcia diagnosed osteogenic sarcoma, an invasive bone cancer. As Dr. Garcia recommended, Melissa had several weeks of chemotherapy followed by surgical removal of the tumor and then several months more of chemotherapy plus physical therapy. Although the hospitalizations for chemotherapy and episodes of fever were no fun, what bothered Melissa most was losing the ability to play her sport ever again. Also, her hair fell out just as school was starting. The social worker on her oncology team helped Melissa to get a wig and, as part of the team's attention to school reentry issues, explained Melissa's situation to classmates and teachers.

The family celebrated the end of Melissa's chemotherapy with a big party. Melissa was sad that only half of her former teammates made it to the party. She commented to the social worker that she had learned through the experience "who her real friends were." The yearbook club and her younger sister's softball games became new focal points.

At a follow-up appointment 13 months after the end of chemotherapy, Dr. Garcia found a spot on the CT (computed tomography) scan of Melissa's right lung. He recommended surgical removal of the suspected tumor to confirm the diagnosis. The surgery was uneventful, and Melissa was pleased there would be no chemotherapy. Six months later, however, scans showed tumors in both lungs. This time, intensive chemotherapy followed surgery. Family and friends and an occasional tutor supported Melissa through the months of hospitalization.

Now almost 17 years old and hoping to plan for college, Melissa did her best to look to the future and regain her strength. By the winter of her senior year, she was back in school full time, working on the yearbook, and seeing a new boyfriend. Then, routine scans showed another recurrence in the lung, but this tumor was too big to remove surgically. Dr. Garcia proposed experimental chemotherapy that would require long hospitalization. Melissa reacted by saying, "I'd rather die than have more chemotherapy" and "you're unreal—I'm going to die anyway." This surprised everyone. Melissa had been "such a perfect patient." Melissa's dad felt the issue was settled. ("It's our decision. She's a child.") Her mother felt that "since it is her body and her life," Melissa should be part of the decision-making and that Dr. Garcia ought to be clearer about what could be expected. The subsequent discussions were emotional but less anger filled as they went along and Dr. Garcia acknowledged that it was unlikely that the experimental treatment would help meaningfully prolong her life and would be arduous.

Melissa explained that she wanted to live what time she had left by doing what she wanted to do: attend the prom, finish the yearbook, and coach her sister in softball a bit more. Melissa was able to do those things. She and her parents and Dr. Garcia ultimately agreed on palliative chemotherapy that was given by mouth. The Devanes' health plan quickly approved referral to a local hospice. Because Melissa was likely to die within six months and because the family had opted for palliative care only, there was no issue of appealing the plan's limits on hospice coverage. The hospice care team gave the family the help it needed to keep Melissa at home with minimal pain. Dr. Garcia continued to keep in regular touch with Melissa and her parents. Melissa died peacefully at home in July in her mother's arms, having lived longer than Dr. Garcia predicted and having seen her sister have a championship season with Melissa's support and coaching.

"Sean Riley"

This story illustrates the increasingly common situation in which a fatal congenital anomaly is diagnosed prenatally and the families await a birth that likely will be followed by death within hours or days (Figure 3.1c). Although many mothers and fathers opt for abortion when faced with such a tragic diagnosis, others—for religious, philosophical, or emotional reasons—choose to continue the pregnancy. A few innovative programs have recently been developed to provide extensive clinical information and preparation and emotional, spiritual, and practical support (e.g., help with coordinating services) to these families following diagnosis and through and after the infant's death (see, e.g., Sumner, 2001). Most parents, however, have limited access to such information, preparation, comfort, and assistance from health care professionals. They may be able to rely on families and friends, and some discover parent-to-parent support groups or other resources.

Catherine and Kevin Riley were delighted to learn that they were expecting a new baby to join their 4-year-old daughter, Caitlin. In Catherine's sixteenth week of pregnancy, she had an ultrasound examination. From the reactions of the technicians, she knew immediately that something was wrong, but no one was willing to tell her anything except that she should contact her obstetrician.

Told initially that the ultrasound results would be reviewed at Catherine's next regularly scheduled visit in four weeks, Kevin called the obstetrician's office to explain the extreme stress they were under and their need to know the results. The obstetrician explained that the fetus had anencephaly (failure of the brain to develop), that he had little training in managing such pregnancies, and that they should consider termination of the pregnancy "because the baby would not live." The Rileys were unwilling to consider termination and requested a referral to a new obstetrician who specialized in high-risk pregnancies. The second obstetrician said that there was nothing to be done for mother or fetus and that if they did not want to terminate the pregnancy, he would see Catherine again when she was ready to deliver (in about five months).

Without access to regular obstetrical visits for further information and preparation, the Rileys drifted in fear, uncertainty, and grief during the following weeks and months. They sought information from the Internet where they found stories from other families about anencephalic infants who had survived "for years" but learned little to answer their questions about why this problem had happened and how they should prepare for what was to come.

Catherine went into labor at 38 weeks' gestation. The Rileys found delivery room nurses who were unaware of her fetus's diagnosis and an unfamiliar obstetrician who was covering for the obstetrician she had last seen. As Catherine's contractions increased in intensity, the nursing staff on the delivery floor became concerned about the fetus's heart rate. The obstetrician suggested delivery by cesarean section. Kevin questioned this recommendation, but the obstetrician and nursing staff both insisted it was needed and that if they refused both parents would have to sign a form stating their refusal. Confused by these demands given the diagnosis and prognosis, Kevin and Catherine requested a second opinion. Before the opinion could be obtained, the fetus's heart rate dropped to dangerously low levels, and the baby was delivered by cesarean section with Catherine under general anesthesia. The obstetrician and anesthesiologist confirmed the diagnosis of anencephaly. Kevin was not allowed in the delivery room because Catherine was under general anesthesia. Neither saw their son, Sean, during his brief moments of life.

After delivery and her baby's death, Catherine was placed on a floor in the hospital to recover where there were no babies or other postpartum women. She noticed that nursing staff avoided her, and she felt very isolated. Her obstetrician saw her once, inquired about her pain control, and said she could go home "when she was feeling better." She was discharged three days later, after receiving an envelope with a lock of Sean's hair, a handprint, and a Xeroxed paper about "grief." Many of the Riley's friends avoided any contact when news about Sean's birth and death became known. Her employer refused postpartum leave or paid bereavement leave because "she had no baby."

Kevin never spoke about Sean again, although he noticed that he became extremely sad unexpectedly for years afterward. Daughter Caitlin had stayed with relatives during the delivery. No one told her much about Sean's birth and death. She began to think that her parents were angry with her. Expectations of both Kevin and Catherine for Caitlin increased significantly, which added more pressure for an already vulnerable child. Five years after Sean's death, the Rileys remain a sad and troubled, though loving, family.

"Johnny Gabrielle"

Although caring for a child with a serious chronic condition is always demanding, the burden is significantly increased when the child is developmentally delayed and cannot communicate his or her needs directly. Most children and families can be helped to lead fairly normal lives for extended *periods, but they may face major financial, bureaucratic, and other problems in actually obtaining such assistance. When death approaches, systems focused on chronic medical conditions may not be prepared to help families face the end stage of illness. In some cases, a child's medical problems severely test the ability of very experienced clinicians and others to identify effective therapies and relieve the suffering of the child and the family.*

Shortly after Johnny Gabrielle was born, the doctors caring for him noted that his head was smaller than expected and that he had certain unusual facial features. A number of specialists examined him and eventually they diagnosed a rare genetic disorder. A pediatric neurologist informed Peter and Laura Gabrielle that Johnny would most likely be developmentally delayed and ultimately mentally retarded and probably would have a shortened life span. Although she tried to prepare the family for what lay ahead, the neurologist could only talk in general terms because so few children with his condition had been treated and their history documented. The neurologist became Johnny's primary physician, assuring the Gabrielles that she would "be there" for them whatever the future brought, would bring other specialists in as needed, and would do everything she could to keep Johnny comfortable and free of pain and other distress.

As predicted, Johnny's development was far behind that of his older brother. He never talked or achieved normal milestones, but his parents learned to recognize his cues. His sunny disposition brightened the lives of all who encountered him. Johnny's main problem was that he never slept through the night but instead awakened repeatedly. Johnny's physicians tried many drugs to induce sleep, but none were reliably successful. The Gabrielles developed a system of shared responsibility for his care at night but always felt tired. They felt fortunate to qualify for assistance under their state's generous and well-managed programs for children with special health care needs. As time went by, they became acquainted with families from other states who had terrible financial problems and even had to sell their homes to pay medical bills.

At about age 5, Johnny became increasingly irritable and was diagnosed with gastroesophageal reflux. Medication and position did not seem to help nor did surgery. Physicians eventually placed a tube directly into Johnny's stomach so he could be fed. Shortly thereafter, Johnny's personality began to change. He became inconsolable at times and would scream out and tighten his body throughout the day. His sleeping became even more disrupted, lasting only an hour at a time before he screamed again. He was hospitalized frequently, but physicians could find no specific explanation for his problems. Morphine slightly reduced his crying and irritability, which led his care providers to believe that he might be experiencing pain at times. Even with pain medications, he was still inconsolable much of the time. His physicians, who now included a specialist in pediatric pain, managed a fine line between relief and excessive sedation and were alert to other potential complications of his treatments. Although the Gabrielles had written documents that listed Johnny's medications and described their preferences for the use of certain life support technologies should Johnny's condition suddenly deteriorate, it was hard for either Johnny's parents or physicians to know what to expect in the near term (days, weeks, or months).

Up every night for weeks, the Gabrielles' relationship with their older son began to deteriorate. None of their large, supportive family could provide real respite because Johnny was so medically fragile and required so much nursing care. Even during hospitalizations, the Gabrielles were always present and responding to nurses' questions about strategies that seemed to help Johnny. The same was true for visiting nurses at home; even when they didn't ask for help, Laura could still hear Johnny crying in his room. Recognizing the Gabrielles' exhaustion, the health care team looked for formal respite care for Johnny, but they never identified an appropriate setting. He was not sick enough for an acute care setting but was too medically complex for the available medical foster care homes.

All involved felt helpless and frustrated. This pattern persisted for approximately four months. One night, when Johnny didn't awaken at the expected one to two hours after going to sleep, his mother went to check. Johnny was dead. The cause was later determined to be aspiration. At the wake, while being consoled by a huge cadre of friends and family, the Gabrielles told themselves that at least now, "Johnny was finally sleeping" and no longer in pain. They appreciated the presence of some of Johnny's main doctors and nurses. They did not seek outside bereavement support but felt ready to face the future.

Summary

Consistent with the experiences of real children and families, these vignettes include examples of good care as well as examples of care that falls considerably short of meeting child and family needs. Bereavement care is particularly limited. Measured against the criteria for a "good or decent" death as defined in Chapter 1, some of the care described is insensitive and some leads to avoidable physical or emotional suffering for the child, the family, or both. No vignette describes a real "horror" story of care that violates norms of decency, although such cases do exist.

The vignettes also suggest that some of the dilemmas facing parents, children, and clinicians may not have a clear or successful answer—even with everyone trying his or her best. This is a particular dilemma when a child suffers from a rare condition that has few cases documented in the literature and no condition-specific research to guide physician's decisions about curative, life-prolonging, or palliative care.

No small collection of stories can adequately portray the struggles that families with a seriously ill child often experience in trying to coordinate care that may involve multiple sites (e.g., specialized referral center, outpatient clinic, community hospital, home), a large and frequently changing array of health care professionals (e.g., generalist and specialist pediatricians, nurses, social workers, child-life specialists, case managers), and differing criteria for insurance coverage of different services (e.g., inpatient care, home health services, hospice, psychosocial services, respite care, outpatient drugs and equipment).

PATHWAYS OF CARE

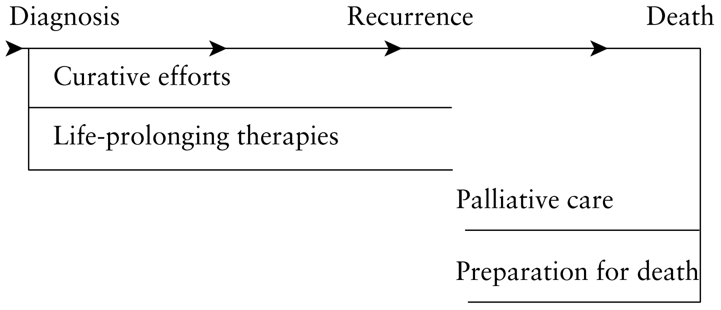
The vignettes suggest that just as pathways to death will vary for children, the pathways of care—that is, the mix of curative or life-prolonging care and palliative care—will vary depending on the child's condition and other factors, including family circumstances and values. Even for some conditions that are invariably fatal, the timing of death may vary considerably. For different children, the same diagnosis and initial prognosis can be followed by quite different pathways that end in death for some and, depending on the condition, extended survival or cure for others.

The unpredictability of many life-threatening medical problems can make it difficult for families to decide when further efforts to save their child will only prolong the child's suffering and dying. Faced with similar facts and uncertainties, families will differ in their responses, and their values and personalities will influence their decisions about the goals of care for their child. Some families will emphasize prolonging life until death removes the choice whereas others will, as death approaches, choose care that is focused entirely on their child's comfort and quality of life. Both may be doing their best for their child, and both may live in peace—or with regrets—about their choices.

The emphasis of care may also reflect the resources—or lack of resources—available to the child and family. For example, as discussed in Chapter 6, few children's hospitals have specialized palliative care services or consulting teams, although all hospitals should be able to provide the fundamentals of such care, for example, effective assessment and management of pain. They may not, however, have clinicians who are trained to explain the child's situation fully and compassionately, to make clear the likelihood of harms as well as benefits from different treatments, and to assure the family that it will be supported in its choices.

Traditional views of patient management have often referred to a "switch" from curative (or life-prolonging) care to palliative care. This

a. From Cure to Care: Traditional Model for Cancer Care



b. Integrated Care from the Time of Diagnosis Through Death into Bereavement

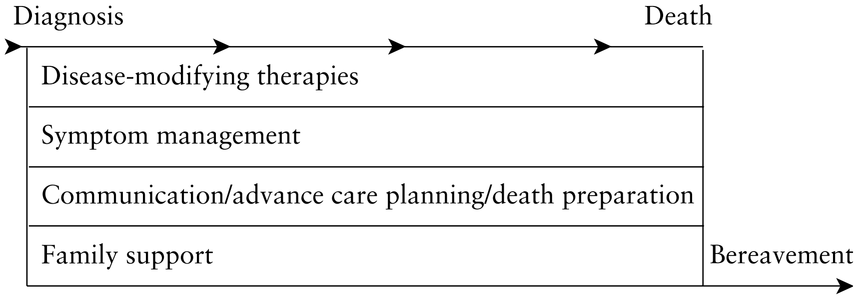


FIGURE 3.2 Sequential versus integrated models of care for advanced illness.
SOURCE: Adapted from IOM, 1997.

phrasing suggests that the two are separate worlds—even mutually exclusive—with an abrupt transition in patient care from one to the other. Figure 3.2a presents this perspective.

An alternative perspective proposes that providing some elements of palliative care closer to the time of diagnosis than happens traditionally may benefit patients and families and may coexist with and support active curative or life-prolonging treatment. For example, not only may meticulous efforts to prevent or relieve the pain and other distress that accompany certain treatments improve a child's comfort and quality of life, it may improve the child's ability to tolerate or cooperate with treatment. Just as hospice providers work with patients and families to reevaluate the goals of cure as the end stage of an illness approaches, "upstream palliative care" involves the periodic discussion of prognosis and care options and, as appropriate, the reconsideration of the goals of care during the early stages of complex chronic illnesses, for example, during "routine" visits and check ups.

Figure 3.2b illustrates the concept of integrated care in which multiple objectives are pursued concurrently after the diagnosis of life-threatening condition. The emphasis and specific elements of care may vary depending on the situation. Thus, some aspects of advance care planning (e.g., discussion of preferences for cardiopulmonary resuscitation, weighing of hospital versus home care as death approaches) are less urgent when a child's condition is possibly curable, treatments are not themselves life-threatening, and early crises such as cardiac arrest are uncommon. Likewise, if early symptoms are minimal, the emphasis may be on reassuring parents that the child's care team will do everything possible to anticipate and prevent problems and to make their child comfortable if treatments or worsening of the condition brings pain or other symptoms.

Although this report emphasizes the model of integrated care following diagnosis, situations exist in which care may indeed switch abruptly from a near total emphasis on cure or life prolongation to a total commitment to palliation, preparation for death, and support for grieving family members. For example, with some seriously injured children, physicians may initially assume—pending further evaluation—that survival is possible and work intensively and virtually exclusively toward that goal. Test results or poor response to treatment may then demonstrate irreversible damage that will lead inevitably and fairly soon to death. At that point, the emphasis of care may shift quickly to relieving any distress that the patient might be experiencing and preparing the patient (if conscious) and family members for death. When this happens, the message is never that "there is nothing we can do" but that "we must refocus on efforts" on comfort and peace and making the most of the family's remaining time together.

Similarly, for some children, the emphasis of care may always be palliative. For example, in the vignette earlier in this chapter, Sean Riley's medical condition was incompatible with extended life, but the family could have been provided active emotional support before, during, and after the birth. Physicians and nurses could have planned and prepared to manage the delivery in accord with the family's goal of having time with the baby after birth. Care would have been intensively palliative from the time of prenatal diagnosis, supporting the parents as parents before and after the baby's death and reducing their sense of powerlessness.

In yet other circumstances, the emphasis or balance of care may fluctuate over time, for example, when a child has with a progressive, fatal condition such as muscular dystrophy or certain heart conditions. In the

Gabrielle vignette in Chapter 3, the parents and other caregivers spent an increasing amount of time trying to relieve Johnny's distress. Periodically, however, Johnny was hospitalized—sometimes in attempt to relieve his apparent pain, sometimes in an intensive effort to save his life following an acute problem (e.g., an infection). The Gabrielles' physicians attempted to extend Johnny's life while doing their best to relieve his intractable distress; they explained their best understanding of Johnny's diagnosis and prognosis but did not take away his parent's hopes. To depict this as a modification of Figure 3.2b, the horizontal lines under the elements of care could increase and decrease in thickness to represent the varying emphasis on life-prolonging care or palliative care.

In sum, the ratio of palliative care compared to curative or life-prolonging care and the ratio of palliative care compared to true end-of-life care will vary for different medical conditions and at different points during the course of a fatal illness. Depending on a child's diagnosis and stage of illness as well as available resources, some palliative or end-of-life care may be delivered by specialized inpatient or home hospice teams, some by palliative care teams, and some by the primary team (e.g., oncology, cardiology, neurology) caring for the child. All will need appropriate education and training, funding, and institutional structures and processes that support the timely, coordinated provision of the right mix of care for the child and family.

The next section of this chapter reviews evidence about the adequacy of palliative, end-of-life, and bereavement care provided to children and families. Additional studies are cited in the discussions in Chapter 4 and 5 of the elements of palliative, end-of-life, and bereavement care.

WHAT DO WE KNOW ABOUT THE FOCUS AND ADEQUACY OF CARE FOR CHILDREN WHO DIE?

> *I had to fight with the doctors to get him on morphine. They tried fentanyl patches and other things. They did not want to send him home on morphine. I screamed and cried and got them to understand that the short time he had left must be without pain, or at a minimum of pain. He had morphine in the hospital, but didn't want it for home use. Finally, they agreed.*[1]
>
> Becky Wooten, parent, 2001

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[1] Fentanyl, like morphine, is an opioid. The parent may or may not have known that but apparently viewed past management of the child's pain as inadequate for a child going home to die. A fentanyl patch works slowly and is appropriate for chronic and essentially unchanging pain. If the pain situation is unstable, it might be the wrong choice because once the patch is in place, clinicians cannot use additional medication to control breakthrough pain (Yaster et al., 1997; Schechter et al., 2002).

The pathway followed by a dying child and his or her family can be marked by competent, consistent, and compassionate care, by care that fails on these dimensions, or by care that falls somewhere in between these poles. In recent years, several studies and reports have attempted to document and understand more systemically the strengths and weaknesses of palliative, end-of-life care for adults (see, e.g., SUPPORT, 1995; IOM, 1997; Webb, 1997; Lynn et al., 2000; Meier et al., 2000; IOM, 2001a). They have described inadequate assessment, documentation, and management of pain and other symptoms, sometimes in combination with overtreatment, including unwanted or ineffective resuscitation and other life-support interventions. Referrals to specialists in palliative and end-of-life care have been late or altogether absent. Poor communication includes insensitive delivery of bad news, inattention to patient and family preferences, and failure to provide accurate, timely information needed by patients and families to guide decisions.

Efforts to remedy these shortfalls in palliative and end-of-life care and to increase public understanding and expectations are growing and becoming more sophisticated (see, e.g., Higginson, 1993; Doyle et al., 1998; Emanuel et al., 1999; Lynn et al., 2000; Ferrell and Coyle, 2001; AAP, 2000g).[2] The goal—still to be achieved—is to create systems that people can trust to provide competent, consistent, and compassionate care to seriously ill and dying patients and that families can count on for support and solace as they experience a loved one's grave illness or death.

What is the picture for children who die and their families? Research on palliative and end-of-life care for children and their surviving families is very sparse. Some of it focuses rather narrowly on decisions involving cardiopulmonary resuscitation, mechanical ventilation, and other life-sustaining technologies—with little investigation of the adequacy of physical, emotional, spiritual, and practical support (e.g., help in coordinating services from multiple different providers) for the children and their families. Such research as the committee did locate generally follows the pattern found for adults, reporting inadequate assessment, documentation, and management of pain and other symptoms; late consideration of the benefits of palliative or hospice care; and problems in communication.

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[2] Useful information and links to other resources are also available on a number of Web sites, for example, those of the Center to Advance Palliative Care, Mt. Sinai School of Medicine (http://www.capcmssm.org); Project on Death in America, Open Society Institute (http://www.soros.org/death); and Last Acts, a coalition initiated by the Robert Wood Johnson Foundation (http://www.lastacts.org).

Assessment, Documentation, and Management of Pain and Other Distress

Pain management practices and problems have been more often discussed and better documented than problems in other aspects of pediatric palliative and end-of-life care. In the past, physicians often discounted pain in children. For example, a 1960s survey of postoperative pain in children argued that they "seldom need medication for relief of pain [and] . . . tolerate pain well" (Swafford and Allan, 1967, cited in McGrath, 1998, p. 1020). Neonates were thought to lack sufficient neurophysiologic and other development to suffer pain and thus not to need pain relief during surgical procedures such as circumcision.

Both behavioral and physiological research have repudiated these arguments and clarified the existence and seriousness of pain in children (see, e.g., McGrath, 1987; Bush and Harkins, 1991; Barr, 1994; Walco et al., 1994; APS, 1995; Duke, 1997; Schechter et al., 1997, 2002; Anand et al., 1999). Nonetheless, misunderstandings and ignorance have continued. As a 1998 editorial in the *British Journal of Medicine* stated, "Current practice still falls short of the ideal of safe and effective pain relief for all children" (Zacharias, 1998, p. 1552).

Groups including the World Health Organization (WHO) and the American Academy of Pediatrics (AAP) still find it necessary to issue policy statements that remind pediatricians of their obligations to recognize and prevent or relieve children's pain and to keep abreast of research on the tools available to do so (see, e.g., WHO, 1998; AAP, 2000a, 2001a). A 1998 WHO statement on pediatric cancer pain reported that 70 percent of children with cancer suffered severe pain at some point and that such pain was often not recognized or, if recognized, not treated adequately. More recently, the AAP specifically stressed that systemic pain medications are essential to manage predictable pain associated with bone marrow aspiration and other procedures (AAP, 2001a). It likewise emphasized that reliance on sedatives or antianxiety agents alone will not only allow children to experience pain but leave them less able to communicate their distress. The AAP identified the following barriers to the appropriate recognition and treatment of pain in children including

1. myths that children, especially infants, do not feel pain the way adults do or that, if they do, there is no untoward consequence;
2. failures of physicians to assess and reassess for the presence of pain;
3. inadequate understanding of children's subjective experience of pain;
4. insufficient knowledge of strategies for assessing, preventing, and relieving pain;

5. concerns that pain management in children is too time-consuming and difficult; and
6. disproportionate fears of adverse treatment effects such as respiratory depression and addiction.

Although most pain now can be relieved (in principle if not in practice), some pain is intractable without sedation (Swarm and Cousins, 1998). Some therapies produce side effects such as nausea, itching, confusion, or sleepiness that can cause considerable distress and require shifts in pharmcologic or other interventions (McGrath, 1998). Pain may also be necessary in pursuit of certain therapeutic benefits, for example, evaluating certain injuries or judging the success of orthopedic surgery during rehabilitation. In the latter case, Walco and colleagues (1994) suggest that clinicians should ask themselves whether a less hurtful approach is possible and whether the pain inflicted on the child is the least possible needed to achieve the benefit.

Research on the adequacy of pain assessment and management in children is scarcer than that for adults, but the findings raise concern. For example, although the majority of pediatric oncologists consider themselves competent in managing pain and other symptoms (Hilden et al., 2001a), a recent study at a leading pediatric cancer center and children's hospital found that 89 percent of children dying of cancer were reported by parents in after-death interviews to have suffered substantially at the end of their lives (Wolfe et al., 2000a).[3] The most common symptoms were fatigue, pain, and shortness of breath. Half of the children suffered from three or more symptoms. The most commonly treated symptoms were pain (76 percent of cases) and shortness of breath (65 percent). Treatment was, however, reported to be successful less than 27 percent of the time for pain and 16 percent of the time for shortness of breath. Fatigue was little treated, and the study authors suggested that physicians may be unaware that some apparently effective treatments are available for this common symptom of advanced illness (or its treatments). Children with cancer who died of treatment-related complications suffered more symptoms than children who died of progressive disease.

Most studies of end-of-life care for children focus on physical symptoms rather than emotional symptoms or quality of life. In their study, Wolfe and colleagues (2000a) reported that parents of children with cancer stated that, in the last month of life, their child had little or no fun (53

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[3] The study by Wolfe and colleagues has been replicated at another institution. Data are still being analyzed, so no findings can yet be reported.

percent), was more than a little sad (61 percent), was not calm and peaceful most of the time (63 percent), and was often afraid (21 percent). Despite the suffering experienced by their children at the end of life, 70 percent of parents described their child's death itself as "peaceful."

In the United Kingdom, several studies of children cared for by Helen House (the first pediatric hospice) documented the serious symptoms experienced by many children. One study reported that more than a third of the children who died of neurodegenerative disorders suffered from pain, most often due to muscle spasms (Hunt and Burne, 1995). More than four-fifths of all patients experienced pain in the last month of their lives (Hunt, 1990). Of 30 children with various conditions who died between 1983 and 1987, 80 percent required strong analgesics during the last month of their lives for pain, shortness of breath, or both. Children with cancer were the most likely to receive analgesics for pain, whereas children with other conditions were the most likely to receive opiates for shortness of breath (Hunt, 1990). The Helen House researchers also reported that one-third of the children who died experienced seizures, and a quarter of them suffered from excessive oral secretions (often accompanied by swallowing difficulties). In addition, they reported that the dying children were commonly described as "frightened," "grumpy," "disoriented," or "anxious and irritable" (Hunt, 1990). Even those children who could not communicate (due to age or disease progression) were described as "distressed, crying frequently" or looking "frightened."

A Canadian study of 77 children who died anticipated deaths in intensive care relied on narrative progress notes to identify how the children died (McCallum et al., 2000). Although 84 percent of the children (who had conditions such as cancer, heart disease, AIDS, organ failure, and cystic fibrosis) received opioid analgesics, only 6 percent had specific pain assessment and treatment notes recorded in their charts, and such recording was sporadic. Systematic assessment and monitoring are essential to effective, reliable pain prevention and management and to quality assurance. The study also reported that the majority of children were intubated prior to their death and that most were "comatose, sedated, or medically paralyzed," which the authors said could be interpreted as indicating "excessively invasive treatment" (McCallum et al., 2000, p. 421). Four-fifths of the patients had do-not-resuscitate (DNR) orders documented during the final hospital admission, but only 8 percent had such orders prior to that admission. The median time from recording of the DNR order to death was less than a day. In only one case did progress notes indicate that the prospect of death was specifically discussed with the child.

One study of 100 deaths in three pediatric intensive care units (PICUs) reported that nearly 90 percent of children who died had received sedatives, pain medications, or both (Burns et al., 2000). Physicians substantially increased the use of sedatives and pain medications before the withdrawal of mechanical ventilation (which was usually one of the first therapies stopped for these children). Relief of suffering (e.g., air hunger, pain) was the justification for this increase, and the only patients not receiving such care were comatose and thought not to be suffering. The researchers reported no use of paralyzing agents, the use of which they considered indefensible.

Parental and clinical assessments of children's pain and other distress may differ. For example, as shown in Table 3.1, Wolfe and colleagues (2000a) found "considerable discordance" for certain symptoms including fatigue, poor appetite, constipation, and diarrhea.

Although some observational tools have been developed to assess certain symptoms in children, clinicians or researchers often depend on parental assessments of children's pain not only in retrospective studies following a child's death but also for very young children, children with cognitive

TABLE 3.1 Discordance Between the Reports of Parents and Physicians Regarding Children's Symptoms in the Last Month of Life

Symptom	Reported by Parent but Not by Physician (N = 92) No. (%)	Reported by Physician but Not by Parent (N = 92) No. (%)	Kappa Statistic (95% CI)[a]	P Value[b]
Fatigue	44 (48)	1 (1)	−0.02 (−0.07 to 0.02)	<0.001
Pain	15 (16)	11 (12)	0.10 (−0.12 to 0.32)	0.56
Dyspnea	19 (21)	10 (11)	0.10 (−0.11 to 0.31)	0.14
Poor appetite	33 (36)	1 (1)	0.29 (0.15 to 0.43)	<0.001
Constipation	31 (34)	7 (8)	0.16 (−0.02 to 0.33)	<0.001
Nausea/vomiting	25 (27)	18 (20)	0.06 (−0.14 to 0.26)	0.36
Diarrhea	20 (22)	8 (9)	0.31 (0.12 to 0.51)	0.04

[a] Data were missing for 10 children for whom there was no documentation of clinic or hospital visits in the last month of life and for 1 child whose records were not available for review. CI denotes confidence interval.

[b] McNemar's test was used.

SOURCE: Wolfe et al., 2000a. Used with permission.

impairments, and children with very advanced disease. One review of studies comparing parental and child assessments concluded that the evidence is mixed but parents tend to underestimate their child's pain (Chambers and Craig, 1999).

A Swedish study of children being treated for cancer interviewed children and parents (Ljungman et al., 1999). It reported that "treatment-related pain was constant and dominant," that treatment- and procedure-related pain was more severe than pain due to malignancy, and that pain evaluations were unsystematic. An older study by McGrath and colleagues (1990) also reported that treatment- and procedure-related pain was common, with more than a third of the children reporting moderate to severe pain from chemotherapy and 61 and 78 percent reporting such pain from lumbar puncture and bone marrow aspiration, respectively. The study did not report on treatment strategies. A 1995 article reporting on severe pain in children dying of cancer concluded that following WHO pain guidelines was adequate for most children but that a subgroup required extraordinary measures (Collins et al., 1995). Individualized management and careful assessment of pain were essential.

Studies by Ferrell and colleagues also suggest the inadequate management of cancer pain in children (Ferrell et al., 1994; Rhiner et al., 1994). The studies assessed the impact on families of living with and trying to manage a child's pain and identified parents' feelings of helplessness and stress.

Additional studies have examined pain assessment and management for broader groups of children. A 1994 article reported on pain management practices in three Canadian neonatal intensive care units (NICUs). It concluded that procedural and disease-related pain is frequently untreated or undertreated (Fernandez and Rees, 1994).

A study by Kazak and colleagues (1996) compared distress during invasive procedures for childhood leukemia as rated by mothers and nurses. Children receiving a pharmacological-only intervention were rated as having more distress than children receiving a combined pharmacological and psychological intervention. Younger children were rated as having more distress than older children. A 1999 review of the literature on psychological interventions for disease-related pain in children identified relatively few studies, most of which had methodological problems (e.g., small sample size, no control group) (Walco et al., 1999). Taken together, the studies suggested benefits of some interventions but they were not definitive.

Unexplained variation in pain management and other practices is also a concern. One study of narcotics use for very low birth weight babies in NICUs reported a 29-fold variation in the use of opioids (Kahn et al, 1998). This kind of variation demands further investigation. Differences may relate, in part, to differences in the degree to which physicians feel legally vulnerable in administering pain medications or have misconceptions about addiction from long-term use of narcotics. Variation in methods used to assess the contribution of pain in prematurely born infants may also play a role. Pain assessment tools that have been validated in premature babies at different gestational ages and at different chronological ages should prove useful in evaluating the adequacy of neonatal intensive care, reduce unexplained variations in treatment, and reduce infants' distress (see, e.g., Krechel and Bildner, 1995).

Palliative Care Consultations and Discussions

The extent of explicit palliative care consultations is little documented for children and families. A recently published study examined all 196 deaths in an NICU between 1994 and 1997 (Pierucci et al., 2001; see also Leuthner and Pierucci, 2001). The authors reported that palliative care consultations were associated with significantly more supportive services (e.g., referrals to chaplains or social workers) for infants and families, fewer medical procedures (e.g., blood draws, radiographs, endotracheal tubes but not intravenous fluids, nutritional support, narcotics), and documentation of family emotional needs and support. Consultations prior to the child's death increased during the period studied from 5 to 38 percent. The authors could not assess whether lack of consultation reflected lack of physician or family readiness for palliative care or other factors. They did not attempt to measure the effectiveness of the supportive services provided in relieving child or family distress.

In the study by Wolfe and colleagues (2000a) cited above, earlier discussion of hospice care was associated with parental reports that their child was peaceful and calm during the last month of life. For about two-thirds of the children who died of progressive disease (rather than treatment complications), charts noted a discussion of hospice care, which occurred, on average, about 58 days before death. Further, suffering was greater in children whose parents reported that the child's physician was not involved in his or her end-of-life care. This pattern held after adjusting the analysis for cause of death, child's age at death, place of death, interval between the child's death and the parental interview, and physician clustering (Wolfe et al., 2000a).[4]

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[4] Authors "adjusted for the possibility that the parents of patients who had the same physician may have had similar responses" and called this "physician clustering" (Wolfe et al., 2000a, p. 327).

Limitations of Life-Support and Disease-Modifying Interventions

A recent examination of the limitation of aggressive life support concluded that much attention had been paid to the question of whether and when to limit these interventions and argued that more research should focus on how to assess and improve the quality of care for patients once the decision has been made (Rubenfeld and Curtis, 2000). Studies of pediatric deaths in intensive care have found that deaths are often preceded by limitations of life support interventions—more than half of the deaths in one recent study (Keenan et al., 2000), more than one-third to one-half in an earlier study (Vernon et al., 1993;[5] Levetown et al., 1994), and more than 70 percent in a neonatal intensive care unit (Wall and Partridge, 1997). The accompanying assessment and management of pain, air hunger, or other distress has been less documented as has the timing of decisions to limit life support.

Even though death is often preceded by limitations of life-support interventions, studies also suggest that during their last month of life, the majority of children who die from chronic conditions receive some form of medical treatment that is regarded as curative or life prolonging. The earlier-cited study by Wolfe and colleagues (2000a) reported that 56 percent of children with cancer received some sort of cancer-directed therapy in the last month of their lives. More than one-third (36 percent) had undergone a bone marrow transplant, and for 60 percent of these children, the transplant was their last cancer-directed treatment. Two-thirds of children in the study had DNR orders. These orders were entered, on average, 33 days before death for children who died of their disease and 1.7 days before death for children who died of treatment-related complications. An earlier study of DNR orders in one children's hospital also reported that most of these orders were written for children who were receiving "aggressive" medical therapy in intensive care units (Lantos et al., 1993, p. 52). Orders were more common for older children than for infants. Wolfe and colleagues suggest that when life-prolonging treatment is pursued to the last, more attention to concurrent palliative therapies might reduce children's suffering.

Possibly reflecting the difficulty of changing a long-term pattern of treatment, one small study suggests that children with chronic illness hospitalized in PICUs were less likely to have life-sustaining treatment withheld or withdrawn than were acutely ill patients (Keenan et al., 2000). Levetown's 1994 study, however, reported no difference between the two

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[5] This article used the terminology "supportive care" to describe life-support interventions, whereas the term is used here and more generally to refer to care that provides comfort to patients or families.

groups on this aspect of care. Additional research on treatment patterns for acute versus chronic conditions could inform understanding of the factors influencing treatment choices. For children with serious, chronic conditions, repeated hospitalizations may be an almost routine part of life. Families may become used to seeing the ill child "bounce back" after numerous life-threatening acute events. Then, as Ann Goldman suggests, "After a lifetime of intensive treatment, it can be difficult to abandon past patterns of care" (Goldman, 1999, p. 30).

With advances in organ transplantation, patients with conditions such as cystic fibrosis (often now young adults) and their families may regard what was previously seen as the end stage of their disease as an opportunity to be listed for a transplant, thus maintaining a hope for survival rather than preparing for death. Long-term survival, while improving, varies for different kinds of conditions (see Kurland and Orenstein, 2001), and a shortage of donated organs limits the number of transplants. Of the 45 patients who died of cystic fibrosis in Canada in 1996, an analysis found that 93 percent had been considered for transplant, 7 (17 percent) had been listed, and 2 (4 percent) had received the transplant (Mitchell et al., 2000). The analysis did not report how many received a transplant and did not die.[6] Palliative care was never discussed for one-quarter of the patients and was discussed a month before death for 40 percent.

Another study, this one in the United States, evaluated records for 44 patients more than 5 years of age who died of cystic fibrosis at one institution between 1984 and 1993. The majority of these patients were over age 20. Four died after lung transplants, and four died on mechanical ventilators in the PICU awaiting transplant (Robinson et al., 1997). Three-quarters of the patients were receiving therapeutic (e.g., intravenous antibiotics, chest physical therapy) or preventive (e.g., oral vitamins) interventions in the last 12 hours of life. Compared to surgical interventions, most cancer chemotherapy, and some other drug regimens, these therapies are less invasive and produce limited side effects. All patients had do-not-resuscitate orders, and nearly all received some opiates for pain (two of six patients who did not refused for religious reasons). Of the 44 patients, one died at

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[6] Three-year survival rates following lung or heart–lung transplantation for cystic fibrosis are generally reported (for the last decade) to be from 40 to 60 percent (see, e.g., Balfour-Lynn et al., 1997; Hosenpud et al., 1998; Mendeloff et al., 1998; Aurora et al., 1999; Vizza et al., 2000). Transplant survival rates are higher for certain other conditions and organs, most notably kidney transplantation for end-stage renal disease. Five-year survival rates above 50 percent have been reported for children with end-stage heart disease (see, e.g., Jenkins et al., 2000; Morrow et al., 2000; Williams et al; 2000). Survival rates improve with experience with the procedure and vary with medical condition (e.g., congenital anomaly, cardiomyopathy).

home under hospice care; the remainder died in the hospital with "many of the important psychological and emotional aspects of hospice" (Robinson et al., 1997, p. 208). The authors of this study noted that while the final outcome of the disease is certain, uncertainty about short-term prognosis and the waxing and waning nature of respiratory failure in cystic fibrosis make it difficult to abandon antibiotics, physical therapy, mechanical ventilation, and similar measures. Again, some of these interventions impose relatively little burden on patients.

Despite prognostic complexities, improvements in the care of patients with unpredictable life-shortening conditions are possible. The strategy of "hoping for the best while preparing for the worst" allows clinicians and families to pursue life-prolonging interventions such as transplants with conviction and, at the same time, to be attentive to symptom management, personal goals (e.g., a family vacation), and other steps to help families make the most of the time they have.

One study of the withdrawal of life support in adults reported that "forms of life support that were perceived as more artificial, scarce, or expensive were withdrawn earlier" and that "once the decision has been made to forgo life-sustaining treatment, the process remains complex and appears to target many different goals simultaneously" (Asch et al., 1999, p. 153). If anything, the complexity of the process and the existence of multiple goals of care are likely to be even more evident when decisions involve children.

Inconsistency in clinical decisions about life-support and disease-modifying interventions is a concern. One survey study of pediatricians' decisionmaking found considerable variation in management strategies about withholding or withdrawing life-support interventions for chronically ill children as described in eight clinical scenarios (Randolph et al., 1999). For six of the eight scenarios, less than half the respondents chose the same intensity of care (e.g., mechanical ventilation, dialysis, antibiotics). For three of the scenarios, at least 10 percent chose the most intensive level of management while at least 10 percent chose comfort measures only. The most important influences on choices were the probability of acute (short-term) survival and parental wishes. Those who rated parental wishes highly were more likely to choose aggressive care when parents wanted it, even when the long-term prognosis was poor. Also, those who rated themselves as more likely than their colleagues to withdraw life support were indeed more likely to make that choice. Although the authors note that decisions in actual practice needed investigation, they observed that "variability in decision-making may lead to unnecessary suffering, lack of fairness when making decisions about neurologically handicapped infants, and inappropriate use of scarce resources in futile cases" (Randolph et al., 1999, p. e46). They recommended clearer guidelines for decisions about limitation of life support for children.

A recent study of European neonatologists also found considerable variability in how quality-of-life was weighed in decisions in the NICU (Rebagliato et al. 2000). The authors concluded that the country in which a physician practices was the most powerful predictor of choices. The researchers also found that physician attitude, seniority of position, length of experience, and working in larger NICUs were significantly correlated with a greater likelihood of a physician's choosing to limit life-sustaining medical interventions based on predicted quality of life.

In the United States, studies examining the attitudes of neonatologists report that neonatologists frequently are willing to limit treatment in severely malformed, premature, or ill babies. One study examined the actual practices of neonatologists at a university medical center as documented in medical records. It found that 73 percent of all neonatal deaths at a tertiary NICU followed the withdrawal or withholding of life-sustaining treatment (Wall and Partridge, 1997). In contrast, a similar study in 1973 reported that only 14 percent of neonatal deaths were attributed to withdrawing or withholding treatment (Duff and Campbell, 1973). In the 1997 study, death attributable to withdrawing or withholding life-sustaining treatment was more common in severely neurologically damaged babies (more than 85 percent) than in babies with major congenital anomalies (67 percent). Neonatologists most commonly noted futility of treatment as the reason for limiting or withdrawing treatment (74 percent). They noted quality-of-life issues in 51 percent of cases (more often mentioning severe disability than unnecessary suffering as the issue). Quality of life, exclusive of any reference to the futility of treatment, was mentioned as the reason for withdrawing or withholding treatment in 23 percent of the deaths. The authors of the study observe that medical records might underdocument the importance of quality-of-life considerations based on concerns about federal "Baby Doe" regulations on treatment of infants with life-threatening conditions (see Chapter 8).

Problems in Communication

Hilden and colleagues observe that physicians report anxiety about discussing an impending death with children and their parents (Hilden et al., 2001a). Anxiety and dread may interfere with a thorough assessment of a child's emotional and spiritual well being and careful evaluation of child and family circumstances (e.g., cultural values, religious beliefs). Inadequate assessment may, in turn, compromise timely efforts to identify and relieve physical and emotional distress.

Clinicians' anxiety may also contribute to poor communication about the child's situation and prognosis, which may deprive children and families of information they need to plan for the future and weigh the pain or other suffering expected from an intervention against its probability of meaningfully extending a child's life. Certainly, most pediatric specialists have less experience than similar adult specialists in communicating a grim prognosis, although both groups have little or no training in this task (see Chapters 5 and 9).

A survey of 122 experienced emergency room physicians published in 1997 reported that few of the respondents reported any training in telling parents about a child's death or any familiarity with guidelines for such notifications (Ahrens and Hart, 1997; Maruyama, 1997). Two-thirds of the respondents described communicating with parents after a child's death as the most difficult part of emergency medicine. A similar percentage said communicating with parents about a child's death was more difficult than communicating with a family about an adult's death. Even more striking in this small survey, more than two-thirds of the respondents said that they had prolonged resuscitation efforts solely to delay telling parents that their child had died.

Khaneja and colleagues (1998) surveyed residents, fellows, and attending pediatricians at one institution to describe their general attitudes toward pediatric death and dying. Of those responding, 61 percent of all attending physicians and 73 percent of attending physicians in specialties with a higher predicted patient mortality rate reported that they sometimes consider a patient's death to be a personal failure. Conversely, residents and fellows rarely felt this sense of personal failure when a patient died. Despite feelings of failure, when a patient died, older physicians not surprisingly felt more prepared to deal with issues of death and dying than younger physicians: 13 percent of residents, 56 percent of fellows, and 71 percent of attending physicians felt adequately trained to deal with end-of-life issues, but the study did not independently assess skills. However, almost all of the physicians agreed that there was a need for further support of health care workers in dealing with death and dying (100 percent of residents, 83 percent of fellows, and 90 percent of attending physicians wanted more support). Most also agreed that the existing support systems in the pediatric department of their hospital were inadequate. Many physicians expressed a desire to attend funerals of patients, for instance, but very few had actually done so. Most cited conflicting clinical duties as a reason they were unable to attend funerals.

Other researchers as well as personal stories also point to physician anxiety and confusion about communicating bad news and discussing death and dying (see, e.g., Solomon, 1993; Nuland, 1994; ABIM, 1996a,b; IOM, 1997; Christakis and Iwashyna, 1998; Bruera et al., 2000; for pediatricians specifically, see Ahrens and Hart, 1997; Vazirani et al., 2000). Although most of these studies involve adult patients and families, it seems reasonable that some of the problems they identify will apply to communication involving children with life-threatening conditions. For example, a study by Lamont and Christakis (2001) reported that clinicians may consciously withhold information or provide cancer patients and families with misleadingly optimistic assessments and that younger adult patients were more likely to receive such misleading assessments than older patients.

A recent project to improve communication about organ donation in adult neurologic and pediatric intensive care units reported on training sessions that involved conversations between health care teams and standardized patient families. As reported in a conference poster session (Williams et al., 2001b), the researchers found that physicians were reluctant to use the "d" words (death, dying), that euphemisms confused family members, and that teamwork among team members (physicians, nurses, transplant coordinators, and clergy) contributed to effective communication. (Following training, organ donation rates increased on the study units.)

One small study of residents' competence in delivering bad news (a diagnosis of lung cancer) to adults concluded that they were not very good at it (Eggly et al., 1997). Using a 16-item instrument, the authors rated residents' skills as displayed during taped interviews with simulated patients. Residents were rated weakest in eliciting the patient's perspective. The authors concluded that the residency program was not doing an adequate job of teaching residents to use a patient-centered approach to discussions with patients. Another small study also used simulated parents as part of the process of assessing the parent counseling and information-giving skills of pediatric residents and emergency department fellows, providing feedback, and assessing improvement in subsequent discussions (Greenberg et al., 1999). The investigators reported improvements in two areas: reducing parents' feelings of dependence and improving feelings of trust. A third small study of pediatric critical care fellows using a somewhat different methodology also showed improvements following feedback by the simulated parents (Vaidya et al., 1999). Other studies have concluded (through self-reports and clinician assessments) that communications training for medical students and residents can improve their self-confidence, comfort, or skills in breaking bad news (Cushing and Jones, 1995: Garg et al., 1997; Vetto et al., 1999).

If physicians cannot face fully a child's poor prognosis and then appropriately communicate their assessment to families, timely reexamination of the goals of care and corresponding adjustments in care plans may be delayed. One retrospective study of parent and physician perceptions of the end-of-life care of 103 child cancer patients found a significant disparity between the time the physician first documented that the child was entering the end-of-life phase of his or her illness and the time the parents reported recognizing that there was no realistic chance for cure (mean difference of 101 days) (Wolfe et al., 2000b). The differences in physician and parent understanding of prognosis were not statistically significantly associated with differences in the care outcomes studied. However, when the physician's and parents' understanding of prognosis correlated more closely early on, the goals of care were more likely to be directed at lessening the child's suffering. Hospice was introduced earlier. Parents also were more satisfied with home care during the end-of-life period. When a psychologist or social worker was involved in the child's care, agreement between physician and parent assessments was more likely.

IMPLICATIONS

Children who die vary in the paths they follow, and some children with grave medical problems survive. Thus, pediatric palliative care—and if death occurs, end-of-life and bereavement care—must be flexible to meet the highly variable, changing, and sometimes difficult-to-predict needs and circumstances of children and families.

Evidence about the adequacy of current care for children with fatal or potentially fatal medical problems is limited but generally consistent with that found for adults in pointing to shortfalls in many dimensions of care. Specifically, pain and other symptoms are inadequately and variably assessed and treated, despite the availability of treatments that are effective, especially for pain. Palliative care consultations appear to increase the use of supportive services, but late or absent consideration of the benefits of palliative or hospice care is a problem. This puts children at risk of needless suffering from invasive and uncomfortable procedures that promise little or no benefit. Routine discussion and re-evaluation of the goals of care, which assists parents in making medical and other decisions, does not appear to be a part of "normal" health care for children with complex medical conditions.

More children with fatal conditions are dying after the limitation of life-support interventions, but the adequacy of care to manage any distress associated with stopping or not starting such interventions is little studied. Little research is likewise available on the prevalence, intensity, and management of symptoms other than pain and of psychological distress in children with fatal or potentially fatal conditions. Different studies point to problems in the communication of information to help families understand what may lie ahead and to make decisions about different courses of care. Barriers to these "just in case" conversations include physicians' discomfort in discussing bad news, fragmentation of care, and financial disincentives.

The literature reviewed in this chapter as well as illustrative vignettes suggest several directions for improving the effectiveness and consistency of pediatric palliative and end-of-life care. These directions include better understanding of the dimensions of pediatric palliative and end-of-life care and better understanding and application of existing knowledge and resources. Other directions include changes in the organization of care that may increase the effectiveness and reliability of such care, better training of health professionals in the principles and techniques of palliative and end-of-life care (including accurate but sensitive communication), and more research on almost every dimension of such care and the medical and other criteria for identifying children and families who might benefit from it. The next several chapters expand on these topics and also review the financing, legal, and ethical context of care for children with fatal or potentially fatal medical conditions.

CHAPTER 4

COMMUNICATION, GOAL SETTING, AND CARE PLANNING

> *It was terribly important for us to do exactly what was right and necessary to help our daughter. . . . Our nurse and social worker made us feel that we WERE, in fact, doing everything in our power to take care of our daughter.*
>
> Kathleen and James Bula, parents, 2001

> *When you first get sick, you have to live.*
>
> Katherine, 19-year-old with cancer (Sourkes, 1982, p. 112)

Except when death comes suddenly and without forewarning, physicians, nurses, social workers and other health care personnel—as well as hospitals and other health care institutions—play a central, even overwhelming, role in the lives of children with fatal or potentially fatal conditions and their families. When a child dies without forewarning, a family's encounter with medical personnel may be relatively brief but still have a profound and enduring impact.

As noted in Chapter 1, these professionals can at best help all involved to feel that they did everything they could to help, and that preventable suffering was indeed prevented. Other times, however, families' encounters with the health care system will leave them with painful memories of their child's unnecessary suffering, bitter recollections of careless and wounding words, and lifelong regrets about their own choices. In between these poles of medicine, families will often experience both excellent care and incompetence, attentiveness and neglect, and inconsistent communication of essential information.

Moving the typical experience of children and families toward the best care and entirely eliminating the worst care is an achievable goal. It is a goal that will depend on shifts in attitudes, policies, and practices involving not only health care professionals but also those who manage, finance, and regulate health care. That is, it will require system changes not just individual changes.

Child- and family-centered palliative and end-of-life care has many dimensions. One way to understand these dimensions is to view them, in a sense, as responses to families' fundamental questions and concerns following the diagnosis of child's life-threatening medical condition.

- "What is happening to me?" "What is happening with my child?" Good palliative, end-of-life, and bereavement care supports children and families with accurate, clear, and timely information about the child's condition and prognosis from the time of diagnosis through death and into bereavement—if death is the outcome.
- "What are our choices? How can we be good parents?" Following diagnosis, child- and family-centered care provides full, understandable, and timely information about curative, life-prolonging, and palliative treatment options that includes descriptions of potential harms or burdens as well as potential benefits of treatments. A central goal is to help the child and family to develop and adjust medical and personal goals based on their values and preferences as well as on medical and other circumstances.
- "How will you help us?" Appropriate palliative and end-of-life care offers a plan of physical, psychological, spiritual, and practical support that is adapted to the goals, values, and circumstances of each child and family. It is always appropriate for a child's plan of care to include such support while curative or life-prolonging therapies are pursued.

The rest of this chapter is organized primarily around these questions. The chapter tends to emphasize the role of the physician as diagnostician and communicator and as the ultimate locus of professional accountability for a child's care, particularly in the hospital. The discussion in Chapters 5 and 6 should, however, make clear that all members of the health care team—nurses, social workers, psychologists, child-life specialists, hospice personnel, and others—have specialized skills that are essential to comprehensive palliative, end-of-life, and bereavement care, including effective communication.

Such communication is especially important because parents may simultaneously hold multiple, possibly conflicting, goals that complicate decisionmaking. On the one hand, they may be profoundly reluctant to accept that their child will die, may need to feel that they have tried every option that might save their child, and may resist or resent certain offers of support (e.g., referral to hospice). One the other hand, parents naturally want to protect their child from pain and other suffering. Empathetic listening by members of the child's care team may help all involved to clarify their understanding of the child's medical situation, assess the goals of care, and fashion a care plan that reflects both medical realities and family priorities.

WHAT IS HAPPENING? DETERMINING AND COMMUNICATING DIAGNOSIS AND PROGNOSIS

"What is happening to me? How bad is it?" "What is happening to my child? Could she die?" General pediatricians and family practitioners may face such questions from children and families, but only infrequently are they the ones who bring the definitive word that a child has a fatal or potentially fatal condition.

In contrast, many pediatric specialists, including emergency medicine physicians, neonatologists, intensivists, oncologists, and neurologists, among others, must frequently, if not daily, inform families of a child's life-threatening condition. They may nonetheless be inadequately prepared to tell families honestly but compassionately what they need to know to make decisions and plan for the future. As described in Chapter 3, they may also so dread the delivery of such information that they fail to provide families with a complete, accurate, and timely picture of a child's diagnosis and prognosis. In addition, despite their considerable experience, they may not appreciate sufficiently the limits on how much bad news and how much complicated information people can absorb at one time.

Determining diagnosis and prognosis and then fully and sensitively informing patients and families require not only technical and intellectual skills but also empathy, education, experience, teamwork, time, and reflection. To be done consistently, it also requires supportive administrative systems (e.g., protocols, checklists, model conversation guides) and financing policies that appropriately value careful communication.

Diagnosing Life-Threatening and Fatal Conditions in Children

Aspects of Diagnosis in Children

Often, parents are the first to realize that something is not quite right with their child. For infants, the parents may recognize that their son or daughter is not achieving the expected developmental milestones—for example, raising his or her head, turning over, "cooing," or sitting. For older children, persistent reports or signs of fatigue may prompt a trip with worried parents to the pediatrician or family practitioner. This initial visit may then escalate into a nerve-wracking and protracted series of specialist consultations and tests to establish diagnosis and prognosis.

Sometimes, a critical problem is quite evident from the start, for example, when a child is badly injured as described in the vignette about "Jimmy Marshall" in Chapter 3. In such situations, a rapid series of assessments may begin with the first-response emergency personnel and continue into the emergency department, operating room, and intensive care unit. Family members may also be seriously injured or not yet located. The unavailability of a parent sometimes complicates diagnosis, for example, if a child seems to be suffering an allergic reaction to an unknown substance and is unconscious or too young to provide relevant medical history.

The technical aspects of establishing a diagnosis of cancer or heart disease may be similar in many respects for adults and children. Young children, however, present special challenges to the extent that they cannot report symptoms reliably or follow instructions (e.g., to swallow or stay still at a particular point) during diagnostic procedures. Cognitively impaired individuals of any age may present similar difficulties. In addition, diagnosing or ruling out a serious illness frequently involves painful or frightening procedures such as surgical biopsies and certain radiological examinations. Although older children and adults may also be unnerved by medical settings, young children are more likely to be upset by strange surroundings and large numbers of unfamiliar people. Child-friendly environments and special pediatric protocols, equipment, and personnel should help prevent or minimize children's pain and fear, but a young child's cooperation with diagnostic procedures may still be unpredictable.

Relatively recent technological developments that allow many fatal conditions to be diagnosed prenatally have extended the point of diagnosis sometimes months before birth. When a potentially fatal problem is identified by ultrasound, amniocentesis, or other means, an obstetrician has the difficult task of informing the parents and helping them to consider their choices. As described in the vignette about the "Rileys" in Chapter 3, perinatal hospice care is an option in some locales for parents who wish to continue the pregnancy. Whether identified before or after birth, certain diagnoses will also raise genetic concerns and should usually prompt a referral to a genetic counselor who can assist families in understanding and evaluating their situation.

Support for Children and Families While a Diagnosis Is Being Established

Frequently, parents and child patients must wait through a period of frustrating uncertainty—a diagnostic limbo—that is filled with great anxiety, hope, fear, and even grief as they anticipate the possible loss of cherished expectations for the future. Even when the basic message is "we don't yet know what's wrong," emotional support and careful and compassionate communication with parents and children are important. Parents may craft terrifying images of future possibilities until the facts are available. To support parents, clinicians may also have to manage their own frustration when a diagnosis is uncertain.

A relatively large number of rare and often or always fatal childhood disorders first reveal themselves—particularly in infants—with nonspecific signs and symptoms. Only as the child develops or the illness progresses does clearer evidence of a particular disorder become apparent. This can be frustrating for parents, who may feel that their concerns are being downplayed or ignored (NORD, 2001). Specifically identifying rare conditions can require extensive testing and may take years. According to a 1989 report to Congress, establishing a firm diagnosis took more than six years in 15 percent of individuals with rare conditions, and for almost one-third, it took more than a year (NCOD, 1989).

Sometimes a child's exact diagnosis remains in doubt, for example, if too little information from family history or from other reported cases is available to establish the significance of a diagnostic finding, such as a genetic mutation. This can cause parents even greater anxiety, especially if they would like to have more children.

Diagnostic uncertainty does not, however, necessarily affect medical management. Pursuing diagnostic clarity for its own sake may be costly, inappropriately expose children to testing risks, and subject parents to needless stress.

In addition to information and emotional support, families seeking a diagnosis for their child's problem usually can use extra assistance in navigating the health care system. Even within relatively integrated health systems, processes for coordinating multiple specialists and diagnostic procedures and their subsequent reports can be complex and imperfect. Delays and mix-ups can add considerably to the strain on children and parents, especially when the child and family have traveled far from home and their normal sources of emotional and practical support. Social workers can be helpful but typically become most involved only after a child is diagnosed.

Information Resources Beyond the Health Care Team

This chapter emphasizes information provided by the child's health care team. In reality, once they learn a child's diagnosis, many families engage in an intensive search for additional information from other sources including relatives, friends, advocacy groups, newspapers, books, magazines, and the Internet. Although not a substitute for information from clinicians, these resources do help many parents better understand their child's condition, their options, the questions they should ask, and the kind of responses they should expect.

Unfortunately, information from these other sources may be inaccurate or misleading. For example, press releases and media coverage of research developments may overstate preliminary findings and more generally create unrealistic hopes of cure or life prolongation. Such overstatements may, in turn, contribute to resistance by parents to some forms of palliative care or lead to requests for ineffective and even harmful treatments that adults might reject for themselves. To identify misunderstandings and misinformation (whatever the explanation), physicians may find it useful to ask parents what they understand of their child's situation.

One increasingly important source of information for parents, indeed all those with medical questions and concerns, is the Internet. The Internet also provides an electronic social support network for many patients and families facing serious medical problems. For example, several sites offer parent-to-parent support for families who have experienced a fetal death (stillbirth) or an infant's death from extreme prematurity or severe congenital anomalies. Sites that provide support and information for families whose child has or had a rare disorder may be especially welcome.

Little research charts how parents (or ill children or their siblings) locate or use Internet-based information, how their use varies during the course of a child's illness, or how the information influences their knowledge, attitudes, or actions. A recent survey found that 62 percent of those who used the Internet reported using it to locate health information, and over 90 percent of that group reported searching for information about a specific illness or condition, often someone else's (Fox and Rainie, 2002). The survey also found that most such users (about three-quarters) did not follow strategies that experts advise for checking a health site's sponsor, noting the date of the information, and taking sufficient time with their information search.

Other studies suggest that what consumers find on the Internet (and in books and other traditional sources) is of widely varying quality and value (see, e.g., Jadad and Gagliardi, 1998; McLeod, 1998; Eysenbach and Diepgen, 1999; Peroutka, 2000; APHA, 2001; Dyer, 2001; Li et al., 2001). Some well-managed sites include much carefully reviewed and thoughtfully presented information. Other sites provide information that is inadequately screened, misleading, inaccurate, incomplete, difficult to locate, poorly organized, outdated, or produced by groups with economic interests that could compromise the information provided. Physicians, social workers, and others advising families should review sites for clinical content and emotional tone before recommending sites, especially sites not associated with reputable governmental, professional, or other organizations.

Economic and educational disparities limit the reach of the Internet and other information resources to many patients and families. Health information, in general, tends to require high-level reading skills, even when it is intended for patients or consumers rather than health professionals (Berland et al., 2001). In addition, both before and after diagnosis, parents may find the information on the Internet overwhelming in both its volume and its content. Material intended for clinicians but available to everyone may be not only highly technical but also alarming in its specifics. Personal stories and photographs may likewise be frightening in their individual details and in their number and diversity. For example, after the birth of a very premature infant, one mother featured in an article in a major medical journal said she found the "horror stories" on the Internet so difficult that she promised herself not to read any more and to rely "more or less" on her baby's doctors and nurses for information (Richardson, 2001, p. 1504). Again, a child's care team may help guide parents to good sites.

The Internet can be more than a resource for general information and for parent-to-parent support. It is also being incorporated in telemedicine applications that support home health care for patients with life-threatening medical problems (see, e.g., Gray et al., 2000; Hersh et al., 2001; Starren et al., 2002). Chapter 6 briefly discusses some uses of telemedicine.

Prognosis: What to Expect Given the Diagnosis of a Potentially Fatal Medical Condition

Sometimes expectations for a child are clear at the time of the initial diagnosis. Certain kinds of congenital anomalies such as anencephaly are invariably fatal, although some infants may survive substantially longer than usual—dying after months rather than weeks or days. For other conditions, once an initial diagnosis is made, additional tests or waiting periods may be necessary to assess the condition's severity, the child's prospects for survival, and the implications for the child's and the family's quality of life.

Unless death comes quickly, for example, following severe injuries in a motor vehicle crash, assessment of prognosis is usually not a one-time event but a process of periodic reevaluation and discussion as time passes, as further testing occurs, and as curative or life-prolonging treatments are tried. For example, children whose leukemia recurs while they are on therapy have a less favorable prognosis than those with recurrence after treatment has ended.

Importance of Prognostic Information

When a child is diagnosed with a potentially fatal medical condition, families need information about the probable course of the condition—

including possible life expectancy and physical or mental consequences and the expected effects of treatments. The uncertainty associated with the information also should be acknowledged.

Full diagnostic and prognostic information may influence not only medical decisions but also other choices (Miller et al., 1998). For example, parents given accurate information about their child's fatal or potentially fatal medical condition may decide that it is prudent to put off the purchase of a new house or rethink a job change that would reduce family income, jeopardize health insurance, or require extensive travel. Others, if finances and the child's condition allow, may decide to take a family "dream" vacation sooner rather than later based on what they have learned. If they have a timely and full explanation of what to expect, parents may act earlier to enlist support from other family members and friends, work with teachers to create a supportive environment for the ill child and any siblings, marshal spiritual resources, and otherwise seek help to sustain them in the difficult times ahead. Likewise, if responses to therapy and the passage of time shift expectations for a child's survival and quality of life from favorable to grim, parents who are given sensitive but full information and counseling can be helped to prepare for their child's death, even if they also choose to continue experimental or other therapies. Conversely, overly optimistic assessments by physicians can deny patients and families opportunities to prepare for death and say their good-byes. It can also contribute to avoidable suffering if inadequately informed families choose burdensome treatments that will not benefit their child.

Chapter 3 reviewed some research suggesting discrepancies in physician and family assessments of prognosis. More research is needed on the causes and consequences of such differences. Possible causes include individual characteristics (e.g., styles of communication related to education or cultural background) and organizational or system factors (e.g., lack of protocols for communicating with families, poor training of health professionals).

Prognostic Uncertainty

As noted in Chapter 1, determination of prognosis is not a precise science. A number of analyses have described the limitations of quantitative and qualitative prognostic determinations for adult patients (see, e.g., Thibault, 1994, 1997; Lemeshow et al., 1995; Lynn et al., 1995; SUPPORT, 1995; Sherck and Shatney, 1996; Lynn et al., 1997; Christakis and Iwashyna, 1998; see also Appendix B). Determining prognosis for children can be even more difficult because the number of deaths is much smaller and because children's deaths from illness are somewhat less concentrated than adults in a few major diagnoses (see Chapter 2). As a result, large databases for reliable statistical analysis of survival patterns are less available and more expensive to accumulate.

For very rare conditions, even qualitative accounts of clinical experience are limited. For instance, certain neurological and metabolic disorders are so uncommon that pediatricians and family practitioners have little experience or information to use in advising families about the future course of the disease or life expectancy. They must rely on their clinical judgment and careful monitoring of a child's development, responses to treatment, and complications to provide parents with their best sense of the child's condition and future course.

Many progressive conditions have a highly variable course in children, but the reasons for this variability are not well understood. For example, research has only partly documented genetic and other factors (e.g., seizures, age at diagnosis) that put children with neurological disorders at higher risk of serious physical disability or early mortality. Similarly, researchers have undoubtedly identified only a small subset of genetic features that affect the likelihood of treatment success for various childhood cancers. Relapsed cancers are clearly harder to cure, but at the time that a relapse is diagnosed, it is not now possible to identify the children likely to be in the small group of survivors. This adds to the impetus to continue curative efforts.

Further, the same condition may follow a different course in children and adults, and a treatment may vary in effectiveness and unwanted side effects depending on the patient's age. For example, the National Cancer Institute presents advice separately for adult and childhood acute lymphoblastic leukemia (NCI, 2001a). To cite just one of many other examples, although tacrolimus has proved a generally effective immunosuppressive drug for adults who have undergone transplantation, some research suggests that children may respond less favorably (MacFarlane et al., 2001). Such differences underscore the importance of drug testing to establish pediatric dosing information (see Chapter 10).

Prognostic uncertainty may have limited practical consequences in some situations. Other times, however, it can be very consequential. As discussed in Chapter 6, for a patient covered by Medicaid or Medicare, eligibility for hospice benefits is contingent on certification by a patient's doctor and the hospice medical director that the person is terminally ill and has a life expectancy of six months or less if the disease has a "normal" course. Patients (or their surrogate decisionmakers) are also required to consent to forgo curative or life-prolonging treatments. These rules limit the ability of hospices to serve substantial numbers of adult Medicaid patients who have conditions such as congestive heart failure for which prediction of remaining life expectancy is particularly difficult and for which medical interventions during crises can add months or even years of life (Lynn and O'Mara, 2001). To the extent that determining prognosis is more difficult and uncertain in children, the rules put Medicaid-covered children and their families at a particular disadvantage if they desire assistance from a hospice.

As discussed in Appendix B, researchers have developed statistical models to assess illness or condition severity for critically ill children and to estimate their risk of death or other outcomes. The value and limitations of these models continue to be evaluated. For example, one recent study of prognosis in a neonatal intensive care unit concluded that—contrary to expectations—accuracy in predicting survival using either a statistical tool or clinical intuition did not improve with time. Instead, "most infants who die after the first few days . . . . seem to 'cloak themselves;' their ultimate demise becoming less apparent with each succeeding NICU day" (Meadow et al., 2002, p. 884). In general, prognostic models and tools tend to be more useful for some purposes such as health services management, quality assessment, and research but less so for other purposes such as guiding decisions about life-sustaining medical interventions for individual patients.

Communicating Bad News

> *Every word that was said the day Becky died is indelibly etched in my mind. I have replayed the words in my mind a million times. It's a never-ending tape.*
>
> Pam Borchart, parent (Maruyama, 1997)

Physicians usually will have the difficult task of telling parents what they cannot bear to hear—that their child's life is in jeopardy or that their child has died. Sometimes, as in the emergency department, physicians will be informing people they have never met before. Likewise, with a dying newborn, the neonatologist and the family may be strangers. At other times, for example, when tests show that a child's cancer has returned, physicians will be informing families they have known for the months or years of the child's illness. In some instances, the news of a child's death may come from an inexperienced resident who happens to be on duty in the intensive care unit but who has had no relationship with the family.

When a child has been injured away from home and taken to a hospital emergency department, a social worker usually serves as the communication and interpretive link between the parent and the team or teams working to save the child. Physicians may make briefer appearances to discuss tests, treatments, prognosis, and decisions. (See the vignette about the Marshall family in Chapter 3.) Nurses rarely take the lead in presenting bad news in either emergency or other situations, but they may help identify situations in which there is a mismatch between a child's condition and a parent's understanding of that condition. When there has been an emergency outside the hospital, parents may seek information from paramedics or police officers at the scene. In certain jurisdictions, death cannot be declared outside a hospital or other medical facility, and paramedics may not be permitted—or prepared—to inform parents of their child's status (Iverson, 1999). These limits do not, however, make good communication skills and sensitivity irrelevant. Communication guidelines or protocols for emergency personnel should cover situations involving both the provision and the withholding of information, including when circumstances may require a police investigation.

Although it seems reasonable that training and experience should improve clinicians' comfort and facility in communicating about life-threatening medical problems and about death, research is limited. Vazirani and colleagues (2000) concluded from a longitudinal study at one institution that pediatric residents became more comfortable with issues of death and dying over the course of their residency. At the same time, they became less comfortable with pain management out of concern that it might hasten death. As discussed further in Chapter 8, education about this and other dimensions of palliative, end-of-life, and bereavement care is limited at all levels of pediatrics training.

Most discussions about breaking bad news focus on adult patients and on families of adult or child patients. The following sections consider conversations with parents and with ill children themselves. One theme is that it is important—from the outset—to consider what, when, and how to communicate with the child patient. Depending on a child's cognitive and emotional development and preferences, the child may or may not be included in the initial discussion.

Talking with Parents

> *Things that are said at that time you remember forever.*
>
> Maruyama, 1997

Parents have tried to describe the impact of learning that that their child's life was in jeopardy. "Nothing in this new world makes sense. . . . In such insanity, you are dumbstruck." (as quoted in Finkbeiner, 1998, p. 5). "I don't think you understand anything until a few months go by. Maybe more than a few months" (as quoted in Finkbeiner, 1998, p.2).

Even sensitive and otherwise capable clinicians may not realize how difficult it can be for a shocked, fearful parent to absorb information. Incorrect assumptions about what parents understand, especially during a single conversation, can create confusion and distress later. If news is presented poorly, parents may recall the additional pain and, often, anger for years afterward. Personal accounts and some research suggest that physicians, whether experienced or not, will often face the telling of bad news with apprehension and inadequate formal training (see, e.g., Nuland, 1994; ABIM, 1996a,b; Christakis and Iwashyna, 1998).

Although many parents "only need to be told once that their child is dying," some may not initially accept or understand the message. For example, in one of a series of interviews about clinician experiences with families, one physician described situations in which "you can say, 'She's getting maximal therapy. She's not getting any better. That really isn't looking well [sic] and we are going to have to start to think about what if she doesn't get better . . . ' [and the parent's response is] 'So, is she going to be healthy when she goes home?' " (Bartel et al., 2000, p. 1128).

If other members of the child's care team are present during discussions with parents, they may sometimes be able to help when communication is not working. They also may participate in a timely "debriefing" to discuss how the conversation with a family went and what might be done differently and better in the future. Unfortunately, when physicians must break bad news during the evening or night, support from social workers, child-life specialists, and others may be limited because these professionals usually do not work those shifts, except for emergency departments.

Most literature on communicating bad news takes the perspective of those who must deliver the news (Girgis and Sanson-Fischer, 1995). Some studies have also sought perspectives from patients or families about what was important to them (Peteet et al., 1991; Krahn et al., 1993; Sell et al., 1993; Ahmann, 1998; Hart and Ahrens, 1998; Jurkovich et al., 2000). For example, one small survey study of 54 surviving family members of patients who had died of trauma reported that the most important aspects of delivering bad news were the attitude of the person delivering the news, the clarity of the information, privacy, and the person's knowledge or ability to answer questions (Jurkovich et al., 2000).

The literature on communicating bad news often includes guidance about how to prepare for and structure the conversation (see, e.g., Girgis and Sanson-Fisher, 1995; Ptacek and Eberhardt, 1996; Chisholm et al., 1997; Ptacek et al., 1999; Baile et al., 2000; Ambuel and Mazzone, 2001; ChIPPS, 2001; Levetown, 2001; Von Gunten, 2001). Again, little research documents whether following this guidance makes a positive difference for patients, families, or physicians (Walsh et al., 1998). As Ptacek and Eberhardt (1996, p. 496) observe, it is not clear "what of the personal, interpersonal, news-specific, situation-specific, and transmission-specific variables are important predictors of giver or receiver reactions." In general, studies suggest that considerable agreement exists between physicians and families or patients about how news should be conveyed (see, e.g., Ptacek and Eberhardt, 1996; Baile et al., 1999; Parker et al., 2001).

Box 4.1 summarizes several general principles for communicating clini-

BOX 4.1
Presenting Bad News to Families

Preparation

- Understand that respectful and clear communication is an essential professional obligation.
- Plan with members of the care team for the delivery of bad news, including the words, the tone, the time, and the place. Have information that is as complete as possible.
- Anticipate that reactions will vary, but be prepared to deal with shock, grief, anger, panic, and other strong emotions.
- Have someone trained to respond to the family's emotional and practical needs who is ready to stay with the family.
- Try to have both parents present, if clinical and family circumstances permit, and ask if they would like their child or others to be present. If the answer is yes, plan for someone to accompany the child if he or she chooses to leave.
- Find a private, quiet place where everyone can be seated comfortably and you can make eye contact with the family members and touch them if that seems supportive.
- Have a trained translator present if necessary.
- Consider taping the conversation and providing the tape to the family.

Conversation

- Indicate at the start that the news is not good.
- Show your concern, empathy, and respect for the child and family.
- Listen carefully.
- Try to get an early sense of the family, including what they already know and how they express themselves. Adjust the style and content of communication—including the use of physical contact—accordingly.

cal information and, more specifically, conveying bad news to parents about their child's medical problem. It assumes that a physician is presenting the news. Other members of the health care team bring additional skills and perspectives to bear on the complex process of presenting information effectively and compassionately. Discussions with ill children themselves are considered separately below, but many of the same points will still apply. Box 4.1 should not be interpreted as a communication protocol. (Chapter 6 includes recommendations for developing such protocols.)

Although many clinicians appear comfortable with communication guidelines and report using them, they also identify obstacles to implementing them (Campbell and Sanson-Fisher, 1998; Dosanjh et al., 2001). These obstacles include lack of time, lack of support from other professionals (especially important for residents) and from institutions, and lack of rou-

- Use the everyday language of the family rather than the everyday language of clinicians, except when clinical terms are likely to be helpful.
- Consider using sketches and diagrams to support explanations of the diagnosis and prognosis.
- Seek guidance from families about the amount and specificity of information they want, and let them control the pace and flow of information insofar as possible.
- Allow time for families to absorb and process information.
- Assess (if the child's condition permits) whether discussion of options, goals, and plans should be initiated or postponed to a defined later time.
- Check family members' understanding of what they have heard and assess what needs to be repeated or reinforced during this or later conversations.
- Reassure families that it is normal to be emotional, confused, or overwhelmed.
- Provide written information and suggest other information resources.
- Offer to help parents prepare for talking with their child if the child is not present
- Encourage parents to write down questions as they arise, so that they can be discussed later.
- Respect parents' need for hope and reassurance but avoid evasions or deceits that may undermine trust and prevent emotional and other preparation for what lies ahead.

Follow-up

- Arrange for further discussions as appropriate, including with the child (if he or she was absent), siblings, and others.
- Document the conversation (in addition to documenting diagnosis and prognosis) as a guide for future discussions.
- Reflect on the conversation and what might be done better in the future.

SOURCE: Adapted from IOM, 1997.

tine processes for feedback and dealing with emotions. As discussed in Chapters 6 and 7, health plan policies that undervalue communication and preclude reimbursement for discussions when the child patient is not present are also discouraging.

Many of the same basic principles listed in Box 4.1 will apply to later discussions with parents as a child's condition changes. Conversations may become less strained when families and clinicians have established a relationship of trust and a familiar style of communicating. This is evident in one parent's description of a crucial discussion with the child's physician after surgery and many months of chemotherapy: "The tears in his eyes when he set up the meeting and then the careful way he described everything were the final message I needed to realize that we had run out of [treatment] options" (Aney, 2001).

Box 4.2 provides an example of how an actual conversation between a physician and mother might be constructed. It does not fully depict but only suggests the professional preparation and system support (e.g., availability of written materials for families, follow up procedures) for the individual conversation.

One point that is not always emphasized is that communication is an interactive process. Early on in a conversation, clinicians can ask questions about parents' understanding of their child's situation and then craft a discussion that builds on this initial information about what parents know and what language they use to describe what they know. Also, as noted earlier, communicating about diagnosis and prognosis is usually not a one-time event but a continuing process as care goals and plans are considered and reconsidered and new information becomes available. Information may also have to be repeated. It may take considerable skill to do this without

BOX 4.2
Example of Communicating a Grim Diagnosis

Starting

Physician: Hello, Ms. Gutierrez. This has been a tough and exhausting time for you. Thank you for meeting with us again. This is Mandy, the social worker and Ranesha, the child-life specialist. I'm glad your friend Carlos is here with you.

Continuing

I wanted to review Maria's situation and give you some additional information about what has us so concerned. First, though, can you tell me what you understand so far?

Mother: Well yes, Maria is having problems breathing.

Checking

Physician: What do you understand is causing that?

Mother: I heard someone say something about pneumonia. My father thinks it may be from the chemical plant.

Physician: You are right that pneumonia could be one cause, and we are treating Maria for that. However, we are concerned that another problem may be causing her troubles. These problems include a form of muscle weakness called muscular dystrophy. Have you ever heard of that?

Mother: No, I've never heard of it. It doesn't sound good.

making some parents feel as if they are being bludgeoned with the message that their child will die. It may also require good communication among members of the care team so that they do not unnecessarily and insensitively go over the same issues or questions or provide conflicting perspectives.

One constraint on the use of repeated conversations to ensure comprehension of important information is that the initial news about diagnosis, prognosis, and options must often be followed quickly by treatment decisions. Parents may be asked to read and sign an "informed consent" document that describes the nature of a planned procedure and its potential benefits and risks. As described by Sourkes (1995a, p.33): "While [the consent form is] intended as a factual document, its emotional impact on the parents cannot be underestimated." To the extent that parents are shocked and only partly comprehending, their decisionmaking capacities may be impaired (Downer, 1996).

Physician: It is not good. Let me tell you more about the problem and what we can do to help. You may not understand everything in this conversation and you may forget some things. That's normal. Don't worry about writing things down. What I tell you is also in the family information notebook that we will give you. Also, that notebook has space for you to write down questions, so you should keep it with you. Then you will have a list of questions you can bring when we meet again.

Listening

Mother: I don't need to write things down.

Physician: It can very helpful. Does something bother you about it?

Mother: Oh . . . I don't write English that well.

Physician: That's okay. We can have someone who knows Spanish to help you. And in a couple of months, we should have a Spanish language version of the notebook ready.

Reassuring

Mother: I'm scared. I'm going to cry.

Physician: That's okay. It's normal to be scared. We do need to talk some right now, but then we can stop if it is too hard and set another time to talk. We will be here for you—not just me but Mandy and Ranesha and the other doctors and nurses who work specially with children like Maria. You'll meet them shortly.

After parents have learned that a child has a life-threatening medical problem, they often must then gather the emotional resources to tell others—the child, his or her siblings, their own parents, friends, teachers, and others. Physicians, social workers, child-life specialists, psychologists, and others can provide guidance and emotional support as parents undertake these difficult conversations. Time pressures, financial constraints, and other circumstances may, however, limit what they can offer.

Talking with Children

> *The ones who tell me are my friends.*
> Benjamin, child with cancer (Bluebond-Langner, 1978, p. 188)

With the advice and support of the child's care team, parents typically decide when and what to tell their child about his or her diagnosis and prognosis.[1] If parents choose not to include the child when a physician first meets with them to discuss diagnosis, they may welcome help in preparing for a later discussion with the child, perhaps even having the child's physician convey the news or at least be present. Older children may want information to come from the physician directly. Although communication clearly must be tailored to the child's developmental status and clinical status, little systematic research is available to guide parents and clinicians about the effects of different styles and amounts of communication for children of different ages and other characteristics (Stevens, 1998; Goldman, 1999).

Qualitative studies of children living with life-threatening medical conditions make clear that they are often aware at some level that they will not live to grow up or that they may die soon (Bluebond-Langner, 1978; Sourkes, 1995a). Such knowledge does not depend on explicit communication. Based on what is happening around them and to them, even young children may develop realistic apprehensions that they are going to die. Bluebond-Langner described the "five-year old boy, lying uncomfortably on his back, [who] when asked if he wanted to be turned over, said 'No, I'm practicing for my coffin'" (1978, p. 191). Another child, asked what he was going be when he grew up, replied "a ghost" (1978, p. 194).

Once it was common to try to "shield" dying children, and often adults, from knowledge of their condition. Now more agreement exists—in principle, if not in practice—that children with life-threatening medical

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[1] The nature of the child's illness may influence parents. For example, parents of children with HIV infection or AIDS have sometimes been reluctant to inform the child of his or her status (AAP, 1999a; Gerson et al., 2001). This can harm children, especially older children who recognize that something is not right with them. With adolescents ready to experiment with sex, failure to discuss such a diagnosis can also increase the potential for harm to others.

problems should normally be informed about their condition, consistent with their intellectual and emotional maturity, medical status, and personal preferences for receiving information (Wass, 1984; Goldman, 1999). Family preferences or cultural values, which must be understood and respected, will not always be consistent with this consensus. For example, in some cultures, talking about death explicitly is seen as risky or not appropriate and in others, involvement of children in discussions about their future is not approved (see, e.g., Jecker et al., 1995; Carrese and Rhodes, 2000). In practice, the parents' values usually seem to prevail if they do not want the child told.

Although scientific research is limited, clinical experience and qualitative studies and reports suggest that failure to provide children with information and the opportunity to discuss their concerns and fears openly can lead to feelings of isolation, guilt, anxiety, and other distress (Bluebond-Langner, 1978; Sourkes, 1995a). Parents also may suffer for their evasions with their child. As one anguished father recalled, "My last words to my son were a lie" (from Goldman, 1999, p. 104). Children, however, may be very protective of their parents and siblings and may cooperate in a pattern of silence, while understanding that they are ill and may die (Bluebond-Langner, 1978). As one clinician described it, "parents want to protect their children, and children want to protect their parents . . . and you're not the parent" (Mildred Solomon, Ed.D., Education Development Center, personal communication based on interviews for the Initiative for Pediatric Palliative Care, unpublished analysis by Hardart et al., 2002).

In deciding about the content, timing, and pace of communication, parents will draw on their knowledge of their child's temperament, emotional resilience, curiosity, intellectual abilities, coping strategies, and past experiences, for example, the recent death of a grandparent (Sourkes, 1995a; AAP, 2000c). Children who have already undergone extensive testing and treatment will likely have provided clues or direct statements about what they understand or suspect and how ready they are learn more.

What is communicated will also depend, in part, on the nature of a child's medical condition and history. For example, the initial communication about the diagnosis of a usually curable cancer may emphasize that good treatments are available, that most children recover, and that the care team is committed to keeping pain and other problems to a minimum. When the diagnosis and prognosis are less favorable or when cancer has recurred, the information cannot be so positive. In these circumstances, finding ways to redefine or reframe—not remove—hope can be challenging. Once again, little research is available to guide these kinds of discussions and suggest what parents find supportive under what circumstances.

For children, cognitive development may limit what they can accurately understand about serious illness and death. A number of analyses have described the evolution of children's understanding of death (see, e.g., Wass, 1984; Stevens, 1998; Davies, 1998; Silverman, 2000). They have generally assessed developmental understanding in terms of four basic concepts: irreversibility, finality, universality, and causation. These analyses have, however, generally focused on healthy children. They may not be applicable to children who have experienced extended periods of illness and medical treatment. As parents and clinicians discuss care options for and with the ill child, they may not fully appreciate the ill child's altered sense of the world compared to well children. Further, adolescents who have lived for years with a serious condition and who may live for many additional years may continue to be treated as if they were much younger. This may interfere with their normal development toward adulthood.

In responding to a child's questions, a parent or clinician will often need to look for an underlying intent or meaning and guard against providing too little or too much information or answering the wrong question. Children's nonverbal communication—including drawings, expressions, and posture—may reveal their desires, concerns, knowledge, or suspicions more clearly than words because they lack the concepts to describe their concerns or emotions (Adams-Greenly, 1984). Stevens recounts, for example, the 5-year-old child who, on the night he died, told his parents that he did not know what to say but then sang a children's song about a rainbow (Stevens, 1998). The question of another seriously ill 5-year-old, "Doctors can't make everyone better, can they?" (Goldman, 1999, p. 96) might be both a request for reassurance and an attempt to understand more about his situation. In addition to artwork, conversations with children may be aided by the use of stuffed animals, dolls, puppets, and other toys, which may also be helpful therapeutically in helping children cope with fear, sadness, and other emotions (Sourkes, 1995a; see also Chapter 5).

For adults, detailed initial and continuing communication about diagnosis and prognosis may be driven by the patient's need to give informed consent for treatment and make financial and other plans. Children usually do not face such pressures. Unless the child needs fairly immediate preparation for surgical or other treatments, communication may be guided to some degree by his or her explicitly or implicitly indicated desire for information (Sourkes, 1995a).

Once they learn of their prognosis, children may or may not want to talk further about it with their parents. For example, one of the parents with whom the committee met felt that he and his daughter really needed to talk, but she was reluctant. Finally, she said, "Dad, okay, this is it, one time, we're going to talk. . . . [When I had] said everything I wanted to say . . . she said, 'Dad, are you finished? . . . You are getting my head all wet'" (Weil, 2001). Perhaps to spare her parents some of her anxieties, the daughter did talk more with her home-school teacher.

Later sections of this chapter consider children's participation in goal setting and treatment decisions. The discussion of decisionmaking includes the committee's recommendation that children be included in discussions and decisions consistent with their intellectual and emotional maturity, medical condition, and preferences. Chapter 8 reviews legal issues related to children's participation in decisions about their care.

Talking to Parents When Their Child Has Died Without Forewarning

> *My husband was called to the hospital where he tried to ask questions but received few answers.*
>
> Patricia Loder, parent, 2001

> *They hadn't laughed with my babies, fed them, burped them, played with them, nursed them to sleep. How could they say now that one of them was dead?*
>
> Esmeralda Williamson-Noble, parent, no date

Sometimes parents will not have to be told of their child's death because they will be there—at home or in the hospital, perhaps following a decision to forgo further life-support interventions or other planning when death is clearly approaching. Other times, physicians will have to tell parents that their child has died in the emergency department or intensive care unit. This will never be easy, even when the child has been seriously ill and treatments have been failing. The task will be particularly difficult when a child has died suddenly and without forewarning, for example, in a car crash.

Appendix F discusses some of the complexities created when a child dies suddenly and without forewarning. Such situations may involve a large cast of providers, possibly including emergency medical technicians, fire and rescue personnel, law enforcement and public safety officers, as well as hospital-based caregivers in emergency departments, on surgical teams, and in intensive care units. Each may interact with family members but under different conditions and with different constraints (including legal constraints). Each needs communication protocols and procedures tailored to these differences.

In emergency situations, some of the usual guidelines for communicating bad news may be difficult to implement, particularly if the parents or other family members have also been injured. Time for planning a conversation may be abbreviated, and time for the conversation itself may be curtailed by the need to respond to new emergencies. The expectation of a continuing relationship is usually absent, although physicians, social workers, or other designated and trained individuals can assure parents that they should call if they have questions later. They can also offer follow-up support as described below, including discussion of autopsy findings that clarify the cause of death.

Given the stressful circumstances of a child's unexpected death, the development of communication protocols and procedures and the corresponding training of emergency medical and other personnel are important but have not necessarily been a priority for health care institutions. For example, a survey of emergency department directors published in 1993 found that most hospitals did not have an organized process for informing and counseling parents whose child was dead on arrival, provided no training in how to tell parents about a child's death, and let the responsibility for doing so generally fall to the least experienced clinicians (Greenberg et al., 1993). Survey results cited in Chapter 3 suggested that emergency room physicians were poorly prepared to tell parents about a child's death and would even uselessly extend resuscitation to avoid telling them.

Recently, under contract from the federal Maternal and Child Health Bureau, the National Association of Social Workers has developed consensus bereavement guidelines for social workers in emergency departments and has received funds to train social workers in emergency services guidelines (Lipton and Coleman, 2000b; NASW, 2000). These guidelines stress the importance of preparation, including establishing protocols and procedures for communication and family support when a child dies in the emergency department; training for all department staff; designating a room to be used for private discussions with families; assigning a social worker, chaplain, nurse or other trained individual to provide support and act as a liaison between the family and emergency department personnel; and developing a plan to follow the family in bereavement. Follow-up studies should assess the implementation and results of these guidelines, which cover both the emotional or psychological dimensions and the practical aspects of working with families. In addition to these guidelines, the recent statement of the American Academy of Pediatrics and the College of Emergency Medicine on care of children calls for development, implementation, and monitoring of policies, procedures, and protocols on death in the emergency department, but the statement is not specific (AAP, 2001b).

Earlier AAP guidelines on death in the emergency department are more specific on topics that should be covered in protocols and checklists. They do not specifically discuss communication protocols but do state that departments should have a private room where family members can talk with physicians, nurses, social workers, or chaplains as well as child protection services representatives or police officers (AAP, 1994a).

When a child has died suddenly and without forewarning from injuries either before or after arriving at a hospital emergency department and the parents are not present, the general view is that a physician should notify the parents in person, for example, asking them to come to the hospital

(Levetown, 2001). Some parents may, however, make it clear in a telephone conversation that they want the news immediately. Each situation is different, and physicians, social workers, or others communicating with families should look for cues from parents or other family members about the content and pacing of discussions.

Although it may be appropriate to withhold specific information in some special situations, the committee heard that lack of information—not even a "we don't know yet" or "we are still working with [the child]"—is another burden for shocked and fearful parents. One parent, who was injured in the accident that killed her two children, told the IOM committee, "My attempts to learn the status of my children were answered only by sedative drugs, not information" (Loder, 2001, p. 4).

In its written statement to the committee, a group supporting families of murdered children highlighted the word "information" throughout the statement to emphasize its importance (NOPMC, 2001). The group also stressed that families can be obsessed with wondering what happened to their loved one and that imaginings can be worse than reality. Failures to tell the truth, even if well meaning, can be damaging, especially since families of murdered children may learn the details during police investigations or courtroom proceedings.

Among the practical matters that need to be handled competently and compassionately by social workers, chaplains, and others are (depending on the circumstances) medical examiner referrals, organ donation requests and referrals, notification of the patient's primary care physician, completion and transmission of death records, identification and notification of funeral home, and authorization for release of the body. These steps, which must be consistent with relevant state and federal laws, are necessary after most deaths, but in the crisis atmosphere of the emergency department, clear administrative protocols and procedures and associated training and monitoring are especially important. Chapter 9 includes an example of training strategies for one sensitive topic, requests for organ donation, that may be relevant for other discussions.

WHAT ARE OUR OPTIONS? ESTABLISHING GOALS

General

A child's diagnosis and prognosis will determine to some extent the kinds of goals, care options, and choices that are possible. Parents of an infant born with certain fatal congenital anomalies will have only short-term options to consider. In contrast, parents of a toddler diagnosed with a slowly progressive, fatal neurodegenerative disorder will have short-term and long-term choices to make over a period of years. The possibilities for a child just diagnosed with an often-curable cancer will differ from those for a child who has relapsed following a second or third round of chemotherapy. It would be inappropriate to emphasize options for end-of-life care during discussions with parents of the newly diagnosed child, whereas parents of the child whose treatments are failing need to learn about options for supportive end-of-life care if they are to make informed choices. In less clear-cut situations, what to tell the parents and when will necessarily be more difficult to judge. Whatever the child's status and whatever a family's goals and choices, parents should, however, be reassured that everything will be done for their child's comfort and the family's well being.

Some discussion of care goals and options will usually occur during the initial conversation about a child's diagnosis and prognosis. As already described, shock, fear, and panic may interfere with parents' abilities to absorb information and make decisions. Thus, their understanding of this initial information cannot be taken for granted. About his own experience with the very premature birth of his son (who survived), psychologist Michael Hynan wrote that some of what happens "is so horrible it must be blocked out. . . . And if you're a perinatal professional trying to explain something to me at the same time, it just doesn't register, even if I'm nodding my head. . . . I ask you [perinatal professionals] to help us when we do silly or dumb things because we are so stressed out" (Hynan, 1996, online, no page). Assessing what parents are understanding or what their reactions mean requires experience, empathy, and concentration—and the assessment may still be imperfect.

Based on their experiences and their own values, physicians and others may have expectations about what patients and families will want. They may often be correct, but one principle of patient- and family-centered care is, "Ask, don't assume" (Gerteis et al., 1993). This principle recognizes both the potential for differences in individual values and preferences and the limits on an individual's ability to absorb information. Checking understanding of diagnosis, prognosis, and treatment options (including palliative care options) should be a part of obtaining informed consent for treatment, whether or not a signed document is required. Otherwise, parents may make decisions without appreciating the expected burdens (which may sometimes be high) and the probability of benefit (which may sometimes be remote). One long-term goal should be for the parents to feel later that they did the right things and did not cause their child needless suffering.

Most parents will want to participate actively in setting goals and making decisions about their child's care. Some parents, however, may consistently defer to physicians, even when the physicians and other members of the care team actively solicit the parents' guidance in the development of care goals and plans. In contrast, in uncommon but usually very difficult situations, some parents may find themselves in conflict with their child's care team to the point that an ethics consultation or other outside mediation is needed. (See Chapter 8.)

Establishing goals and evaluating treatment options may be particularly complicated for children with very rare disorders, when physicians have little experience or literature to guide them or the child's parents. This was one of the challenges facing physicians in Chapter 3's vignette about Johnny Gabrielle and his family. As noted in that chapter, even for more common conditions, children's paths may be highly variable, more so than for adults.

A family's cultural or religious values and personal histories may shape their goals of care and preferences for information, influence their evaluation of treatment options, and affect their level of trust in a professional's advice. Research involving adults has reported differences in cultural attitudes about disclosure of information, participation in decisionmaking, use of traditional or alternative therapies, and end-of-life care (Irish et al., 1993; Blackhall et al., 1995, 1999, 2001; Hopp and Duffy, 2000; Sullivan, 2001). In addition, members of ethnic and cultural communities that have long suffered discrimination and deprivation may interpret a discussion of forgoing resuscitation or other interventions as an attempt to deny beneficial care. Some studies have reported differences in utilization of or preferences for life support and advance care planning among African Americans compared to Caucasians (Garrett et al., 1993; Gramelspacher et al., 1997; Shepardson et al., 1999; Crawley et al., 2000).

Sensitivity to cultural, religious, and other values can help members of the child's care team establish a respectful and constructive relationship with families whose backgrounds differ from their own. Profound cultural misunderstandings can be difficult to overcome, however, as devastatingly portrayed in Anne Fadiman's (1997) *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. Discussing the relationships between the family and physicians caring for a child with epilepsy, the author writes, "It was as if, by a process of reverse alchemy, each party in this doomed relationship had managed to convert the other's gold into dross" (Fadiman, 1997, p. 223). Appendix D discusses cultural considerations in end-of-life care for children in more detail.

Integrating Palliative Care Perspectives from the Time of Diagnosis

Understandably, for parents whose child has a life-threatening medical problem, the overwhelming initial goal or desire will usually be to save their child from death. For example, the study by Wolfe and colleagues (2000b) cited earlier found that parents cited cure as their number one goal at the

TABLE 4.1 Common Goals and Examples of Supportive Care

Goal	Examples of Care
Physical comfort	Using medications and behavioral interventions to prevent or relieve a child's pain, fatigue, or other symptoms Providing physical therapy to improve function and relieve pain
Emotional comfort	Providing psychotherapy including verbal and play techniques Arranging art, music, or other expressive therapies Encouraging visits from family and friends
Normal life	Informing the child and involving him or her in decisions (consistent with intellectual and emotional maturity) Planning with teachers and administrators for a child's return to school Organizing travel or camp experiences
Family functioning	Helping parents make special time for siblings Arranging respite for parents
Cultural or spiritual values	Accommodating religious rituals and traditional customs Encouraging continuation or adaptation of family holiday traditions
Preparing for death	Planning for parents, siblings, and others to be with the child at and after death Planning for remembrances or legacies of the child's life including pictures, videos, locks of hair, and handprints or handmolds

time of diagnosis. Depending on their age, medical problem, and other factors, child patients may be as much focused on cure as their parents are.

One reason for integrating palliative care perspectives with discussion of possible curative and life-prolonging interventions is to encourage families to consider and achieve additional goals related to the child's quality of life and that of the family. Table 4.1 lists a range of such goals, some of which will be most relevant when the child's life-threatening condition extends over months or years. Without explicit consideration, these goals may be neglected—to a family's later regret and sorrow. Only the last of the goals—explicit preparation for death—requires a family to accept that a child will likely die, and even this goal does not require that a family forgo continued effort to prolong the child's life. Nevertheless, some families may be unable to face preparing for their child's death.

Another reason for integrating palliative care perspectives from the time of diagnosis is to encourage sensitive but systematic revisiting of goals and plans as a child's medical condition changes. Parents may be so absorbed in the medical, financial, and practical aspects of caring for their children and surviving day to day that they may find it difficult to recognize the need to redefine goals or identify different ways of reaching them.

When appropriate, early consultations also give families an opportunity to become familiar with palliative care personnel in advance of an expected or possible crisis and to discuss issues such as continued relationships with the child's established care team. Without such preparation, families may react instinctively by feeling that they are being abandoned and by rejecting certain options, including hospice care, without understanding what is being offered.

Given the diversity of the goals, no single health care professional is likely to be fully prepared to discuss ways to fit medical care and family strategies to the goals. Depending on the situation, physicians, nurses, social workers, psychologists, child-life specialists, chaplains, and others will have roles to play. Again, for them to perform effectively, professionals will need to be adequately educated and trained to discuss goals, identify strategies, and guide families to the appropriate and available resources.

Goals and Choices at the End of Life: Advance Care Planning

> *I've had the experience of having to stand at the table in the emergency room and say, it's okay to let him go. And of talking to my son [Joshua] and saying, it's okay to go, if he wants to go. For the most part, the doctors are responsive to that, but they just can't stop themselves from intervening. . . . We need to teach people how to stop and respect.*
>
> Tina Heyl-Martineau, parent, 2001[2]

Much has been written about advance care planning for adults, particularly planning for a time when they are no longer be able to make decisions or communicate preferences. Ideally, this planning is less about documents—although certain documents can be important—than it is about an ongoing process of considering values, preferences, circumstances, and expectations relevant to what a person wants at the end of his or her life (see, e.g., Larson and Tobin, 2000). A variety of initiatives have helped make advance care planning more routine and more informed. Nonetheless, most adults, even older adults and adults with serious illnesses, have not considered their own values about end-of-life care, discussed their views

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[2] Joshua Martineau died June 30, 2002.

with family members, or completed advance directives or medical power-of-attorney documents (see, e.g., SUPPORT, 1995; Grimaldo et al., 2001; Wenger et al., 2001).

In any case, recommendations and suggestions for competent adults have only limited direct relevance for children and their families for various reasons. Except for children judged to be mature or emancipated minors (see Chapter 8), parents have the legal authority to make the medical decisions for their child, including decisions about end-of-life care, although they are often unwilling to face such decisions until the child is very near death. Children may be involved in discussions about their concerns and wishes, but their preferences about treatments will prevail only if their parents agree.

As discussed in Chapter 3, many serious illnesses in childhood run an unpredictable course of relapses and remissions, with acute events that can often be reversed for a period. Modern medical technology continues to advance and therapies that were seen as heroic just a decade ago are now considered standards of practice, such as bone marrow transplantation for relapsed leukemia or cardiac transplantation for certain heart conditions. Even when the prognosis with treatment is grim, children, families, and clinicians can postpone acknowledging an approaching death as they focus on potentially life-sustaining therapies (Goldman, 1999).

Consideration of goals for life's ending and preparation for death involves much more than signing (or not signing) orders about cardiopulmonary resuscitation and other life-support measures. It also provides the opportunity for families to think about how to make the most of their remaining time together, particularly when it is clear that time will be short. Planning for this time can even provide parents some comfort as they anticipate and grieve in advance for their child's death.

Attention to goals and choices in advance of an expected death can also help families reduce the possibility of certain distressing experiences, including unwanted interventions and even legal inquiries. For example, if an ill child dies a planned death at home and the plan explicitly provides for families to manage with no call to 9-1-1 or no race to the hospital (but with the child's care team available for consultation and support), parents may be protected by having a written do-not-resuscitate (DNR) order in their possession,[3] by having alternatives arranged in case their child's physician cannot come to the home to pronounce death, and possibly—even if the child is not under hospice care—by calling the local hospice for advice about local law enforcement practices and expectations. (Although specific

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[3] Because success rates for resuscitation in these situations are very low, DNRs are sometimes called DNAR or "do not attempt resuscitation" orders or AND "allow natural death" orders (see, e.g., Crimmins, 1993).

requirements vary, unexpected child deaths must generally be reported to the medical examiners office.) Misunderstandings about the circumstances of a child's death can add to a family's suffering (Rosauer, 1999; Avila, 2001).

Little has been written to advise either physicians or parents on advance care planning as it may be relevant for children with life-threatening medical conditions (Hilden et al., 2001a,b; Hilden et al., 2000c). Instead, attention has focused more on clinical and ethical aspects of withholding life-sustaining interventions for children than on the goals of care and the role of palliative measures in meeting those goals (see, e.g., Lantos, et al., 1994; AAP, 1994b, 1996; Levetown, 2001). In addition to continued discussion of ethical issues, more needs to be known about variations in parents' responses and decisions when physicians have begun discussions about DNR orders, hospice, and other end-of-life choices. Such knowledge may help guide physicians who believe that continued chemotherapy or other treatments are causing the child suffering without prospect of benefit but who feel they have not been able to communicate this effectively but compassionately to parents who want to continue such treatments. This is not to imply the parents are making "bad" choices but rather to recognize that physicians' primary obligation is to advocate for what they believe is best for their patient.

Barriers to Considering Palliative Care and Advance Care Planning

Successful integration of palliative care perspectives following diagnosis means finding sensitive ways of providing parents—whatever their values and background—with timely and appropriate information about palliative care options and then encouraging their timely consideration of these options and the goals of care. Some options, particularly those related to a child's physical or emotional comfort, may not require parents to acknowledge directly that their child is likely or certain to die. For example, members of a child's care team can encourage parents to consider how to help a seriously ill child achieve a wish or goal, for example, a trip to Disney World or completion of a school activity. Some decisions about end-of-life care must, however, be explicit, for example, deciding on DNR orders or accepting hospice services, particularly if the latter choice requires agreeing to Medicaid's requirements for hospice benefits.

Because parents are often so focused on curative or life-prolonging care, discussion of hospice or end-of-life planning for their child may seem intolerable until death is very near or until continued reliance on life-sustaining technologies is finally recognized as just prolonging suffering and dying. By that time, important opportunities may have been lost to help the child and family avoid needless physical and emotional suffering.

Although few studies have examined palliative and end-of-life care for children, the study by Wolfe and colleagues (2000a) cited earlier found that children for whom hospice care had been initiated earlier were more likely to be reported by their families as peaceful and calm during the last month of their lives.

Notwithstanding the potential benefits of palliative and hospice care, it may be very difficult for parents to accept it, even if it is not presented as an "either/or" choice between life-prolonging and palliative care. For example, a couple responding to questions about their experiences wrote that "we never realized how much we needed and benefited from hospice care. . . . [Still,] we felt that to accept hospice, we were accepting Kelley's dying. Our hospice nurse and social worker would tell us that we could always discontinue hospice if Kelley got better. . . . They had many patients who stopped hospice because they went into remission or their conditions stabilized" (Bula and Bula, 2001).

Another woman who lost her daughter to cancer later wrote a member of the inpatient palliative care team, "I must stress how much I hated having to experience palliative care," and then added ". . . but the team was so comforting and so very compassionate" (Himelstein and Hilden, 2001, no page). The psychologist on the child's care team observed that the mother "dreaded the day you would darken her door."

As indicated earlier, barriers to certain aspects of palliative care and advance care planning may sometimes be cultural. For example, values in traditional Chinese and Navajo cultures may be inconsistent with explicit discussions about death and certain ways of planning for life's end. A child's care team should, however, still have a plan of care that anticipates changes in the child's status.

Recognizing that care under the palliative or hospice care label may be difficult for families to accept, several hospices have sought to make their services more acceptable and accessible to families by developing supportive programs based in their licensed home care units and then identifying them with somewhat indirect names.[4] Unlike Medicare and Medicaid, some private insurers may cover hospice services or consultations without requir-

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[4] Examples include Caricel (Hospice of Northern Virginia), Essential Care (Center for Hospice and Palliative Care, Buffalo, New York), Children's Bridges (Hospice of the Florida Suncoast), and Carousel (Hospice of Winston-Salem and others). In a discussion of pediatric palliative care in Britain, Ann Goldman said her team was often referred to as the symptom care team or, especially early on, as the home care team (Goldman, 2000a). "Most people don't take very long to realize exactly what we do, and occasionally we'll have families who will say, "I don't think we want your help, please. We'll call you when we want you," because of the implication to them that our involvement means that their child isn't going to get better" (Goldman, 2000a, no page).

ing that curative or life-prolonging treatments cease or that life expectancy be certified as six months or less (see Chapter 7). Still, even when both clinicians and parents are prepared to consider palliative or hospice care, lack of financial, organizational, and other resources may limit access to such care.

Although far more limited than corresponding efforts related to adult end-of-life care, some organizations mentioned here as well as others have begun community information and education programs to make options more widely known to families, health care providers, religious leaders, school personnel, and others. These efforts may encourage some parents to consider end-of-life planning earlier and may reduce avoidable distress for some children but are unlikely by themselves to make a substantial difference. More creativity and more research are needed to find strategies that encourage timely discussion of end-of-life care that will prevent needless suffering, help children and families make the most of their remaining time together, and preserve parents' need to feel they have done everything possible for their child.

Involvement of Child Patients

Agreement has been growing that children should be informed about their medical condition and that they should also be involved in discussions about the goals and plan of care, including end-of-life care, consistent with their intellectual and emotional maturity, medical condition, and desire to participate (see, e.g., Brock, 1989; Burns and Truog, 1997; Hilden et al., 2000c; Hinds et al., 2001; Nitschke et al., 2001). In many situations, even children and adolescents with serious cognitive disabilities can indicate their preferences about care. In writing about the death of his 28-year-old sister, who had Down syndrome and developed leukemia, physician Chris Feudtner wrote, "Along with my family, I had contemplated every facet of her life as long as I can remember—asking constantly what mattered to her and why—with efforts simply redoubled once she became sick, commitment deepened to abide by her rules as best we could" (Feudtner, 2000, p. 1622).

Certainly, a child's cognitive and emotional maturity and preferences for involvement must be considered in preparing for initial and subsequent discussions to inform and involve children. What is appropriate for a 6-year-old—perhaps the use of stuffed animals and other play techniques to aid in explaining and assessing understanding—will not be appropriate for a 16-year-old.

Given this country's ethnic, cultural, and religious diversity, family values about discussions of death, medical care, and children's roles must also be taken into account and respected. The child's care team must be sensitive to family values and preferences but can work with families on how to inform and involve children and how to identify and respond to their concerns and wishes. As suggested earlier, failure to inform and involve children can lead to feelings of isolation and other distress. Further, it can prevent parents and clinicians from truly appreciating a child's values, goals, and experience of his or her disease and its treatment and from using that appreciation to guide the child's plan of care.

As discussed in this chapter and in Chapter 8, parents usually have the legal authority to make decisions for their child, but this is no way precludes the child's involvement in discussions and decisions about their care. Chapter 10 notes that children's "assent" to participation in research is normally expected but not necessarily required. Ethical issues may arise if children are led to believe they have choices when, in fact, their choices will be overridden if their parents disagree.

WHAT WILL HELP MY CHILD AND MY FAMILY? FITTING CARE TO GOALS AND CIRCUMSTANCES

Designing a Palliative Care Plan as Part of an Overall Plan of Care

Not all suffering caused by life-threatening medical conditions or by the pursuit of cure or prolonged life can be prevented and not all goals of patients and families can be met. Nonetheless, if suffering or the potential for suffering is not even recognized or if the goals of care are not carefully considered, then opportunities to prevent or relieve distress and to protect quality of life for patients and families will certainly be missed. Regardless of choices about curative or life-prolonging treatments, advocates of palliative care stress—to clinicians, patients, family members, policymakers, educators, researchers, insurers, and communities—that care plans should always include steps to assess and prevent physical, emotional, and spiritual suffering. As described by the American Academy of Pediatrics in its statement on pediatric palliative care, "The goal is to add life to the child's years, not simply years to the child's life" (AAP, 2000g, p. 353).

Designing a care plan that appropriately integrates curative or life-prolonging care with palliative care and preparations for death is a sensitive and sometimes formidable task. Depending on the child's medical condition, the plan of care may include a mix of preventive measures, curative or life-prolonging interventions, rehabilitative services, and palliative care. The mix usually will change over time as a disease progresses, as the goals of care are reconsidered and adjusted, and as the benefits and burdens of therapies are reevaluated based on guidance and counseling from physicians and others.

To illustrate, for a child with an eventually fatal condition such as muscular dystrophy, appropriate care for most of the child's life may include scheduling standard childhood immunizations, treating respiratory infections, providing physical therapy to slow or adjust to declining physical function, and offering psychological counseling in response to emotional distress. As the disease progresses and symptoms intensify, a palliative care plan—whether or not it goes by that name—will increase the emphasis on physical, emotional, and spiritual comfort. The plan might include participation in a camp for children with similar medical problems, art and other therapies that help the child express his or her emotions and creativity, and special arrangements to allow the child to continue in school. Antibiotics, mechanical ventilation, enteral or parenteral nutrition, and hospitalization may be chosen, refused, or adjusted as the child, parents, and health care team assess and reassess the benefits and burdens of each therapy as the condition worsens. Clinicians will ask parents about the use of resuscitation and other life-sustaining interventions such as artificial hydration or nutrition. Their decisions may be profoundly affected by what and how they are told about the likely outcomes of such measures given their child's medical situation.

Box 4.3 summarizes some of the questions that a child's care team (or teams) should consider from the time a child is diagnosed with a life-threatening medical conditions. Again, unless a child's death comes quickly, these questions may be asked repeatedly.

The responsibility of particular health care professionals for these different assessments will vary, as will the responsibilities for implementing various elements of the care plan. Physicians will take the lead in determining diagnosis and prognosis, identifying treatment goals and options to reach these goals, and assessing and explaining their potential benefits and harms to patients and families. Physicians and nurses generally share responsibility for evaluating symptoms and symptom management effects, but physical therapists, psychologists, child-life specialists, and others may also be involved in assessing a child's physical and emotional functioning and his or her reactions to medical interventions. All members of the care team should be sensitive to the emotional and spiritual well-being of the child and family, but social workers, psychologists, child-life specialists, and chaplains will be particularly attentive to this area of assessment.

Based on the multidimensional and multidisciplinary assessments of the child and the family, the child's care team has the primary responsibility—in cooperation with the child (consistent with developmental stage) and family—for developing a care plan to meet the goals of care, and then monitoring its implementation and results and making adjustments as needed. The care plan may include directions related to nursing care, medications, physical therapy, and other interventions as well as provisions for consultations with palliative care specialists, psychologists, or others who

BOX 4.3
Assessments Needed in Devising and Revising a Palliative Care Plan

Disease Status and Symptom Assessment

- What are the child's diagnosis and prognosis? How uncertain is the child's future course?
- Is death expected soon? Would death in a few months be a surprise?
- How is the disease likely to affect the child physically, intellectually, and emotionally?
- What symptoms are present and what symptoms are likely to emerge?

Preferences and Goals

- Has the parents' understanding of their child's medical condition and care options been carefully assessed?
- Has the child's understanding of his or her medical condition and care options and his or her competence and interest in being involved in care decisions been carefully assessed?
- Do either the child or the family need more information or assistance in understanding the information already provided about the diagnosis, prognosis, and treatment options (including palliative care and end-of-life resources)?
- Do the child's and the parents' preferences appear to diverge in significant ways?
- Have the benefits and burdens of different therapy options been carefully explained?
- Have end-of-life issues and plans been discussed as appropriate given the child's condition?
- Have documents (e.g., DNR or allow natural death orders) appropriate for the child's medical status been completed and recorded in the medical record? Are copies of relevant documents available wherever they might be needed (e.g., home, school)?

Psychosocial and Spiritual Assessment: Child (Patient)

- What does the child (taking developmental status into account) understand and feel about his or her medical situation?
- How should discussions with the child take temperament and other characteristics into account?
- What are the child's hopes and fears for the present and the future related to family, friends, school, extracurricular activities, and similar matters?
- Does the child have concerns about religious, spiritual, or existential issues? Has a psychological consult or referral to a chaplain or other spiritual counselor been suggested or arranged?
- Has the child been sufficiently assured that he or she will be cared for and will not be abandoned (assuming that reassurance can be truthfully offered)?

Psychosocial and Spiritual Assessment: Family

- How are the parents, siblings, and other close family members managing?
- How have they managed difficult situations in the past?

- What are the family's main hopes and fears for the present and the future?
- What special psychological or practical issues need attention (e.g., presence of other children in the home, other family illnesses, communication or cognitive problems, history of violence or substance abuse)?
- Has assistance from a psychological counselor or from a chaplain or other spiritual counselor been suggested or arranged?
- Have family members been sufficiently assured that they will not be abandoned as the child's condition changes (assuming that reassurance can be truthfully offered)?

Child's Functional Status

- What can the child do for him or herself?
- What kind of assistance is required at home, at school, elsewhere?
- What can family members do? What outside help is needed for the family? For teachers?

Therapy Review and Evaluation

- What surgical, radiological, pharmacological, or other interventions have been employed? What interventions are planned or under consideration? What is their purpose? What are the results to date? What is expected (good and bad)? When should interventions be reevaluated?
- Are monitoring for side effects and assessment of pain and other symptoms adequate?
- What palliative interventions are being used or should be considered? What are the results to date?
- What health care providers are involved in the child's care? Are the level and mix appropriate?
- If problems arise, is reliable assistance available 24 hours a day, 7 days a week?
- What are the benefits and burdens (for child, family, and caregivers) of the therapies being provided, and what are the alternatives?
- Are the care team's perspectives and the family's perspectives consistent? Are these perspectives consistent with those of the child?

Resource and Logistics Review and Evaluation

- What is the composition of the care team and how is it functioning?
- Are additional professional and nonprofessional personnel needed? What is the availability of such personnel in the community?
- How is care being coordinated and information being communicated? Are there problems?
- What are the child's and the family's preferences about primary location of care, including at the time when death is expected? What barriers exist to accommodating these preferences?
- Are physical facilities in the home adequate (e.g., accessible bathroom)? How do transportation, economic, and other relevant resources match child and family needs? What else can be done?
- What is the financial burden on the family? Do additional sources of assistance need to be sought? Can resources be used more effectively or efficiently?

SOURCE: Adapted from IOM, 1997.

have expertise in assessing and managing particularly difficult problems such as intractable pain, delirium, and psychological distress.

In a set of recommendations for end-of-life care in the ICU, Truog and colleagues (2001) observed that for clinicians accustomed to focusing on cure and life-prolongation, it may difficult to focus on the goals of comfort and symptom management. They suggest, particularly when the end of life is approaching and the failure of curative or life-prolonging therapies is clear, it may be useful to "completely rewrite the patient's orders and care plan, just as if the patient were being newly admitted to the ICU" and then to evaluate each test or intervention in terms of how it serves the goals of care (Truog et al., 2001, p. 2335).

Involving Children in Decisions About Palliative and End-of-Life Care

Parents (or guardians or other designated adults) will in most cases retain legal authority to make decisions about a child's medical care (see Chapter 8). That legal fact does not and should not restrict parents and clinicians from involving children in discussions and decisions about their care, consistent with their intellectual and emotional maturity. As noted earlier, excluding children can lead to feelings of isolation, anxiety, and other distress.

> **Recommendation: Children's hospitals, hospices, and other organizations that care for seriously ill or injured children should work with physicians, parents, child patients, psychologists, and other relevant experts and with professional organizations to create policies and procedures for involving children in discussions and decisions about their medical condition and its treatment. These policies and procedures—and their application—should be sensitive to children's intellectual and emotional maturity and preferences and families' cultural backgrounds and values.**

Assessing children's competence to be involved with decisions is an individual process that considers a particular child's intellectual and emotional development and understanding of the issues, his or her medical condition, and the family's values and relationships (including patterns of communication). Assessments also should consider the specific decisions in question and the probabilities and significance of possible consequences of the decisions.

Some experts see age 10 as the usual age for meaningful involvement in decisions about serious medical problems (Hinds et al., 2001). Nitschke and colleagues concluded from their research involving 43 families with children who had cancer that children as young as 5 or 6 years of age could participate in end-of-life discussions (Nitschke et al., 1982). The researchers also concluded that, in practice, the patients themselves (aged 6 to 20 years) often made the final decision between investigational therapy or supportive care for their end-stage cancer. Of the children studied, 14 chose further chemotherapy, 28 chose palliative care only, and 1 made no decision. The majority of children who chose supportive care were able to talk with their families about their fears and actively participate in family life.

For adolescents, regardless of their legal status, parents may recognize and accept that their teenager has the evident intellectual and emotional maturity to make decisions about care at the end of life. Adolescents may, however, need particularly careful assistance in understanding the available options and their possible consequences (Stevens, 1998; Hinds et al., 2001; see also Rushton and Lynch, 1992; McCabe, 1996; McCabe, et al., 1996). Some research suggests that younger adolescents do not differ greatly from adults in their ability to understand and reason about medical alternatives (Weithorn and Campbell, 1982), but other research suggests that younger adolescents are less able than older adolescents to imagine future risks and consequences of choices (Lewis 1981). Some studies suggest that involving children in decisionmaking increases their capacity to make decisions (Lewis and Lewis, 1990; Alderson, 1993).

Implementing the Care Plan

Devising a good palliative care plan does not ensure implementation. Later chapters of this report suggest how organizational problems, financial obstacles, lack of adequately trained health professionals, and gaps in scientific knowledge can compromise care. For example, institutional policies may restrict the hours during which families can visit a seriously ill child and physical structures may limit the amount of privacy, intimacy, and physical comfort available to families.

Geography is another limiting factor. Children and families in remote rural areas will generally have less access to certain palliative care resources just as they tend to have less access to other health care resources such as advanced pediatric trauma care. Regional information and consulting resources can help (see recommendations at the end of Chapter 6) but cannot overcome all geographic problems.

Supporting the Family

Even with good support from the child's care team and involved institutions, much of the responsibility for implementing and monitoring a child's care plan will rest with family members. As Hilden and colleagues have observed, families coping with a child's extended life-threatening illness "often joke that they should receive honorary medical or nursing licenses" (Hilden et al., 2001b, p. 168). Although the comment may be somewhat tongue-in-cheek, it highlights the complex tasks facing child patients and families—understanding and evaluating great amounts of information, advocating for needed information and services, making informed choices, directly providing care, monitoring a child's status, and negotiating billing, insurance, program eligibility, and other bureaucratic processes. As one parent remarked, "It's like you suddenly have a new small business to figure out and run on top of everything else going on."

The family's role in caregiving is increasingly being recognized, and more resources are being provided by hospitals, family support organizations, and other sources to help them perform this role effectively. Most practical resources appear to focus on caregivers for adults, especially elderly adults (see, e.g., ACP, 1997a,b; Karpinski, 2000; Meyer, 1998; Schmall et al., 2000; but see also CHI, 1991; Houts, 1997; Bayer Institute, 2001), although pediatric hospice programs and state and other programs for children with special needs also consider the needs of parents or other caregivers. Studies and experience suggest that many family caregivers receive little if any explicit training for what can be very demanding physical and emotional care responsibilities (Bull and Jervis, 1997; Levine, 1998; Driscoll, 2000; Rigoglioso, 2000).

In addition to providing information as described earlier in this chapter, Internet sites may suggest questions for parents to ask about the course of particular medical conditions, symptom management, and sources of assistance. Such prompting can help parents participate more effectively and fully in developing, understanding, and implementing their child's care plan. Internet sites may also provide forums for people to seek and offer information about caregiving strategies.

Comprehensive guidance for family caregivers should cover physical and emotional problems and responses for child patients, parents, and siblings (e.g., isolation, depression, anxiety); spiritual resources; practical concerns (e.g., having advance care directives at hand when they are needed, managing health insurance, obtaining help from community agencies or volunteer groups); and bereavement. The next chapter examines the spiritual, emotional, and practical dimensions of care for the child and family.

CHAPTER 5

CARE AND CARING FROM DIAGNOSIS THROUGH DEATH AND BEREAVEMENT

> *"I remember at the funeral the priest saying—he was trying to be comforting but [was] so far from knowing what it was really like those past months—that 'now she wasn't suffering anymore.' . . . It pissed me off . . . we had tried so hard not to make her suffer."*
>
> Susan Rheingold, physician (Himelstein and Hilden, 2001)

The prevention and relief of suffering—physical, emotional, spiritual—is a core mission of palliative care. Although not all suffering can be prevented or relieved, severe pain and other symptoms are not inevitable consequences of serious illnesses or their treatment. Continued research into the mechanisms of symptoms and palliative interventions is essential, but health care professionals and organizations can do more now to apply existing knowledge and resources to spare patients and families from physical and emotional suffering.

A broader goal of palliative care is to help children with life-threatening medical conditions and their families live as normally and as well as possible under the circumstances. Even quite sick children can often take pleasure in playing, seeing friends, continuing classes and other normal activities, and being at home in familiar surroundings. For hospitalized children, administrators and clinicians can look for ways to design physical environments, clinical routines, and special programs to minimize the obtrusiveness of intensive care units and other medical settings, encourage and welcome the presence of family and friends, and provide opportunities for play, education, and other ordinary childhood activities.

As emphasized throughout this report, palliative care is not an "either/or" proposition. Although care may sometimes focus solely on patient and family comfort, the integration of palliative care with curative or life-prolonging therapies can benefit children who survive life-threatening conditions as well as children who die and can thereby support the families of children in both groups.

This chapter examines the physical, emotional, spiritual, and practical dimensions of care for children with life-threatening conditions and their families. Although bereavement care is part of comprehensive emotional and spiritual care for family members before and after a child's death, it is—for emphasis—discussed in a separate section. Recommendations related to the discussion in this chapter are sufficiently intertwined with the discussions and recommendations about the organization and delivery of care in Chapter 6 that they are included in that rather than this chapter.

THE PHYSICAL DIMENSIONS OF CARE

General

Physical comfort should be a fundamental priority in health care for all children, but it is especially important for children who have life-threatening medical conditions and are enduring burdensome therapies. Unrelieved physical distress affects both the child and the family. It can also interfere with beneficial therapies, for example, when children in extreme pain will not cooperate with treatment.

Effective physical care for children requires a solid understanding of both the sources of distress—which can require extensive investigation—and the developmentally appropriate strategies for preventing or relieving that distress. For example, drug regimens shown to be effective in relieving a symptom in adults cannot simply be extrapolated to infants and children because developmental variations in metabolism and body composition (e.g., amount and distribution of fat, water, proteins) may affect the action of drugs. Unfortunately, many drugs have not been tested and labeled for use with children, and understanding of the underlying mechanisms of symptoms and symptom management techniques in children is underdeveloped. Federal regulations and legislation adopted in recent years provide incentives and requirements for pediatric research, including studies by pharmaceutical companies to test drugs in children and develop pediatric drug dosing information (USGAO, 2001b). Chapter 10 discusses these incentives and, more generally, the challenges—practical, methodological, organizational, legal, and ethical—of expanding the knowledge base for pediatric palliative care. It also discusses directions for future research to improve all dimensions of palliative and end-of-life care.

Particularly for younger children, family observations and reports will often be essential in determining the presence, severity, and characteristics of a child's physical distress and in evaluating the success of efforts to relieve it. In addition to providing information and observations necessary for care planning and evaluation, parents and other family members will often provide much physical and other care for their child, particularly when the child is at home. Even in hospitals, however, families may feel comforted by providing some physical care themselves. Moreover, staffing shortages or reductions may prompt them to provide care that might otherwise be provided by nurses or nurses' aides.

Depending on the expected caregiving role of family members, physicians and other members of the child's care team should assess the need of family members for training in both technical tasks (e.g., operating medical equipment or changing dressings) and mundane but possibly risky tasks (e.g., bathing or moving someone with serious medical problems). The team may also have to prepare school nurses and other personnel to help with physical care when a seriously ill child returns to school.

The focus in this section is on physical care for the child, but a comment on care for family members is also warranted. Pediatricians do not serve as personal physicians for parents, although family practitioners often do, and both may care for the siblings of ill children. In any case, if the unit of care is truly the child and the family, then generalist and specialist pediatricians, family practitioners, nurses, hospice personnel, and others should be attentive to the physical and emotional toll that a child's serious illness or death may take on family members. This attention may take various forms, including questions about possible signs of illness or stress, reminders that parents need to take care of themselves and their other children, and suggestions that a formal evaluation be sought for a family member exhibiting signs of possible medical problems. With a parent's permission, someone from the child's team might contact the parent's or sibling's personal physician to include her or him in the family support network and ensure that the parent or sibling gets additional evaluation and support during a very difficult time.

Care for Pain and Other Physical Symptoms

One goal of excellent symptom management is to prevent both disease-related symptoms and treatment-related distress to the extent possible. When symptoms do develop, the goal then is to identify and relieve them as quickly and fully as possible, while minimizing unwanted side effects, for example, the sedation associated with certain pain medications.

Achieving these goals typically involves a mix of pharmacological, behavioral, and other therapies as well as good communication with all members of the child's care team, including the parents and the child (consistent with developmental stage). Careful attention to nutrition, hygiene, posture, mobility, skin care, self-image, and other physical factors also contributes to a patient's comfort and quality of life.

Box 5.1 lists some of the most common physical symptoms experienced by seriously ill or injured children. Compared to adults, the prevalence, distribution, and pathophysiology of pain and other symptoms are poorly mapped for children living with and dying of life-threatening medical problems (Goldman, 1999). This may in part reflect the greater difficulties in communicating with and ascertaining symptoms in infants, other preverbal children, and older children with communication deficits. In addition, it almost certainly reflects a more intense focus on curative care that does not yet include adequate attention to patient comfort.

Symptoms such as pain or nausea may be related to the child's underlying medical problems, treatment for these problems, or both. Some studies of cancer pain in children suggest that diagnostic and treatment procedures may often be more immediately distressing than the disease, especially if the child is too young to understand the implications of the disease and the explanations for painful procedures (Cornaglia et al., 1984; Miser et al., 1987; McGrath et al., 1990; Ljungman et al., 2000). Also, some research suggests that children who receive inadequate pain management during an initial procedure may experience more pain during subsequent procedures than children who have been appropriately managed (Weisman et al., 1998). Given the pain and other burdens imposed by some potentially curative or life-prolonging treatments (e.g., surgical procedures, chemotherapy or radiotherapy regimens), many parents and child patients with advanced disease face emotionally difficult decisions about when the likely burdens of such treatments exceed their likely benefits.

Whatever the choices of families, those caring for children need both to better understand the pain and other distress caused by common procedures (e.g., intramuscular, intravenous, and subcutaneous administration of drugs, including pain medications) and to consider less burdensome alternatives. These alternatives may include reevaluation of the necessity for certain painful diagnostic and other procedures, the use of innovative pharmacological strategies (e.g., disks that numb the skin before injections or other procedures, pleasant-tasting oral formulations of drugs), and the application of nonpharmacologic approaches such as relaxation, imagery, distraction, hypnotic suggestion, massage, and acupuncture. In addition, child- and family-friendly physical surroundings and procedures and the presence of child-life specialists and other personnel trained to work with children may help reduce emotional distress, which, in turn, may reduce physical distress.

Although certain diagnoses tend to be associated with certain symptoms (e.g., bone pain with certain metastatic cancers, seizures with certain degenerative brain disorders, shortness of breath with certain end-stage heart conditions), children with the same initial diagnosis can differ considerably in their experience of disease-related symptoms. Likewise, although certain treatments tend to produce certain symptoms (e.g., vomiting with some forms of chemotherapy, mouth sores with some radiotherapies), children with the same diagnosis and same treatment may vary in their responses, including their experience of treatment-related symptoms. For children with advanced medical problems, the type and intensity of palliative physical care needed may be determined less by the medical diagnosis than by symptoms and other manifestations of the underlying medical condition or its treatment.

Given such individual variability, each child requires an individual assessment of symptoms and the development of a responsive care plan (McGrath, 1998; Goldman, 1999; see also Schechter et al., 1993, 1997). In addition to considering the child's diagnosis and reports of symptoms by the child or parents, clinicians should consider other characteristics of the child (e.g., cognitive capacity, personality, past medical experiences) and the family (e.g., coping behaviors, cultural values and practices). Characteristics of the health care environment may also be relevant to the development and implementation of symptom management strategies (e.g., restrictions on parents' presence during painful procedures involving children, availability of clinicians skilled in treating small patients and managing difficult symptoms, insurance coverage of certain medications or other interventions).

Studies reviewed in Chapter 3 suggest shortfalls in symptom assessment and management and point to numerous opportunities for improvement in the care of children with life-threatening medical conditions. Particularly in the area of cancer pain, one response has been initiatives to develop and implement evidence-based assessment and management protocols that stress the timely and adequate use of appropriate medications and behavioral interventions (e.g., distraction therapies) to prevent and relieve pain in children (see, e.g., WHO, 1998). Chapter 6 discusses the role of such protocols and recommends their broader development and application.

Parents as Experts on Their Child's Comfort

> *Once while explaining Bellini's desire for a certain positioning to a new nurse, I was told by someone watching, "Oh, you're so fussy!" Am I? Am I going overboard to want my son, who has so few options for comfort, to be comfortable, especially when I happen to know what makes him comfortable?*
>
> Susan Hostetler-Lelaulu, parent, 1999

BOX 5.1
Major Physical Symptoms That May Be Experienced by Children with Life-Threatening Medical Conditions

Pain

Key dimensions of pain include intensity, duration, and burden felt by the child. Pain is categorized as somatic, visceral, or neuropathic depending on its apparent origin. Uncontrolled pain significantly interferes with a child's functioning and well being. It can contribute to depression, irritability, and anxiety and can disrupt social relationships.

Nausea and Vomiting

Nausea (feeling that one may vomit) and vomiting are common symptoms for children with certain kinds of advanced cancer and also may be side effects of treatments such as chemotherapy. The neurophysiology of nausea and vomiting in children is not well understood. They may be prompted by a variety of stimuli (e.g., movement, odors, anxiety, medications, past experiences). Underlying causes may include gastric irritation, constipation, elevated intracranial pressure, and disturbances of metabolism.

Bowel Problems: Constipation, Diarrhea

Constipation may be caused by medications (including opioids), emotional stress, reduced intake of food and liquid, abdominal tumors or adhesions, or decreased activity. It can be extremely uncomfortable and, if unrelieved, life-threatening. Children may be somewhat less susceptible than adults, especially older adults who tend to have weak muscle tone and other problems. Diarrhea is less common than constipation in cancer patients. It is often a feature of advanced neuromuscular disorders and extreme mental retardation. Bowel incontinence is, of course, expected in infants.

Seizures or Convulsions

Seizures result from sudden, uncontrolled bursts of electrical activity in the brain. They may involve one or more of the following: a total or partial loss of consciousness; abnormal physical movement; sensory disturbances; and pain or other unpleasant sensations. Seizures can be frightening and disturbing to family members who witness them. Some fatal medical problems (e.g., certain inborn errors of metabolism) are characterized by seizures throughout their course, whereas seizures develop only in the late stages of certain other disorders (e.g., some brain tumors) or they may result from an acute problem (e.g., meningitis). Some children with fatal medical problems may independently have epilepsy or other conditions that cause seizures.

Anorexia–Cachexia Syndrome

This syndrome involves decreased appetite (anorexia) and wasting of soft tissue and muscle mass (cachexia). Severe wasting appears to be less common in children with cancer and AIDS than in adults with these diseases. Loss of appetite occurs in the late stages of many diseases. Some causes are reversible, at least for a time, but anorexia and cachexia may be an intrinsic part of the dying process for certain conditions.

Mouth Problems

Children with advanced illness may be troubled by various mouth problems, including dry mouth, sores, dental problems, and infections related to their medical condition or its treatment. Oral problems can make eating, drinking, and taking of medication unpleasant if not impossible, thereby increasing the risk of dehydration and malnutrition. Meticulous oral hygiene can help prevent such suffering in a child nearing death.

Fatigue

Fatigue may lead to sleepiness, weakness, depression, anxiety, difficulty concentrating, and other problems. It may be caused by both diseases (especially cancers) and their treatment. Extreme tiredness may interfere with a child's ability to move, bathe, or go to the toilet. The mechanisms of pathological fatigue and its treatment are poorly understood.

Dyspnea and Cough

Dyspnea (feeling short of breath) may result from a number of pulmonary, cardiac, neuromuscular, and psychological conditions. Cough can be caused by irritation; excessive mucus and other fluids; and inhalation, certain drugs, and other mechanisms.

Dysphagia

Dysphagia is difficulty in swallowing food or liquids. Developmental immaturity, brain malformations, trauma, infection, cancer, and neuromuscular diseases are common causes of this problem among children. Inability to swallow affects hydration, nutrition, and taking of medication.

Skin Problems

Skin problems that cause distress may arise from the underlying disease or its treatment or both. Problems may include itching, dryness, chapping, acne, sweating, hair loss, and extreme sensitivity to touch. Some problems, such as pressure ulcers, are less common in children than adults. In addition to causing physical discomfort, skin problems may be perceived by patients as indignities to be hidden from others.

SOURCE: Adapted from IOM, 1997, with additional information from Doyle et al., 1998; Behrman et al., 2000; and Goldman, 1999.

Parents of children with severe chronic medical conditions usually come to know their child's physical condition intimately and may become quite expert at recognizing subtle changes and other cues that suggest discomfort. Likewise, their past experience with procedures or actions that have distressed or comforted their child may help them predict how their child will respond to future procedures, which may then be considered in developing a care plan.

Although they may need the physician to interpret medically what they see, parents often act as the "eyes and ears" of the physician, especially when the child is at home. In the vignette about "Johnny Gabrielle" in Chapter 3, physicians, nurses, and others recognized and depended on the mother's expertise, even as they tried with little success to find effective ways to relieve the child's distress and reduce the mother's burden. The committee located no research investigating this topic, but it seems prudent for clinicians caring for a distressed child to inquire about what parents have found increases or reduces the child's distress—just as they inquire about other aspects of a child's medical history.

Physical Care When Death Is Imminent

Reevaluation of Symptoms and Symptom Management

Whether a child is at home or in intensive care, as death nears, certain care that has extended life or maintained comfort may become more burdensome than beneficial. For example, although dehydration is normally treated with intravenous fluids, the use of such artificial hydration for a patient nearing death may not increase patient comfort but may instead cause excessive secretions that, in turn, promote vomiting, coughing, choking, and other problems. If a patient feels thirsty or complains of a dry mouth, ice chips or small amounts of liquid combined with good mouth hygiene may be soothing (see, e.g., Twycross and Lichter, 1998). Although many hospice and palliative care experts are convinced by their experience of the merits of this approach, recommendations and decisions to avoid artificial hydration at the end of life are controversial. Little rigorous research is available to resolve disputes (Twycross and Lichter, 1998; Kedziera, 2001; but see also Finucane et al., 1999).

Depending on a child's medical condition and its progression, control of pain and other symptoms may become an increasing challenge for the care team as, for example, tumors invade vital areas, lung or kidney function deteriorates, seizures multiply, or bleeding becomes more difficult to control. Although all clinicians who care for patients should have good skills in symptom assessment and management, the expertise of a palliative care specialist may be required for difficult or refractory symptoms of advanced disease or severe injury. Families that have been able to manage their child's care at home may now need assistance from hospice or specially trained home care personnel.

Some choices in physical care and symptom management when death is imminent may cause considerable stress for clinicians and families. (Ethical and other issues in making end-of-life decisions are discussed in Chapter 8.) Pain and other symptoms can usually, but not always, be managed without sedation. When symptoms at the end of life remain uncontrolled after other alternatives are tried, one legal and generally—but not universally—accepted option is "terminal sedation," which might more appropriately be labeled "palliative sedation" (Kingsbury, 2001). The practice involves the careful increase in analgesic or sedative doses to achieve deep unconsciousness that relieves a dying patient's otherwise intractable pain, shortness of breath, seizures, hallucinations, or other severe symptoms (see, e.g., Cherny and Portenoy, 1994; Kenny and Frager, 1996; Quill et al., 1997).

Research has not shown a clear association between deep sedation and the timing of death (see, e.g., Stone et al., 1997; Galloway and Yaster, 2000; Thorns and Sykes, 2000). Nevertheless, one uncommon and unintended result of such sedation may be to hasten an impending death. Although death is not the objective, clinicians (including those who engage in palliative sedation or choose it for their family members) and others may incorrectly characterize deep sedation as assisted suicide or euthanasia (which has death as the intended means of relieving suffering) (see, e.g., Asch, 1995). Clearer and more careful education of staff and consultation with families should reduce such misunderstandings and minimize unwarranted anxieties or guilt feelings. Again, a physician should pursue deep sedation only after careful determination that other options are failing the patient and after consultation with and agreement from the parents and the child, depending on his or her condition and maturity (Kenny and Frager, 1996; Burns et al., 2000; Levetown, 2001). Clinical protocols for sedation should be established and meticulously followed.

Life Support Technologies

Just as symptom management strategies may be reevaluated and adjusted as death approaches, so the conventional use of advanced life support technologies (e.g., cardiopulmonary resuscitation, mechanical ventilation, renal dialysis) may be reconsidered and withheld or withdrawn when the physician(s), parents, and possibly the child agree that their use will only prolong dying and increase suffering. These situations are not, as sometimes described, times when "nothing more can be done." Rather, good clinical care and interpersonal skills can help prevent or minimize suffering on the part of the patient, the family, and the health care team itself.

Recent guidelines for end-of-life care in the intensive care unit urge intensivists to become "as skilled and knowledgeable at forgoing life-sustaining treatments as they are at delivering care aimed at survival and cure" (Truog et al., 2001, p. 2332; see also Rubenfeld and Curtis, 2000). Although the guidelines are not specific to children and certain details of care may differ, the general principles and perspective should provide useful guidance for pediatric intensivists. Whatever the decisions and strategies, careful communication with parents and respect for family preferences are essential to good outcomes for all involved (Kirschbaum, 1996) (see Chapter 8).

In some cases, parents may request the removal of mechanical ventilation (extubation) when death is near to allow one last opportunity for unobstructed physical contact (see Levetown, 2001; Sine et al., 2001). Procedures for discontinuing mechanical ventilation at the end of life with minimal patient and family suffering are the subject of some disagreement. Issues involve the intensity of sedation, the use of paralyzing agents, and the removal of the breathing tube (extubation) without prior steps to "wean" the patient by reducing oxygen level and pressure (see, e.g., Faber-Langendoen, 1996; Gilligan and Raffin, 1996; Truog et al., 2000; Levetown, 2001).[1]

Because some children undergo mechanical ventilation at home and children and families may prefer that removal of the equipment occur at home, protocols for discontinuing mechanical ventilation must consider home as well as hospital procedures and supports for both the child and the family. As with any other intervention, parents and other family members who will or may be present should be carefully informed about exactly what will happen as part of removing the equipment, what may happen afterward, and what can be done (e.g., administration of medications, presence of family) to keep the child comfortable.

Continued study of decisions about withholding life-sustaining interventions, the rationales for such decisions, and the associated processes of care, including comfort measures for the patient and family, would help inform the debate over compassionate and ethical end-of-life care. Better descriptive information should also help in identifying administrative, edu-

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[1] Truog and colleagues (2001) have emphasized that use of paralyzing agents alone blocks the ability to communicate distress (e.g., feelings of pain or suffocation) without relieving it and that, even in combination with sedatives and analgesics, the agents make it impossible to determine whether these medications are working effectively. They argue that no patient should have a breathing tube removed while under the influence of a paralyzing agent unless death is expected quickly and waiting for the agent to wear off would be more burdensome than beneficial.

cational, and research strategies to improve decisions, processes of care, and outcomes. As recommended in Chapter 6, a broad-based process to develop scientifically and ethically informed pediatric guidelines for making and implementing decisions about limitations of care (including appropriate clinical procedures and comfort measures, whether life support is continued or limited) might help reduce inappropriate variability in decisionmaking, limit preventable suffering, and increase fairness.

Another issue that has sparked controversy is the presence of family members during resuscitation efforts. A comprehensive, evidence-based statement on various aspects of cardiopulmonary resuscitation recently recommended that health care providers should offer family members the opportunity to be present during resuscitation whenever possible, especially if the patient is an infant or child (AHA et al., 2000a). From their review of research, the authors of the statement concluded that family members generally do want to be present during resuscitation and that those who have been present tend to have less depression, anxiety, and other problems during bereavement than those who have not (see also Bauchner et al., 1991; Eichhorn et al., 1996 Sacchetti et al., 1996; Timmermans, 1997; Robinson et al., 1998; Boyd, 2000; Tsai, 2002).

Many clinicians have, however, feared that uncontrolled reactions by family members could interfere with patient care (as well as require responses by staff in their own right). Even their simple presence could be distracting, and support could require the diversion of scarce resources. The new recommendations specify that a staff person should be designated to be with the parents during a resuscitation attempt to explain what to expect, answer questions, and otherwise provide support.

Physical Care After the Child's Death

Physical care does not stop with death. Care of the child's body after death can be very important to families, who may be comforted by touching, cuddling, rocking, bathing, or dressing their child. Cultural and religious values may also direct such involvement—or discourage, if not forbid, it.

The consensus today among pediatric and palliative care experts is that family members should be offered the opportunity to be with their child after death and that families who lack such an opportunity (or reject it) may later regret the loss of this last time together (Sexton and Stephen, 1991; Goldman, 1999; Iverson, 1999; CPS, 2001; Levetown, 2001). Such accommodation of families is generally easier when the child dies at home rather than in an intensive care unit or other inpatient setting. If it is a priority, however, most hospitals can provide the requisite space, time, and other support. As described in Chapter 6, some hospitals have arranged a well-equipped, comfortable room that is expressly intended as a private area for families to be with their child during and after death.

Physical care after a child's death will be affected by the circumstances of death. For the child who dies quickly from severe injuries, legal requirements and other circumstances may limit care of the body immediately after death, for example, removing resuscitation tubes used in the emergency department. Parents can, however, usually be provided some private time with their child. If, however, a child has been taken to the medical examiner's office before the family arrives, family members may have to identify the child from a photograph and may be forbidden to see the child's body directly (O'Brien et al., 2001). In either situation, emergency department personnel or staff in the medical examiner's office may support families by cleaning away blood, arranging the body, and covering (insofar as possible) disfiguring injuries or wounds with clean sheets. Guidance for these personnel is based primarily on professional judgment and experience with bereaved families (Iverson, 1999; Levetown, 2001).

Stillborn infants may be presented to their parents with much the same cleansing and similar physical care that are provided to infants born alive. More preparation may be considered in other situations, for example, when the fetus has suffered substantial tissue damage (maceration or bruising) due to after-death exposure to amniotic fluid or to induced or spontaneous labor. Nonetheless, physical signs and severe deformities that might normally be shocking may be irrelevant for grieving parents (some forewarned through prenatal diagnosis) who will have only a brief opportunity for physical contact before they go home without a baby.

Parents expecting the birth of child with a fatal congenital problem can be very explicit about their preferences for physical care at birth, many of which can be honored even if the child is stillborn. For example, one parent reported on an Internet support group that she had requested, in advance of the birth of a child with known anencephaly, that the child "be quickly wiped, given a cap for her anomaly, wrapped in a blanket and have the nurse describe what she looks like to the parents before she is handed to her father first" (Kristina's Mom, no date, http://www.asfhelp.com/ASF_files/support_group_files/abiding_heart_files/wish.htm). One objective of perinatal hospice programs is to help families determine their wishes and have them honored during pregnancy, birth, and afterwards, whether or not the child is born alive (Sumner, 2001).

For the ill child who dies an expected death at home or in the hospital, little medically oriented physical care may be necessary afterwards.[2] At

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[2] Sometimes medical equipment may need to be disconnected. In most cases, no legal requirements limit the removal of such equipment in these situations. As discussed in Chapter 4, families may want to have clear written plans and physician orders to minimize the potential for misunderstandings with emergency medical and law enforcement personnel.

their own pace, parents may wish to bathe or dress the child as one of their last physical acts of being the child's mother or father.

Families may wish to accompany their child's body to the morgue, and in some states, they can themselves take the body to the funeral home. Even after the child has been taken to the hospital morgue, it is not unknown for parents to ask to see the child once more or to make the request for family members who could not get to the hospital earlier. If it is expected that parents will see their child after an autopsy (e.g., to dress the child before the funeral), the child's physician, funeral home staff, or other aware personnel should prepare the family for what they will see (Cacciatore-Garard, 2001). Depending on family preferences or religious values, funeral homes may provide physical services after a child's death, for example, preparing the body for viewing before or at a funeral.

THE EMOTIONAL AND PSYCHOLOGICAL DIMENSIONS OF CARE

> *It's okay to be sad. It's okay to be mad. It's okay to cry. It's okay to laugh.*
>
> Ross, young cancer patient (Lewis, 1992).

Just as children with life-threatening problems need specialized medical and nursing assessments of their physical status and symptoms, they should also have a psychological evaluation in order to plan for truly comprehensive care. The broad elements of comprehensive psychological and emotional care include the following:

- evaluation of the child's psychological status and identification of psychological symptoms or disorders;
- provision of appropriate psychotherapy, psychotropic medications, or behavioral interventions as an integral part of the child's overall care;
- advice for the child's physician, parents, and others on additional strategies or steps that they can take to manage or minimize emotional distress;
- evaluation of the child's parents and siblings (and sometimes other family members) for psychological symptoms;
- referral as appropriate to support groups for ill children, healthy siblings and parents that allow them to share experiences in living with serious illness; and
- bereavement support for the family after the child's death.

As discussed in Chapter 6, child psychologists, psychiatrists, and other mental health professionals can provide unique knowledge and skills that broaden and deepen the emotional care of ill children and their siblings. They may gain special insight into the child's concerns, including concerns he or she may be reluctant to share with parents or physicians. Although these specialists bring particular expertise to a child's care, sensitivity to emotional distress is part of every caregiver's responsibility, including the child's generalist and specialist physicians, nurses, and others.

Parents and other family members are usually the mainstays of emotional care for children. To support them in this role, they may benefit from counseling about strategies for protecting their child (and themselves) from avoidable emotional suffering. Respite care, although not usually covered by health plans, may relieve and renew family caregivers. Wish granting programs such as those supported by the Starlight Children's Foundation (http://www.starlight.org) and the Make-a-Wish Foundation (http://www.wish.org) may give children and families a significant positive event to plan for and anticipate (Stevens, 1998).

When a child dies suddenly, bereavement care may be all that can be offered to parents, siblings, other relatives, and friends. Although bereavement care could logically be discussed here, it is, for emphasis, considered in a later section.

Special Elements of Emotional Care for Seriously Ill Children

> *I felt much better because I knew that I had somebody to talk to all the time! Every boy needs a psychologist! To see his feelings!*
> Six-year-old child (Sourkes, 1995a, p. 3)

Sadness and a certain amount of anxiety are normal responses to serious illness and may intensify as curative treatments fail and as death approaches. Although most psychological problems may be characterized as "adjustment" reactions, more severe psychopathology can emerge, particularly for children with preexisting vulnerabilities (e.g., a parent's earlier death or other loss) or with a personal or family history of psychiatric problems.

It is important to recognize normal distress and not overemphasize pathology in children, but minimizing or not recognizing real pathology is also risky. Clinical depression, anxiety, and traumatic stress reactions may seriously compromise the remaining quality of life for a child with advanced illness. They may cause intense emotional suffering, cause or increase physical discomfort, disrupt relationships with family and friends, and interfere with daily rhythms such as appetite and sleep.

Psychological symptoms in seriously ill children often have multiple possible sources. For example, the child's medical condition or its treatment or both may produce disturbing symptoms of delirium. Physical pain, neurological dysfunction, and psychological distress are closely linked if not, at times, inseparable. Because of this ambiguity, clinicians often proceed with psychological or psychotropic interventions as specific symptoms appear, even if they have not determined a precise psychological diagnosis. Preexisting or new stresses within the family may also contribute significantly to the child's distress and anxiety.

Therapeutic Strategies

Psychotherapy for the child or adolescent who is seriously ill or dying can provide the opportunity for the expression of profound grief and for the integration of all that he or she has lived, albeit in an abbreviated life span. Common issues include anger and grief at being ill, anxiety about medical procedures, worries about family members, depression caused by separation from friends and normal childhood activities, and fears of death (Bluebond-Langner, 1978; Sourkes, 1995a; Stevens, 1998). In addition to helping with these issues, counseling may also help children clarify their own views about how they want to live and how they want to prepare for death. This can affect treatment decisions.

Stevens (1998) has suggested several guidelines for health care professionals working with seriously ill children. They include understanding the child's perception of his or her situation, appreciating the child's symbolic language, differentiating reality from fantasy, encouraging the expression of feelings, encouraging self-esteem, and being open to children's ability to respond to their situation with creativity and dignity.

Some children find an outlet for their emotions and creativity in writing poetry, stories, journals, or notes to others (including notes to be read after death), and the child's care team can encourage this. Such writings may reach well beyond a child's family, friends, and care team. For example, 11-year-old Mattie Stepanek, who has a rare form of muscular dystrophy, has touched many with his poetry, which he began writing at a very young age and which includes the collection *Heartsongs* (Stepanek, 2001). Kelly Weil, who died of cancer in 1993 at the age of 11, wrote a story, Zink the Zebra, that has inspired school-based and other programs to teach children about tolerance of those who are different by virtue of physical, cultural, or other characteristics (see Chapter 6).

Psychotherapy with children involves an acute sensitivity not only to language but also to artistic expression, both literal and symbolic. Drawings often attest quite powerfully to emotional distress including sadness, anxiety, helplessness, loneliness, isolation, anger, and fear or terror (see, e.g., Sourkes, 1995a; Clatworthy et al., 1999).

With young children, play is a crucial vehicle of communication and is, thus, a basic clinical tool to facilitate emotional expression and alleviate a child's distress (see, e.g., Sourkes, 1995a; Kernberg et al., 1998; Scott, 1998). Shared imaginative play enables the child to confront the realities of life and death. The use of puppets, dolls, and stuffed animals allows the child to express difficult and painful emotions "through" the voices of these characters. Play techniques can also provide a less threatening way than direct discussion to inform children about their condition and treatments. Other expressive therapies, such as music and dance, are less often part of the psychotherapist's repertoire but also have a place in supportive care for seriously ill children (Cohen and Walco, 1999).

For children who are well enough to participate, camps that accommodate children with special needs can provide emotional support in a variety of ways (see Chapter 6). One common goal is to improve the self-esteem of campers whose medical problem has brought disfigurement, disability, or isolation (Warady, et. al., 1992; Briery and Rabian, 1999). Other goals include improving children's understanding of their illness and improving their competence in caring for themselves (Heim, et al., 1986). Inspired in part by the camp model, other group and individual recreational activities are being adapted to the needs of children with life-threatening medical problems.

While providing enjoyment and enrichment for the child, camps and other activities may also benefit the family by granting it a period of respite. Furthermore, many camps and recreational organizations involve healthy siblings, thus including them in the wider circle of care.

The Psychological Significance of School

For school-age children,, school is "the defining structure" of day-to-day life, providing constancy and routine (Sourkes, 1995a, p. 93). For the child whose routine has been wrested away by illness, school is a "normalizing axis of daily life," separated from the medical world of illness. Preparing teachers, students, and others at a child's school to reintegrate the child is an essential aspect of emotional care.

Many medical centers and hospices now offer education and consultation for schools on the medical and psychological aspects of a child's illness. They can answer questions and allay apprehensions of teachers, school nurses, counselors, and administrators, which are essential if this group is to provide a safety net for the child on a daily basis. Classmates also need to be prepared for a child's return to school. Straightforward explanations of what to expect may help relieve classmates' anxieties and minimize hurtful interactions. More broadly based programs, such as the Zink the Zebra program mentioned above, may benefit a wider group of children vulnerable to discrimination and isolation because they are "different."

Special Issues for Adolescents

The adolescent's psychological situation is qualitatively different from the young child's. "Normal" adolescence is characterized by a sense of open horizons and immortality and by the quest for identity. In contrast, an adolescent who is diagnosed with a life-threatening illness faces the disruption, if not the irreversible halting, of his or her negotiation of an independent existence.

Adolescents vary within and across the early, middle, and late stages of this last developmental stage of childhood. Moreover, family cultural values and practices will often shape adolescent experiences differently. Notwithstanding such variations and differences, certain issues dominate adolescent development: the wish for increasing independence and autonomy, a focus on body image and sexuality, the importance of peers, and the formation of a personal identity oriented to the future, not just the present (Kellerman and Katz, 1977; Zeltzer 1980). Recognition of the difference between young children and adolescents is reflected in the creation of adolescent medicine as a subspecialty of pediatrics.

Emotional care for adolescents who are facing life-threatening medical problems presents particular complexities (Thornes, 2001). During a period when developing "a life of one's own" is paramount, these young people may confront limitations in every sphere of development: physical, intellectual, and emotional. Further, they face life-and-death issues and decisions that most people do not face until much later in life. As experienced by one seriously ill girl, "You have to accept things that . . . [teens] don't normally have to face. I had to automatically be an adult and it was very hard" (Sourkes, 1982, p. 28*)*.

For adolescents living with a medically dictated physical dependence on family and professional caregivers, psychological independence can be a major issue. Reactions of adolescents who are not granted some channel for autonomy (i.e., for making choices) may include depression, anxiety, anger, risk-taking behaviors, and nonadherance to medical regimens.

Although the specifics vary with the diagnosis and stage of illness, an adolescent's life-threatening illness often limits participation with peers, both in school and socially. Physical limitations, lengthy hospitalizations, fears of venturing out in the wider world, and fears of being "left behind" by healthy peers may compound the loneliness and isolation of serious illness. In addition, many adolescents, especially if some consequences of their illness are visible, grapple with the sense of being damaged and deviant in the outside world. "Everything about me is different. My hair is short and thin. I used to have long hair. I'm not tanned and I've lost a lot of weight. My side looks funny where they took out the rib. And you know how teenagers are—being different is the worst" (16-year-old adolescent, Sourkes, 1995b). A poor body image, low self-esteem, and embarrassment about physical appearance may lead adolescents (and younger children also) to withdraw socially.

Seriously ill adolescents may be perceived by parents and professionals as asexual, and they are often deprived of the opportunity and privacy for sexual exploration. The emergence of sexuality is an integral part of adolescents' development, and those who are ill often mourn the fact that they may not live to have the experience of sexual intimacy. Alternatively, they may act out sexually in a quest for acceptance and affirmation. From both a psychological and a public health perspective, sexuality is a critical issue as infants and children infected with HIV now grow into adolescence (Stuber, 1992). For these and other adolescents, caregivers may find it difficult to face sexual issues and provide education and psychological counseling to respond to adolescent needs and anxieties (Joint Working Party, 2001).

Recognizing adolescents' concerns and emotional distress can also be difficult for family members and clinicians because adolescents may prefer to confide in a close friend rather than parents or professionals and because they may cope by denying how ill they are. They may try to hide their worries and fears to protect their parents. Although recognizing that guiding research is limited, Stevens (1998) has suggested some strategies for working with adolescents, including offering and negotiating choices about their medical care and personal matters (e.g., what to wear), recognizing small achievements, encouraging peer support including opportunities for discussion in settings such as camps, and using art and writing therapeutically.

Emotional Care for Families

> *[Michael's doctor] worked the entire way knowing that if Michael didn't make it, we were still going to have to get through it. So she treated us, as well as treated Michael.*
>
> Rose Conlon, parent, 2001

The profound and enduring impact on the family of a child's fatal or potentially fatal condition cannot be overestimated, even when the child survives. From the time of diagnosis, the relationship between the child and the rest of the family pivots around threatened or expected loss. Unless death is sudden, families will experience grief in anticipation of the child's death as well as the grief that follows death, if death is the outcome.

Support for the family may be garnered from many sources: the professional caregiving team, the extended family and friends, and the larger community. The team caring for the child and family must assess the family's needs and the availability of helpful resources. The team must also identify those families who may need more intense psychological or psychiatric intervention. As discussed in Chapter 4, the way physicians, nurses, social workers, and others communicate with families is crucial, beginning with the time of diagnosis and continuing throughout the child's illness and into bereavement.

The discussion below emphasizes emotional support while a seriously ill child is alive. It focuses on parents and siblings, but grandparents and other family members, especially those who have lived with and cared directly for the child, may also need support from the care team. Davies (2001) observes that research on the experience of the family as unit (including the patient) during palliative care is limited. In describing a study of families living with a dying family member, she identifies a complex, nonlinear pattern of responses that include redefining images and relationships, managing change, struggling with the paradox of living with dying, seeking meaning, living day to day, and preparing for death. She suggests emotional support strategies for nurses that focus on maintaining and redefining hope as illness progresses, involving the family in care planning and caregiving, and open communication.

As has been emphasized earlier, although general strategies can guide care for families, each child and family must be evaluated individually. In some cases, the child's care team may recognize emotional problems that warrant referral to other professionals.

Parents

For parents whose child has a fatal or potentially fatal medical condition, an emotional roller coaster of anxiety, anticipatory grief, and other turmoil begins with the recognition that something serious may be wrong with their child and intensifies greatly with the diagnosis of a life-threatening condition. Some parents endure from the outset the news that no options exist to cure or significantly prolong their child's life. Other parents live for a time with uncertainty, hoping that their child will be among those who will be cured but then facing the stress of difficult decisions about how far to pursue potentially curative or life-prolonging interventions.

A repeated theme in discussions with parents is that they want accurate, clear, and timely information, even if only a clear statement that the situation is uncertain. Evasions, half-truths, and other failures to communicate add to emotional distress. Another theme of parents is that they want to be listened to and recognized as experts about their child and that failure to listen to them also creates distress. Thus, much of the discussion in

Chapter 4 considered the emotional as well as the factual or intellectual dimensions of communication between parents and clinicians.

Professional caregivers also should be alert to the many dimensions of emotional distress in parents including, for example, the sense of guilt that parents may feel when they cannot save their child or because they are surviving when their child is not. Parents may also feel guilt that something they did (e.g., during pregnancy) somehow caused their child's medical problem. In some cases, they can be reassured that they were not responsible; in other situations when a parent has unintentionally contributed to a child's injury, reassurance is still important but more complicated. Marital stress is not surprising and should be a concern of those supporting the family, although evidence that a child's death contributes to higher overall divorce rates is inconclusive (see Appendix E).

The preceding discussion of emotional care for a seriously ill child noted that children may be concerned and upset about their appearance. Parents too may be sensitive to their child's appearance. Other adults, even family members and health care professionals, may overtly or subtly avoid the child, thereby contributing to both parents' and children's feelings of isolation.

As discussed later and in Appendix E, bereavement research suggests that mothers and fathers mourn differently. Their responses during the course of a child's fatal or potentially fatal condition may likewise vary, although the committee did not locate specific research documenting this. To the extent that fathers are more likely to be working outside the home and less likely to be with the child during medical visits, physicians, nurses, hospice personnel, and others may hear fewer questions or concerns from fathers and have fewer contacts with them. This means that those caring for the child and family may have to make a concerted effort to include the father and make him comfortable with the care team and the care planning process. As one stepgrandfather of an HIV positive child observed, "we must investigate if there is a male who wants to be involved, even if he is not normally present; an invitation to participate may be all that is necessary" (Smithson, no date).

The main sources of emotional support for parents will often be other family members and close friends, although some parents may find that before as well as after a child's death, others avoid them out of fear or confusion. Although parents should expect sensitivity and emotional support from the child's health care team, some may also seek or be referred for additional counseling and, when appropriate, treatment for clinical depression or other conditions.

Siblings

> *The time that he was sick was so confusing. . . . I hated to see my brother in pain. . . . Sometimes I got mad at my parents. I couldn't communicate with anybody. Really, it was because I felt a little neglected when he was in the hospital. It was lonely.*
>
> Susan Rae, sister (in Romand 1989, p. 21)

Parents with more than one child must find the strength to care for their ill child and for the well siblings, who are also vulnerable. Siblings are too often left out when a brother or sister is dying, both by parents who are overburdened with caring for the ill child and by professionals. Yet these children live the illness experience with the patient and parents and have many years of life ahead to negotiate the effects of the premature loss of a brother or sister. "I'm not sure if anybody could have helped but I think it should be recognized that Karen not only lost her sister, she lost the strength of the other adults in her life and the security of knowing mom and dad could protect her. She learned far too young that the world is a scary place" (Aney, 2001).

Some of the discussion about emotional support for ill children is relevant for their well siblings. For example, siblings can benefit from supportive school and camp programs and from play or other opportunities provided at children's hospitals. For example, one of the parents with whom the committee met described the help provided by child-life specialists for their well daughter, whose thirteenth birthday coincided with her brother's chemotherapy and whose fifteenth birthday came the day before his brain surgery. "[They] fixed up a goody bag for her that says 'I spent my birthday at Children's Hospital,' which is what they give to the patients. . . . That meant a lot to her. . . . They were definitely very accommodating" (Kittiko, 2001).

Siblings may also benefit from professional counseling. As they live with a seriously ill brother or sister or after that child's death, they may experience anger or jealousy, guilt, anticipatory grief, depression, and fear about becoming ill or dying. When parents decide that an ill child should die at home, well siblings may need particular attention in dealing with the intensity of that experience (Silverman, 2000).

Other potentially helpful strategies for siblings include checking for and correcting misunderstandings about their brother's or sister's medical condition, providing opportunities for siblings to "vent" their worries or resentments, alerting a sibling's teachers to the situation and enlisting their support, bringing siblings to the hospital so they can meet and observe the care team, giving them ways to be helpful, and providing the opportunity for them to say their good-byes to their dying brother or sister before and after death. "Children need to be involved and seen as active members of the family, as helpers, and as grievers" (Silverman, 2000, p. 151; see also Martinson and Campos, 1991). Davies (1998) notes that research indicates that living with a sibling who is chronically ill or disabled can have positive as well as negative consequences.

Other Family Members

Some children with life-threatening medical problems are cared for by grandparents, adult siblings, their parent's siblings, or foster parents because neither their mother nor their father can care for them as a result of death, physical or emotional disability, imprisonment, or other reasons. These children and family units are likely to experience many strains beyond the child's illness and to be in particular need of assessment and attention. More generally, caregivers should be alert to the distress of grandparents and other family members they encounter.

THE SPIRITUAL DIMENSIONS OF CARE

General

Spirituality, although often equated with religion, can be viewed more generally as the search for meaning and purpose in life and in death (see, e.g., Daaleman and VandeCreek, 2000; Miller et al., 2001). Discussions of end-of-life care for adults commonly recognize that the diagnosis of a possibly fatal illness and the approach of death may inspire spiritual reflection and a search for meaning or connection with others that may bring serenity and hope in place of fear and despair (see, e.g., Soderstrom and Martinson, 1987; Hay, 1989; Kaczorowski, 1989; Byock, 1997; IOM, 1997; Speck, 1998; Daaleman and VandeCreek, 2000; Sommer, 2001; Lo et al., 2002).

Religions provide frameworks, although not the only ones, for this search for meaning. Even individuals without a religious belief system may value and benefit from discussions with well-trained chaplains, carefully selected hospice volunteers, or others who have special empathy or insight into existential concerns at life's end. Thus, chaplains should be prepared to relate to diverse kinds of families, to support those of different faiths or no stated faith, and when appropriate, to suggest spiritual resources in the community. Hospitals may develop discussion guides for staff and volunteers to help them sensitively identify needs or concerns in ways that respect varying religious affiliations and beliefs. Religious affiliation or belief cannot be assumed from a person's name, language, or appearance.

Health care providers have traditionally made provision for certain religious rituals or practices at the end of life, for example, the "anointing of the sick" (traditionally called "extreme unction" or "last rites") in the Roman Catholic and Orthodox Christian faiths. Hospital chapels may be offered for memorial services. Hospice chaplains regularly officiate at services for children who have died. Religious groups also sponsor many hospitals, hospices, and other health care organizations and organize a variety of community-based supportive services—spiritual and practical—for individuals and families facing serious medical problems. When children are cared for at medical centers far from home, hospital chaplains may help link families to nearby faith communities for support.

The role of spiritual care in overall patient care is recognized in hospital accreditation standards (JCAHO, 1998)[3] and Medicare hospice requirements (HCFA/CMS, 1994). Medicare and other insurance programs do not, however, reimburse separately for religious counseling or other chaplain services, which increases their vulnerability to cutbacks when institutions are under acute fiscal pressure. The involvement of chaplains in spiritual care for dying patients and their families has been little studied in inpatient or home settings, even for adults (Bryant, 1993; Daaleman and Frey, 1998).

Although this discussion focuses on the role of chaplains, families also rely on their own ministers, rabbis, or other sources of spiritual comfort and enrichment. More broadly, "pastoral care" that involves the whole faith community, including lay persons, can expand the spiritual resources available for seriously ill and dying people and their families (Shelp, 2001).

Physicians, nurses, and others have sometimes been uncertain about their appropriate religious or spiritual role or connection with patients, for example, whether or when to offer to pray with them (see, e.g., Post et al., 2000; Feldstein, 2001). Such spiritual care can be profoundly comforting and may be welcomed by some patients (see, e.g., Daaleman and Nease, 1994; Dagi, 1995; Ehman et al., 1999). Still, spiritual support from clinicians has the potential, if offered insensitively, to be offensive and damaging. As suggested elsewhere, at a minimum, "the clinician's role is . . . to avoid obstructing spiritual explorations. Such obstruction is unlikely to be willful but instead to reflect the clinician's own discomfort with death as an existential phenomenon rather than a technical problem to be analyzed and solved" (IOM, 1997, p. 79).

The hazards of well-intentioned but insensitive involvement by clinical personnel in spiritual matters are cited in an employee handout from a religious health care system. It describes the case of a respiratory therapist

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[3] Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) Standard RI.1.3 "The hospital demonstrates respect for the following patient needs: . . . [RI.1.3.5] Pastoral care and other spiritual services" (RI = Rights and Organizational Ethics).

who baptized an infant suffering severe respiratory problems, thereby exposing the hospital to litigation and a $500,000 settlement with the parents (the husband was a local rabbi) (All Saints Healthcare System, 1998). The hospital had a dedicated neonatal chaplain and 24-hour chaplain coverage that included a cantor and a rabbi, but the therapist did not consult them before acting. Such extreme cases, although they should encourage sensitivity, should not discourage efforts to help patients and families with spiritual needs and concerns.

Spiritual Care for Children

a-byss'

My life
Is halfway down
An abyss.
A deep
Immeasurable space.
A gulf.
A cavity.
A vast chasm.
My life
Is not how
I planned it to be.
Is not how
I want it to be.
Is not how
I pray for it
To be.
In the darkness
Of this pit,
I see a small
Light of hope.
Is it possible for me
To climb to such heights?
To rebuild the bridges?
To find my salvation?
The song
In my heart
Is so quiet.
Is so dark.
Is so fearful.
I dare not stay in

This abyss.
Though deep
And vast,
I am only halfway
Down.
Thus, I am
Already
Halfway up?
Let such words
Fall onto my heart,
And raise me from this depth.

Matthew Stepanek, age 11
Used with permission.

Most discussions of spiritual issues in end-of-life care focus on adults and say little or nothing about children facing death. Clearly, children can engage in spiritual reflection and experience spiritual anguish or peace. The poem that accompanies this section shows the spiritual awareness and anxiety about life's end of the 11-year-old author, who has a progressive neuromuscular condition. The poem also documents his prayerful hope that the "song in my heart" can raise him from the depths of fear.

As described by Thayer, children with life-threatening conditions confront "issues of unconditional love, forgiveness, hope, safety, legacy, loneliness, and loss of wholeness" (Thayer, 2001, p. 173). Like adults, children may wonder, "Why me?" or "How could God let this happen?" or "Did I get sick because I was bad?" This questioning of God's purposes or caring (or lack thereof) is reflected in the perspective offered by a 5-year old who, in describing a drawing, observed, "God is a part of our family, every family. He's not doing anything" (Sourkes, 1995a, p. 133). Although some researchers have examined spirituality in children (see, e.g., Fowler, 1981; Kubler-Ross, 1983; Coles, 1990), little research has investigated the spiritual concerns of children with life-threatening medical problems and ways of responding to these concerns (Kenny, 1999; Davies et al., 2002).

The Pediatric Chaplains Network has developed a document outlining the competencies and ethical standards for chaplains serving sick children and their families (PCN, 1999a,b). One responsibility is to link an understanding of the faith development process in children to an understanding of children's intellectual and psychological development.

A careful assessment by a psychologist, social worker, nurse, or other professional of the psychosocial needs of a seriously ill child may also elicit spiritual or existential concerns by asking about a child's hopes, fears, and other emotions. Taking parents' religious beliefs into account, these professionals may be able to help child patients discuss these concerns. If a child raises specific religious or doctrinal questions in discussions with clinical personnel, deference to the family and their spiritual advisers is advised (Sourkes, 1995a).

Like social workers and others, chaplains may use art, music, and play to help children with matters of faith and meaning (see, e.g., Van Eys and Mohnke, 1985; Thayer, 2001). Older children and adolescents may benefit from techniques used with seriously ill adults, such as a spiritual assessment (see, e.g., Puchalski and Romer, 2000) or a "life review" that covers relationships, achievements, regrets, and similar issues (see, e.g., Haight and Burnside, 1993).

As far as the committee could discover, no spiritual assessment tools have been tested systematically with children. A subcommittee of the National Hospice and Palliative Care Organization has observed that the usually brief spiritual assessments by pediatric hospice programs tend to focus on parents (as spokespersons for the child) rather than on child patients themselves. It has proposed guidelines for exploring and discussing children's spiritual concerns and strengths (Davies et al., 2002).

Spiritual care for children involves more than adapting adult rituals and discussions, although the family's religious beliefs and traditions need to be identified and respected. Thayer has pointed out that "children want to have fun" and their spiritual care should reflect this (Thayer, 2001, p. 180). He also recommends that spiritual care should reflect children's developmental inclinations toward activities rather than abstract thinking and mainly verbal rituals. One example is the use of a "magic carpet" that can serve as a prop and inspiration for imagined trips to heaven or a land of no pain, where children can talk about their hopes, wants, and worries. The making of "spiritual bracelets" (akin to friendship bracelets, except that the colors of threads represent different spiritual values) can both prompt discussions about faith and other values and allow the child to create a gift. The construction and decoration of a "prayer or meditation pillow" not only offers opportunities for activity, creativity, and discussion but also leaves the child with a physical object that may later be helpful in meditation or prayer.

Spiritual Care for Family

Religious traditions and practices often provide families with some sense of order, community, and meaning during a time when they feel unmoored and overwhelmed (Silverman, 2000; see also Doka and Morgan, 1993; Davies, 1998; Goldman, 1998). As noted earlier, some rituals, such as the "anointing of the sick" are familiar in hospitals in many parts of the country, although, depending on the faith, some may not be considered appropriate for young children. When a family member is dying, members of the family's religious community may join them in the hospital room for prayers, chants, songs, scripture readings, or similar expressions. They may help plan spiritually comforting and personalized funerals and memorials for the child.

Because families are so central when a child is gravely ill, a spiritual assessment of parents and siblings is often appropriate. Again, the committee found no assessment tool that had been tested for this specific purpose. For adults, a relatively simple set of questions (e.g., do you belong to a spiritual community? how might we help meet your needs?) may be sufficient to identify those who would welcome further attention, including referral to a chaplain (see, e.g., Puchalski and Romer, 2000).

When it is offered with sensitivity and respect, the opportunity to talk with a chaplain or other appropriate person has the potential to help parents, siblings, and others close to a child who is dying or who has died to cope with their feelings of guilt, anger, or helplessness. Such discussion can also offer hope and comfort based on shared beliefs in life after death or other articles of faith.

Awareness of religious or spiritual concerns can also prepare health care personnel to present issues such as autopsy and organ or tissue donation without offense. In addition, chaplains may provide families with practical assistance, particularly if social work resources are limited (Sommer, 2001). Such practical help may include notifying other survivors or the family's spiritual adviser, preparing families if a visit to the medical examiner's office is necessary, identifying bereavement support groups and relevant social service organizations, and providing information necessary for families to make funeral and other arrangements (Iverson, 1999).

THE PRACTICAL DIMENSIONS OF CARE

Most children are legally, financially, and otherwise dependent on their parents, depending on them for food, clothing, shelter, and many other physical, emotional, spiritual, and practical needs. As they develop, children normally assume more and more responsibility for self-care.

Children who have certain serious, chronic disabling conditions may, however, remain or become substantially or totally dependent on others for such daily and recurring tasks as bathing, toileting, feeding, and dressing. Depending on family members' other responsibilities, physical strength, and emotional endurance, they may need and welcome paid outside assistance with these practical tasks. Such assistance is, however, often difficult for families to arrange and afford. As discussed further in Chapter 6, most private health insurance programs limit payment for such assistance, and state Medicaid and Title V programs are highly variable in what they cover or support.

Many families also face daunting practical challenges in identifying and coordinating multiple professional and other providers of care for a child with extensive medical and other needs. Some health maintenance organizations (HMOs) and integrated health systems reduce these burdens by themselves providing most or all of the needed services and personnel and by maintaining a unified information system to support record keeping, appointments, referrals, and other tasks. Whether they are employed by health plans, hospitals, or other organizations, discharge planners, case managers, and other paid personnel can assist families with some of the practical aspects of coordinating care. (These personnel also serve cost-containment goals, for example, helping to shorten hospital stays.)

As noted in the 1997 Institute of Medicine (IOM) report, the practical often overlaps with the physical, emotional, and spiritual dimensions of caring, and the three latter dimensions also mix with each other. For example, for a child experiencing hair loss or other changes in appearance related to chemotherapy, advice—particularly perhaps from someone with personal experience—about using wigs, scarves, or turbans or even about "making baldness a fashion statement" may help both emotionally and practically.

Box 5.2 provides examples of the many dimensions of practical support for children and families who are living with a child's life-threatening medical condition. A number involve the goal of helping the child and family maintain a normal life to the extent possible. Others concern the family's caregiving responsibilities, ready access to important information, and preparation for crises and for the child's death. When a child is seriously ill, outside support with such matters aids the child by aiding the parents.

Opportunities for practical support continue after a child's death. Particularly when a child has died suddenly without forewarning, the aftermath can be filled not only with emotional trauma and grief but also with bureaucratic requirements related to the hospital's release of the body, the medical examiner's jurisdiction, and other matters. Families may welcome assistance with the array of practical issues associated with funeral arrangements. When a child's death is anticipated, some practical matters can be planned in advance, but the particular circumstances of a child's death may still present unforeseen problems.

Given the diversity of child and family characteristics and circumstances, needs for practical assistance will vary enormously as will the challenges of meeting these needs. Although fundamental goals and principles may be consistent, strategies that meet the needs of affluent, well-educated, and stable families are unlikely to fit the single, barely literate, erratically employed parent with unstable family and personal relationships who lives in poverty in an unsafe neighborhood. Parents in the latter situa-

Box 5.2
Examples of Practical Dimensions of Care for Patients and Families

Normal Life

- What to provide for the child's immediate comfort, control, safety, mobility, and privacy: adapting, arranging and decorating the child's physical space (e.g., hospital room, bedroom, bathroom); modifying the family car
- How to manage personal care and appearance changes: developing routines and finding assistive devices for bathing, dressing, and other activities; fitting medical equipment (e.g., wheelchairs, oxygen) into life at home, school, and elsewhere; offering tips for coping with altered physical appearance (e.g., loss of hair, scarring, prostheses)
- How to continue schooling: planning with teachers and other school personnel for medical and emergency support; preparing schoolmates; arranging a shortened school day or home or hospital schooling
- How to provide for play activities and friends: adapting the home physical environment; preparing playmates for a child's return home; selecting or adapting toys, art materials

Family and Others Close to Patient

- What to do for parent caregivers: advising on employment issues and finances including eligibility for government assistance; arranging or providing volunteer or paid assistance with housekeeping, meal preparation, or respite from caregiving; short-term versus longer-term assistance
- What to do for siblings: babysitting; arranging assistance with homework and time for play, friends, and other normal activities

Planning and Quick Reference Information

- Whom to call: having easy-to-locate phone numbers (including after-hours numbers) for physician and other team members; pharmacy, medical equipment company, case manager, or other health care coordinator; family and friends to be notified of death, imminent death, or emergency
- What decisions have been made: having accessible documentation (at home, at school) of family and, as appropriate, child preferences for care (e.g., written orders to allow natural death)
- What to do for pain and other symptoms, problems with medical equipment: providing quick, clear reference guides for relieving symptoms, dealing with equipment problems, and getting additional help or information
- What to expect: providing information on signs of impending death and caregiver response
- What to do after death: plans for religious and other rituals (e.g., funeral, memorial service, wake), creation of mementos, notification of family members, funeral plans, arrangements for care of very young siblings
- What to do in the event of parental incapacity: identifying guardian and location of estate planning, financial, and other records

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SOURCE: Adapted from IOM, 1997.

tion face greater practical and other burdens, but they—or at least their child—may qualify for Medicaid and for programs to help children with special health care needs. Despite their limitations (see Chapter 7), these programs often offer or provide supportive services beyond those usually covered by private health plans.

Most hospices are attuned to practical as well as clinical issues. In general, hospices have found their greatest acceptance among more educated, middle-class patients and families, although many have tried to reach out to disadvantaged individuals, families, and communities. In trying to "diversify" culturally to serve families from different economic, religious, and cultural backgrounds, they may identify a wider range of practical needs.

Assistance from friends, neighbors, employers, and others in the community can make an important difference in the experience of families living with a child's serious illness. For example, having a friend or neighbor offer to stay with a child's siblings can make it less complicated to visit a doctor with the ill child. Having someone baby-sit the ill child may allow parents a few hours respite to have a quiet dinner or to give other siblings special attention. Formal respite services that provide professional or supportive care at home or at a residential facility provide stressed families a greater opportunity to regroup physically and emotionally, whether this involves a short vacation or taking care of neglected household and business matters. Such services, which are central features of British child hospices (Goldman, 1999; Rushton, 2001), are limited in this country.

Employers can help parents whose child has a life-threatening medical problem by being flexible about working hours and leave (including provisions for coworkers to contribute leave). Employee assistance programs offered by many larger employers may help identify counseling and other resources for employees or family members. Employer-sponsored health insurance is critical to families, notwithstanding limits in coverage of palliative and hospice services. Employers will sometimes agree to waive limits in their health plans on benefits for children with life-threatening medical problems. (See Chapter 7.)

Teachers and other school personnel can likewise contribute by making practical and creative arrangements that help a child stay in school. Going to school maintains a dimension of normal life amidst much that is decidedly not normal.[4]

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[4] Since the 1960s, federal legislation and court decisions have essentially established that states must provide free public education and related supportive services for children with disabilities, regardless of the severity of their disability. In 1994, more than 5 million children were receiving special education services as provided for by federal legislation. (For a summary of the relevant statutes and judicial decisions, see NICHCY, 1996.)

As noted earlier, faith communities not only can offer spiritual and emotional support but also can organize to provide more mundane—but very real—aid in the form of meals, transportation, shopping, and respite care. Although they may charge fees to cover some of their costs, volunteer and charitable organizations (Meals on Wheels, Ronald McDonald Houses) can likewise provide help with a variety of practical matters, such as finding accommodations while a child is hospitalized.

GRIEF AND BEREAVEMENT CARE

> *Parenting is a permanent change in the individual. A person never gets over being a parent. Parental bereavement is also a permanent condition. The bereaved parent, after a time, will cease showing the medical symptoms of grief, but the parent does not "get over" the death of the child.*
>
> Klass, 1988, p.178

> *One question I have since my sister died is "When does it stop hurting?" My mom said, "someday," and that helped. . . . I think it never completely stops hurting, but it doesn't hurt as much.*
>
> Martha, sister (in Romand, 1989, p. 31)

Once a child dies, care for that child ends. For the family, however, emotional, spiritual, and practical needs for support continue beyond the child's death. The death of a child is described as one of life's most devastating experiences, affecting parents, siblings, and a wider circle of relatives and friends.

Research suggests that the death of a loved one—whatever the age—puts the bereaved person's physical and emotional health at risk (see, e.g., Maddison and Viola, 1968; Clayton et al., 1972; Schaefer et al., 1995; Prigerson, 2001; Rubin and Malkinson, 2001; Stroebe et al., 2001b). Appropriate psychological, spiritual, practical, and sometimes physical care for bereaved family and friends is intended to reduce these risks.

Although this discussion focuses on research and analytic perspectives on grief and bereavement, the committee recognizes the need to hear the voices of bereaved parents, siblings, and others close to a child who is dying or has died. The statement to the committee from Compassionate Friends urged health care professionals to prepare themselves by reading articles and other writings of bereaved family members and not to limit themselves to the writings of clinicians and researchers (Loder, 2001). This report reflects the committee's effort to do so while being aware that the writings consulted will not reflect the full range of family experiences and circumstances.

The death of a child is never easy, but the circumstances of a child's death will affect the family's experience and the responses of health care professionals. When a child is diagnosed with a fatal or potentially fatal condition, families have some time to grieve an anticipated loss and, in some sense, prepare for the worst. When death comes with no forewarning, bereavement can be particularly difficult. The following discussion considers, first, grief when death follows an extended course and, then, grief when death comes suddenly and without warning. Appendix E provides a further review of literature, questions, and research needs related to bereavement following the death of a child.

When Death Follows an Extended Course

Grief in Anticipation

When a child's death follows an extended course, family members and others close to the child will likely experience some kind of "anticipatory grief," which has elements in common with the grief that accompanies the child's actual death. These elements include strong feelings of sadness, regret, loss, and possibly guilt and anger. When death is possible but not certain (e.g., as may be the case for very premature infants), anticipatory grief can help some parents and others to prepare for the worst outcome as they also mourn the loss of certain hopes (e.g., for a joyful uncomplicated birth and a healthy infant) (Hynan, 1996). Other parents may, however, resist such thoughts.

Grief in anticipation may also follow the prenatal diagnosis of a fatal condition. Some parents will choose to end the pregnancy and may then experience a complex range of emotions with little of the support that is normally offered to bereaved parents. Other parents will choose to try to continue the pregnancy to birth. These parents will at once be preparing for birth and for death. As discussed elsewhere in this report, obstetricians, pediatricians, and hospital personnel can help families with these preparations, as can new but not widely available perinatal hospice programs (Sumner, 2001).

Because the care team will tend to focus primarily on care for the ill child and because family members may suppress their grief or deny their needs, family members may not receive adequate emotional support. They may, as a consequence, experience more intense short- and long-term suffering. Unacknowledged grief in advance of a child's death may interfere with communication, decisionmaking, and preparations for death, which in turn may contribute to strong subsequent feelings of guilt and regret (see more generally, Byock, 1997).

As is also true once a child has died, parents who are living with their child's fatal or potentially fatal condition may receive emotional and spiritual comfort (as well as practical information) from other parents. This comfort may come informally through established friends and acquaintances (including those encountered at medical settings). It may also come through organized advocacy or support groups.

Preparing for Death

Notwithstanding their sorrow, families may find both immediate and lasting comfort and meaning in preparing for a child's death. In some cases, this may involve taking steps to allow the child to die at home. In other cases, it can mean planning for death in the hospital, if indicated by the child's medical problems and the family's preferences. In either situation, members of the care team can work with families to ensure that they and perhaps close friends have time alone with the child before and after death.

When prenatal diagnosis indicates a medical condition that is expected to lead to death at or soon after birth, families may work with hospital and hospice personnel to minimize intrusive and unhelpful medical interventions for both the mother and the infant so that the family may have as much time close to the infant as possible. When this brief time is missed, it is gone forever.

Parents can also be comforted by planning for religious or cultural rituals and arranging for mementos such as prints or molds from the dying or dead child's hand or clips of the child's hair. Many hospitals have protocols and supplies on hand to accommodate these plans or to offer them to family members faced with a loved one's sudden and unexpected death.

"Hoping for the best while preparing for the worst" can enable families to continue doing everything possible to help their child survive while accepting that death is likely and preparing for it. Again, not all families can tolerate such acceptance.

When Death Is Sudden and Unexpected

> *Take care of the wounded souls who are left to grieve their beloved children.*
>
> Patricia Loder, parent, 2001

When a child dies from sudden infant death syndrome (SIDS) or from unintentional or intentional injuries, which are leading causes of death for infants and children, bereavement care may be all that can be offered to parents, siblings, and other relatives and friends. Such care may range from immediate emotional support in the emergency department or intensive care unit to extensive grief counseling.

Research is sparse, but some studies and clinical experience suggest that people who experience the unexpected death of a loved one, especially a younger person, may suffer more long-lasting psychological distress than those who have forewarning (Parkes, 1975; Vachon, 1976; Lundin, 1984; Davies, 1998). Other circumstances—for example, death resulting from murder, a natural disaster, or a very public event—may add to the psychological burden of survivors. Moreover, sudden deaths of children often require investigation by the medical examiner's office, autopsy, and other procedures that can further intensify the stress and confusion experienced by bereaved families.

Yet another complication is that some sudden deaths of children result from parental abuse. Such deaths may cause anger and uncertainty among hospital staff. They may be unsure about how to handle the parents and other family members. Legal requirements have to be met, and the psychiatric status of the apparent abuser as well as other family members may require formal assessment. In these circumstances, it may be difficult to extend support to other family members, who may be viewed as complicit. Nonetheless, hospital personnel are caregivers not policymakers, judges, and juries. It remains their responsibility to offer assistance to those in need.

The discussion earlier in this chapter stressed the complexities and importance of providing information in emergency situations. Sometimes the family spends relatively little time with emergency department personnel when death is pronounced on arrival or within an hour or two thereafter. The family may be on its way home within three hours of arrival. This puts a premium on prompt inquiries and action, for example, to contact other family or friends and the family's spiritual adviser or the hospital chaplain, to offer information about bereavement support resources in the community, and to provide reassurance that family members can call the social worker or other designated person if they need assistance later and that someone will be in touch to see how they are doing.

As mentioned in Chapter 4, the National Association of Social Workers with support from the federal Maternal and Child Health Bureau has developed guidelines for bereavement care in the emergency department (Lipton and Coleman, 2000b). Appendix F considers other efforts to help emergency departments and emergency first responders improve their support for bereaved family members. The authors note, however, the lack of conclusive findings about how well the emergency medical system serves the families of children who die. As one area for future research, they suggest studies to clarify the relationship between posttraumatic stress disorder and bereavement following sudden death and the implications for family support.

Bereavement

> *Her words concerning his death and the choices I made also comfort me. She said, "You did the right thing." Such simple words—but what comfort they give me four years later!*
>
> Peg Rousar-Thompson, parent, 2001

Several earlier sections of this chapter have discussed ways in which health care professionals can support family members after a child's death. These supports extend from the compassion in the telling of a child's death to the offering of time for family members to be with a child after death to the providing of reassurance and various kinds of practical assistance.

Just as families vary in their other needs, they will vary in their needs for support in bereavement. Some will want or need little professional assistance in coping with their grief. Others may experience complicated grief or bereavement that is more intense and endures longer than normal. After reviewing the literature, Prigerson and Jacobs (2001, p. 1370) conclude that complicated grief symptoms "form a coherent cluster of symptoms distinct from bereavement-related depressive and anxiety symptom clusters' . . . endure several years for some bereaved subjects; predict substantial morbidity and adverse health behaviors over and above depressive symptoms and unlike depressive symptoms, are not effectively reduced by interpersonal psychotherapy and/or tricyclic antidepressants." As discussed in Appendix E, research indicates that mothers and fathers tend to mourn differently. Mothers typically report more intense and prolonged grief reactions than fathers.

Bereavement Interventions

Bereavement interventions are diverse (see, e.g., Parkes, 1998; Corless, 2001; Stroebe et al., 2001a; Worden and Monahan, 2001). Some are relatively short term, for example, preparation and protocols for the immediate aftermath of a child's death in the emergency department. Other interventions may cover an extended period or be relatively open-ended for as long as a bereaved individual wants to participate. Some focus on individual family members; others involve the family as a unit. Some are informal and rely on peers; others involve trained professionals including social workers, psychologists, psychiatrists, members of the clergy, and bereavement counselors.

Bereavement services may be sponsored by mental health organizations, hospices, children's hospitals, family-based organizations, and other groups. Internet-based options have multiplied—some offering peer support, others providing ways to memorialize a loved one. Given that death in childhood is so much less common than death in old age in this country, parents, siblings, and others may find few people with this shared experience. For this reason, Internet-based support options offer families potentially important resources, ones that need to be evaluated further for both positive and negative features.

Many questions remain about the effectiveness (and potential for harm) of different kinds of interventions to support bereaved parents, siblings, and others. Chapter 10 and Appendix E identify a number of directions for research. As with other areas of research, priorities include the identification of relevant outcomes, the development of outcome measures, the classification or diagnosis of grief and bereavement responses or symptoms, the relationship between grief and other psychological states (e.g., posttraumatic stress disorder, depression), the identification of risk or protective factors that predict the severity of responses, and the tailoring of interventions to circumstances.

Families Supporting Families

Before a child's expected death, in its immediate aftermath, and long after, family support groups offer parents and siblings comfort, information, and other assistance guided by the shared experience of bereavement. As one adult sibling wrote, although the community of the bereaved is not "a community that any of us wanted to join," it offers "sympathetic arms to hold us" (Scala, 2001, p. 6). Those involved in these family support groups know what the death of a child is like, including what it is like when weeks pass and the active support and concern of many friends, neighbors, classmates, and coworkers diminishes.

Compassionate Friends is perhaps the largest and most comprehensive of the groups offering support to families after the death of a child. A number of more focused groups such as M.I.S.S. (Mothers in Sympathy and Support) focus on families who have experienced a stillbirth, miscarriage, or infant death. In addition, a number of groups focused on specific medical conditions include bereavement support among a range of concerns that typically include support for research, insurance coverage and other financial assistance, and prevention programs.

Siblings

> *I was in a unique situation as a 5-year-old whose infant brother had died. . . . My brother's death was a void, to be sure. But in many ways, my grief, because he was so young, was more about the emotional death of my parents. My grief was about losing my parents at a crucial time in my childhood.*
>
> Jennifer, sister, no date
> (http://www.portlandtcf.org/NL112001_4.html)

> *The other scary feeling I have since Donald died is about myself dying. I thought since he was twelve when he died that I was going to do the same.*
>
> Susan Rae, sister (in Romand, 1989, p. 21)

Most discussions of grief and bereavement following a child's death focus on parents, but the loss of a brother or sister can have a lifelong effect on siblings—either directly from the loss of a significant relationship or indirectly as a consequence of parents' reactions. In 1984, the IOM report on bereavement, which focused on the research base for understanding and responding to bereavement, lacked a section on siblings' responses to the death of a brother or sister because such an information base was essentially missing. Although still modest, information about sibling bereavement is now more available (see review in Davies, 1998, Appendixes 1 and 2).

Clinical experience and the few studies of children who are themselves suffering from life-threatening illnesses suggest that they may have a more advanced awareness of death than other children (see, e.g., Bluebond-Langner, 1978; Sourkes, 1980, 1982, 1995a). For surviving siblings, however, the general literature on children's developmental understanding of death seems most relevant. In this literature, the evolution of children's understanding of death is generally assessed in terms of four basic concepts including irreversibility, finality, universality, and causation (see, e.g., Wass, 1984; Stevens, 1998; Silverman, 2000). Davies suggests that "age alone is not a reliable indicator of children's understanding of death, but it remains the most practical guideline" (Davies, 1998, p. 36).

Each child has an individual personality and way of dealing with life's normal events and problems, and each child who loses a brother or sister will have an individual reaction rooted in part in his or her own age, personality, and experiences, including relationship with the child who died. Reactions may also be shaped by the behavior of parents and others, including how news of the sibling's death is communicated and how parents cope with their own grief. Based on general guidelines about helping bereaved individuals, Davies (1998) advises those counseling parents about their surviving children to encourage parents to be honest about what has happened and what can be expected (taking into account the children's age and maturity) and to involve siblings in discussions and choices about their presence or participation in significant events (e.g., the wake or funeral). She also emphasizes that siblings, like parents, may be able to absorb only limited amounts of information at one time and may need to have information repeated and expanded.

Children of school age may find it unsettling or distressing to return to school after a sibling's death. One child who was 13 when her sister died wrote, "It was embarrassing to go back to school after Bethany died because everybody just sat there like 'What do we say to her?'" (Romand, 1989, p.16). Another child wrote that "at school they think just because [Donald's] dead he's not my brother no more" (Romand, 1989, p.22). In addition to supporting ill children, teachers and other school personnel can help ease the way for a child living with a seriously ill sibling or returning to school after a sibling's death.

Continuing Support from the Child's Care Team

After a child's death, friends, neighbors, grief counselors, peers, hospice personnel, and others in the local community may provide most of the bereavement and practical support for a family, although the extent and adequacy of such support and the extent to which families experience avoidance or neglect needs further investigation. Parents or siblings may also seek care from their primary care physician or a psychotherapist. Still, the child's physicians, nurses, social workers, and other caregivers who have often developed relationships with the family over a period of months or years can be an important source of support for bereaved parents and other family members. An abrupt end to contact soon after the child's death can feel like—and be—a kind of abandonment.

Members of the child's care team may attend the visitation, funeral, or memorial service. Reports from families suggest that condolence letters from members of the care team are welcomed. Care teams can create reminder systems for follow-up notes or phone calls to mark an important holiday or the date of the child's birth or death. Such a system might include a routine for copying the face sheet on the medical record (which will include names, addresses, and the child's birth date), noting the date of death, and putting in a "tickler" file that is checked regularly.

In some situations, families may be disturbed because the cause of a child's death is not be entirely clear. If an autopsy is performed, the physician can meet with the family to explain the findings and answer their questions. Even when an autopsy is not performed, the physician primarily responsible for the child's care should offer to answer a family's questions and refer them, if appropriate, for counseling.

The next chapter discusses further the role of professionals and health care organizations in providing palliative, end-of-life, and bereavement care for children and families. It considers that care within a broader framework of professional, institutional, and governmental efforts to improve the quality, coordination, and continuity of services for seriously ill or injured children. The chapter concludes with the committee's recommendations on a number of the issues covered in this and earlier chapters including communication, symptom management and other care processes, bereavement services, and coordination and continuity of care.

CHAPTER 6

PROVIDING, ORGANIZING, AND IMPROVING CARE

> *"Was there someone in charge of your child's medical care?" "Yes, me. Coordinating the various doctors, nurses and treatments was the most frustrating part of the process."*
>
> Christine Aney, parent, 2001

> *The parents who live with the children know what is best for that child. That was awful, the having to fight for what you knew was best for your child.*
>
> Gary Conlon, parent, 2001

> *The good news . . . is that any health care organization in the country can take immediate steps to improve how it cares for dying patients and those who love them.*
>
> Lynn et al., 2000, p. 35

In the United States, the diagnosis of a child's life-threatening medical condition often launches child and family into a complex and confusing world of technologically sophisticated treatments, arcane terminology, and highly specialized personnel and organizations. In particular, children with a serious chronic condition will likely need both acute and chronic care involving multiple services from multiple professionals and multiple organizations at multiple sites, including the home. The coordination of such care is a difficult and frustrating burden for many parents that leaves them with less time and energy for their ill child, for other family members, and for each other. It is also a well-recognized trouble spot for health care providers.

This chapter begins by considering palliative, end-of-life, and bereavement care for children and their families within a broader framework of efforts to improve the quality, coordination, and continuity of care for children with serious medical conditions. In addition to strengthening accountability for care, these efforts have sought to make health care more child and family centered, to establish a locus of responsibility for the care of children with special health care needs, and more recently, to develop care coordination models for children needing care for fatal or potentially fatal medical conditions. The chapter also provides an overview of the professionals and organizations that care for children with life-threatening medical problems and their families. The final sections return to the issue of continuity and coordination with a discussion of community and regional systems of care and present the committee's recommendations.

ACCOUNTABILITY AND QUALITY

General Concepts

Although this chapter focuses on the organization and delivery of palliative and end-of-life care for children and their families, such care must be understood within the broader health care system in the United States. The deficiencies of that system in providing affordable, universal access to safe, effective, compassionate, patient- and family-centered care are long-standing. Attention often focuses on children and adults who lack insurance, but as discussed in Chapter 7, even for children and families who have health insurance, public and private health plan rules and procedures may limit professionals and organizations from offering the amounts and types of palliative, end-of-life, and bereavement care that they believe would best meet the needs of the individual child and family.

More generally, the health care system in this country is characterized by complex and often confusing organizational, financial, and regulatory arrangements that link health care professionals and institutions with each other and with governments, insurers, and other organizations. "By fragmenting the patient-physician relationship and often putting personal physicians at a distance from their dying patients, these arrangements may diminish the knowledge and intimacy that contributes to a professional's feeling of individual responsibility" (IOM, 1997, p. 122). One unintended consequence is that no health care professional is clearly responsible for seeing that patients gets needed care whatever its emphasis and whether they are at home or in the hospital. Thus, the committee believes that creating accountability for palliative, end-of-life, and bereavement care is a crucial element of any strategy to improve the quality of this care, including its coordination and continuity.

Another IOM committee has defined quality of care as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (IOM, 1990a, p. 21). The literature on quality of care has traditionally distinguished three dimensions for assessment: the structure of care (e.g., information and decision support systems), the processes of care (e.g., assessing, documenting, and preventing or relieving symptoms); and the outcomes of care (e.g., avoidable hospitalizations, pain, perceptions of care). The definition of the goals of care and the development of appropriate and feasible outcome measures are essential steps in assessing and improving the quality of care and in holding professionals and institutions accountable for palliative and end-of-life care. As discussed further in Chapter 10, the development of outcome measures, whether for quality assessment or research, is a particular challenge for patients who are dying and may be sedated or otherwise not able to answer questions about their experience of care, symptoms, or quality of life in the face of death.

Solomon (2001) has noted the challenges posed by limited scientific knowledge and measurement challenges but has proposed several steps that institutions could take now to strengthen accountability and improve end-of-life care. They include establishing continuous quality improvement committees responsible for end-of-life care, collecting data as a catalyst for change, reviewing existing outcome measures and data sources and experimenting with new ones, and beginning with data collection on a small scale.

Under the rubrics of Continuous Quality Improvement (CQI) and Total Quality Management (TQM), the last decade and a half has seen an explosion of interest in the application by health care managers of formal quality improvement strategies (see, e.g., Berwick, 1989; Berwick et al., 1990; IOM, 1990b, 2001b; Horn and Hopkins, 1994; Nelson et al., 1998). Advocates have promoted principles for implementing change that include "targeting systemic defects (e.g., fragmentation and discontinuity in patient care) rather than individual mistakes; encouraging close relationships among the participants in health care transactions (e.g., physicians, patients, purchasers); using planning, control, assessment, and improvement activities that are grounded in statistical and scientific precepts and techniques; feeding statistical information back to practitioners on how their practices may differ from their peers' or depart from evidence-based standards for practice; standardizing processes to reduce the opportunity for error and link specific care processes to outcomes; and striving for continuous improvement in contrast to merely meeting established goals or criteria" (IOM, 1997, p. 126).

Once a problem area, a specific target for process improvement, and desired objectives and outcomes have been identified and investigated, a centerpiece of CQI is the "plan–do–study (or check)–act" cycle. This cycle involves four basic steps: (1) planning a change, that is, developing specific steps (e.g., data collection strategy, selection of study population) and timetable to reach the objectives; (2) doing or implementing the planned change and collecting data on outcomes and processes, including unexpected problems and results; (3) studying the change by analyzing the data, comparing results to expectations, and summarizing lessons; and (4) acting as guided by the analysis, including revising the original plan, expanding it, or identifying a new strategy. Although investments in these strategies have not necessarily been documented by controlled studies to be as successful as promised (see, e.g., Shortell et al., 1998), they have a recognized place in efforts to improve the performance of the American health care system (see, e.g., IOM, 2001b) including the delivery of consistent, effective, and compassionate palliative, end-of-life, and bereavement care (Lynn et al., 2000).

Innovative Quality Improvement Projects in Palliative and End-of-Life Care

A wealth of ideas for systematic quality improvement in end-of-life care have been generated by an initiative cosponsored by the Institute for Healthcare Improvement and the Center to Improve Care of the Dying. Leaders of the initiative subsequently discussed these ideas in *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians* (Lynn et al., 2000; Web site at http://www.medicaring.org/educate/navigate/qi.html).

One chapter of the sourcebook is devoted to reports on strategies tried by a number of health care organizations to reduce fragmentation of care, improve continuity and accountability, and increase satisfaction with care. Specific, measurable objectives for these projects included reducing patient transfers (especially when death is near), providing patients and families with one or two central contact people, coordinating hospice and oncology units in a managed care system to provide a continuum of care and promote consistency in pain management, establishing reliable procedures for professionals to communicate with each other about a patient's care, and establishing and delivering on specific promises (e.g., that a known person will respond to a request for help within 30 minutes, day or night).

Some of the programs described in the sourcebook sought to coordinate care across multiple sites and providers following the model Program of All-Inclusive Care for the Elderly (PACE) that was pioneered by On-Lok Senior Health Services in California. (PACE also provided the model for the Medicaid-based pediatric palliative care demonstration projects described earlier in this report.) Other projects were focused on narrower issues, for example, developing reliable, easy ways for advance care plans to be available, recognized, and honored by providers in all settings and circumstances. The editors of the sourcebook suggested that a useful measure of continuity of care is tracking the number of health care personnel seen by a patient in a short period. They urged that patients and families should have a single point of contact but also become comfortable with several members of the care team.

Additional innovative projects and efforts to improve the quality of palliative and end-of-life care have been described elsewhere (see, e.g., Bookbinder et al., 1995; Higginson, 1993; Bookbinder, 2001; Solomon et al., 2000b, 2001b; Romer et al., 2002; see also the on-line journal *Innovations in End-of-Life Care*, http://www.edc.org/lastacts, and the Web site for Promoting Excellence in End-of-Life Care, http://www.endoflifecare.org/). These efforts do not necessarily involve the specific quality improvement approach outlined in the sourcebook. Most activities involve adult patients, but they may still offer useful direction for quality improvement efforts in pediatric care.

Practice Guidelines and Protocols for Care

Quality improvement efforts in clinical care often involve the development or adoption of formal clinical practice guidelines and administrative protocols.[1] Such guidelines and protocols are one means of providing direction and defining expectations and responsibilities for the health care professionals and organizations that care for children with fatal or potentially fatal medical conditions. As discussed in Chapter 8, they may also be useful in helping to prevent or resolve conflicts between parents and clinicians and among clinicians, for example, by clarifying the science base for medical interventions or by defining communication processes to reduce misunderstandings between clinicians and patients or families.

Insofar as possible, community institutions planning to implement guidelines or care protocols should start with up-to-date, evidence-based guidelines or recommendations that have been developed by experienced professional societies and other national groups and that, ideally, have been tested in practice settings. The rationale is to both reduce the demands on local institutions and improve the quality of the product. Unfortunately, as noted throughout this report, research findings on palliative, end-of-life, and bereavement care for children and families are limited. Even when research findings are available, they may be incomplete or in conflict. Thus, expert judgment and experience—as well as sound assessment methods and

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[1] This discussion draws, among other sources, on IOM, 1990a, 1992, 2001b; Atkins and DiGuiseppi, 1998; Lohr et al., 1998; Woolf et al., 1999; Feder et al., 1999; Browman, 2001; Ellershaw et al., 2001; and Harris et al., 2001.

consensus development procedures—are essential in evaluating scientific evidence and in recommending courses of action in the absence of evidence. Credible and practical guidelines and protocols for palliative, end-of-life, and bereavement care should also consider the experience and perspectives of patients (when possible), family representatives, and others regularly involved in caring for patients who have fatal or potentially fatal medical conditions.

Even when methodologically sound national guidelines are available, roles also exist for local review and adaptation of such guidelines. One justification for local review and adaptation is to increase the sensitivity of care processes and procedures to specific institutional and community characteristics, including the institution's mission and priorities, the population it serves, the institution's financial and other resources, the community's resources and expectations, and state laws and regulations. Another justification is that the practical process of adapting protocols to local circumstances should promote a greater sense of local ownership and commitment to the protocols and the goals they are intended to serve. When local groups modify national guidelines, they should approach the task systematically and explain the reasons for any departures from these guidelines.

Comprehensive protocols to cover patient transfers and other events that cross institutional boundaries may require interorganizational or community-wide cooperation or agreements. Oregon provides one example of such cooperation. As part of more than a decade's work to improve end-of-life care in the state, a statewide task force has developed, implemented, and evaluated Physician Orders for Life-Sustaining Treatment (POLST)[2] as a tool to help patients have their wishes honored regardless of the site of care. This initiative has shown evidence of success (Tolle et al., 1998; Lee et al., 2000; Tolle and Tilden, 2002; see also http://www.lastacts.org/files/publications/polst0599.html).

In a few areas, interventions and care protocols are reasonably well defined and, in some cases, tested. For example, evidence-based guidelines for management of different kinds of pain, including cancer pain in children, have been developed and undergone several years of testing in the United States and elsewhere (see, e.g., AHCPR, 1994; Foley, 1994; Bookbinder et al., 1996; WHO, 1998; Du Pen et al., 1999). In addition, expectations for pain management are now articulated in accreditation standards

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[2] The orders are presented in a bright pink document that is to be attached to the front of a patient's medical record in a hospital or nursing home. Oregon also has changed the scope of practice for emergency medical responders so that they can honor POLST provisions. In addition, the state has revised its advance directive statute and, in general, made comfort care a priority for dying patients (Tolle and Tilden, 2002).

and supporting statements devised by the Joint Commission on the Accreditation of Hospitals (JCAHO, 2001). Specific standards now state that "patients have the right to appropriate assessment and management of pain" (standard RI.1.2.8), "pain is assessed in all patients" (standard PE.1.4), and "patients are educated about pain and managing pain as part of treatment, as appropriate" (PF.3.4). Advocates have also adopted the phrase "pain: the fifth vital sign" to help increase professionals' awareness of pain and encourage the implementation of explicit pain management guidelines and protocols (APS, 1997).

The Joint Commission standards mention other aspects of palliative and end-of-life care. As noted in Chapter 5, one (RI.1.3.5) mentions pastoral care and other spiritual services (JCAHO, 1998). A broader standard (RI.1.2.7) states "the health care organization addresses care at the end of life" (JCAHO, 2001). The Commission explains the intent of the latter standard as covering

- provision of appropriate treatment for any primary and secondary symptoms, according to the wishes of the patient or the surrogate decision maker;
- aggressive and effective management of pain;
- sensitive issues such as autopsy and organ donation;
- respect for the patient's values, religion, and philosophy;
- involvement of the patient and, where appropriate, the family in every aspect of care; and
- attention to the psychological, social, emotional, spiritual, and cultural concerns of the patient and the family.

The committee believes that it is appropriate to generalize the expectation of aggressive and effective pain management to the aggressive and effective management of all serious symptoms. This would likely encourage more active efforts to develop evidence- and consensus-based guidelines for symptoms in addition to pain and to build a broader and stronger evidence base for effective symptom management (IOM, 1997; Goldman, 1999; ChIPPS, 2001; Levetown, 2001).

Unfortunately, the limited research on effective pharmacologic and other symptom management approaches for children is a concern. In some cases, symptom management and other guidelines for adult care may serve as models or starting points for pediatric guidelines, although the latter would likely have a more limited evidence base and more complex analytic task relating to children's developmental differences and other special dimensions of pediatric care. For example, as one resource, pediatric oncologists could look to the series of curriculum modules that the American Society of Clinical Oncology has developed for specific disease- and treatment-related symptoms and symptom control topics (ASCO, 2002).

Notwithstanding the limited evidence base, the committee believes that practice guidelines and administrative protocols are, at a minimum, important tools for articulating institutional expectations and responsibilities and establishing a basis for evaluating processes and performance. Adoption of guidelines does not guarantee desired results. As another IOM committee warned in 1992, "guidelines for clinical practice are a promising but not a quick or sure strategy for improving and rationalizing the overall use of health care services. . . . Persistent commitment over the long term is required from both policymakers and health care professionals" (IOM, 1992, p. 4). The last decade has confirmed that assessment. Even when health care personnel agree with the basic message of a guideline (i.e., have identified, reviewed, evaluated, and accepted the guideline), formidable barriers to implementation exist, including habitual practice patterns, countervailing patient preferences, time pressures, financial disincentives, liability concerns, and lack of supporting information and administrative systems. Some barriers (e.g., inadequate information systems) can be acted on locally, at least in part, but other barriers (e.g., financial disincentives) lie largely beyond the reach of individual institutions and require system-level changes in policies and practices.

THE CHALLENGES OF COORDINATION AND CONTINUITY

Although the rationale for specialized pediatric services to serve seriously ill or injured children is persuasive, the system has some limitations. Many communities lack the population base and resources to support such services, so some children and families must travel long distances to get specialist and subspecialist care. They thus are separated from their normal sources of support including other family members, friends, and the child's usual physician. When the child and family return home, they may have to rely on professionals and providers with limited experience in caring for children with advanced illnesses or providing palliative and end-of-life care. The coordination, continuity, and quality of a child's care may suffer as a result, especially if follow-up protocols, consultation, and other support from specialist professionals and medical centers are limited.

When children can be treated in or near their home community, coordination and continuity can still be difficult and frustrating when multiple providers and services are involved. Even within a single institution, coordination and communication may fail during shift changes, discharge preparation, and other predictable transitions.

In parents' stories of their experiences with a child's life-threatening illness and death, two frequent themes are the burden of coordinating the many elements of their child's medical care in a fragmented care system and the difficulties of maintaining continuity in care and sustaining trusted relationships. Parents find themselves spending hours on the phone trying to identify, schedule, and coordinate providers and services and also struggling with health plan requirements and procedures. They may have to ensure that essential medical information and care plans (e.g., orders about life-sustaining care) accompany their child from one provider to another and still repeatedly explain the child's history and their experiences and preferences regarding the child's care.

Recognizing the financial, psychological, and other costs of poorly coordinated care, health care professionals, administrators, accreditation organizations, insurers, and regulators have created and refined a number of structures and processes for integrating diverse services and smoothing the transition of patients from one caregiver, care team, organization, or setting to another. They may fail in implementation for various reasons (e.g., poor information systems, inattentive management, inadequate resources), but the basic mechanisms are reasonably well accepted. These mechanisms, which may also serve cost control objectives, include the following:

- discharge planning procedures to ensure that patients leave hospitals, nursing homes, and other institutions when it is medically appropriate and when appropriate follow-up care has been planned and arranged;
- case management programs, which may coordinate both health and social services for patients and families, particularly patients with serious chronic problems and limited financial resources;
- disease management programs to improve the continuity, consistency, and effectiveness of care, including self-care, for individuals with specific medical problems such as diabetes or asthma;
- standardized procedures for patient transfers and follow-up among hospitals, home care agencies, hospices, and other organizations that have overlapping service areas;
- patient, family, and general community educational efforts intended to inform people of programs that may assist them in obtaining and coordinating services and of steps they need to take to navigate the care system; and
- medical information systems that follow people across settings and providers of care, so that plans of care, preferences, and records are accessible whenever needed.

These and similar arrangements have not generally been designed with the needs of dying patients and their families in mind. Most could, however, be adapted or adjusted to include objectives and procedures focused on the coordination and continuity of palliative, end-of-life, and bereavement care for adults and children.

In addition to the mechanisms identified above, a number of other coordination strategies have been developed to assist children with special health care needs and their families.[3] The "medical home"—one broad approach for these children and families—is discussed below as is a strategy to integrate and coordinate palliative care for children hospitalized with life-threatening conditions. Both can be seen as elements of larger initiatives that attempt to put the needs and preferences of children and their families at the center of health care systems.

Although many strategies focus on coordinating multiple providers and sites of care, strategies to preserve continuity of care are also important. Continuity is a complex concept that overlaps with but is not identical to coordination of care. Fletcher and colleagues (1984, p. 409) distinguished between "a thread" that ties episodes of care together (continuity) and the relationship of various components of care (coordination) but also noted that the terms may be used interchangeably. As used here, continuity implies that needed services will be provided without disruption. It also implies that a child and family are able to maintain trusted relationships and patterns of care that have been forged and tested over time, especially during the course of a child's serious illness.[4] With discontinuous relationships, it is difficult if not impossible for individual physicians and other members of the care team to promise that they will "be there" when patients and families need them (Lynn et al., 2000).

Some studies suggest that continuity increases patient and family satisfaction with care and can reduce hospitalization and, possibly, costs. For example, one recent cross-sectional study on continuity of care in a primary care clinic reported that continuity of care was associated with higher parent ratings on items about providers' respect for parents' views, careful listening, and understandable explanations (Christakis et al., 2002; see also Gill and Mainous, 1998; Gill et al., 2000; Christakis et al., 1999, 2001).

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[3] As discussed in Chapter 2, these children "have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and . . . also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). Many of these children have conditions such as vision loss, mental retardation, autism, and serious learning disorders that are not expected to lead to death in childhood. A small percentage, however, have congenital anomalies, progressive neurodegenerative diseases, and other conditions that are often or always fatal.

[4] Sometimes continuity refers more narrowly to a "usual source of care," which could be a clinic with no guarantee of continuity with a particular caregiver. Other dimensions may include continuity of records and information. See, for example, Donaldson (2001).

Continuity is usually valued, but other considerations must also be weighed, for example, a family's desire to bring a child home rather than stay at a distant, specialized treatment center. Further, hospital or hospice rules, health plan requirements, licensure restrictions, and other policies can limit continuity, although creative and persistent families, social workers, physicians, and other team members may find ways around some restrictions in individual situations. Nonetheless, unless institutions establish systematic processes and protocols for handling special situations, arranging waivers to rules, and, more generally, making continuity planning a part of the care process, it will be difficult to sustain continuity of care and keep the focus on the child and family rather than on institutional requirements and conventions.

When primary responsibility for a child's care shifts, those who have cared for a child may still seek ways to maintain some degree of continued communication and involvement with the child and family. If a child has been appropriately referred to hospice after the failure of chemotherapy and other cancer treatment, the hospice team and the oncology team can encourage continued relationships, for example, through regular phone calls. Similarly, a child's primary care physician can call to keep in touch while a child is under a specialist's care.

Child- and Family-Centered Care

General

As described by advocates, the movement for family-centered care targets the subordination of the needs of the child and family to the needs of the health care system (see, e.g., Shelton et al., 1987; Johnson et al., 1992; Shelton and Stepanek, 1994; see also Harrison, 1993). Although the ideas championed by this movement have roots that extend back to the 1970s and before, they were given particular emphasis in the late 1980s by advocates for families whose children have special health care needs (as defined in Chapter 2).

The commonly cited elements of family-centered care for children with special health care needs do not explicitly include informing children, involving them in goal setting and care planning, and respecting their individual values and concerns. One reason may be the movement's focus on children who have cognitive limitations or serious emotional disorders. Also, parents have legal authority to make decisions for their child and are usually the child's primary caregivers.

Beyond the special needs community, proponents of patient-centered care have argued for understanding care "through the patient's eyes" (Gerteis et al, 1993). A child-adapted version of that perspective would

BOX 6.1
Elements of Child- and Family-Centered Health Care

- Recognizing that the family is the constant in a child's life, while the role and importance of health care and social service systems vary and the people staffing those systems change
- Understanding and accommodating the individual strengths and characteristics of the child and family, including their coping strategies and their cultural, ethnic, religious, and other values
- Sharing unbiased, timely, complete, responsive, and understandable information with families about their child's diagnosis, prognosis, and care options
- Sharing information with the child and involving the child in goal setting and care planning, consistent with the child's developmental status and preferences and the family's values
- Promoting and assisting collaboration between families and professionals at all levels (i.e., in direct patient care, organizational processes and decisions, and community- or system-wide policies and practices)
- Designing sustainable care processes and care systems that meet the differing developmental needs of infants, children, and adolescents
- Developing care processes, systems, and policies—within both institutions and communities—that respond to child and family needs for flexibility, continuity, emotional and financial support, cultural and ethnic sensitivity, and education about caregiving responsibilities
- Encouraging and assisting family support groups, peer counseling, and other lines of family-to-family communication
- Encouraging child-to-child lines of support and communication, consistent with the child's developmental status and preferences and the family's values

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SOURCES: Adapted from Shelton et al., 1987; Johnson et al., 1992; and Shelton and Stepanek, 1994.

attempt to understand pediatric care "through the child's eyes." To that end, the committee recommended in Chapter 4 that children with life-threatening medical conditions be involved in care planning and decisionmaking, consistent with their intellectual and emotional maturity and with the family's background and values.

In Box 6.1, the committee has amended and supplemented the commonly cited core elements of family-centered care to add explicitly the recognition and involvement of the child whenever possible. In addition to adding child-centered elements, the list of core elements also mentions education of family caregivers. This reflects the importance of appropriately training family caregivers to provide care that is often provided by nurses or other trained health care personnel.

The Medical Home

The "medical home" is a core component of strategies to implement the elements of family-centered care for children. The concept has its fullest expression as a means of improving the continuity and coordination of care for children with special health care needs and eventually supporting the successful transition of these children to adult services. Insofar as possible, the goal is to meet all of the child's and the family's needs—medical, psychosocial, educational—in the local community.

The medical home concept has been developed and promoted by a coalition including the American Academy of Pediatrics (AAP), the federal Maternal and Child Health Bureau, Family Voices, and other groups (AAP, 1992, 1995b, 1999b). As defined by the Maternal and Child Health Bureau (MCHB, 2000a), "a medical home is the collaborative effort between primary care providers and children with special health care needs and their families to ensure that care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and delivered in a culturally competent environment" (MCHB, 2000a). The ideal elements of the medical home, as described by the AAP, are listed in Box 6.2. Some of these elements

BOX 6.2
Ideal Elements of the Medical Home for Children

1. Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, health care supervision, and patient and parental counseling about health and psychosocial issues
2. Assurance of ambulatory and inpatient care for acute illnesses, 24 hours a day, 7 days a week; during the working day, after hours, and on weekends, 52 weeks of the year
3. Provision of care over an extended period of time to enhance continuity
4. Identification of the need for subspecialty consultation and referrals and (the ways to obtain these services); provision of medical information about the patient to the consultant; evaluation of the consultant's recommendations; implementation of recommendations that are indicated and appropriate; and interpretation of these to the family
5. Interaction with school and community agencies to be certain that special health needs of the individual child are addressed
6. Maintenance of a central record and database containing all pertinent medical information about the child, including information about hospitalizations; this record should be accessible, but confidentiality must be ensured

SOURCE: AAP, 1992.

are in place but the concept remains, for the most part, an ideal rather than a generally implemented reality.

The AAP notes that geographic barriers, personnel constraints, practice patterns, and economic and social forces make the ideal medical home unobtainable for many children. For example, many children with special health care needs are covered by Medicaid, but reimbursement for physician services and capitation rates for Medicaid managed care plans are so low that they deter pediatricians from providing that ideal (see Chapter 7).

The goals of the medical home and the goals of palliative care and end-of-life care for children are fully compatible. Efforts to implement the medical home concept for the larger population of children with special health care needs should benefit the smaller group of children who die of complex chronic conditions. These efforts may also provide models for the coordinated care of children with more acute medical problems who alternate for shorter periods between inpatient and community care before they die. In turn, even though generalist pediatricians and family practitioners will usually care for relatively few children who die, their preparation in the basic principles of pediatric palliative care can benefit the much larger population of children with serious medical conditions that are not expected to prove fatal in childhood. (Chapter 9 examines education and training in palliative and end-of-life care for generalist and specialist pediatricians and family practitioners.)

Pediatric Advanced Illness Care Coordination

One strategy for coordinating care that focuses specifically on patients with fatal or potentially fatal diagnoses emphasizes communication and decisionmaking. Following a model originally developed for adults (Tobin and Lindsey, 1998), the Pediatric Advanced Illness Care Coordination (PAICC) program is intended to integrate and standardize pediatric palliative care within the routines of medical care for children with serious medical conditions (Himelstein et al., 2002). The approach also reflects current principles of case management and disease management.

The adult program is operating in 40 institutions in the United States (Dan Tobin, M.D., The Life Institute, personal communication, March 6, 2002). The pediatric program is being introduced in a number of medical centers around the country including The Children's Hospital at The Cleveland Clinic, the Children's Hospital Wisconsin, Hackensack University Medical Center, and the University of Texas Health Sciences Center at San Antonio. The care coordination program can work in tandem with different specialty care teams and with the medical home of a child with special health care needs.

Two central features of the pediatric program are the designation of a care coordinator to work with health care teams and families and the availability of three manuals—one for the child's main physician and other caregivers, one for the care coordinator, and one for parents. The care coordinator keeps the patient and family at the center of care, with a focus on their information needs and psychosocial concerns. He or she also initiates conversations about end-of-life issues and decisions and coordinates and orchestrates care—possibly providing some care but also helping families find, obtain, and coordinate resources. The coordinator offers information and support services to parents while making clear to parents that they can call the coordinator for assistance even if they do not want to accept the services.

The manual for care coordinators is a training guide that includes modules on communicating compassionately and effectively with children and families about diagnosis and prognosis, planning and decisionmaking, helping families cope with fear, and supporting them in preparing for death. The manual for families is intended to help parents gain some control over the experience of having a child with a life-threatening condition. It urges them "not to put this manual down because you do not want to think about the worst" (Hilden and Tobin, 2002, p. 6).

Key elements of planning for PAICC include the identification of resources for palliative and end-of-life care within hospitals and in communities, the identification of sources of referrals for pediatric palliative care (e.g., oncologists, intensive care nurses, discharge planners, health plan case managers, chaplains), and the assessment of clinical services, inpatient palliative care resources, relevant administrative procedures, and potential barriers to program implementation. Other elements include initial and ongoing training of program staff, strategies for educating providers and winning their support, procedures for introducing the program to patients and families, processes and tools for documenting communication and information, and formal evaluation of processes of care and outcomes. Among the outcomes sought by the PAICC model are

- increases in (1) the frequency and timeliness of referrals to palliative care experts and (2) the interval between do-not-resuscitate (DNR) and similar orders or advance care directives and the time of death;
- improved documentation of communication about end-of-life care;
- increases in staff satisfaction with providing end-of-life care and serving children with advanced illness; and
- improvements in children's quality of life and in the satisfaction of children and families with the care and information provided.

Any strategy to improve the coordination, continuity, and effectiveness of care for seriously ill children and their families depends on the commitment, preparation, and support of an array of health care professionals. The following section first discusses individual categories of professionals. It then considers various kinds of pediatric care teams, which also are intended to serve as a means of coordinating the care needed from different categories of health professionals.

HEALTH CARE PROFESSIONALS

To evaluate and meet children's special physical, cognitive, and emotional needs as they develop from infancy to adulthood, an array of specialized health care professionals and health care organizations have evolved over the last century and more. These professionals include general and specialist pediatricians, pediatric nurse practitioners and nurses, child psychologists, child-life specialists, pediatric social workers, and others with training in various aspects of care for infants, children, and adolescents. Children's hospitals specialize in treating ill or injured children, and some home care and residential care facilities also concentrate on care for children.

In addition, children may receive care from professionals and organizations that do not specialize in pediatric services. For example, a seriously injured child may be taken to the nearest Level 1 trauma center but may then be transferred to a center specializing in pediatric emergency and intensive care. The transfer may also be from more to less specialized care, for instance, when children who have returned home after treatment at a center specializing in pediatric oncology may receive follow-up hospital care at a community hospital. This mix of specialized pediatric and other providers complicates efforts to describe, assess, and improve the provision of palliative, end-of-life, and bereavement care to children and their families.

Physicians and Nurse Practitioners

Any physician can legally care for a patient of any age, but pediatricians are uniquely educated to diagnose and treat children. In 1995, data from the American Medical Association showed 50,000 physicians in the United States who designated themselves as practicing pediatricians (board certified and non-board certified) (Randolph et al., 1997; DeAngelis et al., 2000). More than 90 percent were involved in direct patient care.

Family practitioners are also trained to provide primary care to both adults and children, more often older children and adolescents rather than infants and preschoolers (AAP, 1998b). According to data from the 1980s and earlier, family practitioners provided 15 to 25 percent of physician services received by children, possibly more in rural areas (Budetti et al., 1982; Abt Associates, 1991). In addition, about 5,800 pediatric nurse practitioners have been certified (DeAngelis et al., 2000). The amount of care provided to children by specialists and subspecialists who care mainly for adults is not documented (Gruskin et al., 2000).

Because most children are healthy and require mainly preventive and other primary care, general pediatricians and family practitioners are less likely than generalist physicians caring for adults to encounter and care for patients with fatal or potentially fatal diagnoses. When they do encounter such child patients, they typically refer them to appropriate pediatric oncologists, cardiologists, or other subspecialists. The committee identified no data on the nature or extent of generalist involvement in the care of children with life-threatening medical conditions and likewise found no information on the nature or extent of clinical guidance or consultation provided to generalist pediatricians by local or regional specialists. Although committee members were aware that some managed care organizations require that children be returned to the care of primary care physicians if it is judged that continued curative or life-prolonging treatments will be ineffective, they located no systematic information on such policies or their consequences.

Pediatric subspecialists vary considerably in the amount and kind of care and support they provide to seriously ill or injured children.[5] For example, radiologists or surgeons who treat pediatric cancer patients provide essential services but often have relatively limited ongoing involvement and do not have primary responsibility for the child's care. Pediatric emergency medicine specialists may provide very intensive services but for a relatively limited period before a seriously injured or acutely ill child dies or becomes the responsibility of a critical care specialist. In contrast, pediatric oncologists, neurologists, cardiologists, pulmonologists, and certain other specialists may have close relationships with children and families that extend for years. Neonatologists, obstetricians, and other specialists, including the nurses who staff neonatal intensive care units and delivery rooms, provide intensive care—sometimes briefly, sometimes for months—for a substantial proportion of children who die.

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[5] The American Board of Pediatrics recognizes 13 pediatric subspecialties: adolescent medicine, cardiology, critical care medicine, developmental–behavioral pediatrics, emergency medicine, endocrinology, gastroenterology, hematology–oncology, infectious disease, neonatology–perinatology, nephrology, pulmonology, and rheumatology. Certificates are awarded in conjunction with other specialty boards in the areas of clinical laboratory immunology, medical toxicology, neurodevelopmental disabilities, and sports medicine (ABP, 2002).

Each category of specialist should be prepared to provide palliative, end-of-life, and bereavement support appropriate for the children and families they serve. In August 2000, the American Academy of Pediatrics issued a policy statement stating that "all general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children" (AAP, 2000g, p.356). Pediatric specialty groups are also beginning to recognize the importance of more systematic attention to palliative and end-of-life care for children and their families. For example, the Children's Oncology Group has organized an End-of-Life Care Subcommittee that will work to develop the evidence base for palliative care within the framework of clinical trials (COG, 2001). Chapter 9 describes other initiatives sponsored by pediatric professionals that focus on the education of clinicians.

Within the relatively new field of palliative medicine, the emphasis is overwhelmingly on care for adults, especially elderly adults who account for more than 70 percent of Americans who die each year.[6] A small cadre of pediatric palliative care specialists is, however, emerging to provide leadership and support for the larger pediatric care community.

Nurses

> *Both parents had to work. They were very, very poor people. . . . So the nurses just did everything. Every single bit of love those children had in their last moments came from the nurses, and you know that was a gift.*
>
> Salvador Avila, parent, 2001

For nurses as for physicians, specialized training in pediatric nursing recognizes children's unique developmental needs. Further specialization in neonatal and critical care reflects the very particular demands of caring for premature infants, infants with severe congenital anomalies, and critically ill or injured children. Other organized areas of nurse specialization include pediatric oncology and cardiology.

Nurses play a central role in providing day-to-day palliative care and home hospice care for adults. Experienced hospice nurses tend, however, to

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[6] Palliative medicine is not a formally recognized medical specialty. Groups such as the American Academy of Hospice and Palliative Care Medicine (AHPCM) have, however, organized to build the field by promoting and providing education, research, clinical practice guidelines, public information, and advocacy. AHPCM also has developed certification standards, which do not distinguish between adult and pediatric care; the organization has certified some pediatricians as palliative care specialists.

have no training in pediatric care, and experienced pediatric nurses tend to have little training in palliative and end-of-life care.

Even experienced hospice nurses and other hospice staff may fear caring for dying children and find it very stressful, especially if they do not receive specialized training and ongoing support. Some nurses may also find it hard to separate their professional roles from their feelings as parents (Sumner, 2001).

More guidance on pediatric palliative nursing is becoming available. A comprehensive new textbook of palliative nursing (Ferrell and Coyle, 2001) includes three chapters specific to pediatric care (Hinds et al., 2001; Levetown, 2001; Sumner, 2001), and the major text on palliative medicine has from its first edition in 1993 included chapters on care of children (Doyle et al., 1998). (Other educational initiatives are described in Chapter 9.)

In the course of its work, the committee heard concerns that a nationwide shortage of nurses extends to pediatric care, especially pediatric home health care (NAPHACC, 2001). Another issue for home health care nurses is their isolation, which limits their opportunities to learn from peers as well as from the on-site training programs that may be available in hospital settings. Similarly, hospice nurses may also find that visiting patients at home, while rewarding in many respects, leaves them feeling somewhat isolated from other team members. Joint visits with other team members, team meetings, and other strategies, such as joint hospice-hospital or hospice-home care programs, may encourage learning and reduce isolation.

In its statement to the committee, the American Association of Critical Care Nurses (AACCN, 2001) noted that despite the time nurses spend with children in intensive care and with their families, nurses are not the key decisionmakers and are not always consulted in the development of a child's care plan. One result, the group suggested, is that the care plan may be based on incomplete information about the child and family. Implementation of the plan may also suffer as a result of unacknowledged differences in physician and nurse perceptions.

Even nurses who never expected to encounter seriously ill children may become involved in caring for children with life-threatening medical conditions. As discussed further below, as the number of medically fragile children enrolled in schools has increased, school officials and school nurses have been challenged to support medication regimens for these children, to prepare for cardiac arrest and other medical emergencies, and to cope with other challenges once largely unknown to school health personnel (AAP, 2000d; see also Chapter 8). The school nurse also may educate a child's teachers, other school personnel, and the child's classmates and their families about an ill child's condition and ways of easing the child's reentry and continuation in school.

Social Work and Mental Health Professionals

Child psychologists and psychiatrists, as well as social workers, may be called on to provide psychological care for seriously ill or injured children and for their families, before and after a child's death. Social workers have typically been an integral part of palliative and hospice care teams, available to families (parents especially) for help with emotional and practical concerns, including identifying community resources (e.g., home health agencies, funeral homes). In the hospital emergency department and intensive care unit, they often serve as the communication link between parents and the team caring for a seriously injured or suddenly ill child. In these stressful and often confused situations, their role is to help ensure that needed information is successfully communicated and that parents have an adequate opportunity to raise questions and concerns so that they can more effectively participate in decisionmaking about their child's care.

The entry of child psychologists and psychiatrists into the field of palliative care is a relatively recent development. Their inclusion in the care team extends the emotional care available to seriously ill children and their siblings, particularly in assessing and treating symptoms such as depression and anxiety that can substantially diminish an ill child's quality of life.

One important goal for all staff in a children's hospital is to help children maintain as much normal life as possible. Child-life specialists contribute to this goal. Based on a 1998 survey, the National Association of Children's Hospitals and Related Institutions (NACHRI) reported that 97 percent of 112 responding hospitals employed at least one child-life specialist (NACHRI, 1998). Similarly, the American Academy of Pediatrics has reported that 97 percent of children's hospitals and 82 percent of hospitals with pediatric residency training programs (in general or children's hospitals) employed child-life specialists (AAP, 2000c). Large physician groups may also use child-life specialists.

Child-life specialists do not fit neatly into usual professional categories. As experts in communicating with children, they can help "translate" between clinicians and children. They may engage children in developmentally supportive and therapeutic play and in therapies using art, music, and dance. As discussed in Chapter 5, these techniques may help children express and cope with difficult emotions and offer relief from the stress of illness and medical treatment. In addition, child-life specialists may employ distraction and other behavioral techniques to help manage pain and other symptoms. In children's hospitals, they also help provide supportive environments for siblings of sick children to play and interact with siblings of other children who are coping with similar situations. Particularly for children hospitalized repeatedly or for extended periods, child-life specialists become familiar people with whom children can safely share fears, worries, and hopes that might otherwise be unexpressed. With the child's permission, these concerns may be communicated to parents and the care team.

Child-life specialists typically work "9 to 5" and, thus, are not available to support children, families, and physicians when crises arise outside those hours. Unlike psychiatrists but like nurses and, often, clinical social workers and clinical psychologists, child-life specialists cannot directly bill insurers for their services. In times of particular fiscal stress, their services are vulnerable to discontinuation.

Providers of bereavement care may come from a variety of backgrounds including social work, psychology, and nursing. Helping bereaved people may be a full-time responsibility or one aspect of the work of a chaplain, social worker, funeral director, hospice volunteer, or other interested individual.

Other Personnel

Chaplains provide spiritual care to patients and families in hospitals and other care settings. They also provide emotional support and comfort and practical assistance to families coping with the death of a child (Sommer, 2001). As discussed in Chapter 5, provisions for spiritual care are part of hospital accreditation and Medicare hospice requirements. In general, however, the extent of chaplains' involvement with dying children and their families is little documented or evaluated.

Hospital teachers provide individualized and group learning for patients well enough to leave their beds during the day. They also make rounds to help children who are confined to their rooms. Other teachers specialize in home tutoring. Hospital and home teachers can establish close relationships with children, who may feel comfortable sharing concerns with a home teacher rather than adding to their parents' worries and stress (Weil, 2001). In addition, although such links are more the exception than the rule, videoconferencing and other technologies provide opportunities to help homebound children maintain contact with children, teachers, and resources at their regular school (Bowman, 2001).

Phlebotomists, respiratory therapists, physical therapists, and others who are skilled in working with small patients can reduce the physical and emotional distress caused by diagnostic and therapeutic procedures. Ideally, they will have equipment (e.g., needles and other intravenous equipment, breathing tubes, oxygen masks) appropriate for children of different sizes, and they will also develop skills in reassuring or distracting children and otherwise reducing their fears and anxieties. General hospitals with no pediatric unit are unlikely to have such specialized personnel and equipment.

Pediatric Care Teams

Multidisciplinary care teams are a feature of much pediatric emergency, chronic, and acute care, especially for children with complex conditions that require a period of inpatient evaluation and treatment. Thus, the neonatal intensive care team concentrates on the specialized needs of fragile newborns (including premature infants and those with serious congenital anomalies) and their families. The pediatric oncology team cares for children with cancer and their families. Emergency care teams work intensively for a compressed period of time to assess and stabilize children before transferring them to other care teams. Although health services are usually not organized to encourage it, a care team or some members of the team may provide both inpatient and outpatient care (e.g., inpatient and outpatient chemotherapy).

Regardless of the site of care, the usual goals of pediatric care teams working with children with serious medical conditions are multifaceted. They include

- providing and coordinating care appropriate to all the physical, emotional, spiritual, and practical needs of the individual child and family including family needs after the death of a child;
- caring for the child and family as a unit;
- encouraging information sharing and consistency among team members and relevant others so that families do not receive conflicting or confusing messages from professional caregivers;
- integrating family members into the care team and, thus, involving them more fully in establishing the goals of care and in making decisions; and
- preparing for and coordinating transitions in the site or emphasis of care and providing continuity.

Ideally, team care is not only multidisciplinary (i.e., involves members from several disciplines) but also truly interdisciplinary (i.e., "is more than the sum of its parts"). Although the terms multidisciplinary and interdisciplinary are often used interchangeably, as used here, interdisciplinary refers to structures and processes that (1) encourage individual team members to understand and incorporate the perspectives of other disciplines into their own assessments and practices (consistent with licensure and other reasonable constraints), (2) reduce disciplinary misunderstandings, discord among team members, and gaps or discontinuities in care, and (3) forge more productive relationships and practices among individuals with different disciplinary backgrounds.

The composition of pediatric care teams will naturally vary depending on the nature of the child's medical problem and the settings and kinds of services needed. The resources, traditions, and philosophy of the employing organization may also influence team composition. In general, however, the core of an inpatient team caring for a seriously ill or injured child includes a primary subspecialist physician (e.g., pediatric oncologist or cardiologist), one or more nurse specialists, a psychologist or social worker, perhaps one or more residents or fellows, and possibly a child-life specialist. Other subpecialists (potentially, but at present rarely, including a palliative care specialist) are brought in as needed. Supporting members of the team may include pharmacists, respiratory therapists, physical therapists, genetic counselors, dieticians, and chaplains.

Team care is widely viewed as central to inpatient palliative care and home hospice programs for both adults and children and their families. To the extent that inpatient palliative care teams exist in either adult or pediatric care, they generally serve as consultants to other specialty care teams (e.g., oncology, cardiology, nephrology) that retain primary responsibility for a patient's care, especially for children who are continuing to receive curative or life-prolonging therapies. The core of an inpatient consulting team may be nurses supported by a physician who is involved as needed. If the focus of care is primarily palliative and home based and if pediatric hospice services are available in the community and accepted by the parents, a home hospice care team may assume primary responsibility for care of the child and family. Again, nurses usually play a central role in hospice care teams.

When a child goes home for care that is primarily palliative, some families may prefer that the child's oncology or other care team continue to take the lead, especially if the child and family are local. Geographic distance can, however, make this approach to home care impractical, and some families may prefer to have the child's general pediatrician or family practitioner assume primary responsibility for the care of a child at home. As noted earlier, managed care rules may require such a transfer of responsibility if the focus of care shifts from cure or life prolongation to palliation.

Despite their seeming ubiquity, little systematic research appears to have focused on the numbers, structure, or performance of different kinds of pediatric care teams.[7] Given (as reported below) the limited number of

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[7] Team care is often a part of a multi-element intervention in which the individual elements or processes of care are not evaluated separately. Some relevant research may be categorized under "key words" that involve related concepts such as "care coordination." For example, some research has examined the contributions or acceptance of specific professionals (e.g., nurse practitioners, social workers) in different environments (see, e.g., Burl et al., 1994; Inati et al., 1994; Aquilino et al., 1999; Dechairo-Marino et al., 2001). Team care is often associated with the use of formal clinical practice guidelines and quality improvement initiatives to

inpatient and hospice palliative care programs for children, the number of specialized teams providing pediatric palliative and end-of-life care cannot be large. Increased implementation of pediatric palliative care will almost certainly involve more interactions between palliative care teams (both inpatient and home hospice based) and oncology, neonatal, and other care teams. Descriptive research to map the nature and frequency of such interactions among teams would provide useful preparation for subsequent assessments of performance (see Chapter 10).

In general, the effectiveness of care teams has been linked to conditions such as (1) appropriate composition and size of the team, (2) sufficient financial and other resources (e.g., information and communication technologies), (3) successful processes for setting goals, coordinating activities, evaluating performance (both processes of care and outcomes), and preventing or resolving conflicts; and (4) supportive professional and organizational cultures, (see, e.g., Fried and Rundall, 1996; Shortell et al., 1994; Opie, 1997; Mickan and Rodger, 2000). The fourth area—supportive professional and organizational cultures—is widely viewed as a major barrier to successful team functioning. In particular, the preparation of health care professionals to work in teams has been limited.

Although health professions education, in general, has a strong disciplinary and hierarchical character, preparation for teamwork is increasingly recognized as essential (see, e.g., O'Neil et al., 1998; Knebel et al., 2001; see also residency program requirements listed at http://www.acgme.org). Chapter 9 notes the importance of preparation for team care in undergraduate, graduate, and continuing health professions education. Chapter 10 urges more research into the dynamics of team care in different contexts (e.g., inpatient and outpatient care, primary and specialist care), its outcomes, and methods of successfully preparing professionals to function as members of teams.

ORGANIZATIONS AND SETTINGS OF CARE

As described in Chapter 2, more than 56 percent of child deaths (under age 19) in 1999 occurred in inpatient hospital settings, and another 16 percent occurred in outpatient hospital sites (primarily the emergency department). Approximately 5 percent of children were declared dead on arrival at a hospital. Children, unlike adults, rarely die in nursing homes, although some severely disabled children die in other residential care facili-

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reduce unwanted variability in care processes and outcomes. Some studies suggest problems in the multidisciplinary care component of such initiatives, for example, staff turnover or interpersonal conflict (see, e.g., Qualls and Czirr, 1988; Weissman et al., 1997).

ties. For children with complex chronic conditions, the proportion of deaths occurring at home has been growing but is still smaller than for adults with such conditions. For both groups, most will receive inpatient care during advanced stages or exacerbations of their illness.

Inpatient Care

Because so many children die in the hospital and because inpatient curative and life-prolonging treatments so often continue for children until death is imminent, the availability and quality of inpatient palliative, end-of-life, and bereavement care are important for these children and their families. Even though increased availability and acceptance of pediatric home hospice programs may reduce the amount of hospital care provided to children with complex chronic conditions that end in death, inpatient care at the end of life is likely to remain more important for children than for adults.

Inpatient care may increase a parent's sense of security and relieve the family of complex care responsibilities, but it usually affords less privacy, intimacy, and family access and control than does home care (Chaffee, 2001). Whether a hospital specializes in pediatric care may affect these and many other dimensions of care for children with life-threatening medical conditions.

General Hospitals

> *We were shipped back to our local stupid hospital for the last blood transfusions. The staff was used to broken bones and healable stuff. They hadn't a clue about cancer and the finality of Eric's situation.*
>
> Becky Wooten, parent, 2001

Given the limited number and geographic distribution of specialized pediatric emergency and inpatient services, many children with life-threatening medical problems and their families must depend on general hospitals for care. In addition, children and families served by children's hospitals distant from their home community must often rely, at some point, on a local general hospital for follow-up or crisis care, and some children will die there. This makes the quality of pediatric palliative services an issue not just for children's hospitals but for any hospital that cares for children.

The pediatric services of general hospitals vary considerably, ranging from minimal in small rural and community hospitals to intensive and sophisticated in large medical centers. Clinical services provided by pediatric units in these latter centers may differ little if at all from those provided in centers with pediatric units that describe themselves as children's hospitals.

A recent Washington state study reported that 80 percent of the state's nonpediatric hospitals provided some pediatric services and that one-quarter (mostly large hospitals) had separate pediatric units (EMSCWS, 2000). Of the 64 percent of state hospitals with intensive care units (ICUs), two-thirds provided intensive care services to children. Exactly equivalent national statistics are not readily available, but data from the American Hospital Association's 1998 survey of community hospitals indicate that about half of the 4,600 responding hospitals provided some pediatric medical or surgical care (not differentiating between pediatric and nonpediatric hospitals) (American Hospital Association, 2000). About two-thirds of the responding hospitals reported providing (adult) ICU services, but only 9 and 17 percent of responding hospitals reported that they provided pediatric or neonatal intensive care services, respectively.

Children's Hospitals and Related Institutions

In 2001, NACHRI, the association of children's hospitals and related institutions had 161 members, 47 of which were self-governing, freestanding, comprehensive children's hospitals located in 24 states, the District of Columbia, and Canada (NACHRI, 2001a,b). Other member hospitals function as units of larger hospitals, most of them university based. A few members are specialty hospitals that limit services to specific conditions such as neuromuscular or orthopedic problems. A number of hospitals with significant pediatric services are not members of NACHRI, but the committee found little summary information about these institutions.

One emphasis of modern children's hospitals is the design and construction of facilities that incorporate child- and family-friendly physical elements, for example, nonfluorescent lighting, carpeting, play areas in waiting rooms, gardens, and family beds in patient rooms (Komiske, 1999). One potential advantage of freestanding children's hospitals is that they do not have to compete with adult medicine for space or attention when facilities are constructed or remodeled.

Freestanding children's hospitals, although they represent just 1 percent of all hospitals, are said to serve an estimated one-quarter of hospitalized children with congenital or chronic disease, and in combination with pediatric units of major teaching hospitals, they care for a substantial majority of these children (NACHRI, 2001a). In response to surveys, NAHCRI member hospitals have reported that 57 percent of their inpatient admissions, 68 percent of their inpatient days, and 76 percent of their inpatient charges relate to care for children with congenital or chronic conditions.

Many of these conditions are not, however, considered likely to prove fatal in childhood.

The focus of children's hospitals on children with serious medical problems is also suggested by data showing that catastrophic cases (those generating charges of more than $50,000) account for about 5.5 percent of cases in freestanding, acute care children's hospitals compared to 1.5 percent in pediatric programs of general hospitals (NACHRI, 1999). Almost half of the children cared for by children's hospitals are poor or uninsured, emphasizing the "safety-net" role played by many of these hospitals in their communities.

Care for critically ill newborns is sufficiently specialized that they are typically cared for in specialized neonatal intensive care units (NICUs) while infants, older children, and adolescents with critical medical problems are cared for in pediatric intensive care units (PICUs). Although specific figures are lacking, a substantial fraction of children who die will die in these units and will do so following decisions to limit life-support (see Chapter 4).

On average, intensive care beds account for about one-quarter of all beds in freestanding, acute care children's hospitals, compared to about one-tenth of pediatric beds in general hospitals (NACHRI, 1999). Like trauma centers, NICUs and PICUs are classified into different levels. For example, Level III NICUs are expected to serve the highest-risk neonates and to have consultation and transfer agreements with hospitals that have Level I and Level II units or no units.

For cancer and certain other serious conditions, specialized diagnostic, treatment, and research centers have developed, usually as units of major university-based children's or other hospitals. Some research suggests that specialized pediatric cancer centers are linked to better survival outcomes for children with cancer (Meadows et al., 1983; Kramer et al., 1984; Stiller, 1988; Wagner et al., 1995). The committee located no studies documenting differences in quality-of-life outcomes.

In guidelines on cancer centers, the AAP noted that safe but "resolute" use of the treatments (e.g., chemotherapy, radiation therapy) that are emphasized at these centers can have "devastating morbidity and appreciable mortality" (AAP, 1997b, p. 139). The guidelines do not, however, mention specifically the corresponding need for intensive and effective pain and other symptom management capabilities and for psychological, spiritual, and other support for children undergoing these treatments and for their families.[8] An earlier statement on pediatric cardiology centers likewise did

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[8] The guidelines include a general reference to family support services and note the role of social workers is assisting with family fear, anxiety, and worry. They do not specifically mention grief and bereavement support.

not mention palliative care (AAP, 1991). The recent AAP policy statement on palliative care strongly endorses offering such care early in the course of illness for children with an "ultimately terminal condition" (AAP, 2000g). In addition, recent AAP (2001b) guidelines for pediatric emergency medical facilities called for explicit policies related to death in the emergency department and to DNR orders. Unlike earlier (1995) guidelines, the new guidelines do not explicitly mention support and follow-up for grieving families.

Although children's hospitals may emphasize child- and family-friendly environments, one area of concern has been the harsh nature of the traditional NICU with its bright lights, noise, frequent handling, and frequent invasive and painful procedures. Parents of premature infants have noted the lack of research justifying the traditional NICU environment and urged less invasive care and more access for parents and other family members (Harrison, 1993). Recent AAP (2000a) guidelines on the prevention and management of pain and stress in neonates mention the need to minimize noxious environmental stimuli, and an earlier statement focused specifically on noise (AAP, 1997c). Such efforts to "humanize" neonatal intensive care should benefit all fragile neonates—those who survive and those who die—and their families. They also provide an opportunity for research to assess and improve infant quality of life as well as to reduce morbidity and mortality.

The social environment of neonatal and pediatric intensive care may also be unfriendly. For example, time and space restrictions on family access to a critically ill or injured child—especially when death is imminent—may add to the family's emotional and spiritual distress and increase its suffering after the child's death. Thus, the Canadian Pediatric Society's guidelines on care for families experiencing perinatal loss recommend that "visiting policies should be around the clock, including during bedside rounds" (CPS, 2001, p. 471). The guidelines also state that families should have time and a private place to be with their baby after death.

A recent survey of children's hospitals in the United States found that over 80 percent of the respondents reported open visitation policies for parents with children in NICUs, PICUs, and general inpatient units (Susan Dull, NACHRI, personal communication, July 16, 2002, based on data from George Little and JM Harris, II). Approximately 70 percent reported policies allowing parent access to the child's medical record in the NICU or PICU; about two-thirds reported involving parents in the development of the child's care plan.

Availability of Inpatient Palliative Care and Hospice Programs

A number of children's hospitals have created inpatient palliative care or hospice programs, but they do not appear to be the norm. In preparing for its statement to the committee, NACHRI circulated a special survey to its member hospitals to obtain information about their palliative services. Of 161 member hospitals, 48 (30 percent) responded (NACHRI, 2001a). Two-thirds of those responding said they were currently not able to provide the full array of palliative services. Almost a third of respondents indicated limited or no availability of inpatient or home palliative care or hospice programs. More than half indicated that lack of such services in the community limited their ability to discharge patients appropriately. Most but not all respondents (85 percent) reported pain management services; one-quarter of this subgroup reported having a pediatric palliative care team. Three hospitals reported the use of dedicated pediatric hospice or palliative care beds. In addition to these results, the survey cited at the end of the preceding section found that 82 percent of respondents reported regular assessment of children's pain in the PICU, but the figure reported for NICUs was 69 percent.

The committee located no information on pediatric palliative care programs in other hospitals, but the number is likely to be low. For hospitals overall, survey data suggest that palliative care programs are far from common and that formal pain management programs have been slow to develop. The American Hospital Association's 1998 survey of more than 6,000 community hospitals in the United States, which had responses from more than 4,800 hospitals, found that just 15 percent of those responding reported any "end-of-life services" whereas 36 percent reported a formal pain management program (American Hospital Association, 2000; Pan et al., 2001).[9] A follow-up survey of just over 2,000 hospitals with end-of-life or pain management programs or both asked about palliative care programs (meaning an inpatient palliative care unit, a hospital-based palliative care consultation service, an outpatient palliative care service, or a hospital-based hospice unit). Of the approximately 1,100 hospitals responding to this survey, 30 percent reported having a program and 20 percent had plans to establish one (Pan et al., 2001). More than 85 percent of the patients served by the programs reported in the survey had a cancer diagnosis. The most common reason for a consultation was pain management, which accounted for almost two-thirds of consultations, with consultations about the goals of care a distant second (one-quarter of the consultations).

Overall, the two NACHRI surveys as well as other reports and committee experience suggest that the capacity to provide comprehensive, reliable palliative and end-of-life care is quite limited, even in the hospitals that

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[9] End-of-life services were defined as "an organized service providing care and/or consultative services to dying patients and their families based on formalized protocols and guidelines" (Pan et al., 2001, p. 316). Virtually all hospitals have ethics committees and chaplains that are concerned with end-of-life issues.

specialize in treating children with life-threatening medical problems. Lack of pediatric hospice and similar care in the community further compromises the capacity of professionals in children's hospitals to meet the needs of dying children and their families by discussing and providing timely referrals to such services.

Elements of Pediatric Inpatient Palliative Care

Based on home hospice concepts, some of the basic elements of inpatient end-of-life care for children and their families were outlined as early as 1982 (Silverman, 1982; Whitfield et al., 1982). These elements included broadening the decisionmaking process to include the family and the health care team, as well as the child's physician, and providing a comfortable, private room for families of terminally ill children.

Central to most inpatient programs—whether for adults or children—is a referral and consultation service staffed by palliative care specialists, generally including physicians, nurses, social workers, and chaplains (ChIPPS, 2001; Levetown, 2001). Nurses may form the core of the team. Depending on patient and family needs and the concerns of the patient's regular care team, an inpatient palliative care consultant may

- help the patient, family, and their care team to understand and evaluate care options (e.g., starting or not starting mechanical ventilation, accepting hospice care) and determine the goals of care (e.g., prolonging life, emphasizing quality of life);
- work with the family and the care team to develop, implement, monitor, and if appropriate, revise the child's plan of care;
- assist in evaluating and managing patients with difficult symptoms and in providing emotional support to patients and family members including after a child's death;
- make referrals, as needed, to other physicians, psychologists, child-life specialists, chaplains, clinical social workers, and other relevant professionals;
- help with patient transitions between inpatient and home care and advise or otherwise assist home health care and home hospice personnel with developing and implementing the child's plan of care at home; and
- supervise the care of home hospice patients who require hospitalization for symptom management or family respite, whether or not the child and family have previously been cared for at the hospital.

A recent report on one inpatient program for neonatal intensive care portrayed service patterns that were generally consistent with the description above. Based on an analysis of care for nearly 900 infants admitted for neonatal intensive care during a 30-month period ending in June 1998, the researchers found that the primary reasons for palliative care consultations were to assist with home hospice arrangements, advise on comfort measures, support the consideration of options such as DNR orders, and provide comfort to grieving families (Leuthner and Pierucci, 2001). Approximately one-quarter of the 51 infants who died during the study period received a palliative care consultation. An earlier study, which covered all infant deaths at the same institution, reported an increase in consultations over time from 5 percent in 1994 to 38 percent in 1997 (Pierucci et al., 2001).

One objective for inpatient pediatric palliative and end-of-life care is the availability of at least one room with home-like features. Such rooms may be equipped for mechanical ventilators, monitors, and other technologies, but the focus of both services and physical environment is still on peace and comfort (Levetown, 2001). For example, two Texas hospitals (University of Texas Medical Branch at Galveston and Christus Santa Rosa in San Antonio) have created a large room or suite (referred to as "Butterfly" rooms) that provides sofa beds and comfortable chairs for family and friends, kitchenette, television, carpeting, and other similar features. If parents wish the presence and support of extended family and friends when a child's death is expected, the rooms can accommodate more than 30 people.

Box 6.3 presents a number of questions that may be useful for clinicians, hospital managers, and patient and family advocacy groups concerned about the availability, structure, effectiveness, and accountability of inpatient palliative or hospice care in a specific institution. These questions were adapted from a set that focused on adult care and take into account the discussion in Chapters 4 and 5. The committee believes that many of the basic features of inpatient palliative care services apply across the age spectrum.

The committee notes that those providing inpatient palliative or hospice services for children sometimes emphasize that their acceptance criteria do not require that the child's life expectancy be six months or less or that the child and family forgo curative care. As discussed in Chapter 7, Medicaid and some private insurers' hospice benefits include these criteria and also restrict coverage and payments for palliative or hospice care in other ways. Thus, to provide a comprehensive array of inpatient palliative care or hospice services for children and their families, hospitals and hospices will often have to rely on private fundraising and contributions. In Chapter 7, the committee recommends that coverage of pediatric palliative care be expanded and limitations on hospice coverage be eased.

Palliative and End-of-Life Care in the Home

Most home care arrangements assume that parents will provide substantial amounts of patient care, including care that involves advanced technologies such as mechanical ventilation and IV administration of powerful medications. For a child with a progressive neurological disease, such care at home may continue for years and may differ little on a day-to-day basis from care for children with severe conditions that are not expected to prove fatal. For other children, care at home may last only a short period once parents accept that curative or life-prolonging treatments have failed their child and decide that death at home rather than in the hospital will be most comforting to the child and family.

Hospices will serve some of these children and families, although, as described below, many hospices rarely if ever care for a dying child. Further, because families are often reluctant to accept the concept of home hospice care or the coverage conditions imposed by Medicaid and some private health plans, they may turn to home health care agencies for essential assistance.

General

> *The visiting nurse gave me literature on what to look for as death approached. She was the glue that held us together. . . . She came and dressed Eric and made phone calls after he died. She later told me that this was the first death she had dealt with. She was so calm and she kept me from losing it.*
>
> Becky Wooten, parent, 2001

> *We were happy with our home health care company, and things were going well. But when we got home from our spring break vacation, [our son] took a turn for the worse that required the hospice care.*
>
> Winona Kittiko, parent, 2001

Because hospice care may not be acceptable, available, or appropriate for all children and families who could benefit from palliative or end-of-life care at home, it is important to consider the role of home health providers as well as hospices in providing palliative and end-of-life care (Liben and Goldman, 1998). Providers of pediatric home health care services include children's hospitals, other hospitals, home health care agencies, hospices, and independent professionals. Some providers specialize in home health care for children (see, e.g., NAPHCC, 2001), but the committee found no comprehensive data on the pediatric caseloads for these or other home

BOX 6.3
Questions About Inpatient Palliative, End-of-Life, and Bereavement Care for Children and Their Families

Training and Preparation

- Are nurses and others who staff neonatal and pediatric intensive care units, emergency departments, and specialty services trained to recognize children and families for whom the goals of care should be reconsidered?
- Are trained staff and procedures in place for arranging care and consultations to support clinicians, children, and families in assessing and reassessing the goals of care and the ways of meeting those goals as they relate to physical, emotional, spiritual, and practical dimensions of care?
- Have hospital personnel been provided training and assistance in developing skills in communicating bad news, discerning child and family wishes and concerns, and respecting dignity through their language and other behavior?
- What training, clinical practice guidelines, symptom assessment protocols, and other supports are in place to ensure that the child's and family's needs for palliative, end-of-life, and bereavement care are routinely assessed and met?
- Have practices for limiting life-support interventions been reviewed to determine whether they should be modified to reduce distress for patients, families, and staff?
- Are resources and procedures available to help staff cope with the stresses of caring for critically ill and injured children?

Staff, Facilities, and Other Resources

- What internal or external expertise in pediatric palliative and end-of-life care is available to help clinicians and families with clinical evaluation, symptom prevention and management, decisions about life support, advance care planning, bereavement support, and other matters? How is this expertise organized and shared? Are other personnel routinely educated about the availability of this expertise and expected to use it when appropriate?
- What care options are available for dying children within the hospital, for example, a designated bed or unit that provides a home-like setting and is governed by different rules regarding visiting hours, number and age of visitors, and other matters? Are relevant personnel throughout the hospital aware of these options?
- Can hospital procedures and the physical environment be modified in ways that reduce stress and discomfort for children and families wherever care is provided within the institution?

Responsiveness

- How well are children and families informed about who is responsible for the child's care, what they can expect, and to whom they can look for information and assistance? Is continuity in relationships supported?

- How specifically are the preferences and circumstances of children and their families determined, assessed, recorded, and accommodated—throughout the child's medical course?
- Are care processes focused narrowly on written orders or more broadly on a comprehensive care plan? Are all dimensions of care addressed—physical, emotional, spiritual, and practical?
- What support is available for siblings?
- What structures and processes are in place to prevent, moderate, or mediate conflicts among clinicians, families, and children?
- What provisions are made for non-English speakers, cultural minorities, and others who may not fit routine administrative and clinical procedures?

Continuity, Coordination, and Community Resources

- What protocols and procedures are in place to promote continuity and minimize unwanted transfers and other disruptions in relationships, especially at the end of life?
- What structures and processes are in place to help children and families to identify needed resources and assist with appropriate transitions to or from the hospital and other care settings? Are procedures in place to see that care plans (including preferences about life support interventions), contact information, and prescriptions accompany the patient during transfers?
- What relationships exist with home health agencies, hospices, bereavement support groups, and other organizations that care for or assist children and their families?

Information Systems and Evaluation

- Are clinical information systems in place that reliably document and update treatment decisions (including orders about resuscitation and other life-support interventions), symptom assessments, care processes, patient responses and outcomes, and similar matters?
- Do information systems support the timely provision of information to all involved staff in all parts of the institution and at all times of the day?
- Do information systems provide clinical decision support in the form of easy access to guidelines for pediatric palliative care, prescribing protocols, reminders or alerts, and other information relevant to symptom prevention and relief for children of different ages and with different medical problems?
- What structures and processes are in place to evaluate and improve the quality of care provided to children who die and their families?

SOURCE: Adapted from IOM, 1997; see also ChIPPS, 2001; Levetown, 2001; Hilden and Tobin, 2002; and Himelstein et al., 2002.

health care organizations. The caseload of most agencies is dominated by elderly Medicare beneficiaries (HCFA, 1999). In 1996, nearly 14 percent of those age 65 or over had one home health visit compared to less than 2 percent of children under age 6 and less than 0.5 percent of those aged 6 to 17 (Kraus et al., 1999).

The frequency, duration, and type of home health care services will vary depending on the child's and family's needs, geographic location, state licensure requirements, community availability of appropriate personnel, and family insurance and other financial resources. For some children located in rural areas, home health care providers may supplement in-home care with interactive and other telemedicine technologies. The committee found no data describing the extent of such services in this country, but discussions with major vendors suggest that fewer than 200 of the nearly 20,000 home health agencies provide telemedicine services to any of their patients (Field and Grigsby, 2002).

Because families are usually expected to take major responsibility for home caregiving, the AAP guidelines for home care for children with chronic disease recommend that if possible a family should have at least two members who are trained and prepared to take care of the child at home (AAP, 1995c). The guidelines also suggest that family members should, ideally, be prepared for their caregiving role by providing as much care as possible in the hospital before the child's discharge. Further, the guidelines call for children to be included in home care training and education and to be responsible for self-care whenever possible.

Depending on the child's diagnosis and care plan and family circumstances, including the child's insurance coverage, home health care agencies may provide nurses, home health aides, physical therapists, social workers, and others to assist the child and family. Those providing pediatric home health care state that it generally requires more specialized skills and more time, thus allowing care for only two to three children during a day rather than the usual five to six adults (NAPHACC, 2001). (For a general guide to palliative care in the home, see Doyle and Jeffrey, 2000.)

Some children and families are well served by home health care for an extended period but then find at a certain stage that the specialized expertise of a hospice is what the child needs as death approaches. Interviews with home health care personnel indicate that they often would like to obtain consultations on symptom management from hospice personnel, but Medicaid and most private health plans will not pay for such consultations (Huskamp et al., 2001). Chapter 7 recommends changes in such policies to make palliative care expertise more widely accessible.

Many hospices provide home care under both their hospice license and separate home health care licenses. Under their home care license, these organizations may serve some patients who have fatal illnesses but who do not fit the traditional hospice model and coverage rules. They may not fit because their course to death is unpredictable and could be lengthy or because they want to continue curative or life-prolonging treatments. Service under the home care umbrella may also be less painful emotionally for families. If formal referral to the affiliated hospice eventually occurs, care can usually be continued with minimal disruption of continuity in trusted relationships.

Availability of Pediatric Home Hospice Care

In 1983, only 4 of the 1,400 hospice programs in the United States reported that they offered any pediatric services (Armstrong-Daley and Zarbock, 2001). The number has undoubtedly grown, but the committee found no firm count or estimate of the number of hospices that routinely provide care to a sufficient number of children to support specialized staffing, training, and outreach efforts.

Of the 3,000-plus existing hospice programs in the United States, 450 reported in a recent survey that they were prepared to offer hospice services to children (ChIPPS, 2001). The survey results do not, however, make clear whether these hospices actually have much or any experience providing such care. Based on discussions with staff of the National Hospice and Palliative Care Organization (NHPCO) and others and on its members' professional experience, the committee suspects that fewer than 100 hospices have active pediatric programs with trained personnel, protocols, policies, and outreach efforts. As discussed elsewhere in this report, the federal government's Center for Medicare and Medicaid Services is funding demonstration projects to test programs that provide more comprehensive services than those covered by current Medicaid hospice benefits.

Pediatric Home Hospice: Program Elements and Focus

In the United States, the first program of home-based care for dying children originated in the mid-1970s in Minneapolis under the joint sponsorship of a university hospital, a children's hospital, and a large multispecialty physician practice (Martinson, I., 1993). (The original program no longer exists.) The first U.S. hospice also dates to the mid-1970s. In 1979, Edmarc was established as a community-based home hospice serving children (Armstrong-Dailey and Zarbock, 2001). In 1983, the nonprofit Children's Hospice International began to provide resources to support the development of hospice services specifically for children. In recent years, the national association of hospices (NHPCO) has also supported efforts to develop pediatric hospice programs through the Children's International Project on Palliative/Hospice Services (ChIPPS, 2001).

Hospice care for children differs from that for adults in a number of areas: patient characteristics, family concerns and decisionmaking, funding, and organizational resources. As discussed earlier, children's needs are particularly variable, reflecting both developmental differences and differences in underlying medical problems and their course. In most situations, parents are legally responsible for decisions about their child's care. Decisions to limit curative or life-prolonging efforts and focus exclusively on palliative care—as required for Medicaid and some private health coverage—are particularly difficult when the patient is a child.

Reflecting these differences, home hospice care for children builds on traditional hospice principles and practices but adapts them to accommodate the developmental characteristics and needs of children and the values and goals of their families (see, e.g., Goldman, 1996, 1999; ChIPPS, 2001; Armstrong-Daley and Zarbok, 2001; Sumner, 2001). Some hospices may develop special pediatric programs, but smaller hospices may make adjustments to incorporate children in programs that are adult-oriented or refer children to hospices with pediatric programs (Orloff, 2001). Hospice nurses and other personnel need special training to prepare them for the special requirements of working with young patients and supporting the families who are facing the exceptional stress of a child's death. As noted earlier, even experienced pediatric and hospice nurses may have qualms about taking on this role. They may need moral support beyond that ordinarily recognized as necessary for the emotionally demanding work of hospice care.

Models and principles for pediatric hospice care are still being developed and tested. At a minimum, regardless of the patient population, turning palliative care principles into consistent, effective care at home involves certain core organizational capacities. These include

1. offering support for patients and families 24 hours a day, 7 days a week;
2. developing, evaluating, and improving organizational procedures and protocols for reliably and effectively meeting the physical, emotional, spiritual, and practical needs of terminally ill children and their families;
3. constructing interdisciplinary care teams that, taken together, have the necessary knowledge and skills needed to provide comprehensive and continuous care for a child at home under most circumstances;
4. providing reliable and immediate access to inpatient pediatric palliative care and other services for patients and families who require them;
5. training and assisting family caregivers; and
6 working, as appropriate, with the child's specialist care team and general pediatrician.

When a child's family and physicians have recognized that curative and life-prolonging care will fail or is failing, unfamiliarity with hospice and misunderstandings about hospice services may discourage families from fully evaluating the option of hospice care. Sumner (2001) has identified several such misunderstandings and argued that hospice personnel may have to make clear to families and clinicians—and ensure in practice—that hospice personnel do not take over the home or usurp normal parental care and authority but, rather, advise on ways to increase the child's comfort and ease stresses on all members of the family. Further, hospice enrollment should not require or encourage the severing of all relationships with the primary care and specialist personnel who have been caring for the child and family, although health plan rules may limit relationships to unpaid consultations and emotional support. Perhaps most important, families should be assured that parents continue to make the decisions about the child's care with information, consultation, and support from the child's care team, including hospice personnel.

Box 6.4 presents a number of questions, similar to those for inpatient palliative care, that may serve as a guide for those concerned about the adequacy of palliative care and end-of-life care at home. Again, the questions were adapted from a set that focused on adult care, but the committee believes that the basic concerns apply to adults and children alike. The questions were framed somewhat generally so as not to exclude services provided by home health agencies. Given the mission of hospices and regulatory requirements, families whose child needs palliative or end-of-life care will probably find that hospices (and home health agencies closely affiliated with hospices) have more resources, clinical protocols, and experience in palliative, end-of-life, and bereavement care in general. Nonetheless, families cannot assume that all hospices are adequately prepared to care for children.

For children perhaps more than adults, broader access to home hospice care will depend on trusting relationships between hospice personnel and inpatient care personnel in neonatal and pediatric intensive care units, specialized cancer and other centers, and even obstetrical units. The latter relationship has become important as prenatal diagnosis has expanded the number of children diagnosed before birth with fatal medical conditions, and some hospices have begun to offer support to families that want to continue the pregnancy and achieve whatever time they can with their infant in the hospital or at home. Families cannot reliably be offered the option of such care without substantial cooperation from obstetricians and hospital obstetrical facilities and personnel.

Given the relatively small potential base of child hospice patients, a hospice that wants to create a pediatric program will often have to establish relationships with a number of hospitals, each of which will have its own procedures and conventions. If these hospitals have or are developing

BOX 6.4
Questions About Palliative Home Health and Hospice Care for Children and Their Families

Training and Preparation

- Are staff trained and prepared to care for children with life-threatening medical conditions? What continuing education and training related to pediatric palliative and end-of-life care are available to staff?
- What clinical practice guidelines, symptom assessment protocols, referral and consulting arrangements, and other supports are in place to guide staff in assessing and meeting children's needs for care?
- Have practices for limiting life-support interventions been reviewed to determine whether they should be modified to reduce distress for child patients, families, and staff?
- Are resources and procedures available to help staff cope with the stresses of caring for gravely ill and dying children?

Staffing, Facilities, and Other Resources

- What internal and external resources and expertise are available to provide 24-hour coverage, physical and emotional care, spiritual support and counseling, practical assistance, and other aid for children and families? Is residential care available?
- What practice guidelines, symptom assessment protocols, and other tools are used to guide patient assessment and care?
- What are the criteria for accepting children as patients? Are families with a prenatal diagnosis of a fatal congenital problem accepted? Has the organization a made an effort to identify resources that will allow more flexible and comprehensive care than allowed under the coverage policies of Medicare, Medicaid, and some private health plans?
- How is physician support for patient care organized? Are children's primary care or specialist physicians encouraged to continue involvement with the child and family after enrollment in hospice?
- If home care proves insufficient for a patient's needs, what are the arrangements for inpatient care?

inpatient palliative care programs, that good news may be offset by concerns about competition for patients. In building relationships with hospitals and hospital-based specialists, hospice personnel will have be careful not to provoke a defensive reaction among hospital-based physicians, nurses, and others who may feel that their skills in symptom management or family support are being questioned.

Some hospices have actively pursued community and philanthropic contributions that allow them important flexibility in meeting the needs of children and their families. Although the committee recommends changes

Responsiveness

- How well are children and families informed about who is responsible for care, what they can expect, and to whom they can look for information and assistance? Is continuity in relationships supported?
- How specifically are the preferences and circumstances of children and their families determined, assessed, recorded, and accommodated? Are care processes focused narrowly on written orders or more broadly on a comprehensive care plan?
- What support, including bereavement care, is available for parents and siblings?
- What structures and processes are in place to prevent, moderate, or mediate conflicts involving families, children, or home health or hospice staff?
- What provisions are made for non-English speakers, cultural minorities, and others who may not fit routine administrative and clinical procedures?

Continuity, Coordination, and Community Resources

- What protocols and procedures are in place to promote continuity of care, for example, if hospitalization is required?
- What relationships and referral arrangements exist with other health care organizations, for example, hospitals?

Information Systems and Evaluation

- Are clinical information systems in place that reliably document and update treatment decisions (including orders about resuscitation and other life support interventions), symptom assessments, care processes, patient responses and outcomes, and similar matters?
- What structures and processes are in place to evaluate and improve the quality of care?

SOURCE: Adapted from IOM, 1997; see also Armstrong-Dailey and Zarbock, 2001; Sumner, 2001.

in restrictive Medicaid and private health plan policies (see Chapter 7) and recognizes real fiscal constraints on hospice services, it also urges hospices not to define themselves and their mission in terms of Medicare and Medicaid coverage policies.[10] A hospice's refusal to accept a child can be a

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[10] Some palliative care and hospice programs have been very sensitive to the risk that coverage will distort their mission. For example, in discussing one of the older inpatient hospice programs at Northwestern Memorial Hospital, Charles Von Gunten recalls that "the

bitter blow, especially when hospice managers are perceived as showing not the "the least sensitivity" to the gulf between their policies and the needs of parents to do the best for their child (Avila, S., 2001). Every hospice may not be able to mobilize resources to care for children not covered by public or private insurance or who do not fit payer's requirements, but Medicaid policies do not preclude them from making the effort.

Hospices with smaller service areas may, in particular, find it financially and otherwise impractical to routinely extend their capabilities to children. Even for larger hospices, maintaining a high level of pediatric expertise 24 hours a day, 7 days a week can be a challenge. As recommended at the end of this chapter, the development of regional or national telephone or on-line consultation services can provide additional expert resources to hospices as well as generalist pediatricians or family practitioners and community hospitals.

Other Sites of Care

Residential Hospice Services

A few residential care programs are intended specifically to serve dying children and their families. Helen House, the world's first residential children's hospice, was founded in England in 1982, and some 20 additional freestanding hospices have since been established in Great Britain (Goldman, 2000a). These hospices may receive revenue from government sources, but they are private organizations that depend significantly and deliberately on private contributions and philanthropy.

Some hospices in the United States that serve children offer residential services. Examples include the Hospice of the Florida Suncoast, the San Diego Hospice, and Edmarc. A freestanding, residential hospice for children is scheduled to open in the San Francisco Bay Area in 2003 (George Marks Children's House).

One goal of residential hospice care is to offer a short-term alternative to hospitalization for dying children and their families when a child requires more intensive assessment, symptom management, and care planning than can be successfully provided at home. Another goal of residential hospice care, particularly in the United Kingdom, is to provide respite care when families need relief from the demands of caring for their child. Respite services can also be provided at the family home while the parents, siblings, and other family members vacation or visit distant loved ones. Residential

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program resisted becoming certified for the Medicare Hospice Benefit until 1991 because of the risk that palliative care would be defined by a reimbursement mechanism rather than by the principles of good practice" (Von Gunten, 2000, p.166).

respite care offers families the opportunity to rest, attend to neglected family relationships and chores, and do things together without leaving home. As discussed in Chapter 7, funding for this kind of respite care is very limited in the United States.

Long-Term Residential Care Facilities

No matter how much they are loved and cherished, children with severe physical and mental disabilities can create tremendous emotional and financial burdens on their families, whose lives may be completely overwhelmed by a child's care needs or by psychological stress resulting from a child's violent or otherwise disruptive behavior. In 1997 an estimated 24,000 children aged 0 to 21 with mental retardation and developmental disabilities were being cared for outside the family home in residential facilities (Lakin et al., 1998). Another 83,000 were awaiting placement. Facilities range from small home-like settings to larger intermediate care facilities, although the latter have declined substantially in numbers and census in recent decades.

Children in these residential care settings have serious to severe mental retardation and developmental disabilities and suffer from multiple severe chronic conditions such as cerebral palsy, epilepsy, and impairment of hearing, vision, speech, or language. Many are expected to and do live into adulthood, but others are at high risk of death in childhood. The acceptable setting of care for children with severe disabilities is an important and often controversial issue (see, e.g., Rosenau, 2000) that is beyond the scope of this report.

The role and provision of palliative and end-of-life care for adults or children in residential care settings has received little attention. A recently published review of records of deaths at a center for people with severe development disabilities reported during a 30-month period, 38 of 850 residents died and that of this group, 10 deaths involved end-of-life decisions (defined as decisions about end-of-life care that followed formal discussions of what care is in a resident's best interests) (Lohiya et al., 2002). Among all residents, decisions about end-of-life care had been made for 16 individuals, 12 of which involved do-not-resuscitate orders and 4 of which involved continued full medical treatment. Decisions, which could be requested by employees or family members, were made by committee consisting of the resident, attending physician, resident-rights advocate, an uninvolved physician, social worker, clergy, psychologist, caretakers, and family or surrogate, legal conservator, or guardian. Decisions to forgo intrusive care had to be unanimous.

Quality of life is a concern for all residents of long-term care facilities, but comfort care is a particular concern for children who are bed bound or technology dependent. Children who are unable to turn over in bed and those being tube fed appear to be at highest risk of death (Eyman et al., 1993, but see Strauss et al., 1997). Researchers involved in longitudinal studies of one large group of California children have called for controlled trials of tube feeding in these children to help clarify the benefits and burdens of that practice for this group of children (Strauss and Kastner, 1996; Strauss et al., 1996). Although focused on a special group of children in a special setting, such research is potentially relevant to decisions about appropriate palliative and end-of-life care for children being cared for at home and in hospitals.

Schools

The main objective of schools is education not health care. Nonetheless, various federal and state laws, reinforced by judicial decisions, require public schools to educate and assist increasing numbers of children with special health care needs (NICCY, 1996).[11] Some of these children have conditions that are likely to end in death in childhood, but most do not. As discussed in Chapters 4 and 5, a central goal of care for ill children is the maintenance, insofar as possible, of normal life, and school is a major part of normal life for school-age children.

As specified by law, schools must provide or arrange for the provision of appropriate health care services and make appropriate alterations to their physical plant, furnishings and equipment, and procedures to accommodate children with special health care needs. In some cases, this may mean providing individual aides to assist them with movement or other needs; in other cases, school nurses may provide medications and assist in emergencies. Both the American Academy of Pediatrics and the National Association of School Nurses assert that procedures such as the administration of intravenous medicines, catheterization, tracheostomy care, or gastrostomy tube feeding can all be undertaken in the school setting by a school nurse or an appropriately trained and supervised aide (AAP, 1987; NASN, 1996). Chapter 8 discusses legal issues involving family requests that schools respect care plans for their child, including do-not-resuscitate orders.

Perhaps more important than the provision of medical services in school are the efforts of teachers and other school personnel to offer a child with a

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[11] The Individuals with Disabilities Education Act (20 USC §1400) includes several pieces of legislation that, in combination with judicial decisions, establish requirements for public schools to serve children with disabilities. Separate sections of the law cover children age 3 and younger and children age 4 and older.

serious medical condition as normal and supportive an environment as possible given the child's condition and need for assistance. This will normally mean preparing classmates and other children for condition- or treatment-related changes or differences in a child's appearance or functioning. Some children's hospitals, pediatric oncology teams, and other groups have established formal programs to assist families and schools with a child's reentry. School systems and related programs can also offer support to an ill child's sisters and brothers by educating teachers and classmates about children's experiences living with a sibling who has life-threatening medical condition.

These kinds of support and preparation are important because children can be cruel to those who are different. One parent told the committee that he learned after his 11-year-old daughter's death that kids had made fun of her because of her hair loss and were afraid of her because she had cancer—"and the teachers did not how to handle it" (Weil, 2001). His response was to develop a comprehensive educational program—"using cancer as a metaphor for all difference"—to help teach understanding, respect, compassion, and acceptance (Washburne, 2000, p. 2; Weil, 2001). The program gets its name and theme from a short story that the daughter, Kelly Weil, wrote three months before her death about Zink the Zebra, who had spots instead of stripes and was treated differently by other zebras. The program is now available to and being used by preschool programs, schools (kindergarten through eight grade), and scout troops (Weil, 1996).

When a child dies or leaves school for what is expected to be the terminal phase of his or her illness, schools may facilitate support groups for classmates of the child and help the children express their sadness, for example, by making cards for the dying child or for the family after the child's death. Following a child's sudden and unexpected death, for example, from violence or a car crash, schools may organize counseling and bereavement services for classmates. Especially upon the death of older children, classmates and friends may attend the funeral.

Camps

A number of camps have been organized to serve children living with serious medical problems that preclude participation in traditional camp programs. Camps vary in emphasis, but some focus on children with life-threatening conditions such as cancer, end-stage renal disease, cystic fibrosis, or AIDS. Some camps invite siblings to participate or provide special sessions especially for brothers and sisters of children with a life-threatening condition. Unlike their ill brother or sister, siblings may have no contact with other children facing similar circumstances, and thus a special summer camp can be an important resource for them.

Special camps usually rely on trained volunteers, led by just a few paid specialists. Nurses and doctors may volunteer their time, valuing the opportunity to see children other than "on the wrong side of a sharp object." Nurses provide most of the medical care, including distribution of medications, but a physician is available in case of emergencies and serious changes in a camper's health status. Camps may be staffed and equipped to provide chemotherapy, blood and platelet transfusions, intravenous fluid therapy, hemophilia factor replacement, pain therapy, and other curative or palliative therapies. In addition, they may aim to improve the child's medical status, for example, by helping children with cystic fibrosis gain weight (Rubin and Geiger, 1991).

Staff of these special camps must be actively aware of the particular circumstances of each camper. Sometimes they must restrict certain activities for the safety of other campers, for example, excluding HIV-positive children with open sores from the swimming pool (Pearson et al., 1997).

Such camps can be very significant to seriously ill children, important enough to make one of their goals be to live long enough to attend camp again before they die. Occasionally, children do die while at camp. Most camps memorialize campers who have died as a way to recognize their lives, however brief. For instance, a tree may be planted to honor the children who died during the year and then it can be decorated with friendship bracelets or painted rocks made by campers and staff. Such memorials also provide a means of helping other campers and counselors discuss their own feelings and fears about progressive illness and death.

COMMUNITY AND REGIONAL SYSTEMS OF CARE

General

Beyond individual professionals and institutions, special care teams, and medical homes, children who die and their families need community systems of care that respond to the differences in child and family circumstances and values and that provide a range of services and settings of care to accommodate these differences. For some children and families, care provided by home health organizations will be welcome; for others, hospice will better meet their needs. Some children may move from one to the other as their needs change. Flexibility, however, can come at the cost of complexity and fragmentation. This puts a premium on coordinating strategies, including the medical home and improved versions of older mechanisms such as hospital discharge planning and insurer case management.

Box 6.5 presents the basic objectives of a community-focused approach to care at the end of life. A community approach to care that supports these objectives would include a mix of inpatient and home care resources—

BOX 6.5
Objectives of Community Systems of Palliative, End-of-Life, and Bereavement Care

- Making palliative care available wherever and whenever needed by child and family from the time of diagnosis through death and, for the family, after death
- Providing sufficient flexibility in attitudes and procedures that special needs of child and family can be recognized and accommodated insofar as possible at home or in the hospital
- Encouraging timely referral to home hospice for children whose medical problems and personal circumstances make such care feasible and desirable
- Allowing flexible arrangements for home health care for patients whose prognosis is uncertain but for whom palliative services at home would be valuable in preventing and relieving symptoms and discouraging unwanted or inappropriate life-prolonging interventions
- Encouraging, when possible, the continued involvement of the child's primary care physician through the course of the child's life and the continued involvement of specialist physicians and health care teams as valued by children and families after the goals of care have shifted away from cure toward comfort
- Developing protocols and procedures for transition planning that prepare clinicians and others to manage common child and family situations (related to, e.g., medical condition, place of residence, comfort with managing care at home, financial resources)
- Making necessary and helpful information readily available to families and clinicians (e.g., truly portable and accessible records of care plans and preferences, training programs or materials for family caregivers)
- Supporting activities and programs that respond to nonmedical needs of children and families (e.g., camps, schools, religious programs)

SOURCE: Adapted from IOM, 1997.

organizations, personnel, programs, policies, and procedures. In the foreseeable future, it would have to be constructed within and around this country's existing arrangements for organizing and delivering care, which are—on the whole—decidedly nonintegrated, uncoordinated, and yet often inflexible. Rural and smaller communities present particular challenges that call for regional consulting and other supportive services, which are recommended at the end of this chapter.

In some communities, children's hospitals can play a central role in developing programs to coordinate palliative and other care across inpatient, outpatient, and home settings. For example, the Pediatric Advanced Care Team at Dana-Farber Cancer Institute and Children's Hospital Boston involves a multidisciplinary team to advise and assist in the development and implementation of plans of care for seriously ill children and their families before, during, and after the child's hospitalization (Dana-Farber, 2001). It is primarily a consultative service for children admitted to the hospital but includes educational and outreach activities to increase awareness among physicians, families, and the community. An important element of the program is bereavement support for both families and clinician caregivers. For the latter, the program conducts weekly "caregiver bereavement rounds" that encourage reflection on the death of a patient and review of the care plan's adequacy. Like a number of other pediatric programs, it has been funded in part by private foundation grants.

Where community size and resources limit what can be done locally, regional responses may be needed. For example, when a child has returned home after specialized treatment, children's hospitals can provide consulting assistance on pain management and other topics to primary care physicians and community hospitals. Some of this assistance could be provided through on-line clinical practice guidelines and other written resources, but telephone consultations would also be required similar to those provided by hospices. Start-up resources for such programs might be found through government and private grants, but maintenance of a program could be difficult without some kind of health plan reimbursement for consultative services, including those provided by telephone.

Telemedicine as an Option

One option to extend services into rural areas and smaller communities is telemedicine. Defined broadly, telemedicine is the use of electronic information and communications technologies to provide and support health care when distance separates the participants (IOM, 1996b; Field and Grigsby, 2002). Given insurance traditions and limited evidence of cost-effectiveness (see, e.g., AHRQ, 2001c), health insurance coverage is limited for most telemedicine applications beyond radiology, where direct patient contact has not been part of usual consultative practice.

Several projects have tested or are testing telemedicine to support intensive management of serious chronic conditions. Although not designed for patients who are dying, they could provide some useful lessons about benefits, limitations, and costs of such care. Some projects focus on rural areas, and Congress has authorized Medicare payment for certain telemedicine services in rural areas (HCFA, 2001g). An increasing number of Medicaid programs and some private health plans also cover telemedicine services under certain circumstances, and a few states prohibit insurers from reimbursing differently for telemedicine and regular medical services (OAT, 2001).

Some of the telemedicine applications being tested provide both medical monitoring and hardware and software (e.g., sensitive videocameras, instruments to measure heart rate and other physiological parameters that are connected to telephone modems that can transmit the information; software that alerts clinicians to atypical findings). Some also include individual patient Web sites that link patients with physicians, nurse practitioners, and other health care personnel, and some include links to other patients and families. To support patient self-care activities, the Web sites may also provide easy Internet access to targeted clinical and educational information and links.

A two-year study involving hospices in Kansas and Michigan and researchers at Michigan State University and the University of Kansas has been investigating telemedicine to support hospice care. (Whitten et al., 2001). In a preliminary report, the researchers concluded that hospice personnel were cautious but supportive whereas patients and families were uniformly positive, although some families declined the service. The state of Florida is funding Hope Hospice to test a videoconferencing application that will allow a nurse to visually check the patient, medical equipment, and caregiving procedures (Hospice, 2001).

At Beth-Israel Deaconess Hospital in Boston, a federally funded, randomized controlled trial of an intervention for families with very low birth weight infants reported improved family satisfaction and lower costs for the intervention group (Gray et al., 2000). A central feature of this application was an electronic communications link for parents that provided information about their hospitalized infants, including daily photographs, daily progress reports, scheduled live video visits with babies and their nurses, and e-mail access to clinicians. With the end of federal support, the hospital is marketing the program to large employers and Medicaid, and several other hospitals are reported to be trying the program. This program was not designed for children who are not expected to survive, but it could nonetheless provide useful lessons (Halamka, 2001).

Interactive and noninteractive telemedicine has grown slowly in the face of insurer wariness, unfriendly technologies, and physician disinterest. As technological development continues and research clarifies its benefits, limitations, and costs, remote patient monitoring applications of telemedicine are likely to grow.

DIRECTIONS FOR PROFESSIONALS AND INSTITUTIONS

The discussion in this and preceding chapters has identified concerns about the quality and consistency of palliative, end-of-life, and bereavement care in several areas. These include the provision of timely and accurate information, the formulation of goals and plans of care, the effective management of pain and other symptoms, the management of the end-stage of a fatal condition, and the offering of bereavement care.

The experience of advocates of better pain management can help guide the development of strategies to improve other aspects of adult and pediatric palliative and end-of-life care. As described by one leader in national and international initiatives to improve pain management for adults and children, cancer pain was identified in the 1980s as a "wedge issue" because of a strong professional and public perspective that pain relief in cancer patients should be a priority (Kathleen Foley, M.D., Memorial Sloan-Kettering Cancer Center, personal communication, June 19, 2002). As cancer pain relief strategies evolved, it became clear that clinicians could not provide comprehensive, consistent, and effective care for patients with pain without attending to their multiple symptoms and other needs and without considering the needs of their families. That is, the focus needed to expand to patient- and family-centered palliative care conceived broadly. For example, what began in 1986 as a World Health Organization monograph on cancer pain was later broadened to include comprehensive care including palliative services (WHO, 1998).

As part of a comprehensive strategy for care improvement, advocates identified multiple targets for action: government policies including payment for palliative care and access to effective medications; public education to create awareness that effective strategies were available to prevent and relieve pain; professional education about effective use of existing knowledge to prevent suffering; and scientific research to build new knowledge. The strategies were pragmatic and operated on the principle that "nothing would have a greater impact on improving the care of patients with pain than institutionalizing the knowledge we have now." Institutionalizing knowledge meant, for example, developing and implementing evidence- and consensus-based practice guidelines, creating and refining tools for assessing pain and measuring desired outcomes of care, forging collaborations among groups and institutions to develop and test pain management protocols, and formulating supportive public and private policies, including accreditation standards.

Although recognizing that deficits in pain care persist and that more progress is needed on all fronts, advocates of improved palliative, end-of-life, and bereavement care—including many who led efforts to improve pain management—have learned from the pain management experience. The web sites of the Open Society Institute's Project on Death in America (http://www.soros.org/death), the Last Acts program initiated by the Robert Wood Johnson Foundation (http://www.lastacts.org), and other linked sites document their multifaceted approach to care improvement.

The discussion below focuses on steps clinicians, administrators, and others can take—usually in collaboration with others in the community and nationally—to define responsibilities and implement and test strategies for improving care. All those involved in care for children with fatal or potentially fatal conditions should act to remedy deficits in care. However, because care for such children is often concentrated in neonatal and pediatric intensive care units, these units and their governing institutions must play a central role.

Communication, Goal Setting, and Care Processes

Practice guidelines and administrative protocols are, as discussed earlier, one means of providing direction and defining expectations and responsibilities for the health care professionals and organizations that care for children with fatal or potentially fatal medical conditions. If implemented, they should increase the consistency of services and provide a base for evaluation of the effectiveness of the recommended practices and procedures.

Existing literature and committee experience suggest that even hospitals that regularly care for children who die often lack protocols and procedures to guide such basic aspects of palliative and end-of-life care as the assessment and management of pain and other symptoms, the communication of diagnosis, prognosis, and treatment options, and the ethical and competent management of end-of-life decisions and interventions. The committee recognizes that the evidence base is limited but believes that "institutionalizing" existing knowledge and experience is an important step in improving care and building better knowledge to guide future care.

Recommendation: Pediatric professionals, children's hospitals, hospices, home health agencies, professional societies, family advocacy groups, government agencies, and others should work together to develop and implement clinical practice guidelines and institutional protocols and procedures for palliative, end-of-life, and bereavement care that meet the needs of children and families for

- **complete, timely, understandable information about diagnosis, prognosis, treatments (including their potential benefits and burdens), and palliative care options;**
- **early and continuing discussion of goals and preferences for care that will be honored wherever care is provided;**
- **effective and timely prevention, assessment, and treatment of physical and psychological symptoms and other distress whatever the goals of care and wherever care is provided; and**
- **competent, fair, and compassionate clinical management of end-of-life decisions about such interventions as resuscitation and mechanical ventilation.**

As discussed earlier in this chapter, guidelines and protocols should be based on systematically developed expert consensus and on scientific evidence to the extent it is available. Guidelines and similar statements developed by reputable national organizations should be a starting point when possible, but local review and adaptation will often be necessary and helpful to meet local needs and win support from those who must implement guidelines and protocols. Given this country's cultural, religious, and ethnic diversity, guidelines and protocols should also be sensitive to this diversity and flexible enough to accommodate departures from usually advised procedures.

Depending on the aspect of care in question, clinical practice guidelines and institutional protocols may include or be supplemented by ethical guidance, model conversations, checklists, and documentation standards. Once adopted, guidelines and protocols are one obvious candidate for quality improvement projects as discussed earlier.

Bereavement Care

Although many families will rely primarily on support from other family members, friends, neighbors, and spiritual advisors after a child's death, they may also seek care from their primary care physician, hospice personnel, psychotherapists, grief counselors, or family support groups. Still, the child's specialist care team—physicians, nurses, social workers, and others—can meaningfully "be with" the family in a variety of ways in the days and months following a child's death in the hospital or at home. As observed in Chapter 5, an abrupt end to contact soon after the child's death can feel like—and be—a kind of abandonment.

Despite the shortfalls in the research base and the need for more research on bereavement interventions (see Chapter 10), the committee concludes that enough experience and judgment is available to guide the development, implementation, and assessment of systematic processes for offering and providing bereavement support. Such support should become a more consistent and reliable service of hospitals that routinely care for children who die and their families.

Recommendation: Children's hospitals and other hospitals that care for children who die should work with hospices and other relevant community organizations to develop and implement protocols and procedures for

- **identifying and coordinating culturally sensitive bereavement services for parents, siblings, and other survivors, whether the child dies after a prolonged illness or after a sudden event;**

- **defining bereavement support roles for hospital-based and out-of-hospital personnel, including emergency medical services providers, law enforcement officers, hospital pathologists, and staff in medical examiners' offices; and**
- **responding to the bereavement needs and stresses of professionals, including emergency services and law enforcement personnel, who assist dying children and their families.**

Coordination and Continuity of Care

Parents repeatedly cite the frustrations they experienced in coordinating the care needed by a very ill child. Reducing the burdens of care coordination is a formidable challenge. This is especially true for children with complex, chronic problems that require inpatient, home, and community-based services from many different professionals and organizations that may be separated geographically, institutionally, and even culturally from each other. As described earlier in this chapter, interdisciplinary care teams, case managers, disease management programs, and medical homes are important but still incomplete foundations or strategies for care coordination and continuity. These strategies themselves have to be coordinated or linked within and across organizations and sites of care.

The committee recognizes that the development and institutional adoption of guidelines or protocols as recommended above is but one step toward changing practice and improving outcomes. Other steps include the assignment of institutional accountability for the implementation of protocols (including the identification of barriers to implementation), the development of programs to train personnel in the basis and use of the guidelines, and the creation of information systems to make adherence to the guidelines easier and assessment of their consequences—both expected and unexpected—routine.

> **Recommendation: Children's hospitals, hospices, home health agencies, and other organizations that care for seriously ill or injured children should collaborate to assign specific responsibilities for implementing clinical and administrative protocols and procedures for palliative, end-of-life, and bereavement care. In addition to supporting competent clinical services, protocols should promote the coordination and continuity of care and the timely flow of information among caregivers and within and among care sites including hospitals, family homes, residential care facilities, and injury scenes.**

An essential foundation for improved coordination of care—and improvements in the quality and efficiency of health care generally—is better medical information systems that make patient information available whenever and wherever it is needed (see, e.g., the reports and citations in IOM, 1991, 2000c, 2001b and resources listed at http://www.amia.org/resource/pubs/f3.html). Such systems are not yet in place within most individual health care systems much less in forms that allow quick, reliable, and secure access to information across sites of care. Interim information strategies—including paper-based techniques—are also needed.

In addition to investing in better medical information systems, it is also important to continue public and private investments in other system changes that will make it easier for local institutions and communities to improve palliative, end-of-life, and bereavement care for children and families. Chapter 7 outlines directions for change in the financing of care, and Chapters 9 and 10 discuss educational changes and research directions.

Regional Support for Rural and Small Communities

Children with life-threatening medical conditions are often referred to specialized centers for treatment. Some will need little follow-up care, but others will require considerable amounts of care after they return home. Families in rural areas and small towns and the local health care professionals, community hospitals, and other organizations that serve them may need special support in caring for such children. Such support may involve a mix of written protocols, family guides, telephone consultations, Internet-based information, interactive videoconferencing, and other tools. Children's hospitals have an important role to play in developing such consultation and information resources. They may require collaboration with or assistance from state officials, national and state associations and professional groups, community business and philanthropic entities, and other groups.

> **Recommendation: Children's hospitals, hospices with established pediatric programs, and other institutions that care for children with fatal or potentially fatal medical conditions should work with professional societies, state agencies, and other organizations to develop regional information programs and other resources to assist clinicians and families in local and outlying communities and rural areas. These resources should include the following:**
>
> - **consultative services to advise a child's primary physician or local hospice staff on all aspects of care for the child and the family from diagnosis through death and bereavement;**

- **clinical, organizational, and other guides and information resources to help families to advocate for appropriate care for their children and themselves; and**
- **professional education and other programs to support palliative, end-of-life, and bereavement care that is competent, continuous, and coordinated across settings, among providers, and over time (regardless of duration of illness).**

Neither regional support services nor actions to improve the coordination and continuity of care are free. In some cases, these activities and others recommended here may promise and produce savings (e.g., from avoided hospitalizations or transfers) that cover or exceed their costs. The costs and savings may, however, sometimes accrue to different parties (e.g., program costs for hospitals and savings for insurers or families). State and local governments and philanthropic and other organizations may provide funds or services in kind to help establish telemedicine and other supportive programs. If, however, the system for financing the provision of services to individual patients and families fails to cover the kinds of palliative, end-of-life, and bereavement services advised in this report, professionals and organizations may struggle merely to provide basic services much less coordinate them and support them regionally. Chapter 7 examines this country's system for financing health care as it relates to pediatric care and palliative care generally and to pediatric palliative, end-of-life, and bereavement care specifically.

CHAPTER 7

FINANCING OF PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES

> *[Let me mention] the frustrations that we did have with insurance. You need to have a business degree, I think, to deal with these things.*
>
> Winona Kittiko, parent, 2001

> *Wearing my administrator's hat, I myself see [hospital palliative care] programs as a major risk. They . . . require short-term renovation costs and continuing personnel costs, and invite concern about lost long-term opportunities: What if we had put a profitable cardiac [catheterization] unit into the same space or a chemo infusion center?"*
>
> Thomas J. Smith (Lyckholm et al., 2001)

Health insurance—whether public or private—has traditionally focused on acute care services intended to cure disease, prolong life, or restore functioning lost due to illness or injury. It has excluded most preventive services as well as extended care for long-term, chronic illness. Medicaid has been the major exception. From the outset, this federal-state program has covered many long-term care services for beneficiaries with serious chronic health problems and disabilities. Early on, it added a range of preventive services, particularly for children. Medicare and private insurers have gradually added coverage for various preventive services (e.g., screening mammography), influenced in part by contentions that such services could reduce subsequent spending on disease treatment. Medicare and most Medicaid programs and private insurers also now cover at least one form of supportive care—hospice—for patients who are dying.

Nevertheless, gaps and other problems in the financing of palliative and end-of-life services contribute to access and quality concerns for adults and children living with life-threatening conditions. Complete lack of insurance is an obvious problem. Yet, even when a person is insured, coverage limitations, financing methods and rules, and administrative practices can create incentives for undertreatment, overtreatment, inappropriate transitions between settings of care, inadequate coordination of care, and poor overall quality of care. Low levels of payment to providers can discourage them from providing certain treatments and from treating some patients at all.

Obtaining a good picture of financing for palliative and end-of-life care services for children is difficult. Unlike virtually all elderly Americans, children are covered not by a single insurance program (Medicare) but, instead, by thousands of private insurers and a multitude of state Medicaid and other public programs that have differing eligibility and coverage policies. These policies are poorly or not conveniently documented and constantly changing, so such information as is available on private health plans and Medicaid programs may be incomplete or out of date.[1] Further, because death in childhood is relatively uncommon, data from surveys (e.g., of hospice and home care services) may not provide reliable estimates. Insofar as available data permit, this chapter

- describes payment sources for palliative, end-of-life, and bereavement care for children and their families;
- reviews relevant coverage and reimbursement policies for private health plans and Medicaid; and
- recommends directions for changes in coverage and reimbursement policies.

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[1] For those covered by Medicare (particularly the almost 90 percent who are enrolled in the traditional fee-for-service Medicare program), fairly good claims information is available about payment for most kinds of hospital, physician, and other covered services. In addition, the Current Beneficiary Survey tracks service use, out-of-pocket payment, supplemental coverage, health status, and other information that provides a broader picture of health care use and spending for Medicare beneficiaries. These data have been analyzed to determine the share of Medicare spending accounted for by care during the last six months of life, assess the proportion of expenses for different kinds of health services not paid by Medicare, and evaluate beneficiary use of hospice and other services. No such data are available for children.

WHO PAYS FOR PALLIATIVE AND END OF LIFE CARE FOR CHILDREN?

General

Sources of Payment

Policymakers have long made children, especially poor and sick children, a special focus of programs that promote healthy growth and provide access to needed health services. At the national level, the creation of the Maternal and Child Health Bureau in 1935 (Title V of the Social Security Act) was an important affirmation of the federal government's interest and involvement in services for pregnant women, infants, and "crippled" children (Gittler, 1998).[2] Since then, the program has expanded its focus to include other children with serious chronic health problems. The creation of Medicaid in 1965 significantly expanded access to health insurance and health services for children in low-income families, whether or not they had medical problems. Recently, the State Children's Health Insurance Program (SCHIP) has sought to extend coverage for poor children through Medicaid expansions or other strategies.

Most children (and adults) are, however, covered by private health plans sponsored by employers. As summarized in Figure 7.1, in 2000, almost two-thirds of this country's 72 million children (under age 19) were covered by employment-based or other private health insurance (AHRQ, 2001b). An estimated 20 percent of children had public insurance (primarily Medicaid and then SCHIP).[3] A significant proportion of children—some 15 percent of those under age 19—were not insured. (For those aged 19 to 24, the figure is 33 percent.)

National figures on coverage do not reflect the substantial variation across states. For example, in Maryland in 1997, approximately 78 percent

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[2] An earlier Maternity and Infancy Act, which was passed in 1921, expired in 1929. The Children's Bureau dates back to 1912. In 1985, Congress changed the terminology for the relevant Title V components from "crippled children" to "children with special health care needs" to reflect expansions in the program's focus and changing attitudes. (see www.ssa.gov/history/childb2.html and www.mchdata.net/LEARN_More/Title_V_History/title_v_history.html).

[3] Under special provisions, Medicare covers those diagnosed with end-stage renal disease who are insured under Social Security or who are spouses or dependent children of such insured persons. In 1997, approximately 2,200 individuals under age 15 were receiving Medicare-covered dialysis (see http://www.hcfa.gov/medicare/esrdtab1.htm). According to the United Network for Organ Sharing, about 600 children under age 18 received kidney transplants in 2000 (http://www.unos.org/Newsroom/critdata_transplants_age.htm#kidney).

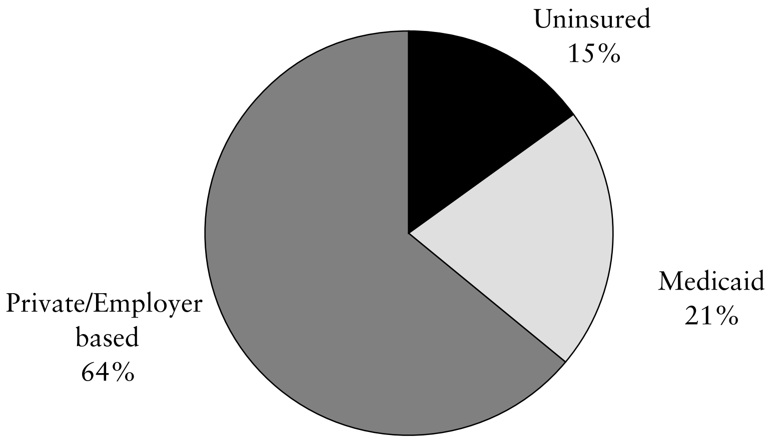

FIGURE 7.1 Source of health insurance coverage for children ages 0 to 18.
NOTE: Figure combines data reported separately for the 0–17 and the 18-year-old age groups.
SOURCE: Compiled from data from Center for Cost and Financing Studies, Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey Household Component, 2000.

of children were covered by private insurance, 6 percent by Medicaid, and 16 percent had no insurance (Tang et al., 2000). In neighboring West Virginia, the comparable figures are 54 percent, 35 percent, and 11 percent, respectively. Arizona, Alaska, and Texas had more than 25 percent of children uninsured compared to less than 8 percent in Hawaii, Minnesota, Vermont, and Washington state. These variations reflect a mix of factors including state economic conditions, immigration, demographics, and political choices about such matters as taxation and spending priorities.

In 1999, of children in poor families (at or below 100 percent of the poverty level or $13,290 for a family of three in that year), an estimated 26 percent were uninsured. Of children in near-poor families (up to 200 percent of the poverty level), an estimated 21 percent were uninsured (Broaddus and Ku, 2000).[4] In 1999, an estimated 85 to 94 percent of low-income,

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[4] One study of high-cost children in California (including those with conditions not likely to cause death in childhood) suggested that children with high health costs were more likely than other children to be covered by private insurance (about one-half) than by Medicaid (about one-third) or other sources (Ku, 1990). In this study, which included individuals up to age 25, younger children were more likely to have costs covered by private insurance and older children (over age 17) were more likely to be uninsured.

uninsured children were eligible for Medicaid or SCHIP, but their parents or guardians had not enrolled them (Broaddus and Ku, 2000; Dubay et al., 2002a). Approximately two-thirds of the eligible but uninsured children were eligible for Medicaid and the other third for SCHIP. Among children identified as eligible for Medicaid, participation in the program ranges from a high of 93 percent in Massachusetts to a low of 59 percent in Texas (Dubay et al., 2002b; see also HCFA/CMS, 2000g). For children with serious medical problems, hospital social workers or other health care personnel often assist low-income families in enrolling the child in Medicaid, SCHIP, or any other special programs. A recent survey indicated that from 1997 to 2001 the number of uninsured children (under age 18) dropped from 12.1 percent to 9.2 percent while the percentage of children reported to have difficulty getting care dropped from 6.3 to 5.1 percent during this period (Strunk and Cunningham, 2002).

Access to Care: More Than Just Insurance Coverage

Lack of insurance does not necessarily mean the lack of access to all health care, especially for children with life-threatening medical conditions. Uninsured children may have some care paid for or provided by their families, "safety-net providers," philanthropy, and other sources, but they may also go without needed services. Improved financing of care is one cornerstone of improved access to care for children, including children and families living with life-threatening medical conditions (IOM, 1998; Lambrew, 2001).

When children are insured and parents are not, children may still suffer. For example, some research suggests that insured children are less likely to have preventive care if their parents are uninsured (Gifford et al., 2001). As a result, some federal and state insurance initiatives are also reaching out to parents. For example, states can apply for waivers of SCHIP or Medicaid requirements to cover parents directly or through subsidies for enrollment in employer-based plans (AHSRHP, 2001).

Variability in Coverage of Palliative, End-of-Life, and Bereavement Care

Coverage of end-of-life and palliative care services for children who die and their families varies tremendously, both across payer types (e.g., private insurance, Medicaid) and among payers of the same type. Regional variation in coverage policies and their day-to-day interpretation is substantial, as is variation by size and other characteristics of employers. Moving across a state border or changing jobs can result in substantial changes in services covered for seriously ill children and their families.

The next sections of this report review what is known about how three major sources of insurance (private, Medicaid, and SCHIP) cover important palliative, end-of-life, and bereavement services. Other sources of funding for children's care—including federal Title V programs, safety-net providers, philanthropy, family out-of-pocket payments, and clinical trials—are discussed briefly. The focus is on coverage of hospice, home health care, inpatient care, pharmaceuticals, psychosocial services, and respite care. Provider payment methods and levels and other important financing issues are discussed in subsequent sections.

Employment-Based and Other Private Insurance

General

As noted above, almost two-thirds of children in the United States are covered by private health insurance, mostly through plans sponsored by employers that also offer—usually for an additional charge—coverage for an employee's family. Many employers, especially small, low-wage employers, do not offer health insurance, in part because their profit margins are slender and in part because premiums are typically much higher for small firms. Even when employers offer insurance, some employees do not "take up" coverage because the required employee contribution is too high or because better or less expensive coverage is available through a spouse.

Some self-employed and other parents are able to buy family coverage individually. These individuals tend to face high premiums, and those with past medical problems may have difficulty obtaining any coverage. Older children may be able to obtain coverage in their own right as an employee or college student. Some states have programs to help provide private insurance to uninsured individuals.

Summary data on coverage rates do not depict the extent of instability in employer-sponsored coverage. Insurance coverage for children and families may be interrupted or altered for a variety of reasons. Parents may lose their jobs or take new jobs that either offer coverage from different health plans or do not include health benefits at all.[5] In addition, employers may change the scope of benefits they offer or switch health plans, which may mean changes in provider networks or administrative procedures. This can affect continuity of care, a particular concern for families with a seriously ill child. As discussed in Chapter 5, other employer-provided benefits, includ-

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[5] Federal law generally requires that firms with 20 or more employees allow eligible former employees and covered spouses and children to pay for continued coverage at group rates (actually, at 102 percent of the group premium) for up to 18 or 36 months, depending on the circumstances (http://www.dol.gov/dol/pwba/public/pubs/COBRA/cobra99.pdf). Not all individuals or families can, however, afford such continuation coverage.

ing paid or unpaid leave, may help children with serious medical conditions and their families. Flexible spending accounts, funded with pre-tax dollars, can pay for health care services not covered by an employee's health plan and for deductibles, copayments, and coinsurance that are required for covered services.

Many states have laws requiring that private health plans cover or offer coverage for a wide range of services (e.g., infertility treatments, breast implant removal), some of which (e.g., hospice, mental health care) are relevant to palliative and end-of-life care. Self-insured employers generally claim freedom from such requirements under the Employee Retirement Income Security Act of 1974, commonly referred to as ERISA. Most large and many middle-sized employers are self-insured.

Private Insurance Coverage of Home Hospice Care

As an insurance benefit, hospice coverage normally includes home-based nursing care, physician services, physical or occupational therapy, respiratory therapy, medical social services, medical supplies and certain equipment, and prescription drugs. The benefit usually includes a limited amount of inpatient care if needed for respite or symptom management.

A study by Gabel and colleagues (1998) analyzed information about private hospice coverage from a national random sample of more than 1,500 employers with 200 or more employees each. It also drew on information from focus groups that included employee benefits managers and their insurance advisers. The researchers found that a substantial majority of employers surveyed (83 percent) offered formal hospice benefits. Most of the rest covered a similar range of services through high-cost case management programs that allow case managers discretion to pay for and assist in arranging services not otherwise covered by a health plan. Large employers were more likely to offer hospice benefits than were mid-size employers.

Many private insurance plans have adopted the hospice eligibility and coverage rules used by the Medicare program. Almost half of respondents to the survey by Gabel and colleagues reported that their health plan hospice benefit restricted eligibility to individuals with a life expectancy of six months or less. Another 30 percent did not know whether such a requirement existed in their plan. Unlike Medicare, 28 percent of the plans were reported to include an individual dollar cap on hospice benefits (e.g., $5,000), and 31 percent limited the length of stay.

A second study by Jackson and colleagues (2000) reported an analysis of booklets that summarized benefit plans for 70 large employers. According to these summaries, most employers (88 percent) offered hospice benefits. Most required a physician's certification of a terminal illness, but only half specified a prognosis of six months or less of remaining life. Most plans did not require cost sharing (e.g., paying a fixed amount per visit or a percentage of the charge) for the services, and the majority did not set lifetime day or dollar maximums. Further, in interviews with nine employer representatives, the researchers found more flexibility in the administration of benefits than was suggested by the written plan summaries. The typical comment was that waiving certain benefit restrictions on hospice care was "the right thing to do" (Jackson et al., 2000, p. 4).

Based on their interviews, Jackson and colleagues categorized the nine employer plans as following a Medicare-like model, a comprehensive model, or an unbundled approach. Only two plans followed the Medicare approach of requiring the suspension of curative treatment. Two of the three managed care plans used an unbundled approach, placing the plan's case manager in a central position to enroll individuals in hospice and approve individual care plans and services.

In contrast to the studies described above, Bureau of Labor Statistics (BLS) data, which are based on a large sample of large- and medium-sized private employers (those with 100 or more workers), showed lower rates of hospice coverage in 1997—just 60 percent across all categories (BLS, 1999). The BLS data indicated that health maintenance organization (HMO) plans were more likely to cover hospice than other plans (69 percent versus 43 percent, respectively). A separate BLS survey of state and local government employers reported that 64 percent offered hospice coverage in 1998 (BLS, 2000).

No individual employer example can represent the variability described above, but as an illustration, Table 7.1 presents the hospice coverage listed in the 2002 benefits description for the large Blue Cross Blue Shield options for federal employees. Among other restrictions, the plan requires prior approval. Coverage excludes bereavement services but includes inpatient care to provide brief respite for family members. As with all the other health plans offered to federal employees, the benefit structure is approved and sometimes directed by the federal Office of Personnel Management rather than unilaterally determined by the insurer or health plan.

Private Insurance Coverage of Home Health Care

Health plan rules, licensure regulations, and physician and family reluctance to accept hospice can make home hospice coverage less helpful than it might otherwise be for children who die and their families. For these children and families, home health care providers, including those affiliated with hospices, may offer an array of supportive medical and other services including home nursing care. Also, home health agencies may start providing care before a child is recognized as dying. Continuity with the same organization and personnel may be reassuring to a child and family, even

TABLE 7.1 2002 Hospice Coverage Benefits for Blue Cross Blue Shield Federal Employees Health Insurance Plan

Hospice Care	You Pay–Standard Option	You Pay–Basic Option
Hospice care is an integrated set of services and supplies designed to provide palliative and supportive care to terminally ill patients in their homes. We provide the following **home hospice care** benefits for members with a life expectancy of six months or less **when prior approval is obtained from the Local Plan** and the home hospice agency is approved by the Local Plan: • Physician visits • Nursing care • Medical social services • Physical therapy • Services of home health aides • Durable medical equipment rental • Prescription drugs • Medical supplies	Nothing	Nothing
Inpatient hospice for members receiving home hospice care benefits: Benefits are provided	Preferred: $100 per admission copayment	Preferred: $100 per day copayment up to $500 per admission

when home hospice care is covered by the family's health plan and would otherwise be acceptable to parents.

The Bureau of Labor Statistics reported that 85 percent of large and medium-sized private employers provided some home health care coverage (BLS, 1999). HMO plans were more likely to cover these services than other plans (93 percent versus 81 percent).

Health plans that pay for home health care may, however, exclude certain services that are often or sometimes included in hospice benefits (e.g., physical therapy, bereavement care). Moreover, state licensure requirements may restrict licensed home health care providers from providing certain end-of-life services such as bereavement care. In addition, employer-sponsored plans often limit coverage for home health care to a certain

TABLE 7.1 Continued

Hospice Care	You Pay–Standard Option	You Pay–Basic Option
for up to five (5) consecutive days in a hospice inpatient facility. Each inpatient stay must be separated by at least 21 days. These covered inpatient hospice benefits are available only when inpatient services are necessary to: • Control pain and manage the patient's symptoms; or • provide an interval of relief (respite) to the family Note: **You are responsible for making sure that the home hospice care provider has received prior approval from the Local Plan.** Please check with your Local Plan and/or your PPO directory for listings of approved agencies.	Member: $300 per admission copayment Non-member: $300 per admission copayment plus 30% of the Plan allowance, and any remaining balance after our payment	Member/Non-member: You pay all charges
Not covered: Homemaker or bereavement services	All charges	All charges

NOTE: PPO = preferred provider organization.
SOURCE: Blue Cross and Blue Shield, 2002 Service Benefit Plan, p. 63, http://www.fepblue.org/pdf/2002sbp.pdf (emphasis in the original).

number of nursing or therapy visits (e.g., 60 visits per year) or require that care be expected to lead to improvement in the health condition. Thus, services needed by chronically or terminally ill patients on an ongoing basis such as nursing visits, respiratory therapy, and physical therapy may be limited or excluded altogether under an employer's plan.

In one study of Medicare financing of end-of-life services, end-of-life care providers (including home health agencies as well as hospices) reported the need for end-of-life consults from a hospice team for dying patients not enrolled in hospice in order to assist in symptom management and end-of-life care planning (Huskamp et al., 2001). Such consultative services for a patient receiving home health care would not ordinarily be covered by private health insurance (unless the health plan waived coverage restrictions as described earlier). In these situations, lack of coverage for consultations by hospice or other palliative care experts may lead to avoidable pain and other suffering for dying children and their families.

As discussed in Chapter 6, telemedicine could help extend information and advice to support home health providers for children and families in smaller communities and rural areas. Private insurer coverage for telemedicine services is limited (OAT, 2001).

Private Insurance Coverage of Inpatient Hospital Care

The centerpiece of most private health insurance has traditionally been coverage for inpatient hospital services, which continue to be generously covered compared to other services. Thus, much of the emergency, intensive, and palliative care—including nursing care, diagnostic tests, medications, and many other services—that is provided to children with life-threatening conditions is routinely covered.

If, however, patients, families, and physicians choose to forgo curative or life-prolonging care in favor of inpatient care that is exclusively but intensively palliative, some health plans may refuse to pay if the plan limits inpatient coverage to treatment intended to cure or restore function. (As discussed later, even if coverage is not an issue, the case-based and other payment systems for hospitals are based on data and assumptions that exclude modern palliative services, which is a disincentive for hospitals to provide these services.) The committee found no systematic information on the extent to which coverage is approved or denied when inpatient pediatric care is exclusively palliative.

Private Insurance Coverage of Outpatient Prescription Drugs

Unlike Medicare, most employers that offer insurance to employees cover outpatient prescription drugs, subject to various limitations such as cost sharing requirements. Information from a large survey of employers indicates that nearly all employees (96 percent) covered by employer health plans had prescription drug coverage in 1997 (Marquis and Long, 2000). Even for small employers and low-wage employers, more than 85 percent provided outpatient drug coverage.

BLS data for medium- and large-sized private employers also show very high levels of employer coverage of outpatient prescription drugs (BLS, 1999). For nearly 80 percent of covered workers, the level of cost sharing for prescription drugs was no higher than for physician services; about 18 percent faced higher cost sharing for drugs.

Spending for prescription drugs has increased dramatically during the last decade. Health plans have responded by increasing the level of cost sharing and using pharmacy benefit managers (PBMs) to manage drug benefits separate from their general health plan or plans (Cook et al., 2000; Mays et al., 2001). Elements of these programs typically include negotiated price discounts with manufacturers, a mail order service, drug utilization review to detect inappropriate prescribing patterns, processing of drug claims, and formulary management. In an insurance context, a formulary is a list of covered drugs.

Most HMOs, preferred provider organizations (PPOs), and PBMs report using some kind of formulary that sets forth what prescription drugs are routinely covered and what exceptions are permitted under specified circumstances (Wyeth-Ayerst, 1999). Some plans have closed formularies, meaning that they refuse to pay for drugs not on the list. These plans often offer an exemption process that allows coverage of an unlisted drug if a patient's physician provides documentation that the particular drug is medically necessary for the patient. The flexibility of this "exemption" process varies across plans.

A three-tier approach to pharmacy benefits has become increasingly common. Although the specifics vary, the first tier, with the lowest copayments, typically consists of generic drugs (e.g., generic amoxicillin). The second tier consists of brand-name drugs that the organization considers to be safe, effective, and reasonably priced. The third tier consists of nonpreferred brand drugs, for example, those that the plan judges not to provide better outcomes for their extra cost. Drugs considered to be primarily "lifestyle-enhancing" in nature (e.g., Propecia for baldness, Viagra for sexual dysfunction) may also be included in the third tier, or they may be excluded from coverage altogether.

Depending on the values, knowledge, and choices of the health plan and the PBM about, for example, pain medications, these programs could make effective drugs more or less costly for children with serious medical problems (Motheral and Henderson, 2000; Motheral and Fairman, 2001). Formulary provisions could also lead parents and physicians to select less costly drugs that are also less effective for a particular child given, for example, his or her ability to metabolize certain opioids or other drugs.[6]

A separate and often controversial issue with employment-based health plans is the introduction of therapeutic substitution policies. Such policies

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[6] Not all persons are created equal in the enzymes needed to metabolize medications. The absence of certain enzymes can render some drugs pharmacologically inert. One example is codeine, a pain medication suited to mild-to-moderate pain that is commonly prescribed for children (although other medications may have fewer side effects). Recently, researchers reported that that 10 percent of Caucasians, 3 percent of Asians, and 1 percent of African-Americans in the United States lack the liver enzyme CYP2D6 need to convert codeine to its active form, morphine. Neonates and infants also have lower levels of this enzyme (see the review in Williams et al., 2001a).

allow pharmacists to substitute an alternative drug (a different chemical entity) considered therapeutically equivalent[7] in place of the drug prescribed by the physician. Such policies are controversial because designations of therapeutic equivalence may not adequately reflect the physiological variability that a clinician may recognize in an individual patient's response to a drug but that has not yet been demonstrated scientifically.

Private Insurance Coverage of Psychosocial, Respite, and Other Services

Most employer health plans provide coverage for mental health services that may help children with life-threatening medical problems and assist families before and after a child's death. Some health plans cover (i.e., allow direct billing by and payment to) for services provided by a clinical psychologist or clinical social worker. Child-life specialists, art therapists, music therapists, chaplains, or other personnel are rarely if ever reimbursed directly for their professional services.

Except through hospice, health insurance plans generally do not cover bereavement care as such, although insured parents or siblings may be covered for services to treat depression, anxiety, and certain other emotional problems experienced during bereavement. One disadvantage of coverage contingent on these diagnoses is that bereaved family members may receive a diagnostic label that could jeopardize their future ability to qualify for health insurance, especially individually purchased insurance. Even as part of their hospice benefits, private health plans do not universally cover

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[7] The Food and Drug Administration (FDA) "classifies as therapeutically equivalent those products that meet the following general criteria: (1) they are approved as safe and effective; (2) they are pharmaceutical equivalents in that they (a) contain identical amounts of the same active drug ingredient in the same dosage form and route of administration, and (b) meet compendial or other applicable standards of strength, quality, purity, and identity; (3) they are bioequivalent in that (a) they do not present a known or potential bioequivalence problem, and they meet an acceptable in vitro standard, or (b) if they do present such a known or potential problem, they are shown to meet an appropriate bioequivalence standard; (4) they are adequately labeled; and (5) they are manufactured in compliance with Current Good Manufacturing Practice regulations. The concept of therapeutic equivalence, as used to develop the List, applies only to drug products containing the same active ingredient(s) and does not encompass a comparison of different therapeutic agents used for the same condition (e.g., propoxyphene hydrochloride vs. pentazocine hydrochloride for the treatment of pain). Any drug product in the List repackaged and/or distributed by other than the application holder is considered to be therapeutically equivalent to the application holder's drug product even if the application holder's drug product is single source or coded as non-equivalent (e.g., BN). Also, distributors or repackagers of an application holder's drug product are considered to have the same code as the application holder. Therapeutic equivalence determinations are not made for unapproved, off-label indications." (FDA Orange Book; http://www.fda.gov/cder/ob/docs/preface/ecpreface.htm#Therapeutic Equivalence-Related Terms).

bereavement counseling for family members. (See, e.g., Table 7.1 and other illustrative examples at Presbyterian Health, 2001; and Aetna Insurance, 2001).

Traditionally, most private insurance plans have imposed special benefit limits (e.g., higher copayments or coinsurance, caps on the number of visits or total payments during a year or lifetime) for mental health services that they did not apply to other types of covered health care services. In the Mental Health Parity Act of 1996 (P.L. 104-204, reauthorized for one year in 2001), Congress required that if an employee health benefit plan covers mental illness, the plan cannot set lower annual or lifetime spending limits for mental health services than those set for services for physical or surgical illnesses (Otten, 1998).[8]

Employer plans may cover limited amounts of respite care as part of hospice benefits. Otherwise, benefits for respite care appear to be rare.[9] Most discussions of expansion in respite services focus on public programs (see, e.g., Silberberg, 2001). When a child has a severe chronic condition, families may bear extraordinary physical, emotional, and financial burdens because neither regular paid assistance nor occasional respite care is covered.

Innovations in Coverage

Some private health plans have developed or are testing innovative programs of coverage for palliative and end-of-life care focused on adults. For example, a recent publication sponsored by the Robert Wood Johnson Foundation (RWJF) described nine programs involving Blue Cross and Blue Shield plans in various parts of the country (Butler and Twohig, 2001).

Two plans (Regence Blue Shield and Premera Blue Cross) participated with the state of Washington in an RWJF-sponsored research project led by the Children's Hospital and Medical Center of Seattle. Regence's program covered any child under age 21 in a health plan that included a benefits management clause that allows waivers of certain plan restrictions under certain circumstances. After the project began, the plan added payment for

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[8] Plans can, however, set lower limits on the number of covered outpatient visits or hospital stays and can require higher cost sharing (deductibles, coinsurance, or copayments) by patients (Aston, 2001). They can also choose not to offer coverage at all. More than 30 states have some kind of mental health parity legislation, some going beyond current federal law. Some restrict parity to a subset of mental health diagnoses only, whereas others encompass substance abuse as well as mental health services. As noted earlier, ERISA frees self-insured employers from these mandates.

[9] Limited respite care benefits may be provided as part of long-term care insurance plans, which usually must be purchased directly by individuals. These policies are intended for adults who are basically healthy at the time of purchase.

a child's participation in well-designed clinical research as a case management option, and it is developing a palliative care "add-on" feature to offer as part of future benefits packages. The Premera program was designed to assist early access to hospice care, promote active case management, and encourage creative use of home care benefits. Both plans used a "decision-making tool" (developed by medical ethicists at the University of Washington) that provided a comprehensive framework for discussing all aspects of a child's care and taking into account medical circumstances, family preferences and situations, quality of life, and financial issues. Challenges identified by the two health plans included early identification of children and families who might benefit from hospice care and changing the relationship with hospices from adversarial to cooperative. Cost and satisfaction data are still being collected and analyzed.

Blue Cross Blue Shield of Montana is participating in a multisite project, this one testing the Advanced Illness Coordinated Care model that was developed by the Life Institute and is described in its pediatric format in Chapter 6. This program is unusual because the plan will fund participation in the program of 120 people under age 65, whether or not they have coverage from the plan. The program is organized around six to nine home visits made by case managers to individuals who have a fatal diagnosis but do not meet hospice criteria. The case management services are paid for by the plan under a contract with the Life Institute. The plan anticipates that the discussions will lead to some cost savings based on advance care planning and avoidable hospitalization.

In addition, as one outgrowth of its involvement in community initiatives to improve end-of-life care, the Blue Cross Blue Shield plan (Excellus) in Rochester, New York, recently established payment for palliative care consultations by physicians certified in hospice and palliative medicine (BCBSRA, 2002). The plan also has established a program called CompassionNet aimed at children who meet one of the following criteria:

- a diagnosis of a potentially life threatening illness,
- two unplanned hospitalizations in the preceding six months (other than for asthma),
- an acute exacerbation of a chronic illness that creates an extreme risk, or
- a prognosis of three years of life or less.

Medicaid

General

The state–federal Medicaid program is a critical source of funding for services to low-income children. It covers large numbers of children with chronic illnesses and serious disabilities.[10] Consistent with Title XIX of the Social Security Act, federal law establishes requirements for states that participate in Medicaid, which all states now do. Among other services, states must cover

- children ages 6 to 18 with family incomes at or below 100 percent of the federal poverty level (in 2001, $14,630 for a family of three) (to be fully phased in as of 2002) and
- children under age 6 and pregnant women with family incomes at or below 133 percent of the federal poverty level.

About 80 percent of Medicaid-enrolled children are covered under the mandatory categories. The remainder, whose families have higher incomes, are covered at the discretion of states. The optional coverage categories for children include

- infants up to age 1 and pregnant women, who are not covered under the mandatory rules and whose family income is no more than 185 percent of the federal poverty level (with the specific percentage set by each state),
- children under age 21 who meet the income and resources requirements for Aid to Families with Dependent Children (AFDC) that were in effect in their state on July 16, 1996, and
- children under age 18 who qualify under complicated federal and state rules as "medically needy."

In general, the option for "medically needy" children allows a state to extend Medicaid coverage when the family's income is too high to qualify otherwise but the child has very high medical expenses. The family "spends down" to eligibility because the child's medical expenses reduce the family's income below the state Medicaid maximum. If a state has a medically needy program, it must include certain children under age 18 and pregnant women who would otherwise be eligible as "categorically needy" under the optional coverage requirements.[11]

Overall, children comprise just over half of Medicaid enrollees, roughly 21 million out of 40 million total in 1998. Reflecting their generally good

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[10] Unless otherwise indicated, data in this section come from HCFA/CMS (2000b; 2001d).

[11] States may also allow families to establish eligibility as medically needy by paying monthly premiums to the state in an amount equal to the difference between family income (reduced by unpaid expenses, if any, incurred for medical care in previous months) and the income eligibility standard (HCFA/CMS, 1997; http://www.hcfa.gov/medicaid/meligib.htm).

health, however, children accounted for only about 14 percent of Medicaid expenditures of nearly $170 billion dollars that year (Kaiser Commission on Medicaid and the Uninsured, 2001).

Within federal requirements (and monitoring capabilities), states have considerable discretion to establish eligibility for Medicaid, determine the scope of services covered (e.g., number of physician office visits during a year), set levels of enrollee cost sharing for adults except pregnant women (e.g., $5 per office visit), establish methods and rates of payment for services, and administer the program. Federal law requires, however, that state Medicaid programs cover a generally broader array of services for children than for adults. The major vehicle for achieving this objective was 1969 legislation (P.L. 90-248) and subsequent amendments requiring coverage for early periodic screening, detection, and treatment (EPSDT) services for those under age 21. In 1989, Congress specifically defined the required EPSDT benefits (P.L. 101-239). It also required states to provide necessary health care, diagnostic services, treatment, and other measures to "correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan" (42 USC §1396d(r)(5)). (See also HCFA/CMS, 2001c). Some states responded by expanding their list of covered services; other states provided that decisions about services not usually covered be made on a case-by-case basis (NASMD, 1999). Box 7.1 lists the services specified in the 1989 legislation.

The EPSDT provisions would seem to require states to provide children (including those with life-threatening medical conditions) access to almost any medical and supportive service identified as needed through screening.[12] In practice, reflecting the potentially large additional costs they would face, states have often been slow to implement EPSDT provisions or have been very restrictive in their interpretations of the provisions (Perkins, 1999; O'Connell and Watson, 2001). These responses have prompted a number of lawsuits, several of which have focused on services for children with mental or developmental disabilities, including those on waiting lists for

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[12] Screening has been unconventionally defined in this context to include certain visits prompted by symptoms. "Interperiodic EPSDT Screening Services are physical, mental, dental, vision or hearing screens described in subsection (b) that, in furtherance of the preventive purpose of the EPSDT benefit: (i) occur at a time other than the applicable periodic EPSDT screening services referenced in subparagraph (A); and (ii) is requested by an enrolled child's family or caregiver or by an individual who comes into regular contact with the child and who suspects the existence of a physical, mental or developmental health problem (or possible worsening of a preexisting physical, mental or developmental health condition)"(CHSRP, 1999, http://www.gwumc.edu/chpr/sps/part1.htm). See also the State Medicaid Manual discussion of medically necessary interperiodic screening (HCFA/CMS Publication 45; http://www.hcfa.gov/pubforms/progman.htm).

home and community-based services. In any case, it is not clear what EPSDT services are effectively available to Medicaid-covered children in each state.

Adding to the complexity of summarizing state Medicaid coverage, most states have been rapidly enrolling beneficiaries in managed care programs, whose specific coverage and other policies also vary. Under Section 1915(b) waivers of "freedom-of-choice" provisions of Title XIX, states can require Medicaid enrollees to enroll in comprehensive or specialized (e.g., behavioral health) managed care plans (HCFA/CMS, 2001a). The Balanced Budget Act of 1997 allows states to institute mandatory enrollment through an amendment to their state plan and thereby bypass this waiver process. One exception is that states must still get a waiver to require managed care enrollment for children with special health care needs, a group that will include some children with fatal or potentially fatal medical conditions (Gruttadaro et al., 2001). This restriction recognizes the particular care requirements and vulnerabilities of special needs children.

In 2000, 56 percent of Medicaid beneficiaries were enrolled in some form of managed care, up from 40 percent in 1996 (HCFA/CMS, 2000b).[13] These percentages include some who were enrolled in more than one kind of plan. In 1998, the percentage of Medicaid beneficiaries enrolled in managed care plans ranged from zero in Alaska and Wyoming to more than 75 percent in a dozen states (HCFA/CMS, 2000b). More than 55 percent of all Medicaid managed care enrollees were children.

In addition to the freedom-of-choice waivers, states can also obtain waivers that allow them to include additional populations or services not otherwise covered under Medicaid. As discussed further below, under Section 1915(c) waivers, states can provide additional home and community-

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[13] As defined by the Health Care Financing Administration (HCFA), now CMS, several Medicaid managed care options exist. *PCCM* (primary care case management) provider is usually a physician, physician group practice, or an entity employing or having other arrangements with such physicians who contracts to locate, coordinate, and monitor covered primary care (and sometimes additional services). This category includes PCCMs and those prepaid health plans that act as PCCMs. *PHP* (prepaid health plan) provides less than comprehensive services on an at-risk basis or provides any benefit package on a nonrisk basis. For example, medical-only PHP, dental PHP, transportation PHP, mental health PHP, substance abuse PHP, etc. *Commercial MCO* (managed care organization) is an HMO, an eligible organization with a contract under Section 1876 or a Medicare+Choice organization, a provider-sponsored organization, or any other private or public organization that meets the requirements of Section 1902(w). These MCOs provide comprehensive services to commercial and/or Medicare enrollees, as well as Medicaid enrollees. *Medicaid MCO* provides comprehensive services to Medicaid beneficiaries, but not to commercial or Medicare enrollees. *HIO* (health insuring organization) provides or arranges for the provision of care and contracts on a prepaid capitated risk basis to provide a comprehensive set of services. *"Other" managed care entity* is used if the plan is not considered a PCCM, PHP, MCO or HIO.

Box 7.1
Scope of Medicaid EPSDT Services for Enrolled Children Required by Federal Statute (42 U.S.C. § 1396d(a)(22))

- Inpatient hospital services (other than services in an institution for mental disease)
- Outpatient hospital services
- Rural health clinic services (including home visits for homebound individuals)
- Federally qualified health center services
- Other laboratory and x-ray services (in an office or similar facility)
- EPSDT services
- Family planning services and supplies
- Physician services (in office, patient's home, hospital, nursing facility, or elsewhere)
- Medical and surgical services furnished by a dentist
- Medical care or any other type of remedial care
- Home health care services (in place of residence)
- Private duty nursing services (in the home, hospital, and/or skilled nursing facility)
- Clinic services (including services outside of clinic for eligible homeless individuals)
- Dental services
- Physical therapy and related services (including occupational therapy and services for individuals with speech, hearing, and language disorders)
- Prescribed drugs
- Dentures
- Prosthetic devices
- Eyeglasses

based services as an alternative to institutional care (Smith et al., 2000).[14] Waiver services do not have to be provided on a statewide basis or to all those with similar levels of need.

Under yet another waiver authority (Section 1115), states can undertake demonstration projects to test innovative program ideas or service concepts. As noted in Chapter 1 and discussed further below, Congress has authorized several state demonstration projects to test innovative approaches to providing comprehensive palliative and end-of-life care for

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[14] When developed for children with disabilities, Section 1915(c) waiver programs are often referred to as Katie Beckett programs for the child dependent on a ventilator whose situation prompted national attention and initial legislative action (Federal Tax Equity and Fiscal Responsibility Act of 1982, P.L. 97-248).

- Other diagnostic, screening, preventive, and rehabilitative services, including medical or remedial services recommended for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level (in a facility, home, or other setting)
- Services in an intermediate care facility for the mentally retarded
- Inpatient psychiatric hospital services for individuals under age 21
- Services furnished by a midwife, which the nurse-midwife is legally authorized to perform under state law, without regard to whether or not the services are performed in the area of management of the care of mothers and babies throughout the maternity cycle
- Hospice care
- Case management services
- Tuberculosis-related services
- Respiratory care services
- Services furnished by a certified pediatric nurse practitioner or certified family nurse practitioner that the practitioner is legally authorized to perform under state law
- Community-supported living arrangement services (e.g., personal assistance, habilitation services, assistive technology), to the extent allowed and defined in 42 U.S.C. §1396u
- Personal care services (in a home or other location) furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease
- Primary care case management services
- Any other medical care, and any other type of remedial care recognized under state law, specified by the secretary (includes transportation and personal care services in a recipient's home)

SOURCE: Perkins, 1999.

children and families. Eligibility for services provided under this demonstration waiver authority is not restricted to low-income families. A condition for both Section 1915(c) and Section 1115 waivers is that they be budget neutral (i.e., not generate costs to the federal government more than occur without the waiver).

As discussed in a later section on professional and provider payment, Medicaid coverage for specific services is less an issue for many physicians, hospitals, and Medicaid enrollees than is the level and predictability of payments. A significant fraction of physicians do not accept Medicaid patients because payment levels are low and claims administration can be frustratingly inconsistent (Yudowsky et al., 2000; see also AAP, 1999d). This can result in access problems for children covered by Medicaid.

Medicaid Coverage of Home Hospice

Under federal Medicaid requirements, hospice is an optional benefit for adults. Most state Medicaid programs include hospice, but programs in Connecticut, Nebraska, New Hampshire, Oklahoma, and South Dakota do not (Tilly and Weiner, 2001). For children, however, the 1989 EPSDT amendments cited earlier include hospice as a covered service. Therefore, children should have coverage for hospice even in states that do not provide hospice coverage to adult Medicaid enrollees.

The Medicaid hospice benefit follows the Medicare benefit in defining covered services, payment categories, and payment rates. Like Medicare enrollees, Medicaid enrollees must be certified as having a life expectancy of six months or less and must agree to forgo curative treatment (interpreted to include life-prolonging therapies) of their terminal illness in order to be eligible for the hospice benefit (MedPAC, 2002). Even when children are enrolled in Medicaid, hospice services may not be covered because the physician is unable or reluctant to certify a six-month prognosis. As discussed in Chapter 4, determining prognosis is even more difficult and uncertain for children than for adults. Also, families seeking assistance from hospice may still want the option of potentially life-prolonging interventions for their child. Medicaid home health benefits (discussed below) may cover some but not all of the services provided by hospices.

Although Medicaid beneficiaries have to forgo curative care to receive hospice benefits, federal law no longer requires that Medicaid beneficiaries receiving hospice care give up other supportive Medicaid services. Specifically, the Omnibus Budget Reconciliation Act of 1990 (P.L.101-508) allows "payment for Medicaid services related to the treatment of the terminal condition and other medical services that would be equivalent to or duplicative of hospice care, so long as the services would not be covered under the Medicare hospice program. This means that Medicaid can cover certain services which Medicare does not cover" (HCFA/CMS, 2001b).

Nonetheless, it appears that some state Medicaid programs (e.g., New York) may force families to choose between hospice and more benefits for home and community-based services (Tilly and Weiner, 2001). Hospice personnel have repeatedly mentioned this as a concern in discussions with committee members and staff. The apparent divergence between federal policy and some state practice requires further attention as an inappropriate barrier to needed services for dying children.

In addition, Huskamp and colleagues (2001) have noted access problems for some high-cost hospice patients (e.g., those requiring expensive pain medications, blood transfusions[15]) enrolled in Medicare. Providers

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[15] The committee understands that some hospices lack staff expertise to manage blood or platelet transfusions and that some view transfusions as too aggressive for a palliative inter-

reported that hospices would not enroll some patients because the hospice felt it could not afford to provide the high-cost services needed by a patient, given the Medicare (and Medicaid) per diem rates for hospice care. Alternatively, patients might be enrolled under the condition that certain high-cost items would not be provided by the hospice. The extent to which Medicaid patients—adults or children—experience this kind of access problem warrants investigation.

Medicaid Coverage of Home Health Care

A child's eligibility for home care services under Medicaid can be difficult to determine given the complexity of federal Medicaid provisions and the variability in state Medicaid policies (see, e.g., Smith et al., 2000). Under federal law, required home health services for eligible beneficiaries include nursing care, home health aides, and medical supplies and equipment.[16] Optional home health services include physical and occupational therapy. States have the option to cover personal care services, including assistance with bathing, dressing, and other routine daily activities.

Nearly all state Medicaid programs also provide some home care coverage under Section 1915(c) waivers that—as noted earlier—encourage a wide range of home and community-based services as an alternative to institutional care. The federal waiver provisions specifically mention home health, personal care, case management, respite care, adult day health services, habilitation services, and homemaker services. Eligibility for services provided to children under this waiver authority is not necessarily restricted to low-income families, but coverage need not be state wide, and the groups targeted for assistance may be quite narrow (e.g., persons with brain injuries).

Again, notwithstanding general Medicaid policies, EPSDT provisions would appear to require that a range of home care and home health services

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vention. Other hospice and palliative care experts believe that such transfusions are appropriate (but costly) ways to prevent or manage serious visible bleeding associated with the late stages of certain cancers and other diseases (see, e.g., Goldman, 1999).

[16] A recent report has noted confusion about Medicaid home health benefits. "Since 1970, home health services have been mandatory for persons entitled to nursing facility care. Confusion about eligibility for home health services has arisen because the term entitled to nursing facility care has sometimes been erroneously interpreted to mean that people must be eligible for nursing facility care—i.e., that they must meet a state's nursing facility level-of-care criteria—in order to receive home health benefits. This erroneous interpretation has persisted notwithstanding its conflict with home health regulations prohibiting a state from conditioning eligibility for home health services on the need for or discharge from institutional care" (Smith et al., 2000, no page number).

be covered for children for whom such services are necessary. Also, as discussed below, other federal and state programs—primarily those funded by Title V—may assist with home and other services for children with special health care needs and their families. Medicaid coverage for telemedicine services in the home is limited. Compared to private insurers, however, states appear to have been somewhat more receptive to arguments for such coverage (OAT, 2001; see also http://www.hcfa.gov/medicaid/telemed.htm).

Medicaid Coverage of Inpatient Hospital Care

As is the case for private insurance, much of the emergency, intensive, and palliative care provided to children who die is covered as an inpatient service. The EPSDT services listed earlier in Box 7.1 do not include inpatient palliative care specifically, but EPSDT coverage requirements would seem to extend to almost any medical and supportive service identified as needed by a child. The committee found no information on coverage in practice for hospitalized children receiving only palliative services. The same kinds of reimbursement issues mentioned in the review of private coverage of inpatient palliative services apply in a general sense to Medicaid and are discussed further below.

Medicaid Coverage of Outpatient Prescription Drugs

Prescription drug coverage is optional for adults covered by Medicaid, but federal EPSDT policy requires coverage for children and also prohibits cost-sharing requirements (Bruen, 2000, 2002). Some states set no restrictions on the number of covered prescriptions for children, whereas others require prior authorization once a numerical limit is reached. For example, a South Carolina survey reported that five of eight southeastern states had no restrictions on the number of prescriptions for children, but three required preauthorization for prescriptions above a specified number (e.g., six per month in Georgia and North Carolina) (Legislative Audit Council, 2000). Limits on the number of prescriptions covered could create a barrier to effective symptom management for children with life-threatening medical problems and multiple or difficult symptoms.[17]

Federal legislation passed in 1993 (P.L. 103-66) allowed states to institute a number of restrictions on coverage of prescription drugs, including

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[17] As discussed in Chapter 10, many drugs approved for use with adults do not have dosing information for children, and recent legislation includes incentives and requirements to stimulate the research needed to provide such information.

prior authorization requirements and closed formularies (Kaiser Commission, 2001).[18] If a drug is excluded from a formulary, patients must still be able to seek coverage through a prior approval process. Several state Medicaid programs (e.g., Michigan, Florida) recently announced an intention to implement a closed formulary (Bruen, 2002). As is true for private health plans, one goal of formulary implementation is to negotiate lower drug prices or additional services (e.g., chronic disease management programs in Florida) with manufacturers.

How restrictive closed Medicaid formularies are or will be is still unclear, as is how they may affect children with life-threatening medical conditions and their families. Their restrictiveness will depend on the burden imposed by the prior approval process and on the extent to which the formulary includes an adequate number and choice of drugs effective for the palliation of pain and other symptoms.

Managed care introduces another complication for assessments of outpatient prescription drug coverage. A 1999 report on Medicaid formularies concluded that "some states do not monitor to see whether managed care organizations are assuring that Medicaid recipients receive the Medicaid pharmacy benefit. Since often only a closed formulary is available to their commercial members, providers [managed care plans] may not treat Medicaid recipients differently" (Bazelon, 1999, online, no page number).

Legislation in 1990 (P.L.101-508) required states to develop retrospective and prospective Medicaid drug utilization review programs. A retrospective program could, for example, involve profiling of providers in an attempt to reduce inappropriate prescribing patterns. A prospective program could involve the use of automated systems that produce an alert when prescriptions might result in drug–drug interactions for a patient. The goals of these programs can include monitoring safety and quality of care as well as cost containment (Kaiser Commission, 2001). The effects on children living with life-threatening conditions could be positive or negative depending on which drugs were monitored and what safety or quality criteria were used.

Medicaid Coverage of Psychosocial, Respite, and Other Services

State Medicaid programs are required to cover a broader range of mental health services for children than for adults. Most attention has

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[18] Federal law allows Medicaid programs to exclude drugs from their formulary under two conditions: (1) when the exclusion is based on labeling or information in official medical compendia and (2) when the drug offers no clinically significant advantage related to safety, effectiveness, or health outcome over other drugs (Omnibus Budget Reconciliation Act of 1993, P.L. 103-66).

focused on EPSDT-required services for the early identification and treatment of children's mental health problems and on long-term services for children with developmental disabilities or mental illness.

A number of different categories of professionals provide mental health services, but state policies vary on whether they directly reimburse psychologists, social workers, clinical nurse specialists (psychiatric), and other nonphysicians for services provided to Medicaid beneficiaries. According to a 1995 analysis by the American Psychological Association, 42 states allowed direct payment to psychologists for EPSDT services (APA, 1995).

With increasing numbers of children enrolled in managed care plans, scrutiny of these plans includes contract provisions and plan practices (e.g., prior authorization based on "medical necessity" determinations) that may affect the availability and quality of mental health services for children, especially those with special needs (see, e.g., NIMH, 1998; Stroul et al., 1998). Scrutiny is also being directed at the practices of specialized managed behavioral health organizations into which states have directed Medicaid beneficiaries with behavioral health problems. Some studies suggest that families tend to have difficulties getting timely referrals from Medicaid managed care plans for mental health services—even short-term services—for children with special needs (see, e.g., Fox et al., 2000).

Although problems with Medicaid coverage of mental health services will affect some children who die and their families, they do not appear to be high-priority concerns for this population. Clinicians and families are generally focused on other issues.

Bereavement services for family members of a child who dies are not explicitly covered by Medicaid outside the hospice benefit. (As discussed later, payment for such services is included in the per diem payments to hospices, which end with the patient's death.) A parent or sibling covered by Medicaid in his or her own right might, however, be able to receive supportive mental health services upon referral for a diagnosis of depression or certain other emotional problems.

As Box 7.1 indicates, state Medicaid programs are not required under federal law to provide respite care, which offers family members rest and relief from the demands of caring at home for a child with major health care needs. Some states have applied for waivers to cover such services, but these are usually limited to a subset of diagnoses or conditions (e.g., severe mental retardation) (see, e.g., http://ddd.state.wy.us/Documents/kathy1.htm and http://www.dhs.state.tx.us/programs/communitycare/mdcp/services.html). In reality, Medicaid in-home services for a child may provide respite to the child's family caregivers, but this is not their explicit purpose.

Innovations in Medicaid Coverage

In 1999, Congress appropriated funds for a series of demonstration projects to support the development of children's hospice programs that provide integrated medical, social, and other services to children with life-threatening medical conditions (CHI, 2002). A major task for these projects, called Programs for All-Inclusive Care for Children and their Families (PACC), is to identify obstacles to such integrated care that are related to Medicaid and other regulations. In its solicitation of proposals from these states (HCFA/CMS, 2000c), the government described the most burdensome obstacles to pediatric palliative care:

- requirements that limit hospice eligibility to children certified by a physician as being within six months of death;
- regulatory limits on the array of services that a child may need, including skilled, intermittent, and 24-hour nursing care, respite care, music and other therapies designed to meet children's developmental needs, and bereavement care;
- payment limits that discourage hospices from accepting children who require expensive care;
- waiver program provisions (e.g., requirements that a child needs an institutional level of care) that are not fitted to the needs of children who could benefit from hospice care; and
- EPSDT programs that are inconsistent or too narrow.

The goals of the demonstration projects include (1) identifying children and families who could benefit from better integration and coordination of palliative, end-of-life, and bereavement services; (2) devising integrated care strategies and identifying necessary waivers of restrictive regulations; (3) reducing hospital use by increasing services in the community; and (4) increasing awareness of state officials, providers, and health care professionals of unmet needs and stimulating interest in further initiatives to meet those needs. Projects must show that the programs are not expected to increase a state's Medicaid costs.

As specified in the appropriations conference agreement for FY 2000, the five initial projects are located in Florida, Kentucky, New York, Utah, and Virginia. A project in Colorado has since been approved. The projects differ in scope and strategies (CHI, 2002). Appendix H describes the approach in New York state to developing the demonstration project.

State Children's Health Insurance Program

Congress created the State Children's Health Insurance Program in 1997 as Title XXI of the Social Security Act.[19] The objective was to increase health insurance coverage for lower-income children through Medicaid expansions or creation of separate state programs or both. (If a child is legally eligible under a state's Medicaid program requirements, he or she is supposed to be enrolled in Medicaid as such.)

With federal matching funds, states can extend coverage to children in families with incomes that are 200 percent of the federal poverty level. For states that had already expanded Medicaid eligibility to optional groups, the law raised the income threshold to 50 percent above the state's existing limit. Certain technical actions (i.e., use of "income disregards" allowed for in Medicaid under Section 1931 of Title XIX) can allow other states to exceed the 200 percent figures (AHSRHP, 2001). State SCHIP programs are, like state Medicaid programs, highly variable.

Separate SCHIP programs may or may not provide the same covered benefits as the state Medicaid program and may or may not use state-approved Medicaid managed care plans to provide services. A recent analysis indicated that "among the 34 states with separately administered SCHIP programs in effect in 2000, 32 states use coverage exclusions that would not be permissible in Medicaid" (Rosenbaum et al., 2001, p. 2). Services that tended to be excluded from separate SCHIP programs were hospice, case management services, and home and community-based services. Depending on the availability of other support, the result could be inadequate palliative and end-of-life care for children and their families. Also, if the state creates a separate SCHIP program, it is not precluded—as it would be for its Medicaid program—from requiring copayments.

For states with separate SCHIP programs, coverage may be part of the basic program or part of a program designed specifically for children with special needs. Some state programs, for example, Wisconsin's BadgerCare program, also offer coverage to low-income uninsured parents who have a child under age 19 living with them (see http://www.dhfs.state.wi.us/badgercare).

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[19] For general information about SCHIP, several Web sites provide useful descriptions or analyses including CMS/HCFA (http://www.hcfa.gov/init/children.htm); George Washington University's Center for Health Services Research and Policy (http://gwhealthpolicy.org); American Academy of Pediatrics (http://www.aap.org/advocacy/schip.htm); and American Public Health Association (http://www.apha.org/ppp/schip/); and Health Services Research (http://www.hsrnet.com/pubs/pub04.htm).

Other Sources of Financing

Title V Maternal and Child Health Block Grants

In addition to public insurance programs such as Medicaid and SCHIP, Title V block grant programs in each state provide services directly to a broad range of chronically ill children (Gittler, 1998; MCHB, 1998).[20] In 1989, Congress required state Title V programs for children with special needs "to provide and promote family-centered, community-based, coordinated care . . . and to facilitate the development of community-based systems of services for such children and their families" (MCHB, 2000b, online, no page number; P.L. 101-239).

As discussed in Chapter 2, children with special needs are those who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Children covered by Title V programs have conditions that tend to fall into three broad, overlapping groups: (1) developmental disabilities or delays (e.g., mental retardation); (2) chronic illnesses or ongoing medical disorders (e.g., diabetes, severe asthma); and (3) emotional or behavioral problems (e.g., attention deficit disorder). Depending on state eligibility criteria, children who have diagnoses such as fatal neurodegenerative diseases and certain cancers could be eligible for Title V services. Overall, however, most children covered by Title V programs have chronic conditions and disabilities that are not usually expected to lead to death in childhood, and the programs are not explicitly intended to provide or assist end-of-life care.

The Maternal and Child Health Bureau administers the federal Title V program. It conceptualizes Title V-supported activities as a "pyramid" consisting of (1) direct personal services, (2) enabling services that assist children and families in obtaining coverage or services, (3) population-based preventive services, and (4) infrastructure-building activities (e.g., support for information systems, standards development, program evaluation). One long-standing positive feature of state programs for children with special health care needs is their concern with the organization, coordination, and availability of services (Ireys, 1996).

Children with special health care needs may be identified for assistance in many ways, including family inquiries about the availability of assistance, referral by physicians and other care providers, and state outreach

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[20] In addition to information from the Maternal and Child Health Bureau, this discussion draws on reports and analyses prepared by Ireys, 1996; Fox et al., 1998; Fox et al., 2000; Kaye et al., 2000; and AHRQ, 2001a.

programs. In addition, when the Social Security Administration determines that a child under age 18 is eligible for Supplemental Security Income (SSI),[21] the child and family are referred to state programs for children with special health care needs for assistance in securing needed services and enrolling children in Medicaid. In some states, Medicaid enrollment for children with SSI is automatic.

Within the requirements of federal law, states have considerable discretion to establish the scope and organization of programs for children with special health care needs. They have different criteria for financial eligibility, provide different services in different ways, and vary in the definition of qualifying diagnoses or conditions. Congress has, however, required state programs to provide and promote family-centered, community-based, coordinated care. A major recent emphasis of Title V programs has been on promoting enrollment of children with special health care needs in managed care plans, monitoring results, and encouraging program and plan adjustments to better serve these children and their families.

Family Payments and Caregiving

Figure 7.1, presented earlier, includes information on the source of insurance coverage for children rather than the source of payment for services. Thus, it does not refer to out-of-pocket payments by families. Little specific information is available on the share of palliative and end-of-life care for children that is paid for by families out-of-pocket, although some hospices can identify the share of their income derived from family or individual payments.

Young families with children often have limited resources—both income and savings—to cover the considerable health care costs generated by a child's serious illness or injury. Some qualify for Medicaid coverage or other public programs only after they have "spent down" their own financial resources, lost or given up their jobs to care for a child, or otherwise impoverished themselves.

As described in Chapters 4, 5, and 6, families also support their ill or injured children by personally providing much health and supportive care. Although the care provided by a mother, father, or other relative cannot be valued merely in economic terms, a comprehensive analysis of the economic

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[21] Under the Social Security Act, a child is eligible for SSI payments if he or she has a physical or mental condition or conditions that can be medically proven and that can result in marked and severe functional limitations and that must last, or be expected to last, at least 12 months or be expected to result in death.

aspects of child illnesses would include not only out-of-pocket payments but also unpaid care and time lost from caregiver's paid work.

In addition to initiatives to extend insurance coverage for children, efforts to assist family caregivers through training, respite services, and other support have been growing. Public and private financing of assistance for caregivers is, however, still limited and often offered only to narrowly defined groups, such as families of children with severe developmental disabilities or adults with dementia. A recent review for the American Associated of Retired People of 25 state programs for caregivers concluded that many have such limited budgets that they can serve only a small number of caregivers. The review also concluded that increased funding would help more people seeking to keep a family member at home, but increased flexibility is also needed to fit the diverse circumstances and needs of family caregivers (Coleman, 2000).

Health Care Safety Net

This country's so-called health care safety net for the uninsured and underinsured has been characterized as "a patchwork of providers, funding, and programs tenuously held together by the power of demonstrated need, community support, and political acumen" (IOM, 2000a, p.17).[22] In addition to direct Medicaid and Medicare payments for patient services, the resources for safety-net providers are a variable and often unreliable mixture that includes other local and state government support, patient payments, philanthropy, volunteer services, and federal payments for hospitals caring for a "disproportionate" share of low-income patients.

As defined in a recent Institute of Medicine (IOM) report, the health care safety net consists of "those providers that organize and deliver a significant level of health care and other related services to uninsured, Medicaid, and other vulnerable patients" (IOM, 2000a, p. 3). Core safety-net providers are those that "either by legal mandate or explicitly adopted mission . . . maintain an 'open door,' offering access to services for patients regardless of their ability to pay" (p. 3–4).

For many seriously ill children, children's hospitals, academic medical centers, community hospital emergency departments, and other providers act as an important but precarious safety net. Nonetheless, given its un-

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[22] In decades past, public and private insurance payments subsidized care to the uninsured. Today, the opportunities for such cross-subsidies are limited or nonexistent in a world of competitive markets, health plan contracts, discounts from charges, global per-case payments related to diagnosis, and other cost-control strategies (see, e.g., IOM, 2000a; MedPAC, 2000a).

stable financial base, this system cannot promise reliable, continuing, coordinated care to uninsured and underinsured children with life-threatening conditions.

Philanthropy and Volunteer Funding and Services

Philanthropy clearly plays a role in funding some palliative and end-of-life services for children and their families, but no data on the level or trends in such funding are available. Examples of philanthropic support for pediatric palliative care include

- targeted community events to raise funds for palliative and hospice services for children and families,
- inclusion of pediatric hospices in United Way campaigns,
- foundation grants to support pediatric palliative care programs in children's hospitals,
- sponsorship of "make-a-wish" and similar programs,
- grants and fundraising for camp programs that serve sick children or siblings, and
- organization of community-based and on-line support groups.

Faith communities also support grieving families spiritually and emotionally. In addition, many enlist clergy and volunteers to provide counseling, visiting, transportation, meal delivery, and other services to families with sick children. Some also fund parish nurse and other programs that provide health and supportive services.

Some philanthropic contributions support direct services for individuals. Other funds go to projects intended to improve the quality of such services, for example, through the assessment of community needs or the development of tools for assessing symptoms and the adequacy of symptom management.

Even in countries in which most health services are financed publicly, hospices may out of choice or necessity rely substantially on private philanthropic contributions and volunteer services. For example, in England, most children's hospice programs were established outside the structure of the National Health Service, although they may receive government payments as well as philanthropic grants and volunteer services.

Clinical Trials

Most clinical trials are designed to test therapies that researchers hope will prevent, cure, or slow the progression of disease or save injured persons from death or disability. Some trials are intended to test therapies that will prevent or relieve pain, nausea, and other symptoms that arise from illnesses and injuries or their treatment. Trials may involve problems that are not life threatening, but many enroll patients with very serious conditions. Thus, although usually not intentionally, some end-of-life care is financed by research grants and other funds for clinical trials.

Insurance payments for those participating in clinical trials have long been controversial. Some private insurers have agreed to pay for certain trials or for routine care associated with trials, although many today and in the past have undoubtedly paid for such care without knowing it (IOM, 2000d; NCI, 2001b).[23] In June of 2000, the President directed that Medicare explicitly authorize payment for routine patient care costs and costs to treat complications associated with participation in clinical trials.[24] A recent study found that nearly 90 percent of Blue Cross Blue Shield plans already pay for routine care in clinical trials, and some encourage the creation of clinical trials to test certain therapies (IOM, 2000d). Coverage of investigational drugs is permitted by a few Medicaid plans, but the committee found no comprehensive information on such policies.

HOW PHYSICIANS, HOSPITALS, AND OTHER PROVIDERS ARE PAID

Overview

How insurers pay providers and how much they pay them can significantly affect child and family access to palliative and end-of-life care and

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[23] Routine costs have been defined to be those items or services that are "(1) typically provided absent a clinical trial (e.g., conventional care); (2) required solely for provision of the investigational item or service (e.g., administration of a noncovered chemotherapeutic agent), the clinically appropriate monitoring of the effects of the item or service, or the prevention of complications; and (3) needed for reasonable and necessary care arising from the provision of an investigational item or service—in particular, for the diagnosis or treatment of complications" (HCFA/CMS, 2000d).

[24] The Health Care Financing Administration (HCFA), now the Centers for Medicare and Medicaid Services announced in September 2000 that clinical trials with a therapeutic purpose that will qualify automatically include "1. Trials funded by NIH [National Institutes of Health], CDC [Centers for Disease Control and Prevention], AHRQ [Agency for Healthcare Research and Quality], HCFA, DOD [Department of Defense], and VA [Department of Veterans Affairs]; 2. Trials supported by centers or cooperative groups that are funded by the NIH, CDC, AHRQ, HCFA, DOD and VA; 3. Trials conducted under an investigational new drug application (IND) reviewed by the Food and Drug Administration [FDA]; and 4. Drug trials that are exempt from having an IND under 21 CFR 312.2(b)(1) will be deemed automatically qualified until the qualifying criteria are developed and the certification process is in place" (announcement at www.hcfa.gov/coverage/8d2.htm). Because Medicare covers few children, this program change will have little impact on children and their families unless Medicaid and private payers adopt similar policies.

also influence the quality of that care. Depending on the specifics, methods and levels of payment can encourage undertreatment, overtreatment, inappropriate transitions between settings of care, and inadequate coordination of care.

The past two decades have seen major changes in the way Medicare pays physicians, hospitals, and other care providers for their services. Many Medicaid and private insurers in the United States have followed Medicare's lead and changed their payment methods to mirror those of Medicare. Even when other payers have not adopted the same payment methods as Medicare, they may use elements of those methods for analytic and monitoring purposes. Thus, even though Medicare covers few children,[25] Medicare payment policies may have significant spillover effects on children and adults covered by Medicaid or private payers. Further, because Medicare is such an important payer, providers may develop perceptions and standard operating procedures based on Medicare policies that they then apply to patients covered by other payers and other payment methods. For these reasons, it is useful to understand Medicare payment policies and methods.

In 1983, Medicare adopted a prospective payment system (PPS) for inpatient hospital care. Under the PPS, Medicare reimburses hospitals a fixed payment per inpatient discharge regardless of length of stay. As explained below, the level of payment for each discharge varies based on the diagnosis-related group (DRG) into which the discharge is classified. The Balanced Budget Act of 1997 mandated the adoption of PPSs for other services, including home health care and skilled nursing facility care. Later legislation modified some provisions, but the basic direction of change—toward prospective payment—remains.

The primary goals of prospective payment methods have been to limit the rate of increase in health care costs, increase efficiency in health care, and make cost trends more predictable. In addition, they also may reduce certain kinds of administrative burdens and allow health plans more flexibility. Depending on how providers react, the quality of care could improve (e.g., if unnecessary services are cut) or decrease (e.g., if beneficial services are curbed or patients are discharged before they or their out-of-hospital care providers are ready).

Prospective reimbursement systems can, however, threaten access to care for patients with particularly high-cost needs (i.e., needs for which the cost considerably exceeds the fixed payment for care). As noted above, Huskamp and colleagues (2001) documented reports from multiple loca-

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[25] As noted in an earlier footnote, the Medicare End-Stage Renal Disease Program covers a small number of children (HCFA/CMS. 2000e).

tions of patients with high-cost care needs being denied access to hospice because the cost of the services required would far exceed the hospice per diem payment. Efforts to "risk-adjust" Medicare payments to match patient characteristics continue, but no approach is yet considered satisfactory (MedPAC, 2000a).

The use of separate payment systems by Medicare and other payers for different types of services also creates incentives for shifts in the setting of care that may not be most appropriate for patients. Huskamp and colleagues (2001) documented providers' reports of transitions between care settings that were attributable to financial incentives in the Medicare fee-for-service program and that negatively affected the quality of care for the dying patient in the view of the provider.

The choice of payment method inevitably involves trade-offs between desired goals such as cost containment and other goals such as equity or quality of care. Methods that put hospitals and physicians at greater risk (e.g., DRGs, capitation) have the potential to stimulate reductions in both appropriate and inappropriate care. Quality monitoring systems can identify some unwanted responses, but these systems have their own costs and limits. Payment methods that put providers at higher risk also may jeopardize the survival of needed safety-net institutions, rural providers, or others whose services are not easily replaced.

The choice of payment level also involves trade-offs. On the one hand, stringent payment levels may promote efficiency and economy. On the other hand, if a health plan's payments are below costs for an efficient provider or are less than what other plans pay, providers may refuse to serve that plan's enrollees. Such payments may also threaten the survival of physician practices and hospitals, especially in low-income areas where few patients are covered by better-paying health plans.

Hospital Payment

Hospitals are paid by a variety of methods. The per-discharge DRG method used by Medicare is important because Medicare is the major source of inpatient revenue for most acute care hospitals serving adults. Some other payers have adopted DRG-based payment methods. Others use older cost-based reimbursement methods (usually in the form of a per diem payment), pay a specified percentage of hospital charges, or use hybrid methods. Many managed care plans have negotiated general or specialty capitation rates with hospitals. To the extent they can pay anything, individuals without health insurance (or with insurance that does not pay for certain care) may have to pay hospital charges, which do not necessarily bear much relationship to the cost of providing services and are typically significantly higher than DRG, cost-based, or negotiated payment rates.

Initially, children's hospitals, as well as psychiatric, rehabilitation, long-term care, and cancer hospitals, were excluded from Medicare's shift to prospective case-based payment. In the Balanced Budget Act of 1997 (P.L. 105-33) Congress specified that a PPS be implemented beginning in 2001 for rehabilitation hospitals and in 2002 for long-term care hospitals. In the Balanced Budget Refinement Act of 1999 (P.L. 106-113*)*, Congress also required the Health Care Financing Administration (HCFA), now the Centers for Medicare and Medicaid Services (CMS), to report on a modified prospective payment system (per diem) for psychiatric hospitals and psychiatric units of other hospitals. Medicare payments to children's hospitals continue to be based on current costs or historical costs adjusted for inflation, whichever is less.

The move by Medicare—and other payers—from cost-based, retrospective reimbursement to prospective payment has had many effects on hospitals and other parts of the health care system (see, e.g., ProPAC, 1989, 1996; MedPAC, 2000b, 2001).[26] It has put pressure on hospital operating margins, encouraging efficiency but also affecting hospitals' willingness and ability to subsidize care for patients unable to pay for services. Hospitals have raised charges for privately insured patients, and private insurers have reacted by also adopting DRGs, negotiating discounts or capitation payments, and taking other protective steps. These steps have, in turn, made uncompensated care an even more critical problem and generally put services perceived as "nonessential" or "not contributing to the bottom line" in jeopardy. Safety-net providers, who serve many poor children, have been particularly affected.

Prospective per-case payment provides strong incentives for covered hospitals to shorten lengths of stay, and this effect or mind-set may extend to patients covered by other programs. In the 1980s, reductions in lengths of stay led to concerns that some patients were being discharged prematurely. Research has been mixed on this point (see, e.g., ProPAC, 1989; Kosecoff et al., 1990; Rubenstein et al., 1990). In any case, many patients who were discharged to nursing homes, personal homes, or elsewhere clearly had greater needs for out-of-hospital care than such patients previously did.

Because hospital care is generally better insured than other care, shifting care to nonhospital settings often increases the financial burden on patients and families. The pressure for quick discharges may make it difficult to mobilize appropriate hospice care or other alternatives promptly

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[26] Medicare uses an outlier payment mechanism to reimburse hospitals for particularly high-cost inpatient hospital stays. Hospitals are reimbursed 80 percent of expenses above the hospital threshold for the DRG, a number based on estimates of marginal costs for a hospital. Medicare also adjusts payments to reflect differences in local wage rates as well as other factors.

enough. It also limits time for teaching the family about how to provide needed, sometimes complex, care at home. This has been a frequent concern of hospital palliative care teams and hospices (IOM, 1997).

Concerns about possible negative effects of DRG-based payment on quality of care reinforced Medicare's efforts to develop better methods for measuring, monitoring, and improving the quality of hospital and other services provided to Medicare beneficiaries (see, e.g., IOM, 1990b; MedPAC, 2000a). Like the introduction of the payment method itself, this focus on quality measurement and monitoring appears to have had spillover effects, influencing the care for other patients.

Payments for Hospital Care Provided to Children

General Children's hospitals and other acute care hospitals serving children are most directly affected by DRGs to the extent that they are used by Medicaid and private payers. Medicare accounts for less than 0.5 percent of discharges from children's hospitals (MedPAC, 2000b), mainly for children with end-stage renal disease (ESRD) and young adults with serious disabling conditions who are continuing with pediatric providers.[27] The committee did not locate information on the proportion of children's hospital discharges (or discharges of children from general hospitals) accounted for by Medicaid programs and other payers using DRG-based payments.

For children not covered by a payer using some form of DRG-based payment, hospitals face an array of other Medicaid, private insurer, and other payment methods and rates. Within a state, Medicaid and other state programs may use different payment strategies for urban and rural hospitals, make exceptions or adjustments for children's hospitals or safety-net hospitals, or treat certain classes of patients or services (e.g., children with special needs, labor and delivery, neonatal) differently. For Medicaid-covered children enrolled in a private managed care plan, the plan's payment strategy will apply, subject to any requirements specified in the contract with the state.

DRGs and Pediatric Care For professionals and institutional providers serving children, a central issue has been the appropriateness of using DRGs

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[27] Because Medicare covers few children, teaching hospitals serving them do not benefit from the payments for graduate medical education (GME) incorporated in Medicare payments. In 1999, Congress provided for a two-year program of GME payments to 56 independent children's hospitals. The Health Resources and Services Administration, which administers the payments, provided almost $40 million in FY 2000 and $265 million in FY 2001, (http://bhpr.hrsa.gov/childrenshospitalgme/).

designed primarily for adults to pay for children's care or to analyze or monitor that care. Although the original analyses on which DRGs were based created groupings for neonatal care, they were based on data from a small sample of community hospitals and did not adjust for birth weight of infants (Schwartz et al., 1991).

Concerned by these methodological problems, researchers have worked to develop appropriate adjustments for infants' and children's care (see, e.g., Payne and Restuccia, 1987; Schwartz et al., 1991; Vertrees and Pollatsek, 1993; Hanson et al., 1998; Muldoon, 1999). In the 1980s, the National Association of Children's Hospitals and Related Institutions (NACHRI) sponsored analyses to develop "pediatric-modified" DRGs (PM-DRGs) and other adjustments (Averill et al., 1998). This project expanded the seven initial neonatal DRGs to 46 DRGs that took into account birth weight and use of surgery or mechanical ventilation. The Department of Defense adopted these modified neonatal DRGs for its civilian health insurance program, which uses its own DRG-based payment method (DOD, 1999). An Internet search suggested that at least three states (Michigan, Iowa, and North Carolina) had devised adjustments for neonatal DRGs. Several Nordic countries are also supporting a project to improve neonatal and pediatric DRGs (NCCD, 2001). An Australian analysis suggested the need to focus on higher costs associated with children less than three years of age and children with congenital anomalies and chronic illnesses (Hanson et al., 1998).

A more general effort to modify DRGs for care provided to patients under age 65 led to work on "all-patient" DRGs (AP-DRGs), since evolved to become all-patient-refined DRGs (APR-DRGs). This work, which takes comorbidities and complications more fully into account, has built on DRG adjustments that NACHRI developed for pediatric care (Averill et al., 1998). Although several states are using the APR-DRG system for various purposes, it is not clear whether any state (other than Maryland) is using it in setting Medicaid payments for hospitals.

An analysis of several DRG systems (sponsored, in part, by NACHRI) concluded that the use of Medicare DRGs for nonMedicare patients would result in underpayments, especially for hospital care provided to "nonnormal" newborns and chronically ill and other children (Averill et al., 1998). To the extent that care for chronically ill children is concentrated in a subset of children's and other hospitals, Medicaid and other payments based on Medicare DRGs will more seriously affect these institutions. (In principle, this could be mitigated with provision for outlier payments and possibly other adjustments.)

A subsequent analysis undertaken by NACHRI concluded that Medicare DRGs overpaid for normal newborns but substantially underpaid for newborns treated surgically, neonates transferred from other facilities or discharged to home health care, and neonates who died (Muldoon, 1999). The analysis also concluded that Medicare DRGs underpaid for care provided by freestanding acute care children's hospitals and major teaching general hospitals.[28]

Because the diagnosis component of DRGs is tied to the clinical modification (CM) of the International Classification of Diseases (ICD), weaknesses in this coding scheme can translate into weaknesses in DRGs. Experts on pediatric disease classification have criticized the current version of the classification system, ICD-9-CM, for the lack of specificity for many congenital anomalies and perinatal conditions. For example, a few codes contain as many as 100 different conditions. As one critic noted, "Although many of these diseases may be rare or low in prevalence they can account for extensive inpatient hospital stays, multiple surgical encounters and outpatient health care consumption" (Wing, 1997, p.1). ICD-9-CM codes undergo constant revision and adjustment, but pediatric groups have complained that the pace of revision is too slow. Implementation of a major revision of the codes, ICD-10-CM, is pending. NACHRI, in collaboration with Children's Hospital and Medical Center in Seattle, is developing a grouping system called Classification of Congenital and Chronic Health Conditions (CCCHC).

Even if an appropriate diagnosis-related classification and grouping scheme is used for inpatient care, the factors selected to convert relative values into actual payments may be set too low to cover the cost of efficient, appropriate services. Analyses show that Medicaid's payment-to-cost ratio improved during the 1990s, although the much higher ratios of private payers were beginning to drop (MedPAC, 2000b).

Payment for Inpatient Palliative Care

Although most inpatient palliative care programs will benefit adults (since adults account for most deaths), the development of more such pro-

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[28] In June 2000, the commission that advises Congress on Medicare payment recommended that the Secretary of the Department of Health and Human Services direct the adoption of a system such as APR-DRGs so that payments would more accurately reflect differences in severity of illness for hospitalized patients (MedPAC, 2000b). The APR-DRG system has about 1,400 groups compared to about 500 for Medicare DRGs. The commission's analysis indicates that such a change, combined with other recommended changes related to calculation of DRG weights and outlier payments, would raise payments for hospitals that treat more seriously ill patients. In response, HCFA agreed that the change could reduce distortions in the current system. However, the agency stated that it would not propose such a change unless it had statutory authority to offset any increases in payments that resulted from changes in hospital DRG coding practices associated with a new classification system (HCFA, 2000f, p. 47103).

grams may stimulate greater attention to inpatient palliative care for children. As described in Chapter 6, approximately one-third of the children's hospitals responding to a recent survey reported that they provide palliative care services, but few have organized programs.

For those who have formally elected hospice care and need inpatient care related to their terminal condition, Medicare and Medicaid payments for inpatient care are made on a fixed per diem basis. The inpatient rate is higher for acute services (e.g., management of intractable pain) and lower for respite care.[29] One study found at least 20 percent of Medicare hospice beneficiaries who used the benefit in 1996 had at least one day of inpatient hospital care covered by the hospice benefit (Gage and Dao, 2000). The committee identified no equivalent information for Medicaid programs or private payers or for those children receiving inpatient hospice care. The commission that advises Medicare on provider payment has noted that hospice rates were developed in the 1980s and has recommended that they be reevaluated for adequacy (MedPAC, 2002).

DRG and other per case payments for other hospitalized patients are likewise based on analyses that largely predate modern palliative care services and technologies for gravely ill patients. Although Medicare adopted a secondary diagnosis code for palliative care in 1996, use of the code does not affect payment under a DRG. An analysis by HCFA concluded that a palliative care DRG was not needed, but the agency's analytic methods have been questioned (MedPAC, 1999). Because per case payment encourages early discharge, including patients who are near death and primarily in need of comfort measures, some hospitals have developed "compassionate nondischarge policies" to allow such patients to remain in the hospital when desired (Smits et al., 2002).

For adult or pediatric inpatient palliative care programs, the reality is that they will have to develop a case for hospital adoption that is based not only on clinical or ethical arguments but also on fiscal considerations.[30] In a world of DRGs, discounted payments, and other constraints, hospital executives for children's hospitals—like their adult hospital counterparts—

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[29] For hospice patients receiving inpatient care, the Medicare per diem payment for acute care was $475.69 ($110.62 for inpatient respite care) in late FY 2001 (HCFA/CMS, 2001f). The aggregate number of inpatient days (general inpatient and inpatient respite) may not exceed 20 percent of the aggregate total number of days of care provided to all Medicare beneficiaries by a hospice during a year. How much the hospital receives would depend, for example, on whether the care was provided under a contract with a community-based hospice and what that contract specified.

[30] Helping palliative care experts develop the business analysis for inpatient programs is one objective of the Center to Advance Palliative Care at Mt. Sinai Medical School, funded in part by the Robert Wood Johnson Foundation (see, e.g., CAPC, 2001; Spragens and Wenneker, 2001).

may view organized palliative care programs as optional rather than as "a core service in the sense that it will help us survive" (Cassel et al., 2000, p. 169). In competing for scarce resources with existing services that already have been pared back to cut costs, advocates will have to develop information or credible arguments that a program

- will offset added costs by reducing other patient care costs (e.g., by allowing a patient to be discharged sooner or moved to a less resource-intensive inpatient area);
- has reliable sources of funding;
- can help the institution meet external accreditation or performance standards set by outside purchaser, patient advocacy, or regulatory groups;
- will increase patient or family satisfaction and attract desirable future admissions; or
- will have some combination of these characteristics.

Some hospitals report tapping foundation grants and philanthropy to fund adult inpatient palliative care programs. For example, Diane Meier, M.D., the director of Palliative Medicine at Mt. Sinai School of Medicine in New York City, described stresses in managing an inpatient palliative care program. "The fiscal environment in New York City teaching hospitals makes it nearly impossible to obtain hospital operations budget support for the program's clinical services. Billing income for physician services covers approximately 10 percent of clinical costs. The rest of the staff's salaries and benefits come from overlapping foundation and federal grants and from philanthropy. The head of nursing at our hospital recently agreed to cover 50 percent of the nurse coordinator's position and is considering covering 50 percent of a second nurse to be hired soon. We do not have enough money to hire a social worker, volunteer-program coordinator, or pastoral counselor" (Meier et al., 2000, p. 141). Meier noted that the lack of staffing raises the risk of burnout among existing personnel and compromises efforts to provide high-quality clinical and educational services. Philanthropy, which can be especially useful in supporting program development and initation, cannot substitute for adequate Medicare, Medicaid, and private insurer payments for inpatient palliative care.

Payment for Physicians and Certain Other Professionals

General

Physicians Until fairly recently, insurers often linked payment for physicians' services directly or indirectly to charges physicians set for their services, although some of the links to an individual physician's fees became rather remote over time.[31] Surgeons and certain other physicians typically received "global payments" that bundled reimbursement for the procedure with some pre- and postprocedure services including time spent communicating with patients and their families. A few health plans (what later came to be called staff model HMOs) established physician groups whose physicians were salaried (as were many physicians working for government institutions).

In 1992, after years of planning and development work, Medicare began to implement a new physician payment system using a resource-based relative value scale (RBRVS) (PPRC, 1988, 1993). The relative values for a service are, in principle, based on (1) the amount of physician work (time, skill, mental effort, stress) that is involved in providing the service, (2) the practice expenses (e.g., office staff, equipment) associated with the service, and (3) the professional liability costs for the service. A conversion factor translates the relative value units associated with a specific service into an actual payment amount. Payments are also adjusted for geographic differences in expenses. The relative values are reexamined every five years and adjusted as appropriate.

A number of Medicaid and private payers have also moved to pay physicians based on elements of the RBRVS. A 1995 study reported that about 40 percent of Medicaid programs and 25 percent of managed care plans used some elements of the RBRVS to pay physicians and that one-quarter of managed care plans did (PPRC, 1995; see also Reisinger et al., 1994). According to the American Academy of Pediatrics (AAP), approximately 60 percent of Medicaid and private payers have adopted an RBRVS method of paying physicians (AAP, 2001e). Some payers have changed relative values to encourage provision of certain services (e.g., primary care). Payers may also use different conversion factors, with Medicaid, in particular, making adjustments to pay physicians less than Medicare.

In addition to or instead of adopting an RBRVS payment strategy, some health plans have negotiated contracts providing for payments to physicians based on substantial discounts from their charges. Other health plans have sought to capitate payment to physicians or physician groups for some (e.g., primary care) or all services using a prospectively set, per-person payment for a defined population, time period, and set of services.

A 1997 survey of 130 managed care plans serving Medicaid beneficiaries found that about 70 percent used capitation for primary care physi-

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[31] For example, under private "usual, customary, and reasonable" methodologies, an individual physician would be paid the lesser of charges or an amount related to that physician's median past charge for the service, a percentile (e.g., the 75th or 90th) of other area physicians' charges for the service, or certain other factors. Medicare originally used a similar payment method.

cians with most of the remainder using discounted fees and a few paying physicians on a salaried basis (Landon and Epstein, 2001). About half of the plans also employed other financial incentives such as bonuses related to individual or group financial performance. A survey of its members by the AAP found that almost 32 percent of respondents reported that their state Medicaid program paid on a capitated basis, 42 percent reported payment on a discounted fee-for-service basis, and 22 percent reported payment on a traditional fee-for-service basis (Yudowsky et al., 2000). For SCHIP enrollees, respondents reported a generally similar distribution of payment methods: 32 percent capitated payment, 47 percent discounted fee-for-service payment, and 18 percent traditional fee-for-service payment. The survey did not cover payments from private health plans.

Other Professionals Separate, direct reimbursement for inpatient services provided by pediatric nurse practitioners, clinical psychologists, clinical social workers, and other professionals is limited, although it has been expanding. Services by some professionals such as nurses, social workers, child life specialists and pastoral counselors are typically part of the overhead expenses for hospitals. They, thus, are vulnerable when hospitals are under financial pressure to look for ways to cut costs.

Pediatric physician groups also may employ various other health professionals who usually cannot bill directly for their services. This means that payments to physicians for their patient care services must also cover the services of these professionals or their employment will be discouraged (Hilden et al., 2001b). Approval to bill payers directly, which is a major objective of many nonphysician professionals, would almost certainly increase the provision of many psychosocial and other supportive services to children covered by Medicaid and private payers. Approval of payments to pediatricians for team conferences (without the patient present) to discuss a child's care could indirectly help support the patient care services provided by nonphysician professionals.

For other professionals who can bill directly, insurers may define the specified procedure or service codes for which they can bill. Payments for the same code may vary by type of professional. States also specify what level of physician supervision (e.g., general versus direct)[32] is required for services provided by nonphysicians.

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[32] "*General supervision* means that the procedure is furnished under the physician's overall direction and control but the physician's presence is not required during performance of the procedure. The training of nonphysician personnel who actually perform the diagnostic procedure and the maintenance of the necessary equipment and supplies are the continuing

Payments to Pediatricians and Others Who Care for Children

RBRVS and Pediatric Care As was the case for DRGs, the research and data analyses for the Medicare RBRVS emphasized services provided to adults by generalist and specialist physicians who care primarily or entirely for adults. Pediatrics was one of the 32 specialties studied, but relatively few services were examined in each specialty. The analyses, in general, did not consider differences in the work required to provide a service (e.g., a surgical procedure) to a child compared to an adult (AAP, 1998a).

Although systematic evidence is limited, providing services to a child may require more resources than providing similar care for an adult (Arnold and Alexander, 1997; AAP, 1998a). For example, it may take several tries to get a wiggling toddler to stay still for a physical examination, especially when some discomfort is involved. Similarly, it may require considerable probing and rephrasing of questions to elicit useful information about physical symptoms from an anxious or upset 6-year-old. Information from parents is often required, and treatment must be discussed with parents, who have legal authority to make treatment decisions and who often must implement them. The AAP (1998a) has also argued that practice expenses (one component of the RBRVS) may be higher for pediatricians than for comparable adult physicians because staff must spend extra time collecting laboratory samples, waiting for a child to dress or undress, and conducting telephone triage.[33]

Level of Payment Internists, pediatricians, and other physicians who provide mostly nonprocedural services have long asserted that payers pay too little for these services compared to surgical, radiological, and other procedures (see, e.g., ASIM, 1981). One goal of physician payment reforms has been to realign payments to reflect resource use. Pediatricians caring for children with life-threatening medical problems continue to be concerned about recognition of the time needed for explanation and counseling of

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responsibility of the physician. *Direct supervision* in the office setting means that the physician must be present in the office suite and immediately available to furnish assistance and direction throughout the performance of the procedure. It does not mean that the physician must be present in the room when the procedure is performed. *Personal supervision* means that a physician must be in attendance in the room during the performance of the procedure" (HCFA, 2001, http://www.noridian.com/medweb/notices/revised%20physician%20super.pdf).

[33] In 1999, HCFA expressed interest in whether there are pediatric services not described in the payment codes it uses or whether there are codes that describe both adult and pediatric services, but for which work varies between the two. Thus, the agency seems to have been receptive to the possibility of such differences (HCFA/CMS, 2001e).

children and parents, an especially critical element of palliative and end-of-life care. Reimbursement for this time-consuming and challenging care is typically very limited and may be entirely unavailable, for example, if the child is not present during discussions with parents (Hilden et al., 2001b).

Most complaints about level of payment focus on Medicaid. In 1994, a government commission concluded that Medicaid fees were still less than 75 percent of Medicare fees and less than half of what private insurers paid (PPRC, 1994). In 2001, the federal government's General Accounting Office reported to Congress that Medicaid fees in the states surveyed were only 29 to 61 percent of Medicare levels for the same services (U.S. GAO, 2001a). In 1997, Congress repealed Medicaid requirements that states reimburse pediatric services at rates sufficient to secure physician participation and access to care similar to that for the general population in the area (see the AAP analysis at http://www.aap.org/advocacy/schippro.htm#reim).

The variability and often low level of Medicaid payments is evident in AAP data on payments for services commonly provided by pediatricians (AAP, 1999d). For example, for a "high-complexity" evaluation and management visit for a new patient, Medicare paid $168 and Medicaid averaged $102 (AAP, 1999d). Among states, Medicaid payments for this visit category varied more than sixfold. New Jersey, Pennsylvania, and Missouri paid less than $25 for each visit, whereas Alaska, Arizona, and Connecticut paid more than $150. To cite another example, fees for newborn resuscitation (CPT 99440—see the explanation below of Current Procedural Terminology [CPT] codes) averaged $124 for all states but ranged from $29 in Maryland and $33 in Rhode Island to $243 in Idaho and $288 for Alaska (AAP, 1999d).

Some states provide higher payments for certain pediatric office and outpatient department visits than for corresponding adult visits (see, e.g., Prestowitz and Streett, 2000; Katz et al., 2001). This is consistent with Medicaid's usually more generous coverage of services for children compared to adults.

Some physicians respond to low levels of Medicaid reimbursement by choosing not to serve Medicaid patients or by limiting the number of such patients they will see. A recent survey of members of the AAP reported that 67 percent of pediatricians in direct patient care accepted all Medicaid patients, considerably higher than the 48 percent reported in the organization's 1993 survey (Yudowsky et al., 2000).[34] The figure varied among states from 48 percent in Oklahoma to 94 percent in Massachusetts.

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[34] The response rate was 67 percent. Members of AAP account for about one-third of all pediatricians in the United States.

Of those responding, 69 percent reported accepting all SCHIP patients, and 76 percent reported accepting all private patients. Overall, nearly 90 percent of respondents reported participating in Medicaid and SCHIP and accepting some patients from these programs.

Of the AAP respondents who limited acceptance of Medicaid patients, 58 percent cited low reimbursement as a very important reason (Yudowsky et al., 2000). The next most common reasons cited were paperwork concerns and unpredictable payment, both cited by around 40 percent of respondents. Margolis and colleagues (1992) reported that participation decisions were also associated with location (higher participation rates in metropolitan areas), "busyness," and availability of other sites of care for Medicaid patients.

Payment, Procedure Codes, and Coverage Policies Another continuing source of discontent among pediatricians as well as family practitioners, internists, and many other physicians is that most payers do not cover certain types of common physician services. Among pediatricians, two frequently mentioned omissions are telephone calls and team conferences. A few Medicaid programs cover telephone consultations, and some cover team conferences (CPT code 99361) as a separate service (AAP, 1999d). Team conferences are an important tool for managing the care of children with complex medical problems and complicated family situations.

Proponents of payment for these services may argue their case by noting that these services have Current Procedural Terminology (CPT) codes that are approved by the American Medical Association (AMA) and are required for billing purposes by Medicare, Medicaid, and other payers.[35] Payers, however, respond that just because the AMA provides a code does not automatically mean that a service is or ought to be covered by a health insurance plan. Although the primary use of the codes is in payment for clinical care, they are also used for internal practice management, research, and other billing purposes (e.g., billing for travel time or testimony in worker compensation or other legal proceedings). Thus, the coding system attempts to be very comprehensive. Establishing a CPT code for a service

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[35] CMS/HCFA's Common Procedural Coding System (HCPCS) incorporates many but not all CPT codes. It also includes some additional codes (termed Level II codes) for nonphysician services that are covered under Medicare Part B (e.g., "J" codes for injectable drugs). Organizations that administer Medicare payment may establish local codes (Level III codes) under certain circumstances (e.g., for a new service not yet assigned a CPT or HCPCS code). In addition, various modifier codes can be added to the CPT codes to indicate special circumstances or provide additional information for payment or monitoring purposes. Use of HCPCS is required by Medicare and many Medicaid programs.

gives the service a certain legitimacy and may be one step in an effort to secure health insurance coverage. (CPT codes for telephone consultations were added in 1995.)

As noted earlier, one conventional principle of health insurance is that insurance is to cover services to cure or restore the functioning of the insured person. Thus, health insurance does not cover autopsies or purely custodial care. Insurance has, however, broadened in purpose to cover an increasing number of preventive services.

On the principle that insurance is for the insured person, Medicare and other payers generally refuse to pay for services when the patient is not physically present, for example, telephone conversations or discussions with family members only. Although limited, some exceptions to the "patient presence" rule exist, and they suggest rationales for some further exceptions that would recognize important realities of decision making and care for children with advanced illness. For example, in 2000, Medicare clarified that in determining payments to a physician for critical care services, it would include time spent with a family member to obtain a medical history, review the patient's condition, or discuss treatment (including limitations of treatment) when the patient was unable or incompetent to discuss his or her own care, provided such discussion was "absolutely necessary for treatment decisions under consideration that day" (HCFA/CMS, 1999). Except for the limitation to decisions on the day of the discussion, these circumstances characterize the situation for many pediatricians and parent decision makers who need to discuss and decide elements of a child's condition or treatment when the child is not present.

To cite another example of coverage for physician services when the patient is not physically present, Medicare began paying in 1995 for physicians (and recently nurse practitioners) to provide "care plan oversight" under certain circumstances for beneficiaries receiving home health or hospice services who require complex multidisciplinary care. The payment can cover a physician's time in discussions with other professionals (including telephone discussions), but it does *not* cover time in similar discussions with family caregivers. Given that family members are often central caregivers for patients at home, this restriction is a disincentive for physicians to oversee family members' understanding and performance of crucial, complicated tasks. Low payments rates are also a disincentive for physicians to provide such oversight (OIG, 2001). Some Medicaid and private plans pay for care plan oversight, but the committee found no comprehensive information about these policies or their implementation.

Claims Administration Claims administration is also a major source of confusion and problems for physicians and others who can bill insurers directly for their services. Procedures for documenting and filing claims for physician care are often complicated and burdensome. For example, for hospice patients, Medicare allows direct billing only by the physician of record. If another physician provides care related to the patient's terminal condition, the hospice must bill Medicare and pay the physician. Some physicians and hospices are unaware of this requirement and, thus, experience claims denials (Huskamp et al., 2001). Such denials may contribute to physician reluctance to care for hospice patients. (As noted earlier, Medicaid programs follow Medicare hospice policies and requirements.)

Another problem involves claims denials when a surgeon and a nonsurgical specialist appropriately provide care to a child on the same day. For example, even when a Medicaid program has explicitly stated a contrary policy, it appears that administrative entities sometimes deny payments to a pediatric oncologist or cardiologist for consultative services on the same day that a child undergoes a surgical or other procedure performed by another physician (Hilden et al., 2001b). In other situations, payment is denied for appropriate care because two physicians should use different procedure codes but their billing systems cannot coordinate this. Thus, when a surgeon concludes that surgery will not save a patient with cancer or a heart defect, the child's oncologist or cardiologist may find a claim denied for his or her difficult and time-consuming work of communicating the grim news and discussing care options with parents. Many groups provide seminars and other services to help physicians and physician office staff understand coding and billing procedures.

Other problems relate to the complex documentation required for claims, particularly physician evaluation and management services (MedPAC, 2000a).[36] These services constitute a large part of pediatric palliative care. (In general, the codes for evaluation and management services are used to categorize the intensity, comprehensiveness, and complexity of services that a physician provides during a patient visit. Different codes are used for new and established patients and for visits in different locations, such as hospitals or physicians' offices.)

Documentation issues are not well described for Medicaid programs and private payers, but these payers may follow claims administration procedures established for Medicare. The committee understood that claims for the EPSDT services that are covered for children but not adults sometimes cause confusion for Medicaid claims administrators. With payment levels for Medicaid often very low and not always consistent, physicians

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[36] In a survey by the American Medical Association, three-fifths of the physicians responding reported that the Medicare guidelines for evaluation and management services were their biggest paperwork headache (Editorial, 2002).

may feel that it is not worth the staff administrative time to submit a claim for certain services (Hilden et al., 2001b).

Finally, one last concern for physicians, especially physicians in less well-paid fields of practice, is delayed payment of claims. A number of states have adopted "prompt payment laws" that establish varying definitions of and financial penalties for delays (see, e.g., NCSL, 2001a).

Payment for Palliative and End-of-Life Care by Physicians

For patients enrolled in hospice (which few children are), the physician of record can bill Medicare, Medicaid, or private insurance for services provided to that patient subject to certain conditions. Most hospice care is, however, provided and managed by nurses and other nonphysicians. Their services are covered under the hospice per diem payment. As suggested earlier, the adequacy of these payments needs examination in the context of modern palliative care practices, including the use of effective but very expensive medications.

For patients not enrolled in hospice, many palliative services (e.g., an inpatient or office visit to assess symptoms and adjust medications) fit within the evaluation and management services mentioned above. The same concerns about payment levels and claims administration practices, thus, apply. Although most home care is provided by nurses or other nonphysicians, very low payments for home visits may discourage physicians who judge that a home visit is the best way of managing child and family problems when a family wants a child at home but hospice care is not covered or available.

Physicians who provide palliative care will be especially affected by Medicaid or private health plan refusals to pay for team conferences, care plan oversight, telephone calls or consultation and information visits with parents when the child is not present. For children with life-threatening medical problems, consultations with parents are some of the most important, difficult, and time-consuming services provided by physicians.

As noted earlier, depending on the payer, the service, and the circumstances, pediatric nurse practitioners, child psychologists, and certain others who provide palliative services to children can bill directly. When such services are instead considered part of the overhead of a hospital or pediatric practice, these professionals must compete for resources with many other organizational priorities, and underprovision of their services is a frequent concern.

Because much physician care for children with life-threatening problems is provided in hospitals, payment for inpatient palliative care services provided by physicians is important. For example, medical centers and children's hospitals may track the collections of different clinical services in faculty practice plans as one indicator of a service's economic value to the institution. However valuable they may be to dying children and their families, services that are not reimbursed or are reimbursed at a low level put the services in jeopardy of understaffing or elimination.

Payment for Hospice Care

Under Medicare and Medicaid, hospices are paid on a per diem basis. These rates were based on data from a demonstration project that ended in the early 1980s and have not been adjusted to reflect the introduction of many effective but expensive palliative medications and other interventions (MedPAC, 2002).

Different per diem rates apply for four categories of hospice service: routine home care, continuous home care (for patients requiring eight or more hours of hospice care during a day), general inpatient care, and inpatient respite care.[37] In addition, hospices face caps on overall payments and on total payments for inpatient care (HCFA/CMS, 2001a). Use of these interventions could consume much of the current per diem for routine care (or exceed it). As noted above, this may create access problems for patients with particularly high-cost needs.

Private insurers may also use per diem payments, but some pay separately for certain expensive services such as palliative radiology, chemotherapy, durable medical equipment, and medications (Huskamp et al., 2001). To the extent that private payers cover such expensive services separately, hospices are under less pressure to restrict potentially effective palliative services or to refuse potentially expensive patients.

Concerns about prognostic and other requirements for Medicare and Medicaid coverage of hospice care were discussed above. The major issue related to hospice payments per se (not coverage and election requirements) has focused on the level of per diem payments and not the per diem method itself (Lynn and O'Mara, 2001). One advantage of per diem compared to per service payment is that it allows providers more flexibility to focus resources where patients need them most.

The level of per diem payments set by Medicare and Medicaid represent public policy decisions about the desired quality and type of hospice care. To increase legislators' understanding of the adequacy of per diems and to inform decisions about the need to re-base payments given signifi-

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[37] For FY 2002, Medicaid rates are $110.56 for routine home care; $644.70 for continuous home care ($26.86 hourly rate); $120.23 for inpatient respite care; and $491.19 for general inpatient care (HCFA/CMS, 2001a).

cant changes in palliative care in the last two decades, Congress should direct CMS to undertake a comprehensive analysis of the costs of effective palliative care and then ensure that per diem rates reflect these costs.

MANAGED CARE AND END-OF-LIFE CARE

In many respects, health care in the United States has been transformed in the last decade by the growth of managed care. By 1999, 91 percent of individuals with employer-sponsored private insurance were enrolled in managed care, including HMOs, PPOs, and multiple variants on these structures. As indicated above, the use of managed care by state Medicaid programs has also become widespread, with more than half of the children covered by Medicaid now enrolled in managed care plans. Both across and within managed care plan types, benefit design and administrative practices vary greatly.

In general, the recent trend in employment-based plans has been somewhat away from the most restrictive or tightly managed plans toward plans that offer more flexibility in choice of provider and somewhat fewer administrative hurdles such as prior approval of services (Draper et al., 2002).[38] Such choice and flexibility often means higher costs.

Management Techniques with Implications for Palliative and End-of-Life Care

Managed care plans use a variety of techniques to control costs, including utilization review, restricted provider networks, and payment incentives for economical provider practice. Some techniques pose potential problems for patients and families, especially for children with fatal or potentially fatal medical problems (see, e.g., Sulmasy, 1995; Morrison and Meier, 1995; IOM, 1997; Fox, 1999; Huskamp et al., 2001).

Utilization Review

Managed care plans may employ several utilization review procedures to control costs. These procedures include requirements for authorization prior to the use of services and retrospective review of services. Plans will

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[38] In 2001, 48 percent of insured individuals with private employer-sponsored coverage were enrolled in PPO plans (up from 41 percent in 2000), 23 percent were in HMO plans (down from 29 percent in 2000), 22 percent were in point-of service (POS) plans, and 7 percent were in indemnity plans (down from 27 percent in 1996 and 73 percent in 1988) (KFF, 2002).

usually require prior authorization for families with children needing home hospice care.

In managed care plans with tight utilization management processes and stringent criteria for authorizing services, the gap between nominal and meaningful coverage for certain services can be substantial. The committee found no systematic documentation of the extent to which children with life-threatening medical conditions and their families encounter serious problems with review requirements for hospice, home care, or other services to meet their needs for palliative or end-of-life care.

Provider Networks

Most managed care plans select a subset of providers in the area to be members of their provider network. These plans then provide patients financial incentives to use network providers as opposed to providers who are not members. More restrictive plans such as staff model HMOs cover services only if provided by network providers, with exceptions for emergency services under certain circumstances. Less restrictive plans typically require higher cost sharing when members use nonnetwork rather than network providers.

By creating networks, plans can negotiate discounted rates with many providers who are willing to accept lower fees in exchange for the higher level of patient volume likely to result from being listed as a network provider for a health plan. Plans may also choose to retain providers in the network based on analysis of the costs they generate or their practice patterns. A defined network of providers may make it more feasible for insurers to analyze and monitor provider practice patterns and outcomes and then design and institute remedies to identified problems.

The use of provider networks raises several concerns for dying children and their families. The breadth and depth of provider networks vary across plans. Some plans may not include specialists appropriate for treating a fatal or potentially fatal condition (e.g., the network may include a specialist in adult cases—but not child cases—of a particular condition) or may not include appropriate geographic representation of various specialists. Even if a plan's network includes appropriate specialties, it may not include a sufficient number of qualified physicians in each specialist category. This may create unacceptably long waiting times for children in need of specialized care. Arrangements may exist for referral to outside specialists, but families may find their options unsatisfactory. In general, free choice of physician and medical center is a particular issue when a child is seriously ill.

Other concerns include turnover of network providers, which can disrupt continuity of care and relationships of trust. An employer's switch to a new health plan can mean that new relationships must be established with a number of unfamiliar physicians and other providers. (In some regions and for less tightly controlled plans, overlap in provider networks may be substantial and thus minimize this problem.)

Shifting Financial Risk

A third type of cost-control tool involves passing financial risks for enrollee care to providers. As noted earlier, health plans are increasingly passing financial risks to groups of clinicians or, in some cases, to individual clinicians through the use of capitation, withholds, and bonuses.

Some health plans capitate primary care physicians for their own professional services, such that the physician absorbs all the extra costs if utilization is higher than expected. Under a withhold arrangement, a percentage of a clinician's payment is withheld at the time of service delivery. These funds are then distributed to clinicians if they meet certain performance targets, such as controlling pharmacy costs, controlling total health costs, or limiting the number of specialty referrals. Alternatively, plans may pay bonuses when such targets are met. These payment arrangements are intended to encourage cost-effective practice patterns. The concern is that these arrangements create incentives to reduce service provision or to reject sicker patients with higher-cost needs. Many children with fatal or potentially fatal problems fall in this category.

Medicaid Payment to Managed Care Plans

States initially found managed care plans receptive to enrolling Medicaid beneficiaries. More recently, like Medicare, state Medicaid programs have found less enthusiasm, particularly from plans with large private enrollments. Some plans are refusing to enter or continue in the Medicaid market, and others are limiting Medicaid enrollments. Particular complaints include low capitation rates and burdensome administrative requirements (Holahan et al., 1999). In a survey of state Medicaid agencies in late 2000, agency staff cited financing as the reason for about 70 percent of managed care plan departures from their state program (NASHP, 2001). Publicly held companies may be particularly sensitive to Wall Street assessments of their Medicaid participation (CSHSC, 1999).

States have argued, in part, that the plans were paid too much in the early days of voluntary enrollment, when they attracted healthier beneficiaries, and that rates are now more appropriate. In addition, federal requirements set upper limits on what states can pay relative to comparable populations with fee-for-service coverage. As a cost-containment feature, this provision makes sense, but it may not support some of the goals of Medicaid managed care, including greater coordination of care. According to Holahan and colleagues (1999), this provision is one reason why states with high Medicare capitation rates tend to have high Medicaid capitation rates. Other reasons for rate variations include a state's cost-containment objectives and the age of a program.

With new programs and voluntary programs, managed care plans may benefit from enrolling healthier beneficiaries, including those without established physician relationships (see, e.g., Freund et al., 1989; Leibowitz et al., 1992). With mandatory enrollment and more mature programs, the lack of satisfactory risk adjustment for the health status or riskiness of populations served becomes a serious concern for health plans (see, e.g., Buntin and Newhouse, 1998; MedPAC, 1998a). This is especially the case when Medicaid payment rates are well below Medicare and private rates.

Mandatory enrollment without a satisfactory risk adjustment strategy may create financial incentives for undertreatment, a particular threat to children with special health care needs. In establishing interim criteria for states enrolling these children in capitated managed care, HCFA (now CMS) required only that states use a payment mechanism that "accounts" for special needs populations (criterion quoted in Kaye et al., 2000, p. 149).

In 1999, just two state Medicaid programs—Colorado and Maryland—used health-related risk adjustments, although some states used elements of risk-adjustment for subsets of beneficiaries (e.g., Michigan for Title V children and Delaware for SSI enrollees [Kaye et al., 2000]). Some states use only demographic variables (e.g., age, sex) to adjust rates. In general, demographic variables alone do not perform well in predicting variation in beneficiary costs. Many state Medicaid programs use multiple rate categories as a blunt method of risk adjustment, although the rate categories are usually sufficiently broad that they achieve little risk adjustment. Even with adjustments based on health status, it may be difficult to set an adequate prospective capitation rate for high-risk children (Fowler and Anderson, 1996).

Some states deal with predictably high-expense groups, including children with special health care needs, by "carving out" special programs for them (Andrews et al., 1997; Inkelas, 2001). Payments for these programs may or may not be based on capitation and may or may not include adjustments for differences in population risks. One study in California of a carve-out for children with special health care needs suggested that the problem increased the identification of such children as eligible for services (Inkelas, 2001).

DIRECTIONS FOR POLICYMAKERS AND INSURERS

Positive Aspects of the Current Financing System

Notwithstanding its well-publicized inadequacies, this country's complex and unwieldy mix of public and private insurance, philanthropy, and other arrangements funds many needed medical and other supportive services for seriously ill or injured children and their families. In focusing on the system's weaknesses, it is important not to forget its strengths including access for many to helpful services and advanced technologies that save and extend lives, restore function, and otherwise prevent or reduce much illness and suffering.

Children whose parents are covered by health plans sponsored by large employers often have excellent access to care to cure or prolong life. Coverage for palliative and supportive care—often to supplement curative and life-prolonging care—may also be generous. Even when employer plans have restrictions on palliative and supportive care, plan administrators may waive or work around many of these restrictions to provide needed services to gravely ill children and their families.

For children in low-income families, Medicaid and other federal or state programs cover a wide range of services, including long-term home and community-based services, that are often excluded or very restricted in private insurance plans. This care is particularly important for children and families living with neurodegenerative disorders and other severe chronic conditions. State programs often include case management services that help families find and coordinate the complex array of services and providers needed by such children.

Required enrollment by Medicaid beneficiaries in managed care may have some negative features as discussed below, but it also may provide the foundation for more coordinated care and better monitoring of the quality of care for those with complex health problems. One reason that Title V programs are interested in managed care is that its structures should, in theory, make it easier to link children with special health care needs to a medical home that coordinates their complex care.

Finally, it is important to recognize that coverage limitations, payment limits, and other restrictions are not designed to cause suffering or to frustrate patients, families, and physicians—although they frequently do. Rather, the intent is to control the cost of health insurance and health services so that they are affordable for governments, employers, and individuals.

Problems with the Current Financing System

General

Perhaps the most obvious deficiency in this country's health care system is the lack of universal coverage—public or private—for all children and adults under age 65. Although public or private insurance does not guarantee access to reliable, effective, coordinated care and lack of coverage does not mean that care is unavailable, uninsurance does have negative consequences for children and families. For children with serious medical conditions and their families, lack of insurance and underinsurance can seriously disrupt the provision, coordination, and continuity of care—although most will receive at least crisis care. The struggle to find crisis care and other needed services may, however, drain family resources (and sometimes lead to bankruptcy), put parents' jobs in jeopardy if they must substitute for paid caregivers and case managers, trigger a frustrating search for so-called safety-net or free care providers, or all of these.

In addition, as employers or states restructure their programs, families are often subject to switches in health plans offered, revisions in a health plan's terms of coverage (e.g., reduction in home health care benefits), or changes in a plan's provider networks. These changes may be disruptive, resulting in the end of coverage for a valued service or the loss of continued access to trusted and familiar providers.

A less visible consequence of uninsurance or underinsurance is that physicians, hospital staff, and others may—instead of providing care—have to spend valuable (uncompensated) time trying to locate some source of payment or service for seriously ill children. Further, parents distracted by financial worries may find it difficult to provide all the emotional support their children need from them.

Finally, physicians, hospitals, and hospices may find levels of payment too low to allow them to provide the services they believe are needed by a child. In some cases, they may refuse to serve patients covered by a low-paying plan or program, notably state Medicaid programs, which typically pay providers considerably less than other public and private programs.

Although all of these problems affect seriously ill children and families, most can be addressed only by broad policy changes—for example, policies that extend public or private insurance to all—that are beyond the charge to this committee. The committee's recommendations deal with more specific deficits in the financing of palliative, end-of-life, and bereavement care for children and families. Based on its experience and judgment and review of relevant research and proposals of other groups, the committee recommends several changes in public and private coverage of hospice services for children, additional changes to encourage the integration of palliative services with curative or life-prolonging care, and analytic work to support the design and implementation of these changes. Chapter 10 includes directions for further research to refine and support these recommendations and assess their implementation and consequences.

Hospice

Several factors contribute to low use of hospice care by children who die, including physician and parent attitudes or lack of knowledge and the large proportion of child deaths that are sudden and unexpected. Coverage limitations also constitute a barrier in state Medicaid programs and some private insurance plans. In particular, although state Medicaid programs must (under EPSDT provisions) cover hospice care for children even if they do not cover it for adults, the six-month prognosis requirement and the requirement that curative care be forgone (both of which are federal rules) are a problem. If the federal government abandons or fails to enforce EPSDT requirements, then children in six states would, like adults in those states, not be covered for hospice care. Many private insurance plans also use the six-month prognosis requirement. Some hospices successfully rely on philanthropy to serve Medicaid-covered children who fall outside restrictive rules for hospice benefits; others cannot, or they may have other priorities.

Health plans may impose a variety of additional restrictions on hospice and other palliative services. These include caps on the number or amount of services covered, preauthorization requirements for each use of a service or use above a certain level, variable cost-sharing requirements, prescriptions restricted to a closed formulary, waiting lists, or limited “slots” for certain expensive services.

In general, hospices have been comfortable with the per diem payment method created when Medicare first added hospice coverage. Over the last two decades, however, the beneficial but often expensive advances in pain management and other palliative care strategies have strained hospice budgets and led some to limit acceptance of patients with high-cost needs or to forgo effective but costly palliative interventions. At a minimum, the adoption of an outlier payment provision should counter the incentive to refuse very high cost patients. Other options that should be considered include reevaluation of each category of per diem rates, higher per diems for the more expensive first two and last two days of care (a response to late referrals and short lengths of stay) and separate payment for pharmaceuticals, blood transfusions, and similar products. The federal advisory committee on Medicare payment policies recently recommended that the adequacy of Medicare’s hospice payment rates be evaluated to determine whether they are adequate given the current costs of providing appropriate care (MedPAC, 2002).

Recommendation: Public and private insurers should restructure hospice benefits for children to

- **add hospice care to the services required by Congress in Medicaid and other public insurance programs for children and to the services covered for children under private health plans;**
- **eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care (possibly in a case management framework); and**
- **include outlier payments for exceptionally costly hospice patients.**

Extension and Integration of Palliative and Bereavement Care

Even with these recommended changes, additional reforms are needed to promote the integration of palliative care from the time of diagnosis through death and into bereavement and to make palliative care expertise more widely available. No child should die in pain or other distress because health plans fail to cover specialized expertise in symptom management. Families should also not have to face a choice between expert palliative care for their child and publicly funded home health assistance for children with special needs. When families choose home care for a seriously ill child, palliative care consultations should be available to children whose home care personnel lack the necessary expertise and experience to manage their physical or psychological symptoms.

Further, in recognition of the central role of parents and guardians in decisionmaking for children (as opposed to adults) with life-threatening conditions, physician reimbursement should cover extended and intensive communication and counseling of parents or guardians, whether or not the child is present. Informing and counseling parents of children with life-threatening conditions is a critical but time-consuming obligation for clinicians that is undervalued in current reimbursement policies.

Another pillar of competent and compassionate care for families who have suffered a child's death is bereavement care, which health plans should cover in its own right. Parents or siblings who seek counseling under their health plan's mental health benefits generally will be covered only under diagnoses such as depression and perhaps not even then, depending on health plan coverage criteria and practices. The recording of such diagnoses can result in later problems in securing health insurance, especially outside an employer-based plan.

The committee recognizes the cost pressures on employers, private health plans, and state Medicaid programs, particularly during periods of recession or slow economic growth. Because Medicaid covers many children with serious chronic health problems, the cost to states of even limited coverage expansions must be considered. Thus, the Centers for Medicare and Medicaid Services should develop estimates of the cost of adopting these recommendations in Medicaid, taking into account the possibility of avoided costs (e.g., hospitalization related to inadequately managed care at home). The analyses being undertaken for the demonstration projects described earlier in this report and in Appendix H should be helpful.

Recommendation: In addition to modifying hospice benefits, Medicaid and private insurers should modify policies restricting access to other palliative services related to a child's life-threatening medical condition or death. Such modifications should

- **reimburse the time necessary for fully informing and counseling parents (whether or not the child is present) about their child's (1) diagnosis and prognosis, (2) options for care, including potential benefits and harms, and (3) plan of care, including end-of-life decisions and care for which the family is responsible;**
- **make the expertise of palliative care experts and hospice personnel more widely available by covering palliative care consultations;**
- **reimburse bereavement services for parents and surviving siblings of children who die;**
- **specify coverage and eligibility criteria for palliative inpatient, home health, and professional services based on diagnosis (and, for certain services, severity of illness) to guide specialized case managers and others involved in administering the benefits; and**
- **provide for the Centers for Medicare and Medicaid Services to develop estimates of the potential cost of implementing these modifications for Medicaid.**

Implementation

To implement the recommendations related to improved benefits for palliative, end-of-life, and bereavement care, eligibility criteria must be defined. Federal officials should work with state Medicaid officials, pediatric organizations, and private insurers to define diagnosis and severity criteria to establish children's eligibility for pediatric palliative care and hospice services and family members' eligibility for bereavement services. In addition, federal officials should also take the lead in examining the appropriateness of diagnostic, procedure, and other payment-related classification schemes that were originally developed for adult services. These schemes include DRGs for hospital payment and an RBRVS for physician payment. Many private payers and Medicaid programs have adopted these classification schemes (although not necessarily the level of payment associated with them). Given the confusion about billing for palliative care services and the frequent denials of payment for improper coding or documentation, access to care may also be improved by providing clearer guidance about accurate coding and documentation of covered palliative services. Although providers faced with claims denials and hassles may sometimes render services without billing for them, they may also opt not to provide the services or to avoid patients that need such services.

> **Recommendation: Federal and state Medicaid agencies, pediatric organizations, and private insurers should cooperate to (1) define diagnosis and, as appropriate, severity criteria for eligibility for expanded benefits for palliative, hospice, and bereavement services; (2) examine the appropriateness for reimbursing pediatric palliative and end-of-life care of diagnostic, procedure, and other classification systems that were developed for reimbursement of adult services; and (3) develop guidance for practitioners and administrative staff about accurate, consistent coding and documenting of palliative, end-of-life, and bereavement services.**

Again, these recommendations target only a subset of financial barriers to competent and reliably available palliative, end-of-life, and bereavement care. Uninsurance, underinsurance, certain managed care requirements, and radically low levels of provider payment also constitute significant barriers. Reducing or removing these barriers will require far more comprehensive changes in policies.

CHAPTER 8

ETHICAL AND LEGAL ISSUES

> *I think in particular of two times when we made a particular request and were told that the ethics committee would be called. I'm now on the ethics committee at Children's Hospital here and . . . [I advocate there] that ethics committees not be viewed like the legal system. That's not helpful or open to families but one other thing to be really frightened about.*
>
> Deborah Dokken, parent, 2001

Questions and disagreements about what constitutes appropriate medical treatment or limitations of treatment for infants and children with severe and often fatal medical problems are a staple of the bioethics literature. They are rarely—but then very visibly—the subject of litigation and legislation. Even so, when parents question or disagree with the health care team or hospital management, they may perceive some responses as legalistic and intimidating rather than constructive and compassionate.

One goal of palliative and end-of-life care is to minimize avoidable conflicts related to poor communication, cultural misunderstandings, deficient clinical care, and approaches to decision making that fail to assure families that they and the health care team are doing their best for the child. Such failures can haunt family members and clinicians long after a child's death.

Not all conflict raises ethical or legal concerns, and ethical concerns about clinical decisionmaking certainly may arise in the absence of conflict. This chapter provides an overview of the ethical and legal context for decisions by clinicians, parents, and children about pediatric palliative and end-of-life care. It

- describes several categories of decisions that have prompted ethical or legal questions and disagreements;
- outlines the key ethical obligations of clinicians as commonly identified by clinicians and bioethicists;
- discusses the potential for conflicts among ethical obligations;
- identifies some strategies for preventing or resolving conflicts among those involved in decisions about a child's care; and
- reviews some ethical and legal questions about the care of children, including the status of children as decisionmakers and certain boundaries on parental authority.

This discussion focuses on clinicians' decisions rather than on parental obligations or societal issues of resource allocation and burden sharing. The discussion does not consider a number of ethical and legal controversies. These include the declaration of brain death in anencephalic newborns, continuation or discontinuation of pregnancy following prenatal diagnosis of a fatal medical problem, use of certain alternative or complementary therapies at the end of life, and euthanasia. The chapter also does not discuss licensure issues, some aspects of which are considered in Chapter 6. Chapter 10 examines ethical issues in research involving children. Although this chapter does not include formal recommendations, the committee believes that the strategies for preventing and resolving conflict discussed here should be considered and tested as institutions develop the procedures and protocols recommended in Chapters 4, 5, and 6.

Many legal and ethical questions considered here are relevant for palliative and end-of-life care for both adults and children. Some issues are, however, unique to children. One example is whether schools serving medically fragile children must honor parental requests that cardiopulmonary resuscitation not be attempted for their child. Another involves getting permission from an abusive parent to withdraw life support when the parent will be charged with murder after the child's death. Not unique but especially wrenching when a child is involved are questions about the ethics of using or forgoing certain medical interventions when disease is far advanced.

Although it is important to understand the limits that courts or legislatures have imposed on decisionmaking by clinicians or parents or both, these limits will not affect most decisions about palliative and end-of-life care for children. Similarly, the legal limits on children's decisions about medical treatment are not inconsequential, but they should not constrain efforts by clinicians and parents to inform children about their condition (consistent with their intellectual and emotional maturity) and to determine and consider children's treatment preferences. An assumption of this committee and most sources consulted by the committee is that litigation should be a last and rare resort when clinicians and family members disagree.

As with other aspects of palliative, end-of-life, and bereavement care, the legal system and ethical frameworks discussed here reflect this country's history and dominant culture. Although the legal system of the United States and arguments based in biomedical ethics may sometimes confuse or surprise those raised in this country, people raised in other cultures may find them incomprehensible or possibly shocking. Particularly in legal matters, flexibility to consider cultural differences may be limited. Nonetheless, it is still both humane and prudent for clinicians, social service personnel, and legal counsel to be sensitive to differences in cultural values and experiences and to try to minimize conflict and family distress related to such differences. (See Appendix D for additional discussion of cultural diversity.)

TYPES OF DECISIONS

In recent decades, many legal disputes and ethical debates about care for infants and children have involved decisions to start or stop medical interventions. Other disputes focus on the limits of parents' authority to decide about their child's care and on whether and to what extent quality-of-life and financial considerations should influence decisions about life-sustaining treatments. This section briefly describes these decisions and the questions they have raised. Much of the initial discussion of some of these issues, for example, withholding and withdrawing life-support technologies, occurred in the 1970s and 1980s and predated the increased attention to the techniques and benefits of palliative care. Again, the issues are not necessarily unique to children but tend to be more emotionally charged and difficult for all involved.

Decisions About Who Decides

In general, parents have the legal right to make decisions about medical care for their child. This parental authority is occasionally challenged, usually when parents refuse treatment recommended by their child's physician. In addition, adolescents have sometimes sought control over crucial decisions about their future, often in situations involving reproduction but sometimes involving care for far advanced illness. Sometimes they succeed. For example, in 1994, state officials unsuccessfully tried to force a 15-year-old boy, who had received two liver transplants, to take medications that he refused on grounds of unbearable pain (Penkower, 1996; see more generally McCabe, et al., 1996).[1]

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[1] For the situation in which a child's participation in research is involved, federal regulations normally require both that parents give permission and that children also "assent" to participation. Chapter 10 discusses ethical issues related to the involvement of children in research.

That parents have the legal right to make decisions does not and should not, however, mean that parents and clinicians should simply exclude children from discussions and decisions about their care. Failing to provide children with information and the opportunity to discuss their fears, concerns, and preferences can isolate them and add to their anxiety and other distress. In Chapter 4, the committee recommended that children and adolescents be informed and involved in decisionmaking—consistent with their condition, maturity, and preferences and with sensitivity to the family's culture and values. Involving the child and trying to see care through the child's eyes is also an element of child- and family-centered care as discussed in Chapter 6. Particularly for adolescents, restricting participation in decisionmaking "may unnecessarily create tension where a therapeutic alliance is needed" (Burns and Truog, 1997, p. 73). Many medical care consent forms include a section documenting "assent" to care by adolescents.[2]

Care must, however, be taken not to give the false impression that parents will never override their child's expressed wishes. Decisions by child patients—and by parents and adult patients—may be constrained by organizational or governmental policies or by environmental factors. For example, state laws may require emergency medical services providers to attempt resuscitation even for adults or children with DNR orders (Sabatino, 1999). Likewise, deeply held cultural values may lead parents to reject proposals to involve the child or even provide the child with information about his or her condition. Clinicians may respect these values but still be dismayed. Years of experience may temper such reactions. As one clinician observed ". . . more and more I've realized that it's going to unfold the way that family needs it to unfold" (Mildred Solomon, Ed.D., Education Development Center, taken from interviews conducted for the Initiative for Pediatric Palliative Care, unpublished analysis by Hardart et al., 2002).

Although it is important to understand the ethical and legal context for decisionmaking, most disagreements about care are resolved informally through discussion and reflection. For example, the vignette about the Devane family in Chapter 3 described how an adolescent with recurrent cancer prevailed in refusing further burdensome experimental treatment (wanted by her physician and parents) and in living her remaining time doing what she wanted to do.

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[2] The AAP defines the steps to securing assent to include helping the child understand his or her condition and what to expect, assessing the child's understanding of his or her situation and identifying any inappropriate pressure on the child, and seeking an expression of the child's willingness to accept treatment (Kohrman et al., 1995).

Decisions About Treatments

Stopping Versus Not Starting Treatment

Ethicists and judges generally agree that there is no meaningful ethical or legal difference between deciding not to initiate a treatment and deciding to discontinue a treatment (assuming that appropriate attention is paid to such matters as patient comfort) (see, e.g., President's Commission, 1983; see also AMA, 1994a).[3] Nonetheless, in the committee's experience, both clinicians and parents may find it more emotionally difficult and morally challenging to stop a treatment once begun than not to initiate it in the first place.

Implementing a decision to stop a life-sustaining medical intervention may also be technically challenging as demonstrated by ongoing discussions of which strategy for removing a ventilator or breathing tube best meets patient and family needs (see Chapter 5). These needs may vary, depending on the patient's condition and the family's values. Some clinicians may even be reluctant to start such interventions when they might be useful for fear of not being able to stop them if they prove nonbeneficial. Thus, it is important for those responsible for such interventions to be thoroughly knowledgeable about all clinical and ethical aspects of initiating and stopping them.

A recently reported survey of clinicians involved in pediatric intensive care found that although 78 percent of physicians agreed that the decision not to start an intervention (such as mechanical ventilation) and the decision to stop it were ethically the same, only 57 percent of nurses did (Burns et al., 2001). Another recent survey at seven children's hospitals or pediatric units of general hospitals found that majorities of nurses and residents and a near majority of attending physicians disagreed with this proposition of moral equivalence (Solomon et al., 2000c). Yet other research suggests that decisions about which interventions are forgone—and when—may not be supported by clear clinical or ethical rationales (see, e.g., Faber-Langendoen, 1996; Asch et al., 1999; Truog et al., 2000).

Clinicians' attitudes and practices related to the use of life-sustaining medical interventions may be influenced by a number of factors including their cultural or religious values and their emotional response to a child's grave illness or injury. Other factors include (1) ignorance or misunderstanding of the evidence about the benefits and burdens of specific interven-

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[3] Some religious groups do make a major distinction between withholding and withdrawing (in non-brain dead patients) life-sustaining treatments at the end of life (see, e.g., Steinberg, 1998).

tions at the end of life, (2) insufficient education in clinical ethics and reinforcement of ethics in day-to-day practice, and (3) feelings of helplessness related, in part, to inadequate knowledge of palliative strategies to prevent or relieve distress when life-sustaining interventions are forgone. This lack of palliative knowledge may contribute both to the continuation of nonbeneficial interventions and to needless suffering when interventions are halted, for example, when the removal of a breathing tube is managed with paralytic agents that do not relieve distress but prevent the patient from communicating it (Rushton and Terry, 1995; Truog et al., 2000; Henig et al., 2001).

Life-Sustaining Treatments

With advances in medical technologies in the second half of the twentieth century has come increasing anxiety among clinicians, ethicists, and the informed public about the appropriate use of life-sustaining interventions, especially when a patient's chance of survival is very low. Cardiopulmonary resuscitation is perhaps the best known of an array of such interventions that may be attempted (or forgone) when death is imminent.[4] Other life-support measures include mechanical ventilation (for reasons in addition to respiratory arrest), mechanical provision of nutrients or fluids (artificial nutrition or hydration), blood transfusions, antibiotics, and dialysis.[5]

Decisions about life-sustaining interventions—especially resuscitation attempts—are often made in an atmosphere of crisis and even panic, but this is not always the case. For example, mechanical ventilation may be begun in a child with a progressive neuromuscular disease such as muscular dystrophy after extended discussion and profound reflection by the family, the child, and the care team on the benefits, risks, and burdens of this action.[6] Still, even when parents know that their child has an invariably

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[4] Resuscitation involves aggressive measures to restore spontaneous breathing and blood circulation following cardiac or respiratory arrest. It may involve electric shocks to the heart, the insertion of breathing tubes to allow mechanical ventilation, and medications to stimulate the heart and restore breathing. Mouth-to-mouth respiration and chest compressions—which can be forceful enough to break a patient's ribs—may be used by either laypeople or medical personnel until more advanced technologies are available.

[5] Unlike resuscitation, these interventions are also used routinely in many noncritical situations. For example, during and following surgery with general anesthesia, life may be temporarily sustained by mechanical ventilation and intravenous administration of fluids (artificial hydration).

[6] Although some have questioned such care, most pediatricians believe it is appropriate when the child patient and the family have been fully informed about benefits, risks, and burdens (Orenstein, 2000; Gibson, 2001).

fatal condition, such as Tay-Sachs disease, and have been counseled that cardiac or respiratory arrest can be expected when functional and cognitive deterioration is advanced and even when they understand the ultimate futility of attempting resuscitation, they may still—in their distress at that stage—call "9-1-1," thereby triggering full-scale resuscitation efforts.

It is now generally accepted among clinicians, ethicists, policymakers, and the informed public that forgoing life-support measures is often appropriate as death approaches (see Chapter 5). Notwithstanding such consensus, the parents of a dying child may not accept a clinician's assessment that life-support no longer has the potential to benefit the child and may insist that it be continued. Much of the discussion later in this chapter focuses on strategies for understanding the reasons for family rejection of physician counsel and for resolving disagreements without harm to the patient, the family, or the health care team.

Some controversy about forgoing specific interventions persists. For example, discussion continues about whether artificial nutrition and hydration at the end of life are morally or clinically different from other interventions and whether they should be maintained when other life-support measures are forgone (see, e.g., Nelson et al., 1995; Burck, 1996; Post, 2001; Gillick, 2001). Surveys of pediatric specialists have found that specialists are much more willing to forgo resuscitation or mechanical ventilation than artificial hydration given the same clinical situations (Nelson et al., 1995; see also Smith and Wigton, 1987). Other studies suggest that clinicians may believe mistakenly that artificial nutrition and hydration are always legally required in situations or jurisdictions in which that is not the case (Meisel et al., 2000). Although research findings are limited and inconsistent, some suggest that artificial nutrition or hydration when death is near may be more burdensome than beneficial in some circumstances (Finucane et al., 1999; Brody, 2000; see also Chapter 5). Again, whatever clinicians may believe and whatever the evidence may be, family values and understandings may differ.

Another controversy, noted earlier, involves whether schools will honor do-not-resuscitate (DNR) orders for medically fragile children, an increasing number of whom attend school (see, e.g., NEA, 1994; Rushton et al., 1994; AAP, 2000d, Hoffpauir, 2001). Some districts have refused to honor parents' wishes, partly out of concern about the impact on staff and other students (see, e.g., Tucson Unified School District, 1996; Laramie County, 1996). Other districts have worked with parents on a case-by-case basis to develop a plan of care. State policies vary. In its discussion of this issue, the American Academy of Pediatrics (AAP, 2000d) does not make a blanket recommendation about what schools should do. Rather, it recommends that pediatricians and parents meet with relevant school personnel to explain the child's medical condition and the goals of care and to hear the concerns of other parents and school personnel, for example, about liability and effects on other children. It also urges that all parties be realistic, flexible, and ready to negotiate.

Other Treatments

Interventions such as resuscitation and mechanical ventilation are usually intended to sustain life temporarily, for example, when a patient is incapacitated as a result of surgery or injury and when recovery or prolonged meaningful life is a realistic goal. They are not intended to cure or to alter the underlying disease. Other interventions such as surgery, chemotherapy, or radiotherapy are usually intended to cure the child's medical problem or provide extended remission of disease.[7] Decisions about these interventions sometimes arise in emergency situations, but they ordinarily follow a less urgent assessment of the child's condition. Although the underlying ethical, legal, or clinical issues may be similar for decisions in both situations, the bias "to do something" (meaning something beyond providing comfort) seems most evident in an emergency.

Decisions About the Criteria for Decisions

Many ethical and legal criteria for decisions about end-of-life care are well accepted, although disagreement may exist about how to apply and weigh them in specific situations. Two criteria have, however, aroused particular controversy. One criterion involves the consideration of quality of life, particularly in decisions made on behalf of a patient who is not able to describe his or her own experience or preferences. The other criterion involves the consideration of organizational or societal costs in treatment decisions.

Quality of Life as a Criterion in Decisions

At both the societal level (when the well being of populations is the focus) and the clinical level (when the well being of individual patients and their families is the focus), there is more to health care decisionmaking than preserving life. As expressed by the American Academy of Pediatrics, "the goal [of palliative care] is to add life to the child's years, not simply years to

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[7] They may also be used to relieve pain or other symptoms, but such palliative uses, in and of themselves, rarely generate ethical or legal conflicts. Palliative uses may, however, trigger disputes with insurers that argue that such care is not covered.

the child's life" (AAP, 2000g, p. 353). When physicians and others are identifying, explaining, and weighing the potential benefits and burdens of different courses of care, the implications for quality of life—not just the quantity of life—need attention. Chapters 4 and 9 and Appendix C discuss concepts and measures of quality of life (and their limitations) in more detail.

Judgments about quality of life involve both factual issues (e.g., what do data and experience suggest about a child's prognosis with or without the treatment in question) and subjective elements (e.g., when has a child's suffering become so great that it outweighs any benefits of the treatment). For infants and very young children as well as older children who are cognitively limited or comatose, judgments will rely on parents' or others' values and assessments.

Although ethicists, theologians, and clinicians may disagree among themselves about issues such as assisted suicide or euthanasia, most have come to agree that palliative actions intended to relieve suffering (i.e., protect the quality of life) are justified even when one unintended consequence or effect may be to hasten death (i.e., limit the quantity of life) (see, e.g., Cherny and Portenoy, 1994; Fleischman, 1998; Jonsen et al., 1998; Sulmasy, 2000; but see also Beauchamp and Childress, 1994, for a review of critiques of such arguments). Many professional organizations have also endorsed this perspective (see, e.g., AMA, 1994a; AAP, 2000g). As discussed in Chapter 5, the practice of terminal or palliative sedation involves this kind of "double-effect" reasoning.

Still, the role of quality-of-life considerations continues to prompt discussion (see, e.g., Kuhse, 1987; Beauchamp and Childress, 1994; Pellegrino, 2000). For example, are life-sustaining measures ethically or legally required for a permanently comatose infant? What about infants with profound impairment short of this state? Some take the position that, absent a double-effect situation, it is never acceptable to forgo life-sustaining treatments based on quality-of of-life considerations, regardless of family wishes. What are the obligations of clinicians to patients and families when unwanted interventions leave a patient profoundly impaired cognitively and physically? As described below, controversy over these questions has in a few instances prompted litigation and even legislation that has sought to preclude or restrict clinicians and families from considering quality of life in decisions about infants with severe birth defects.

Resources as a Criterion in Decisions

As health care costs have escalated since the 1960s, clinicians and others have become increasingly concerned about real or potential conflicts between clinicians' responsibilities to individual patients and their obligations to support the prudent use of limited societal or institutional resources. One view is that, by and large, so much nonbeneficial treatment exists that eliminating it will preclude the need to limit or ration beneficial care. An alternative perspective is that control of health care costs also requires decisions to limit or ration care that is thought to offer some benefit but not enough to warrant its provision, given higher priorities. Disagreements often arise, however, over the judgment that a service is not beneficial.[8] Many clinicians worry about the appropriateness of "bedside rationing."[9] The traditional consensus in the clinical community has been that resources should not enter into physicians' judgments about individual patients unless those judgments are governed by clear principles and procedures that follow public deliberation, reflect general community consensus, and are consistent with available scientific knowledge (see, e.g., Angell, 1985, Sulmasy 1992; AAP, 1996).

ETHICAL CONSIDERATIONS

Ethical analyses may focus on obligations at an individual or a collective (organizational or societal) level. Regardless of the level of analysis, cultural diversity and sensitivity to individual and family differences must be factored into discussions, decisions, and practices.

Ethical Obligations at the Individual Level

At the individual level, ethical analyses generally focus on the obligations of clinicians, first, to individual patients and, second and less often, to those close to or responsible for a patient. Most analyses of clinical decisionmaking devote little attention to parental responsibilities, focusing instead on the responsibility of clinicians and others to guide and redirect those parents who are viewed as acting against their child's best interests.

Notwithstanding children's stage of development or legal status, most

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[8] Thus, the controversy over mammography screening, particularly for women under age 50, has pitted those who argue that no adequately controlled scientific research clearly documents the benefits of such screening against those who agree that research is flawed but argue that the theoretical possibility of benefit is sufficient when such a dreaded disease is involved. Pediatrics has its share of disagreements over an array of interventions such as screening for scoliosis, metabolic screening for Gaucher's disease, and screening for conditions such as Huntington's chorea with no effective treatment (other than palliation).

[9] Ubel and Goold argue that "bedside rationing" occurs when these conditions are met. "The physician must 1) withhold, withdraw, or fail to recommend a service that, in the physician's best clinical judgment, is in the patient's best medical interests; 2) act primarily to promote the financial interests of someone other than the patient (including an organization, society at large, and the physician himself or herself); and 3) have control over the use of the beneficial service" (Ubel and Goold, 1997, p. 74).

issues related to their care can be considered within the same broad ethical frameworks that are widely applied to care for adults. During recent decades, general agreement has emerged on the core ethical obligations of clinicians to patients (see, e.g., Beauchamp and Childress, 1983; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research [hereafter, President's Commission], 1983; Jonsen and Toulmin, 1988; McCullough, 1988; Brennan, 1991). In common parlance,[10] these obligations are to

- do good (e.g., by relieving a child's pain or providing emotional support),
- avoid doing harm (e.g., by not providing life-sustaining treatments that impose burdens on a child without benefit),
- respect patient autonomy (e.g., by generally attempting to consider care "through the child's eyes" even though young children have no legal autonomy), and
- treat patients equitably (e.g., by seeking to provide or arrange needed care for children regardless of a family's ability to pay).

These ethical obligations may sometimes be in conflict and may not be equally weighed in practice. For example, a single action may involve both benefits and harms that have to be balanced in view of the patient's overall circumstances and understood preferences. The obligations to avoid harm and to respect autonomy have been exhaustively considered in debates about forgoing life-sustaining treatment. In contrast, one recent study of such situations concluded that the value of providing effective palliative care when life-sustaining treatment is forgone "remains underanalzyed and needs more rigorous examination" (Burns et al., 2000, p. 3060).

Other obligations or other formulations of clinical and, more generally, medical ethics exist.[11] Ethicists may, for example, cite the obligations of

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[10] In the language of bioethics, these obligations are often described as *beneficence*, the obligation to provide care that improves health or well-being (or, as it is sometimes expressed, to do to others their good); *nonmaleficence*, the obligation to prevent or avoid harm; *autonomy*, the general duty to respect people's right of self-determination regarding choices about their life and body; and *justice*, the duty to avoid discrimination on the basis of irrelevant characteristics (sometimes expressed as treating individuals [or equals] equally in morally relevant situations) or, under the label *distributive justice*, the duty to distribute health care resources in ways that can be defended as fair and equitable and not arbitrary or capricious.

[11] Medical ethics extends beyond clinical practice to cover legal obligations, relationships with other professionals, and community responsibilities. For example, the American Medical Association's principles of medical ethics, among other provisions, state that physicians should report other physicians who have deficits in character or competence and that they should, except in emergencies, be free to choose the patients they serve (AMA, 2001).

"fidelity" and "professional integrity." Fidelity is the responsibility of health care professionals to place the interests of their patients first. Professional integrity can be viewed as a broad obligation of physicians to act ethically in all their relationships and to be faithful to their moral values when they are challenged (see, e.g., Beauchamp and Childress, 1994; Alpers and Lo, 1999).

The clinician's primary obligation is to his or her patient, and ethical discourse has focused on this obligation. In pediatrics, the principle that the "child and family are the unit of care" raises the issue of the clinician's obligations to parents and other family members. These obligations do not appear to have been systematically interpreted using the ethical framework outlined above, although the potential for conflict between a child's interests or preferences and a family member's interests or preferences has been discussed (see, e.g., Randall and Downie, 1999).

A few observations about clinical ethics in this context can be offered. First, the communication strategies discussed in Chapter 4 and the consensus building strategies described below should usually help clinicians to do good for parents (e.g., by helping parents to feel they have done their best for their child); avoid harming parents (e.g., by helping them avoid choices they will later regret); and treating parents fairly (e.g., by providing understandable information and generally respecting their values). Second, in most situations, when clinicians fulfill their obligations to a child of doing good, avoiding harm, and treating fairly, they are doing likewise for parents because parents usually want to advance their child's best interests. Third, in rare cases, as discussed further below, clinicians may conclude that doing good for the child requires opposing parental preferences and values.

Most discussions of clinical and medical ethics focus on the obligations of individual professionals rather than care teams. As discussed further below, different members of a child's care team may sometimes have different views of what constitutes ethical care. Although physicians usually have the legal and professional authority to prevail, the persistence of unresolved and unacknowledged conflict can compromise the implementation of decisions, damage team members, and subtly (sometimes explicitly) undermine patient and family trust in team members. Some conflicts may reflect individual values, characteristics, and personalities; others may be rooted in different professional socialization and norms.

Ethical Obligations at the Collective Level

Clinicians may sometimes perceive their obligations to their patients individually to be in conflict with their obligation to do good or avoid harm for patients collectively. To cite a dramatic but atypical example, in emergency departments and critical care units, an unusual surge in injured patients may outstrip available personnel, space, and equipment. In response, clinicians and others have established triage protocols to guide decisions about how to allocate—that is, ration—treatment resources in such situations. Appendix B describes how prognostic tools (e.g., assessments of a patient's likelihood of survival with or without treatment) have been developed to aid in formulating and applying such protocols (and for other purposes).

Debates about the appropriate use of limited resources arise across the spectrum of clinical decisions. Some involve routine elements of patient care, for example, how much physicians (and certain nonphysicians) should be paid for informing and educating patients compared to performing surgery or other procedures.

Once again, however, some of the most widely publicized disagreements about resource use focus on care for newborns who have conditions that—even with treatment—are incompatible with extended life or with neurological function beyond the most primitive level (Fost, 1999). One highly publicized case in the 1990s, that of "Baby K," raised questions about the limits of parental demands on community resources—and on providers who are convinced that such demands violate their professional ethics and integrity (16 F 3d 590, CCA 4, 1994; Glover and Rushton, 1995). In this case, which is discussed in more detail below, the mother of an anencephalic child (who lacked all parts of the brain except the brain stem) insisted on repeated resuscitation. Federal trial and appellate courts held that emergency care could not be denied under the federal Emergency Medicine and Active Labor Act. (See, e.g., Clayton, 1995; Brown, 1996; and Maragakis, 1996, for critiques of this interpretation of the legislation, which was passed to prevent emergency department "dumping" of uninsured patients.)

Often, physicians may join with parents in a desire to "do everything" to prolong the life of a gravely ill child, including providing some treatments of marginal or no benefit. They may argue that such care provides emotional comfort and hope to the parents and allows all involved freedom from any guilt they might experience had they not pursued every option. In other cases, physicians may resist such treatment because they believe it harms the child, violates their clinical values, and misuses limited community resources.[12]

Indeed, the effort to define a quantifiable concept of "futile" treatment

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[12] These physicians may, however, accept that it is humane to provide a limited amount of care that cannot benefit a patient but that can reduce the suffering of family members. Thus, even when a child is, by clinical criteria, brain dead, a physician may delay removal of life support to give parents time to absorb the information, to come to terms with the decision to remove life-support equipment, and to say their good-byes in peace.

has been driven in considerable measure by physicians who want more protection against family demands for treatments with no or virtually no potential for benefit (see, e.g., the perspectives in Zucker and Zucker, 1997; see also Schneiderman et al., 1990; Rushton and Hogue, 1993; IOM 1997; Avery, 1998; Goldstein and Merkens, 2000). While accepting the concept that medical treatments are futile in certain situations, some ethicists, clinicians, and researchers have concluded that the term is so variably and imprecisely used that, in general, it ought to be avoided (Beauchamp and Childress, 1994).[13] Others have concluded, further, that it is impossible to craft a precise operational definition of futility that can reliably and validly govern subsequent real-world clinical decisions (see, e.g., Lantos et al., 1989; Truog et al., 1992; Waisel and Truog, 1995).[14] Rather, assessing futility is a judgmental process requiring "judicious balancing" of effectiveness, benefit, and burden specific to each patient and treatment (Pellegrino, 2000). In addition, some argue that proposals to limit futile treatment may mask "prejudices about those who are disabled, who come from disadvantaged social groups, or who are dying" (AAP, 1996, p.150; see also Krakauer and Truog, 1997).

Efforts to define futile care have also been motivated by the expectation or hope that the application of such a definition in practice could help control health care costs. Two studies of pediatric intensive care in single institutions concluded that only a small percentage of patients met any one of several definitions of futility and that their care generally involved relatively limited resources (Sachdeva et al., 1996; Goh and Mok, 2001).

The allocation of resources for medical care is just one element of a broader set of issues of about the allocation of community resources and responsibilities. Families of a seriously ill or injured child often must shoulder heavy financial burdens, sometimes extending to job loss, home loss, bankruptcy, and homelessness. Even if they have private health insurance, it will usually not cover all the home health care and nonmedical home care and other services needed by a child and family. Medicaid and other gov-

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[13] Beauchamp and Childress (1994, pp. 212–213) list the many differing descriptions of what is futile: "whatever is highly unlikely to be efficacious (statistically the odds of success are exceedingly small), a low-grade outcome that is virtually certain (qualitatively the results are expected to be exceedingly poor), whatever is highly likely to be more burdensome than beneficial, and whatever is completely speculative because it is an untried 'treatment.'" They note that these interpretations go beyond situations in which benefit is physiologically impossible to situations that are characterized by competing value judgments and interpretations of probabilities.

[14] Although the American Medical Association has more recently offered guidance about the development of policies on medical futility (AMA, Policy E-2.037, 1997), it argued earlier that "denial of treatment should be justified by reliance on openly stated ethical principles and acceptable standards of care, . . . not on the concept of 'futility,' which cannot be meaningfully defined" (AMA, 1994a).

ernment programs may cover more services but, in most cases, only after a family's resources are virtually exhausted.

Ethics in Practice

Notwithstanding the moral passion and intellectual energy devoted to ethical analyses and positions, the greater challenge may be in matching practice to principles, even when the principles are, by and large, not in dispute. Financial constraints and time constraints may undermine ethical practice, for example, when clinicians face appointment schedules that leave them little time for the kind of consensus-building discussions described below.

Violations of ethical practice and avoidable patient and family suffering also may arise from missteps involving what should be routine organizational procedures and actions. For example, despite years of attention, patients and families cannot be guaranteed that decisions made in advance about the use of life-sustaining medical treatments will be honored because information about advance directives may not follow the patient, for example, during a transfer from home to hospital. Such failures prompted the Oregon effort, described in Chapter 6, to develop tools and implement procedures that have increased the likelihood that patients will have their wishes honored (Tolle et al., 2002).

In some cases, health care professionals and health care organizations may be constrained by licensure or other regulatory restrictions from providing care they believe appropriate. For example, hospices may be restricted not just by Medicare and Medicaid coverage limits but also by licensure from providing a broad range of palliative services to all adults and children in need. Eliminating or revising these restrictions would take state and national action.

Further, despite various educational efforts, it is clear that physicians and other care team members sometimes misunderstand both the evidence base and the ethical context for life-support interventions and are not properly prepared—intellectually or emotionally—to inform and advise patients and families. Even with a correct understanding of science and ethical principles, some clinicians may lack the skills and attitudes to provide compassionate and effective communication with seriously ill children and their families. Education is not sufficient to change practice but it is necessary to provide requisite skills and it can shape attitudes and values.

Consistent with studies of care for adults, studies of pediatric care have documented considerable variation in attitudes about and use of life-sustaining technologies in real or hypothetical situations (see, e.g., Levetown et al., 1994; Randolph et al., 1997, 1999; Keenan et al., 2000; see also Asch et al., 1995; Fins, 1999; Breen et al., 2001; Puntillo et al., 2001). Variations in attitudes can lead to variations in decisions and practices, although variations in knowledge, habits, and organizational protocols also may contribute. Patients and families may, as a result, be unable to expect consistency in care, fairness, and freedom from avoidable suffering.

Creating organizational and societal environments for ethical practice requires persistent, cooperative efforts to change virtually every dimension of medical care—including professional education, arrangements for institutional governance, mechanisms for professional collaboration, patient-clinician decisionmaking, information and performance evaluation systems, and financing principles and policies (see, e.g., Rushton and Brooks-Brunn, 1997; Brodeur, 1998; Jonsen et al., 1998). Although not identical in purpose or method, the principles and strategies for integrating ethical principles into organizational culture and routine professional practice have much in common with those guiding many of the continuous quality improvement initiatives discussed in Chapter 6.

The following section focuses on strategies for resolving conflicts. Some of these strategies, for example, the development and successful application of clinical practice guidelines, also can help in transforming statements of principles into effective practice.

STRATEGIES FOR PREVENTING OR RESOLVING PARENT–CLINICIAN AND OTHER CONFLICTS ABOUT CLINICAL CARE

As noted earlier, conflicts cannot always be avoided. Conflicts may even be productive or beneficial in some situations, for example, when parents pursue an issue in disagreement rather than capitulating to a course of action and later regretting their silence. The same point may hold when members of the health care team challenge and argue with each other. In the face of disagreement, overly confident or assertive clinicians may become more sensitive to parental concerns and values. Nonetheless, extended or severe conflict about care of a gravely ill or injured child may be very destructive to all involved and may subject children to needless suffering, for example, as clinicians and family argue about treatments.

Strategies to prevent or resolve conflicts about clinical care can operate at the individual level. That is, they come into play when a particular dispute arises or the potential for dispute exists, but they do not establish general rules or formal precedents to govern subsequent cases. Conflict resolution strategies can also operate at the organizational or system level, for example, in the form of ethics committees or ethics consultation protocols. In addition, research can be useful in preventing or resolving disputes, for example, by clarifying the benefits and burdens of specific medical interventions in different clinical situations. Although some efforts have been made to document the implementation and results of strategies to prevent or resolve conflict, more research is needed to assess their strengths and limitations and guide adjustments to produce better results.

Individual-Level Strategies

Continued Discussion and Involvement of New Parties

At the individual level, attempts to resolve conflicts involving specific clinicians, parents, and sometimes children typically involve continued discussion of the situation. Following the identification of a conflict, new participants may become involved in the discussion. Thus, a child's care team may meet as a group with the family and perhaps the child to discuss a disagreement that has arisen during discussions involving the family and the child's main physician. Sometimes, during such a team meeting, a nurse, social worker, or other physician may recognize that despite an individual physician's best efforts to communicate clearly, the family lacks or misunderstands crucial clinical or other information and terminology. The conflict, in essence, turns out to be not so much about differences in values as about differences in information or understanding of the "facts" of a situation or differences in the way language is understood. When organizations make family conferences or protocols for counseling routine elements of pediatric care, they become system-level strategies for preventing or managing conflict (see, e.g., Hansen et al., 1998; Curtis et al., 2001).

Team conferences without family members present may also be employed to deal with conflicts among care team members, for example, when physicians and nurses disagree about the use of a life-sustaining intervention. If such conflicts are routine, then system-level approaches may be appropriate and could include cooperative development of practice guidelines based on systematic assessments of evidence and consensus-building processes.

Counseling and Consultations

Some conflicts may be less about facts or values (e.g., whether it is ever morally acceptable to withhold medically provided hydration) than about emotional issues of power, loss, distrust, guilt, anger, or fear of abandonment. Psychological counseling (usually involving the patient or family but sometimes involving a physician or other clinician) may defuse these emotions and, thus, the conflict.

Sometimes, ethics consultants (see discussion below of ethics committees) are brought in to help resolve conflicts through continued discussion or, at minimum, to help provide a framework for the further discussion. Sometimes discussions may focus on information and exploration of values, but they may also uncover and address issues of trust, fear, anger, or other emotions, including personality conflicts.

Consensus Building Techniques

At the request of the American College of Physicians–American Society for Internal Medicine (ACP-ASIM), three experts in adult palliative care proposed a consensus-based approach to decisionmaking for those who are unable to make decisions about their own care (Karlawish et al., 1999; see also Hoffman, 2001). The authors also offer suggestions about how to handle situations when discussion has not resulted in a consensus about the care of a patient who cannot make decisions about his or her own care. These suggestions, which should be tested further, include the following:

- postponing decisions and recommending that those involved take more time to think about and discuss concerns and goals;
- seeking interim steps such as a time-limited trial of a medical intervention rather than insisting on an all-or-nothing decision;
- continuing to identify and understand each participant's views on the goals of medical care for the patient and the care options for achieving those goals;
- bringing in a trusted third party such as an ethics or palliative consultant or religious adviser; and
- avoiding language or actions that personalize conflicts, turn decisionmaking into a power struggle, or attack the religious, cultural, or other values of the participants.

Regardless of the specifics, discussion strategies place a premium on communication skills and advance care planning as discussed in Chapter 4. Poor communication skills as well as failures of empathy and compassion are undoubtedly behind some of the disputes with parents that require interventions of the kinds discussed here. Based on the guidance developed from the ACP-ASIM, Table 8.1 presents examples of discussion steps and illustrative language that can be employed to guide discussion toward consensus. Because the original guidance focused on adult care, the text has been slightly altered. Again, further assessment of these strategies is desirable.

Discussions of the kind outlined in Table 8.1 take time, which is often in short supply as clinicians respond to health systems, hospitals, hospices, private insurers, Medicaid programs, and other state programs that are trying to control costs. Nonetheless, investments in careful initial communications with families can help limit subsequent investments in discussions

TABLE 8.1 Structuring Discussions to Reach Consensus About Care for Patients Who Lack Decision-Making Capacity

Step	Discussion Lead
1. Identify the main participants	"We need to make some decisions about the care of [child's name]. Is everyone here who could help us think through what we should do?
2. Invite the participants to narrate how the patient has reached this stage	"Can you tell me how she's changed, how things have gone for all of you?" Or "I know I've been caring for [child's name] for some time, but it helps me if you can tell me how she's changed, how things have gone for each of you."
3. Teach the decisionmakers about the expected clinical course of the patient's disease	"[Child's name] has an incurable, progressive, and ultimately fatal disease. I can't say for sure when she'll die . . . but given [the situation], we shouldn't be surprised when she does."
4. Advocate the patient's quality of life and dignity	"We ought to care for her in a way that makes us confident that after she's gone, we can say we did the best for her."
5. Provide guidance on the basis of existing data and clinical experience	"For patients like [child's name], feeding with a tube does not significantly reduce the risk for pneumonia. On the basis of my experience, a speech therapist may give us some useful hints on ways to feed her that will allow her to continue to eat by mouth."

SOURCE: Adapted from Karlawish et al., 1999, for the American College of Physicians—American Society of Internal Medicine. Used with permission.

to provide fuller information, correct misunderstandings, and defuse conflicts over goals of care. In certain situations, they may also reduce the potential for expensive litigation. Nonetheless, when capitation payments for physician services or fee-for-service payments for physician office visits are unreasonably low, as is often the case with Medicaid, and when payment policies limit or preclude payment for counseling, team conferences, and other kinds of communication, financial incentives clearly do not support the communication strategies described here and in Chapter 4. Thus, just as research, professional education, and organization structures have to support good clinical practice, so must financing policies.

Organization- or System-Level Strategies

The discussion in the preceding section focuses on the resolution of disputes at the individual level but also points to the need for organizational- and system-level responses to prevent or resolve conflicts. If distrust related to ethnic or religious differences appears to be at the heart of some disputes, are there organizational or community sources of distrust or misunderstandings that should be investigated and responded to by health care organizations and their communities? If misunderstanding of facts or terminology is a consistent problem, can training programs and protocols be created to help clinicians communicate more successfully or might public education programs be helpful?

Ethics Committees

Ethics committees and similar groups constitute a system-level effort to assist in the resolution of disputes about clinical care (see, e.g, Fletcher, 1991; AAP, 1994b, 2001d; AMA, 1984, 1994b; Dugan, 2001). They developed as hospitals struggled with the increasingly difficult questions that advances in medical technology have created. In 1983, the President's Commission endorsed the creation of hospital ethics committees. Such committees are now part of the institutional fabric of most American hospitals. The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) accepts such committees as one approach to meeting certain of its requirements, for example, having a "functioning process to address ethical issues" (JCAHO, 1998, Standard RI.1). A number of organizations have set forth guidelines for the creation, composition, and operation of ethics committees. Box 8.1 presents the recommendations of the AAP.

To a considerable degree, ethics committees have focused on articulating processes and providing consultative resources for resolving disputes without necessarily establishing guidelines or rules to address the substance of such disputes. For example, committee consultants may be useful in identifying when a persistent conflict in values may be best handled by transferring responsibility for a child's care to another physician or trying to arrange for the child's transfer to another institution. More generally, they may set forth processes for attempting to determine when a dispute is grounded in misunderstanding of facts or terminology and when it is grounded in true differences in values about the goals of care or the benefits of treatments. Box 8.2 summarizes the elements of such a process.

Ethics committees may also propose and try to develop professional consensus on institutional policies for specific issues such as DNR orders. In addition, committees usually have an educational role in teaching other

BOX 8.1
Institutional Ethics Committees (IEC): Recommendations of the American Academy of Pediatrics

1. Membership on an IEC should be diverse and reflect different perspectives within the hospital and general community.
2. An IEC should have responsibility within an institution for clinical ethics consultation, review of policies, and education of professional, administrative, and support staff about ethical issues, regardless of whether these functions are delegated to other subcommittees or programs.
3. An IEC that is engaged in clinical ethics consultations should have policies and procedures that conform to ethical principles of fairness and confidentiality.
4. An IEC should establish continuing education and training programs that ensure that IEC members are qualified to perform their specific duties within the IEC.
5. Independent ethics committees, such as an infant care review committee, should be dissolved or restructured to report to the larger IEC.
6. IECs within a general hospital setting should ensure an adequate degree of multidisciplinary expertise for addressing ethical issues specific to pediatrics.

SOURCE: AAP, 2001d.

BOX 8.2
Due Process Approach to Disputes About End-of-Life Care

1. Earnest attempts should be made in advance to deliberate over and negotiate prior understandings between patient, proxy, and physician on what constitutes futile care for the patient and what falls within acceptable limits for the physician, family, and possibly also the institution.
2. Joint decisionmaking should occur between patient or proxy and physician to the maximum extent possible.
3. Attempts should be made to negotiate disagreements if they arise and to reach resolution within all parties' acceptable limits, with the assistance of consultants as appropriate.
4. Involvement of an institutional committee such as the ethics committee should be requested if disagreements are irresolvable.
5. If the institutional review supports the patient's position and the physician remains unpersuaded, transfer of care to another physician within the institution may be arranged.
6. If the process supports the physician's position and the patient or proxy remains unpersuaded, transfer to another institution may be sought and, if done, should be supported by both the transferring and the receiving institution.
7. If transfer is not possible, the intervention need not be offered.

SOURCE: AMA, 1997, Policy E2.037.

members of the hospital community about the application of ethical concepts in clinical situations.

A number of questions have been raised about the goals of ethics committees and their ability to meet the goals set for them (see, e.g., Povar, 1991; Nelson and Shapiro, 1995; Gillon, 1997; Casarett et al., 1998; Mitchell and Truog, 2000). Some questions involve who (e.g., nurses, social workers) can bring questions to these committees. Others concern whether committees have sufficient resources and expertise to provide ethics consultations.

Questions about the independence of ethics committees have also arisen. In an environment of fiscal stress and resource restrictions, ethics committees run the risk of becoming and being perceived as partisan institutional agents (see, e.g., Kelly et al., 1997; Howe, 1999).

Draft standards for ethics consultations have been developed by a task force that included the Society for Health and Human Values, the Society for Bioethics Consultation, and several other organizations (SHHV/SBC, 1998). Research on the consequences of ethics consultations or ethics committee involvement in decisions about patient care is limited, but some studies suggest a positive role (Dowdy et al., 1998; Schneiderman et al., 2000). Further research may guide these committees by identifying individual- and system-level factors that affect family perceptions about end-of-life decisions. For example, in retrospective interviews, Abbott and colleagues (2001) found that family members identified several sources of comfort and support, including pastoral care, prior discussion of treatment preferences, and lenient visiting rules.

Protocols for Communication and Decisionmaking

Organizational- or system-level strategies for preventing and resolving conflicts take varied forms. Box 8.3 summarizes one example of an organization-level strategy to reduce clinician–family conflict in the intensive care unit (ICU) by improving teamwork and communication with families of patients nearing death. Clinicians, administrators, and ethicists developed the approach in part to reduce the potential for certain troubling ethical dilemmas and in part to reduce institutional exposure to liability based on patient or family dissatisfaction with care. An evaluation of this process is under way.

The discussion below considers two other organizational or system approaches to preventing or resolving conflicts about clinical care: research- and evidence-based practice guidelines and public policy (litigation and legislation). In addition, although individual clinicians are obligated to consider how they may improve their skills and attitudes, corresponding action at the organizational and system levels also must be considered, for ex-

BOX 8.3

Conflict Prevention in the ICU: One Cooperative Strategy to Reduce Conflict by Improving Care for the Critically Ill

In combination with other strategies to either prevent or manage conflicts, several adult intensive care units associated with Harvard University have been cooperating to develop and implement a strategy to reduce conflicts between clinicians and families about aggressive use of life-sustaining technologies for patients nearing death. They began with a period of intensive data collection—both personal interviews and surveys—to better understand the experience of patients and families and to identify their characteristics, concerns, and areas of dissatisfaction. Based in part on this information and on information from physicians and nurses, they then developed a four-step process to prevent conflicts.

1. "The clinical team identifies families at high risk for conflict using four criteria: expressed anger or conflict, prolonged length of stay in the ICU, absence of an identified surrogate decisionmaker, or an ICU admission triggered by an iatrogenic event.

3. The unit social worker or another clinician skilled in interpersonal communication performs a structured interview with the patient or family, focusing upon four domains: information giving and understanding, communication, conflict, and psychosocial support.

3. The social worker or other clinician meets with the clinical team on rounds the following morning and provides feedback to the team about the findings from the structured interview.

4. The clinical team develops a list of recommendations that it will pursue, based on the information received. These recommendations may range from scheduling a team meeting, to obtaining a second opinion for the patient, to obtaining formal input from the hospital ethics committee."

Other elements of the strategy include developing palliative care guidelines and developing a procedural approach to assessing when care is "futile."

SOURCE: Summarized from Truog, 2000. Quoted material used with permission.

ample, in the form of continuing education programs, changes in undergraduate and graduate medical education, competency testing, and funding to support these initiatives.

As discussed throughout this report, the procedures and policies of managed care organizations, insurers, and cost-conscious hospitals or other providers can contribute to conflicts and misunderstandings. System-level finance reform is essential, although it will never provide all the resources that health care professionals and families want. Some conflict over resources is inevitable.

Strengthening the Knowledge Base for Decisionmaking

Better scientific knowledge will neither prevent nor resolve all debates and disputes. For example, in the Baby K case mentioned earlier, clinical facts were not central to the mother's insistence on repeated resuscitation of her infant with anencephaly. Likewise, as discussed in Chapter 6, efforts to synthesize scientific knowledge in the form of guidelines for clinical practice are important but implementation of guidelines cannot be assumed in the face of contrary institutional, financial, and cultural influences (Rushton and Brooks-Brunn, 1997).

Nonetheless, doing good is easier when practice is guided by research demonstrating what works and what does not work to produce desired outcomes—whether those outcomes are cure for a disease or relief from suffering. Scientific research can also help defuse some controversies by challenging contradictory factual premises (explicit or implicit) on different sides of a dispute.

For example, in the United States, the 1980s saw considerable discussion of the appropriateness of correcting physical defects in newborns with significant mental retardation and other severe physical deficits. In one notable case, after parents would not approve surgical repair of a correctable defect in a child with Down syndrome and after a judicial challenge to their decision failed, politicians responded with the so-called Baby Doe regulations, toll-free telephone hotlines for people to report similar cases, and subsequent legislation to require treatment of handicapped newborns except in specified situations (see, e.g., Pless, 1983; Lantos, 1987; AMA, 1992; Weir, 1992; Caplan et al., 1992). Since this episode, research has indicated that many affected infants have a better prognosis than clinicians and parents previously assumed (Teddell et al., 1996; State et al., 1997; Amark and Sunnegardh, 1999). That is, the infants often have reasonably good prospects for many years of dependent but apparently enjoyable life.

Clinical practice guidelines or protocols represent one focused system-level strategy to create a credible, authoritative, evidence-based framework to guide individual patient care decisions (IOM, 1990a, 1992). Procedures vary in rigor and credibility, and methods for developing guidelines continue to be debated and refined. Generally, the more rigorous processes for guideline development bring together clinicians, methodologists, and sometimes consumers, ethicists, and others to define the issues at stake, identify and evaluate relevant scientific evidence or facts, and set forth statements about appropriate care that are based on an explicitly described combination of evidence, clinical judgment, and values.

Recent international guidelines on cardiopulmonary resuscitation, for example, assessed a considerable body of research that attempts to link resuscitation outcomes (e.g., survival to hospital discharge, neurological function) to patient characteristics (e.g., diagnosis, age). These guidelines note that cardiac arrest in children, unlike adults, is uncommon and is rarely a sudden event. It typically results from other than a primary cardiac cause and often is the final event associated with progressive shock or respiratory failure related to trauma, respiratory or neurological disorders, sepsis, or unexplained causes (sudden infant death syndrome [SIDS]) (AHA, 2000a). Survival is uncommon, and children who survive are often neurologically devastated. The guidelines note these dismal outcomes and urge the development of a consensus definition of when resuscitation would be futile. The guidelines mention only two specific circumstances in which not initiating resuscitation is indicated: (1) when patients have a clear advance directive asking health care workers not to begin resuscitation in the event of a cardiac arrest and (2) when patients show signs of irreversible death such as rigor mortis, decapitation, and dependent lividity or postmortem hypostasis (purple coloration from pooling of blood in dependent body areas) as agreed upon by a consensus of the medical community. The guidelines emphasize the lack of rigorous research to support many common elements of resuscitation and identify many areas for further research.

To the extent that research helps to reduce disagreement among clinicians, this will be a benefit in itself. Further, reducing disagreements among clinicians should also reduce clinician–patient or clinician–family conflicts that are stimulated or reinforced by evident variations in clinician views and practices.

Throughout this report, the limited knowledge base for much pediatric palliative and end-of-life care is documented. Chapter 10 includes recommendations and directions for research to strengthen the knowledge base for effective palliative and end-of-life care for infants, children, and adolescents. The recommendations focus on knowledge to improve clinical care, but better knowledge is also important to inform ethical and legal decisionmaking.

Litigation and Legislation

Disputes about which values should prevail in a patient's care may end up in court when other conflict resolution approaches fail and death or another outcome has not intervened to make the conflict moot. The judicial system provides a socially sanctioned process for resolving individual disputes within a framework of statutes, regulations, and case law (i.e., precedents established by prior decisions). As courts have increasingly faced disputes that involve highly technical issues, judges and policymakers have struggled with questions about the ability of judges and juries to understand and weigh scientific and technical information, often presented by experts who differ in their presentation and assessment of this information.

In general, litigation tends to be a costly, disruptive, and unpredictable vehicle for resolving conflicts that is stressful for all parties.

Statutes or administrative regulations constitute a different kind of system-level response to controversies about clinical decisionmaking. The development of statutes or regulations may or may not take scientific evidence into account and may or may not attempt to reflect or create clinical or community consensus about an area of disagreement. For example, state laws about adolescent decisionmaking "form a patchwork quilt of rights and limitations" that neither reflects nor contributes to a coherent view of adolescent capacity to make medical decisions (Oberman, 1996, p. 127).

Oregon offers an example of the rare jurisdiction that set out—not without problems and controversies—to employ careful and explicit strategy to (1) develop community consensus on priorities for medical care; (2) use clinical research and judgment to assess the relative benefits of treatments for common medical problems; (3) cover the most beneficial treatments within predetermined spending levels; and (4) expand health coverage to more people using the savings from reductions in services of marginal or no benefit (see, e.g., Bodenheimer, 1997; IOM, 1997). The priority-setting framework explicitly included comfort care (e.g., hospice, pain management) among the essential services (Cotton, 1992). Oregon's strategy has provoked continuing political, ethical, and analytic debates as well as legal challenges that have limited its application to and beyond the state's Medicaid program. State budget problems have limited the move toward universal coverage (see, e.g., Rojas-Burke, 1999). Despite, or perhaps as a result of, the attention paid to the Oregon approach, it has not been replicated by other states.

Debates about rationing care often focus on expensive versus inexpensive health care services. The real issue, however, is not the expense per unit of *service* but, rather, the expense per unit of *benefit* (for example, years of life or days free from pain). High-volume services with low unit costs are less dramatic but not necessarily less important than very expensive, low-volume services. Systems must inevitably make trade-offs among alternative ways of using available resources to benefit large groups (their members), and different systems have made different choices. Some of the implicit means of rationing potentially beneficial services rely on price or inconvenience. The next section discusses legal issues related to several kinds of disputes that can arise in the treatment of children.

LEGAL CONSIDERATIONS

Although the committee views litigation as a last resort in cases of conflict about care for children with life-threatening medical problems, situations will arise that make recourse to the courts appropriate or unavoidable. Litigation often takes a significant emotional and financial toll on all involved and can result in decisions and precedents that have unanticipated repercussions far beyond the original case. The following discussion reviews various legal issues related to decisions about medical care for children.

Parent–Physician Conflict

Parental Refusal of Treatment

As medical care becomes more complex, so do the types of legal problems arising out of parental refusals of treatment (Holder, 1983). Some refusals stem from religious convictions; for example, some Jehovah's Witness members object to blood transfusions for children as well as adults (Stanfield et al., 2000). Other refusals are based on a parental view that a child with a serious illness (such as cancer) should not be subjected to the side effects of treatment and that "alternative therapies" such as laetrile offer as much benefit as chemotherapy without the side effects (see, e.g., *Schiff* v. *Prados*, 112 Cal Rptr 2d 171, 2001; *Marshall* v. *Sackett*, 907 SW 2d 925, Tex 1995; *Green* v. *Truman*, 459 F Supp 342, DC Mass 1978; see also Faw et al., 1977; Horwitz, 1979). Some parents, who accept the fact that their child is probably dying, want to stop painful or other unpleasant treatments to prolong the child's life in an effort to provide as much peace as possible (*Gerben* v. *Holsclaw*, 692 F Supp 557, DC ED Pa 1988; see also Nealy, 1995).

Court intervention, based on the legal principle that failure to obtain adequate medical care for a child is a violation of state child neglect laws, is always an option if physicians consider it appropriate. Until recently, when a physician testified that a child would die or be permanently disabled if treatment were not provided at once, the court order would be automatic. This is not so uniformly true today, but it is still clearly the case in situations where parents refuse treatments that would likely cure or substantially modify the course of the child's illness.

Religious conviction is never a defense for a refusal to provide medical care for a child (see, e.g., In the Matter of D.R., 20 P 3d 166, Okla Civil Appeals, 2001; *Hoang* v. *State*, 250 Ga App 403, 2001; AAP 1997d). For example, if a 3-year-old child of a Jehovah's Witness is in an automobile accident, needs a blood transfusion to which the parents object, and is expected to recover completely, a court order would be issued in any court in the country (*Jehovah's Witnesses of Washington* v. *King County Hospital*, 390 US 598, 1968). Similarly, if a child had acute appendicitis but his parents refused to consent to any medical care at all, a court order would be issued. When the need for life-saving treatment is urgent, a physician or hospital that provides such treatment without a court order and over parental objection will not be liable, as long as it is clear that there was no time to apply for and receive a court order (*HCA, Inc.* v. *Miller*, 36 SW 3d 187, Tex App 2000).

Failure to provide medical care to a child can be prosecuted as a criminal offense. Convictions of manslaughter and even murder (*Commonwealth of Pennsylvania* v. *Nixon*, 2000, 563 Pa 425, 761 A 2d 1151, 2000; *Commonwealth of Pennsylvania* v. *Barnhart*, 345 Pa Super 10, 497 A 2d 616, 1985) have been upheld when a child died without medical care. In these cases, the state must prove by "substantial medical evidence" that the illness or accident would not normally have been fatal if the child had been treated with usual and appropriate interventions.

When cure for a child's medical problem is unlikely or impossible, however, courts have been increasingly willing to allow parents to make decisions based on their subjective analyses of risks and benefits (*Newark* v. *Williams*, 588 A 2d 1108, Del 1991; In the Matter of Matthews, 225 A.D. 2d 142, 650 NYS 2d 373, 1996). If another physician can be found who agrees with the parents and testifies that she or he will assume responsibility for the care of the child after the original physicians declined to follow the parents' wishes, all courts will permit parents to remove their child to the other physician, even if the original physicians are convinced that the new physician's therapies are outside any accepted medical standard (In re Hofbauer, 47 NYS 2d 648, 419 NYS 2d 936, 393 NE 2d 1009, 1979). If a child's life is not *immediately* threatened, even if the underlying condition is desperately serious, most courts' longstanding practice is to refuse to order that high-risk therapies be given over parental objection (In re Hudson, 1955, 13 Wash 2d 673, 126 P 2d 765, 1942; In re Seiferth, 309 NY 80, 127 NE 2d 820, 1955).

It is one thing to treat a child in the hospital under court order when the child will then leave the hospital to return to normal life at home. It is quite another to obtain a court order to administer chemotherapy or other treatment over parental objections when the parents' cooperation is required to bring the child for continuing outpatient services. If their objections are sufficiently adamant, they can leave the state with the child (In re Chad Green [In re: Custody of a Minor], 379 NE 2d 1053, 393 NE 2d 836, 1979). This raises the prospect that if a court order is obtained, the child will have to be either hospitalized during the entire period or removed under court order from his parents and placed in foster care. To inflict this on a family and a child at a time of suffering and perhaps impending death is something that should be considered only under the most extraordinary circumstances and when there are strong reasons to believe that the achievable goal is long-term remission or a potential cure.

In sum, a physician confronted with parents who, for whatever reason, are "uncooperative" may assume correctly that she or he can get a court order to treat the child. The ultimate question is whether such a step will, on balance, benefit the child. In many situations, it will not.

Parental Insistence on Treatment

The converse physician–parent conflict arises when the physician feels that further aggressive life-prolonging interventions for a dying child are futile or will cause suffering in excess of any potential benefit and the parents refuse to accept that decision (Paris et al., 1990). Some but not all of these conflicts arise when parents, for religious or other reasons, will not accept the concept of brain death.

If a patient (child or adult) is, by standard medical criteria, brain dead (see Chapter 1), no permission is required to pronounce the patient dead (see, e.g., *Lovato* v. *District Court*, 198 Colo 419, 601 P 2d 1072, 1979; *Alvarado by Alvarado* v. *New York City Health and Hospitals Corporation*, 145 Misc 2d 687, 547 NYS 2d 190, 1989). Even if the family objects, the physician may sign the death certificate and then remove the respirator (thus demonstrating that the patient was dead *before* life support was removed) (see, e.g., *Law* v. *Camp*, 116 F Supp 2d 295, 2000, 2001 WL 868354, CCA 2, July 27, 2001).

In some circumstances, however, physicians may find it advisable to obtain a court order before terminating life support over parental objections. One of these circumstances is when the child's condition is or may be the result of abuse inflicted by the parent (In re L.H.R., 253 Ga 439, 321 SE 2d 716, 1984; In re M.D., 758 A 2d 27, DC CA 2000.). When a parent will face a murder or manslaughter charge as soon as the child is pronounced dead, he or she will almost never consent to withdrawal of life support (AAP, 2000e). Since the circumstance of pronouncing the child dead will be the major issue in the parent's trial, it is important to have a clear record of the circumstances, including a judge's order to terminate life support—even if the child meets all criteria for brain death (*Truselo* v. *Carroll*, 2000 WL 33324536, Del Fam Ct 2000; In re Tabatha v. Ronda R., 252 Neb 687, 564 NW 2d 598, 252 Neb 864, 566 NW 2d 782, 255 Neb 818, 587 NW 2d 1909, 1998; In re Haymer, 115 Ill App 3d 349, 450 NE 2d 940, 1983; see also Massie, 1993; Fleming, 1999).

In most litigation involving parental insistence on treatment, however, the child is not brain dead but is in a persistent vegetative state. The physician feels that in the absence of any hope of recovery, continued maintenance of the patient on life support is a mistake. In contrast, the parents are simply thankful their child is "not dead" and refuse to allow termination of life support (see, e.g., *Velez* v. *Bethune*, 219 Ga App 679, 466 SE 32d 627, 1995; Moore, 1995). Even if they agree with the physician's judgment that there is no hope of improvement, they may take the position that if the child is not dead, he or she is still alive and should be treated. In one recent case (*Burks* v. *St. Joseph's Hospital*, 227 Wisc 2d 811, 596 NW 2d 391, 1999), a woman delivered a baby at 22 weeks of pregnancy. She was told (as she would be in virtually all hospitals in the country) that her 7 ounce daughter, even though she was breathing at birth, had no hope of survival. Although she asked that the baby be taken to the Newborn Special Care Unit, she was told that extensive efforts at resuscitation were inappropriate, and the baby died $2^1/_2$ hours later. She sued the hospital and the court held that she had a right to pursue the claim. Whether she will win and recover damages has not yet been determined.

The best known of case of this type was the case of Baby K, which has already been mentioned (In re Baby K., 16 F 3d 590, CCA 4, 1994; see also, In the Matter of Infant C., 1995 WL 1058596, Va. Cir November 17, 1995). Baby K was anencephalic but, for reasons still unclear, was put on a respirator in the delivery room. Her mother refused to permit a DNR order or removal of the respirator. She firmly believed that God would heal her child. Baby K was eventually discharged to a nursing facility that accepted babies. She was readmitted to the hospital several times for treatment of respiratory distress. Finally the hospital asked for an order from the court stating that it did not have to provide extraordinary medical treatment to this hopeless case. The court found that the federal Emergency Treatment and Active Labor Act, which requires any hospital to provide essential care to emergency admissions, applied to Baby K and the hospital could not refuse to treat her in the emergency department. The trial judge's decision was upheld when the hospital appealed to the United States Court of Appeals for the Fourth Circuit. Baby K finally died in the pediatric nursing home at age 14 months, still on full life support (Fletcher, 1997).

Thus, it is increasingly clear that before a physician may terminate life support on any patient, adult to newborn, when the parent or next of kin objects, she or he should assume that it is necessary to ask a court for an order. Refusal of such a request should not, however, come as a particular surprise (Massie, 1993). An ethics committee consultation may help mediate the issues and might persuade the parents to change their minds, particularly if the basic problem is the parents' lack of trust in the physician. Nonetheless, the findings of an ethics committee have no legal standing and cannot be used alone as the basis for termination of life support.

Parent–Child Conflict

Based on their experience, many physicians recognize that even very small children know when they are very sick. As discussed in Chapter 4, they are often far more aware of death than adults may realize.

Medical and nursing care of seriously ill children includes helping them to achieve a developmentally appropriate understanding of their illness and making sure that they know what to expect from tests and treatments. Their views should be taken seriously, but these views may or may not be the deciding factor in therapeutic decisionmaking.[15]

Preadolescent children are rarely, if ever, asked if they want the medical care their physician and parents decide is best for them. No one asks a 6-year-old if he wants an injection. He is told that he is going to get one and what it will feel like. (A child can still be offered choices such as which arm to use and can still be advised on what he or she can do to make it hurt less.)

For adolescents, the picture is more complicated. Under English common law, a minor was emancipated if he (not she) was a young man who was not subject to parental control or regulation. In all aspects of his life, he was considered to be a legal adult and could buy and sell property, sign contracts, get married, or do anything else adults could do.[16] The American legal system adopted the concept. In twenty-first century America, an emancipated minor is one who is married, is in the military (a much less frequent occurrence than it was when the age of majority was 21 instead of 18), or is self-supporting and living away from home. If a minor's marriage is dissolved, he or she remains emancipated. In addition to these categories of emancipated minors, many states have enacted statutes providing other contexts in which a minor (with or without a court order) is emancipated and, thus, whose parents have no further legal responsibilities for him or her.

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[15] In distinguishing legal consent to treatment from a child's assent, the American Academy of Pediatrics (1995a, online, no page number) described the process of securing assent (consistent with the child's stage of development) as including at least these elements: "(1) helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition; (2) telling the patient what he or she can expect with tests and treatment(s); (3) making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy); and (4) soliciting an expression of the patient's willingness to accept the proposed care." The AAP noted with respect to the last point that if, in fact, "the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived."

[16] At the time, women of any age could not own property or sign contracts, so there was no reason to consider emancipation for girls.

Adolescents now are being allowed to make decisions about their own medical care and other areas of their lives at a level that would have been astonishing 50 years ago (Holder, 1987; *Caldwell* v. *Bechtol*, 724 SW 2d 739, Tenn 1987; AAP, 1995a; Hartman et al., 2000). Beginning about 1950 with the epidemic of venereal diseases in adolescents, physicians realized that if a teenager knew that his or her parents would be contacted to provide consent for treatment, thus discovering what their son or daughter had been doing, the adolescent would forgo treatment, thus spreading the problem. As a result of physician influence, by the mid-1960s all states had enacted legislation permitting minors to be treated for venereal disease without parental notification, and today almost all states have similar laws allowing confidential treatment for drug and alcohol problems. At the time, some states began enacting minor treatment statutes giving a minor of a specified age (usually 16, but in some states as young as 14) the right to consent to any medical treatment on his or her own without parental consent.

Even in the absence of state statutes allowing minors to consent to treatment, it has been more than 40 years since a court awarded damages to parents against a physician who treated a child without their consent, as long as the adolescent patient gave a knowledgeable consent to the procedure. These court rulings have become known as the "mature minor" rule. The standard accepted by courts in virtually all states is that if a young person (14, 15, or older) understands the nature of the proposed treatment and its risks and expected benefits as well as an adult could, he or she may give consent. The maturity of the particular adolescent and the gravity of the illness must be factored into the assessment.

One might assume that if a patient may consent to treatment, then that patient may also refuse it. In fact, it is very unusual for a court in this country to allow an adolescent to refuse treatment that is clearly necessary (e.g., an appendectomy) even if it is not incontrovertibly life saving (see, e.g., Rosato, 1996; Skeels, 1990; Lonowski, 1995; Bidari, 1996; Penkower, 1996; Derish et al., 2000). In a few cases, all of which involve adolescent Jehovah's Witnesses and their refusal of blood transfusions, courts allowed adolescent patients to refuse transfusion based on a demonstration that they understood the nature of the illness, could articulate their own religious objections to the blood transfusion (i.e., were not merely reflecting parental pressure), and understood quite clearly the permanence of death. In at least one case involving a 16-year-old with leukemia, the child died (In re E.G., 133 Ill 2nd 98, 549 NE 2d 322, 1989; *Belcher* v. *Charleston Area Medical Center*, 188 W. Va 105, 422 SE 2d 827, 1992; Traugott and Alpers, 1997). Many more cases, however, have held in identical or similar circumstances that while the right to refuse treatment is available for any mentally competent adult, no such right exists for minors (*Novak* v. *Cobb*

County—Kennestone Hospital Authority, 849 F Supp 1559, DC Ga, 74 F 3d 1173, CCA 11 1996).

Except for West Virginia, states do not permit a minor, even if legally emancipated, to create a legally enforceable living will, durable power of attorney, or other statement that he or she would want treatment stopped in case of serious illness or accident (Hawkins, 1992).[17] This does not mean that the physician should neglect to find out what the child's views on continuing treatment may be if the long-term prognosis is not good (AAP, 2000g). Those views should still be taken into account when decisions are made (In re Chad Swan, 569 A 2d 1202, Maine 1990).

When parents and an adolescent patient disagree, the physician is the patient's, not the family's, advocate. If the prognosis is poor and the patient has "had enough," the physician is professionally obligated to do everything she or he can to persuade the parents to let the child's views control. Therapies that the physician considers inadvisable may not be required by distraught parents. On the other hand, if the prognosis is good but the patient does not want to continue therapy, the physician's responsibility is to understand and respond to the child's fears and help her or him through the treatment.

Parent–Parent Conflict

Although there may be instances in which parents are bitterly divided on the wisdom of continuing life-sustaining treatment for a child who is likely to die, the committee located only one case on the question. A terminally ill 13-year-old girl was in a coma. Her mother agreed with her physicians that a DNR order was the appropriate next step. Her father adamantly disagreed and wanted her treated as aggressively as possible. The hospital turned to the court for guidance, and the trial court and state supreme court each held that both parents had to agree before a DNR order could be written (In Re Jane Doe, 262 Ga 389, 418 SE 2d 3, 1992).

In cases of this sort, the parent who wishes the child to continue "living" is likely to be upheld by a court. If the parents are divorced, the legal custodian is likely to prevail in such a conflict (*Durfee* v. *Durfee*, 87 NYS 2d 275 NY 1949).

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[17] In 2000, West Virginia passed the Health Care Decisions Act (Annotated Code of West Virginia, Chapter 16, Article 30, Section 3(b)), which defines an adult, for purposes of health care decisionmaking including advance directives, as "a person who is eighteen years of age or older, an emancipated minor who has been established as such pursuant to [other laws], or a mature minor." A mature minor is "a person less than eighteen years of age who has been determined by a qualified physician, a qualified psychologist or an advanced practice nurse in collaboration with a physician to have the capacity to make health care decisions."

Children Who Are Wards of the State

State officials must approve medical care provided to children who are wards of the state, for example, children in foster care or correctional facilities. State officials and policies, which are not always in writing, determine whether health care providers can obtain consent for measures such as DNR orders or removal of mechanical ventilators. Although committee members had considerable experience with state refusals to grant consent for such measures, written information on policies and their application is very limited. This leaves physicians in a difficult position and potentially encourages substandard care and preventable suffering.

The Newborn with a Correctable Defect or Extreme Prematurity

The care of newborns with severe handicaps or extreme prematurity became a political issue during the 1980s following the well-publicized case of a baby with Down syndrome and a tracheoesophageal fistula who died because his parents refused to consent to surgery. An anonymous person tried to get a court to order surgery, but the local juvenile court held that the baby's parents had the right to make the decision. The Indiana Supreme Court concurred, and the baby died while an appeal to the United States Supreme Court was being sought.

The Department of Health and Human Services (HHS) then issued regulations requiring treatment of all handicapped infants except those who would inevitably die of their irreparable conditions (Shapiro, 1984). These regulations applied only to children with birth defects who had not yet had their first birthday. They did not apply, for example, to a healthy newborn severely injured in an automobile accident on the way home from the hospital or to a 13-month-old child with birth defects. The regulations were struck down, republished, and finally declared unconstitutional by the United States Supreme Court in 1986 (*Bowen* v. *American Hospital Association*, 476 US 610, 1986). In the meantime, however, the American Academy of Pediatrics and HHS reached agreement on regulations requiring any state seeking federal funds for child abuse programs to agree to enact state regulations to require that handicapped infants be treated except in certain specific circumstances. Those circumstances are that the infant was irreversibly comatose, the treatment would be "inhumane," the treatment would be "futile," or the provision of treatment would merely prolong the infant's dying (Child Abuse Amendments of 1984, P.L. 98-457).

Since the 1980s, the federal government has not intervened on behalf of any allegedly neglected newborn. As was the case before the "Baby Doe" regulations, state courts have dealt with conflicts arising when physicians wish to override a parent's decision to withdraw a treatment from a baby

(Stahlman, 1990). The federal investigations and rules may have, at least for a while, made neonatologists more fearful of forgoing life-sustaining interventions that they truly believed to be unwise (Kopelman et al., 1988).

CONCLUSION

High-profile litigation, regulations, and legislation about decisions at the end of life are uncommon but may create anxiety and fear among clinicians that have the potential to distort the way physicians inform and counsel patients and families (see, e.g., Kopelman et al., 1988). Some of this anxiety and fear is based on misunderstandings of statutes, regulations, and judicial decisions, although some may also be based on excessive caution on the part of hospital or other legal counsel and management. Efforts by professional societies, health professions educators, and organizations to improve end-of-life care may help correct erroneous views and overcome undue caution. These groups may also help to promote wider discussion and evaluation of strategies for preventing, resolving, and managing conflicts about care for dying patients.

Not all conflicts can be avoided, but they can be handled in ways that increase or decrease the potential for damage to the involved parties. Strategies include developing evidence- and consensus-based guidelines for care, improving communication skills, fostering sensitivity to cultural differences, and developing organizational procedures for identifying and defusing potential conflicts and promoting trust. Although the emphasis of these strategies will often be on physicians and parents as decisionmakers, as recommended in Chapter 4, children should be involved in discussions about their care consistent with each child's intellectual and emotional maturity and preferences and with sensitivity to family cultural background and values.

The next chapter discusses directions for improving health professions education in palliative, end-of-life, and bereavement care. It notes that education in these issues is often restricted to ethical concerns and argues that competence in palliative and end-of-life care cannot be achieved without guided clinical experience and training that is backed by a good understanding of available scientific evidence.

CHAPTER 9

EDUCATING HEALTH CARE PROFESSIONALS

> *The medical student population is probably the one that on a daily basis, offends parents the most. . . . I have been vocal with residents, like this person needs 101 in how to work with a parent. . . . But there is no real formal process set up for that feedback.*
>
> Tina Heyl-Martineau, parent, 2001

Whether the issue is insensitivity to feelings and emotions, inattention to pain and other symptoms, or inadequate information, children and families suffer when they encounter pediatricians and other professionals who are ill-prepared to offer them competent, consistent, and compassionate palliative, end-of-life, and bereavement care. Although education alone cannot ensure such care, undergraduate, graduate, and continuing health professions education is necessary to provide an essential foundation of scientific knowledge, ethical understanding, and technical and interpersonal skills.

Even for medical conditions that are invariably or often fatal, the focus of classroom lectures, clinical rotations, and textbooks is almost exclusively on the pathophysiology of disease and the conventional or experimental interventions that might prolong life—often with little regard for the likelihood of success and with little attention to the burdens experienced by dying patients and their families. In one recent survey of pediatric oncologists, respondents reported that the most common way they learned about end-of-life care was “trial and error” (Hilden et al., 2001a). Although a substantial fraction of children diagnosed with cancer die, only 10 percent of the pediatric oncologists reported having taken a formal course in end-of-life care, and only 2 percent reported a rotation in a palliative care or hospice service. Unstructured and unguided learning by experience puts patients and families at risk of much preventable suffering.

Most efforts to improve education in palliative, end-of-life, and bereavement care, not surprisingly, have emphasized older adults. Recently, however, several educational initiatives have focused on children who die and their families. For example, a new text on palliative nursing includes chapters on pediatric care (Ferrell and Coyle, 2001), and succeeding editions of the major text on palliative medicine have been enriched by discussions of care for children who die (Doyle et al., 1998). A recent manual on palliative medicine for psychiatrists also includes chapters on pediatric care (Chochinov and Breitbart, 2000). A series of self-study programs developed by the American Academy of Hospice and Palliative Medicine will include a monograph on pediatric care. The National Hospice and Palliative Care Organization and the Children's International Project on Palliative/Hospice Services are also developing educational materials.

The 1997 Institute of Medicine (IOM) report on end-of life care included an extensive examination of health professions education. This chapter draws on that discussion, much of which applies generally to the education of pediatricians and other professionals who care for children who die and their families. It also draws on other pediatric-specific sources, including Appendix G. The rest of this chapter considers

- basic elements of competence-building education in pediatric palliative and end-of-life care,
- deficiencies in current professional education in palliative and end-of-life care,
- responses to those deficiencies, and
- directions for further changes in health professions education.

The committee recognizes that educational reforms, albeit a commonly urged strategy for changing clinicians' attitudes and practices, are often difficult to achieve and that documentation of their success (especially over the long-term) in achieving desired objectives is often sparse. If the rewards for clinicians—financial, professional, and organizational—are not supportive of these objectives, then educational changes may be more symbolic than consequential. Educational reform is certainly not "the" solution to deficits in palliative and end-of-life care and might sometimes distract from the pursuit of other, potentially more important changes. Nonetheless, the objectives and information emphasized in health professions education are important symbols of what the professions should value. Educational reforms—and persistence in seeking and evaluating such reform—are one necessary element in a comprehensive strategy for improving palliative, end-of-life, and bereavement care as outlined elsewhere in this report.

BASICS OF HEALTH PROFESSIONS EDUCATION FOR PEDIATRIC PALLIATIVE AND END-OF-LIFE CARE

The committee believes that educational strategies to improve palliative and end-of-life care should begin with the early stages of a health professional's education, intensify and gain focus during more specialized training, and then provide reinforcement and updating as needed throughout a professional's career. At each stage, the aim should be, in individual terms, to produce the foundation of knowledge, skill, and attitudes appropriate to a professional's or future professional's role in the health care system and, in social terms, to generate a sufficient level and range of medical, nursing, and other expertise to meet diverse patient and family needs. Thus, educational strategies should include elements suitable for

- beginning students of medicine, nursing, social work, and other fields;
- medical residents in different specialties and fellows in different subspecialties;
- psychologists, social workers, and others in relevant graduate or advanced study programs;
- practicing generalist and specialist professionals in hospitals, hospices, and other settings; and
- paramedics, law enforcement personnel, staff of medical examiners' offices, and others who respond to sudden or traumatic deaths or are involved with survivors of such deaths.

In pediatric medicine, even though a general pediatrician will usually refer children with life-threatening medical problems to specialists, he or she may continue to care for the child, for example, after a disease-related treatment regimen concludes or after a child returns home following treatment at a distant center. He or she may also care for the child's siblings and, generally, may be a trusted resource for a family even after a child has been referred or died. Undergraduate and graduate medical education should prepare general pediatricians for these roles. Clinicians who specialize in pediatric critical care or oncology should be more intensively prepared for their extensive involvement with seriously ill or injured children and their families.

Because the number of child deaths is very small compared to the number of adult deaths, attention to end-of-life issues in pediatric education may seem peripheral to some, especially given the competition for time in the medical curriculum. This committee acknowledges the pressures on educators to add a long list of new topics—ranging from attention-deficit and hyperactivity disorder to the ethics of genetic screening—to an already crowded curriculum. It believes, however, that strengthening education in end-of-life care will not impose an undue burden. As argued by an earlier group (IOM, 1997, p. 212):

> First, palliative care is not a special interest issue; its principles of whole-patient care and teamwork provide a model for many other areas. Second, curriculum change need not be just an expensive addition but can also be an enrichment of established educational content and formats. Third, the use of existing program models and sharing of information can reduce the curriculum development burden on any single school. Fourth, the need to look beyond the hospital setting for educational opportunities is not unique to end-of-life care, but can be considered as part of a more general effort to develop non-hospital arrangements for improved training in primary care, chronic care, and outpatient care.

Moreover, many of the concepts, principles, and research findings that guide education for professionals who care for adults are broadly relevant to the education of those who care for children and their families. Some adaptations in educational goals and content will, however, be necessary to reflect the special needs of infants, children, and adolescents with life-threatening illnesses. For example, education in pain assessment, prevention, and management will have to consider the particular challenges of assessing symptoms in infants and preverbal children and in prescribing analgesic medications given the frequent lack of research-based information on doses for children at different developmental stages.

The development of a group of specialists in pediatric palliative care clearly has begun, often with support from the larger group of palliative care specialists who focus on adult care. These pediatric palliative care specialists are already helping to focus the attention of other clinicians, educators, professional societies, research funders, managers, and policymakers on strengthening educational and organizational resources for pediatric palliative care and enlarging the scientific foundation for that care. Consistent with the 1997 IOM report, this committee strongly supports the continued evolution of palliative care "as a defined and accepted area of teaching, research, and patient care expertise" (IOM, 1997, p.227).

At any level, professional competence has intellectual, interpersonal, and moral elements (Papadatou, 1997; Epstein and Hundert, 2002). It evolves as a professional accumulates training and experience and develops the capacity to integrate knowledge and awareness gained in varied clinical, organizational, and social contexts. Box 9.1 lists a set of basic competencies in four areas: (1) scientific and clinical knowledge; (2) interpersonal and other skills; (3) ethical and professional principles of care; and (4) organiza-

BOX 9.1
Preparing Health Care Professionals to Provide Palliative, End-of-Life, and Bereavement Care to Children and Families

Scientific and clinical knowledge and skills, including the following:

- Learning the biological mechanisms of end-stage medical conditions as manifested in infants, children, and adolescents
- Understanding the pathophysiology of pain and other physical and emotional symptoms as it interacts with children's physiologic development and medical condition
- Developing appropriate expertise and skill in the pharmacology of symptom management in children, taking advantage of advances in pediatric drug research and labeling
- Acquiring appropriate knowledge and skill in nonpharmacological symptom management, including complementary and alternative medicine and behavioral strategies
- Understanding the tools for assessing patient symptoms, status, quality of life, and prognosis that have been developed or adapted for children at different developmental stages
- Recognizing when consultation with palliative care specialists is appropriate
- Understanding the epidemiology of death in childhood
- Learning clinical indications for and limits of life-sustaining treatments

Interpersonal skills and attitudes, including the following:

- Listening to child patients, families, and other members of the health care team
- Conveying difficult news to children and their families
- Providing clear, timely, relevant information and guidance on prognosis and options
- Understanding and managing child and family responses to a child's life-threatening illness, including anticipatory grief and bereavement
- Sharing goal setting and decisionmaking with the care team, including family members

tional skills to help patients and families navigate the health care system. In general, the list is oriented toward pediatricians as those most broadly accountable for patient and family care. Given the range of professionals involved and skills needed, no single set of competencies in pediatric palliative and end-of-life care can comprehend all relevant issues.

Beyond the basics, education must prepare clinicians who specialize in care for children with life-threatening medical problems for the special clinical, psychological, and other challenges of such care. These challenges, in particular, include the risk of "burnout" and other emotional problems

- Developing skills in avoiding and resolving conflicts involving patients, family members, and other members of the health care team
- Cultivating empathy, compassion, humility, and altruism
- Developing sensitivity to religious, cultural, and other differences among children and families and among professionals and relevant others
- Recognizing and understanding one's own feelings and anxieties about the death of a child

Ethical and professional principles, including the following:

- Acting as a role model of clinical proficiency, integrity, and compassion
- Determining and respecting child and family preferences, taking into account children's stage of development and legal requirements
- Learning principles of pediatric palliative and end-of-life care, including advance care planning
- Understanding societal and population interests and resources
- Balancing competing objectives or principles
- Being alert to personal and organizational conflicts of interests

Organizational knowledge and skills, including the following:

- Developing and sustaining effective professional teamwork
- Identifying and mobilizing supportive resources (e.g., hospice, school, and other community-based assistance), including resources for children with special health care needs
- Understanding and managing relevant rules and procedures set by health care organizations, insurers, and government units (e.g., medical examiner's office, social welfare agencies)
- Protecting children and their families from harmful rules and procedures
- Assessing and managing care options, settings, and transitions
- Making effective use of existing financial resources and cultivating new funding sources

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SOURCE: Adapted from IOM, 1997, with additional information from Appendix G.

that may arise after intensive, day-to-day care of children who die and their families.

Hospices, in particular, have recognized the need for strategies to help professionals cope with the stresses of end-of-life care (see, e.g., Harper, 1977, 1993; Dean, 1998; Sumner, 2001). Some of their strategies focus on organizational policies and environments (e.g., assigning shared responsibility for care, ensuring emotional support and empathy from administrative staff and coworkers). Other strategies emphasize coping mechanisms as part of initial training and continuing education programs.

CURRENT STATUS OF PROFESSIONAL PREPARATION IN PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES

Despite an increasing list of educational programs that incorporate or focus on palliative and end-of-life care, surveys and other assessments continue to reveal shortfalls in the preparation of health professionals to care for adults and children who die and their families. These shortfalls characterize undergraduate, graduate, and continuing education. Most assessments have focused on physician education, but nursing and social work education appears to show a similar pattern of inattention.

The major—and not unexpected—exception to the pattern of inattention involves on-the-job and continuing education for the many different professionals who provide hospice care. Hospices also offer training both for volunteers and for family members who provide physical care to dying loved ones.

Undergraduate Medical Education

> *After discussing this . . . [the attending physician] casually told the intern and myself to tell the patient she had end-stage cancer, that we would be doing tests to find the source, and that was all we could do for her. I could not believe it. Finally I understood the difference between knowing and understanding.*
>
> Fourth-year medical student (Wear, 2002, p. 272)

This period in the education of physicians involves profound processes of professional socialization that affect attitudes and practices throughout their professional life. By the time medical students end their fourth year, they will have been directly involved with hospitalized patients, typically with little preparation for the interpersonal aspects of caring for gravely ill individuals and their families. One educator's survey of fourth-year medical students suggested that students sometimes became involved with dying patients as a result of an attending or resident physician's discomfort or lack of concern. The disbelieving student quoted above offered one example of such involvement. Another student reported that he felt his inept and unguided effort to discuss a patient's preferences for resuscitation "doomed" the patient to a terrible, prolonged death. Although students knew that textbooks and lectures could not substitute for direct involvement with real patients, this kind of "sink-or-swim" experience was deeply troubling and not constructive (Wear, 2002). The discussion below has to be understood in this context. (For other personal accounts, see the physician narratives published by the American Board of Internal Medicine [ABIM, 1996b].)

One review of the literature on training for end-of-life care in medical education from 1980 to 1995 concluded that even though most medical schools appeared to include some formal instruction in the topic, “there is considerable evidence that current training is inadequate, most strikingly in the clinical years” (Billings and Block, 1997; see also Barnard et al., 1999). Several subsequent surveys have documented continued deficiencies in medical school and residency programs.

For example, results from the 1997–1998 survey of medical schools by the Liaison Committee on Medical Education (LCME) indicated that one-third of the schools reported no required instruction in at least one of three key topics (death and dying, pain management, palliative care), and half offered no elective courses related to end-of-life issues (Barzansky et al., 1999).[1] Most schools reported that they covered these issues in their basic curriculum. Only 4 of 125 medical schools reported that a course in death and dying was required. The next LCME survey (1998–1999) indicated that one-fifth of medical schools required no experience in home hospice or inpatient palliative care, and one-fifth did not even provide the opportunity for such experience on an elective basis (Barzansky et al., 1999). In principle, students could seek some experience through volunteer activities, for example, with children’s hospitals, hospices, or camps for children with advanced illness, but only the most aware and dedicated are likely to do so. Another challenge in medical education is that students in their last undergraduate year often are already thinking about specialization.

The LCME surveys give only the most general picture of medical school instruction in end-of-life care. Coverage of end-of-life issues in the basic curriculum might involve no more than a single lecture or a set of readings. The lecture or readings might or might not reflect the clinical, professional, and other principles of palliative and end-of-life care endorsed in this and similar reports. As discussed further below, many opportunities exist to use end-of-life care or questions to illustrate more general themes related to compassion, humanism, ethics, patient- and family-centered care, behavioral interventions, and many other topics. Such an effort to diffuse palliative and end-of-life topics more broadly in the curriculum would, however, take creativity and persistence.

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[1] The LCME, which is supported by the American Medical Association and the American Association of Medical Colleges, accredits medical schools.

Graduate Medical Education

Results from the American Medical Association's (AMA's) 1997–1998 survey of residency programs showed considerable variability in their attention to end-of-life issues, not unexpected given the difference in clinical focus of various specialties (Barzansky et al., 1999). Almost all critical care residency programs reported some kind of structured curriculum in end-of-life care as did more than 90 percent of programs in family practice and internal medicine. Percentages were lower—between 60 and 70 percent—for programs in pediatrics, obstetrics–gynecology, psychiatry, and surgery. A more recent review by Weissman and Block (2002) reported that most surgical residency requirements were limited to ethics. For the 46 specialties reviewed, the most common requirements related to ethics (25 specialties) and psychosocial care (22). Only five mentioned clinical experiences.

In Appendix G, Himelstein and Kane report on a recent survey of pediatric residency program directors and pediatric residents in training. In contrast to the routine annual surveys by the LCME and AMA, this survey generated a low response rate from program directors (22 percent) and residents (42 percent), so the results may not be generalizable. Although 62 percent of respondents reported that their residents were involved in end-of-life situations, only 42 percent indicated that their residents received direct education in palliative care. Only one program director reported that hospice care was a scheduled resident rotation, and one-quarter of respondents thought that their program included no experts in palliative care. Virtually all responding residents in training indicated that they had been involved in end-of-life care for at least one child, and 86 percent said that they had been actively involved. Active involvement by a resident does not necessarily mean that his or her performance was guided or assessed. An earlier survey of medical residents found that one-third said that they had never been observed in a discussion with a patient about a do-not-resuscitate (DNR) order and most had only been observed once or twice (Tulsky et al., 1996).

As noted elsewhere, arranging clinical experiences involves a number of challenges (IOM, 1997). One is to provide adequate oversight, guidance, and feedback and thereby limit experiences that are little more than unstructured observation of clinicians and unguided interactions with patients. Maintaining such oversight and guidance is especially difficult as clinical experiences increase and trainees move into the community.

Nursing, Social Work, and Other Professionals

The committee located no detailed assessment of the inclusion of palliative care or end-of-life content in nursing, social work, or other health professions curricula. The American Association for Collegiate Nursing has concluded that "end-of-life education and training is inconsistent at best and sometimes completely neglected within nursing curricula" (AACN, 1998). The American Psychological Association similarly concluded that no systematic efforts have been undertaken to educate psychologists about end-of-life issues. The organization now encourages psychologists to obtain training in ethics as applied to end-of-life decisions and care and endorses "psychologists' acquisition of competencies with respect to end-of-life issues, including mastery of the literature on dying and death and sensitivity to diversity dimensions that affect end-of-life experiences" (APA, 2001a, no page).

Based on their review of program requirements, Himelstein and Kane (Appendix G) identified no structured training in palliative care or end-of-life care for clinical social workers. In general, however, educational requirements for social work are supportive of the approach to palliative and end-of-life care presented in this report. With private foundation funding, several social work educators are developing educational materials and programs to strengthen social workers' formal preparation to support people who are dying and to assist their families (PDIA, 2001a,b).

Various groups, including individual religious organizations, set standards for ministers, priests, rabbis, and others involved in pastoral care. As generally described in Appendix G, these requirements focus on knowledge, attitudes, and behaviors that are consistent with the principles of palliative care, but the committee located no formal assessments of these requirements, their implementation, or their effectiveness.

Professionals with varied backgrounds provide bereavement care, and the field is still evolving. Several organizations offer training and certification, but as yet, no generally accepted national standards for training exist. The National Hospice and Palliative Care Organization (specifically, its section for bereavement professionals) is collaborating with the National Council of Hospice and Palliative Professionals to develop guidelines for hospice bereavement care. The guidelines are expected to discuss, among other topics, education for bereavement care providers (Personal communication cited in Appendix G from Barbara Bouton, Bridges Center, Louisville, Kentucky).

In addition to training their own new and established staff, many hospices have education programs for community health care providers. Some hospices offer rotations or other experiences for medical students and other health professionals in training. For example, in a recent survey of approximately 4,000 hospices, about 10 percent reported training for pharmacists, who can be a valuable resource for professionals treating adults and children with symptoms of advanced disease (Herndon et al., 2001).

Appendix G lists the organizations responsible for setting accreditation, licensure, and similar standards for other professionals including social workers, child-life specialists, and clergy. It also reports what the authors found on organizational Web sites and through personal conversations regarding inclusion of material about palliative and end-of-life care, including care for children. For the most part, coverage was slight to nonexistent. An in-depth survey might uncover more, but the committee suspects that the basic conclusion would be the same: most educational programs and resources ignore the end of life.

Health Professions Textbooks

Medical textbooks have traditionally paid little attention to the description or management of either the end stages of diseases such as cancer and heart disease or the symptoms and distress commonly experienced by gravely ill or dying patients. One study of four widely used general medical textbooks concluded that they had little that was helpful to say about end-of-life care and that discussions of specific diseases usually dealt with "only prognostication and medical treatments to alter the course of the disease" (Carron et al., 1999, p. 82). A more comprehensive review of 50 medical textbooks likewise concluded that top-selling medical specialty textbooks "generally offered little helpful information on caring for patients at the end of life" and that discussions of specific disease had "no or minimal end-of-life care content" (Rabow et al., 2000, p. 771). A separate investigation of four leading surgical textbooks concluded that "disease epidemiology, prognosis/prevention, progression, and medical interventions were generally well discussed in all textbooks . . . [but] little helpful information was provided [about] breaking bad news/advanced care planning, mode of death, treatment decision-making, effect on family/surgeon, and symptom management" (Easson et al., 2001. p.34).

A similar analysis of the content of 50 leading nursing textbooks found that pain was the most commonly discussed topic related to end-of-life care, but such discussion comprised less than one-half of 1 percent of the text content (counted by pages) (Ferrell et al., 2000). The reviewers also found that the discussion of pain was often deficient in scope and sometimes inaccurate. A similar survey of social work textbooks is planned (PDIA, 2001a,b).

The committee found no similar, systematic assessments of pediatric textbooks. However, editors of one text have begun to include more information on end-of-life issues and palliative care (Behrman et al., 2000). Still, in this and other texts, the sections on many conditions that are usually or often fatal include little or no discussion of the end stage of the disease or attention (directly or by cross-reference) to the care of dying patients and their families.

INITIATIVES TO IMPROVE EDUCATION FOR PEDIATRIC PALLIATIVE AND END-OF-LIFE CARE

General

Changing health professions education is not easy. Deans of health professional schools, department chairs, residency program directors, certification and accreditation bodies, textbook authors, and other leaders face an avalanche of demands for new topics or perspectives to be included in curricula, residency program requirements, and other elements of health professions education. Academic medical centers and medical, nursing, and other health professions schools or programs also face financial pressures, particularly when state governments are trimming health and education budgets.

Change often requires a years-long process of developing, reviewing, ratifying, and implementing new educational requirements or methods. For example, a change in residency requirements usually involves years of preparation, discussion, negotiation, and review before adoption, which is then followed by more time to allow implementation before programs are assessed for compliance. Changing course offerings and requirements in a medical or nursing school, particularly adding a requirement, is often a highly political process as different disciplines compete for priority in an already overloaded curriculum. Thus, those promoting educational reforms may also pursue less formal strategies such as persuading individual instructors to include palliative care issues as illustrations in existing courses.

Efforts to improve the education of health professionals in palliative and end-of-life care can take several forms. They can include actions to

- improve curricula, clinical experiences, or resources (e.g., faculty preparation) for single educational institutions or programs or for consortia of institutions;
- set curriculum or other standards for a category of educational institutions, programs, or professionals;
- develop faculty expertise and other educational resources, including textbooks and Internet sites; and
- expand educational opportunities available to practicing professionals.

Some initiatives focus on the development of materials or models that have general application across institutions, for example, standards for educational programs or requirements for licensure. The Robert Wood Johnson Foundation has supported work by the National Board of Medical Examiners (which administers the physician licensing examination that is an element in state licensure requirements) to develop examination questions on end-of-life care (RWJF, 2001). Coverage of palliative care and end-of-life issues in licensure examinations is intended to reinforce curriculum standards.

The Residency Review Committee for Pediatrics, a subcommittee of the Accreditation Council for Graduate Medical Education, establishes requirements for the more than 200 pediatric residency programs. Box 9.2 lists requirements that specifically mention terminal conditions, death, some aspect of symptom management, or decisions about life-sustaining medical interventions. Other, generally relevant requirements include those relating to communication and interpersonal skills, team care for chronic or complex conditions, cultural dimensions of care, and quality assessment and improvement. The list mentions pain management but not quality of life or the symptoms other than pain that are common consequences of many life-threatening medical conditions or their treatment.

Recently, some pediatric subspecialties—emergency medicine, hematology–oncology, and neurology—have added provisions related to palliative or end-of-life care (also shown in Box 9.2). The specifics vary. Although subspecialty programs are supposed to cover skills related to “complications of death,” residency requirements for some subspecialties that care for significant numbers of children who die—notably neonatalogy, pediatric critical care, and pediatric pulmonary medicine—are silent on palliative and end-of-life care. Requirements for family medicine are also relevant. They refer to integration of “end-of-life issues” into the educational experience (ACGME, 2000).

Some states have acted to encourage attention to end-of-life issues in health professions education. For example, California added training in end-of-life care and pain management to the requirements for candidates for medical licensure, effective June 1, 2000 (Medical Board of California, 2000). In New York, a voluntary statewide effort is attempting to improve coverage of palliative and end-of-life care in the medical curriculum. One element of that effort has been the development of the Palliative Care Assessment Tool, which is intended to help medical schools in New York state assess and strengthen their curricula (Abele Meekin et al., 2000).

The creation of such general standards for education programs can provide a broad stimulus for change. Nonetheless, support for education in palliative and end-of-life care still has to be mobilized on an institution-by-institution or organization-by-organization basis.

Educational Strategies and Tools to Improve Palliative, End-of-Life, and Bereavement Care

Integration and Illustration

Ethics courses or course segments offer many opportunities for adult or pediatric end-of-life issues to be raised, for example, informed consent, double-effect decisionmaking, rationing, and truth telling. The humanities, which have become a more visible element of health professions education in recent years (see, e.g., Charon et al., 1995; Charon, 2001; Skelton et al., 2001), likewise provide rich opportunities to consider the human meaning of serious illness, suffering, and death.

Competence in palliative and end-of-life care cannot, however, be achieved if these topics are isolated in ethics and humanities seminars. Scientific education and clinical training are also necessary in many areas. These include understanding the pathophysiology and natural history of life-threatening medical conditions; determining diagnosis and prognosis; assessing, preventing, and managing physical and mental symptoms of advanced disease; evaluating the potential benefits and burdens of pharmacological, behavioral, and other treatment options; and understanding how children's developmental stage may affect pathophysiology, diagnosis, prognosis, symptoms, and treatments.

More generally, a basic principle of education is repetition and reinforcement of—not one-time exposure to—important concepts. To use an analogy, "You give the immunization in the first year of medical school, but then you've got to boost them at two, and then you've got to boost them again at four and at six."

To this end, many opportunities exist to use palliative care and end-of-life issues as powerful illustrations in teaching other concepts, principles, and techniques during the didactic and clinical components of undergraduate medical education and the similar stages of nursing and other health professions education. One advantage of an "illustrative" strategy is that it is less threatening to established interests than changes in requirements. Also, educators are often interested in finding compelling and challenging examples and teaching materials for lectures, small-group discussions, and other experiences. For resident physicians, end-of-life issues can be considered in mortality and morbidity conferences and similar sessions based on the circumstances of actual patients. With educational materials increasingly available through the Internet, the traditional content constraints related to textbook selection and library resources are less of an impediment to curricular enrichment than in the past.

BOX 9.2
Program Requirements for Residency Education

Common Residency Program Requirements (February 2002)

Programs must prepare residents to demonstrate competence in six areas:

- Patient care that is compassionate, appropriate, and effective for the treatment of health problems and the promotion of health;
- Medical knowledge about established and evolving biomedical, clinical, and cognate (e.g., epidemiological and social–behavioral) sciences and the application of this knowledge to patient care;
- Practice-based learning and improvement that involves investigation and evaluation of their own patient care, appraisal and assimilation of scientific evidence, and improvements in patient care;
- Interpersonal and communication skills that result in effective information exchange and collaboration with patients, their families, and other health professionals;
- Professionalism, as manifested through a commitment to carrying out professional responsibilities, adherence to ethical principles, and sensitivity to a diverse patient population; and
- Systems-based practice, as manifested by actions that demonstrate an awareness of and responsiveness to the larger context and system of health care and the ability to effectively call on system resources to provide care that is of optimal value.

Pediatric Residency Program Requirements That Mention Death, Terminal Conditions, or Palliative Care (September 2000)

Programs must provide instruction that enables residents to develop skills related to

- Impact of chronic diseases, terminal conditions, and death on patients and their families (behavioral developmental pediatrics);
- Pain management (procedural skills); and
- Relationship of the physician to patients, e.g., initiating and discontinuing the treatment relationship, confidentiality, consent, and issues of life-sustaining treatments (additional curricular requirements, medical ethics).

Techniques and Tools

Beyond lectures, an array of education techniques and tools exists to help health professionals develop competence in clinical care, including its psychosocial, ethical, and cultural dimensions. Common goals include improving patient–physician communication, encouraging teamwork among health professionals, and extending students' experiences into physician office, nursing home, home, and other community settings. Many tools and

Residency Program Requirements for Subspecialties of Pediatrics: General (July 2000)

This curriculum should include the pathophysiology of disease, reviews of recent advances in clinical medicine and biomedical research, conferences dealing with complications and death, as well as instruction in the scientific, ethical, and legal implications of confidentiality and of informed consent (education program, curriculum).

Residency Program Requirements for Child Neurology (February 1999)

The resident must receive instruction in appropriate and compassionate methods of terminal palliative care, including adequate pain relief, and psychosocial support and counseling for patients and family members about these issues (education program, clinical teaching).

Residency Program Requirements for Pediatric Emergency Medicine (June 1998)

There must be an emphasis on developing a compassionate understanding of the stress associated with sudden illness, injury, and death so that the resident may be responsive to the emotional needs of the patients, their families, and the staff of the emergency department. Discussion and appreciation of the many ethical issues involved in pediatric emergency medicine should be part of the educational program (curriculum).

Residency Program Requirements for Pediatric Hematology–Oncology (September 1999)

The subspecialty resident should participate in the activities of the tumor board and in the provision of comprehensive care to the child with cancer and should have experience in support of the patient, family, and staff in dealing with terminal illness. Residents should be guided in the development of skills in communication and counseling, including the recognition and management of psychosocial problems in pediatric patients (education program, clinical experience).

SOURCE: Accreditation Council on Graduate Medical Education (http://www.acgme.org).

techniques have the additional goals of improving the effectiveness of education by engaging students more directly in the learning process, strengthening problem-solving and reasoning skills, increasing the connections between scientific knowledge and clinical practice, and better preparing students for lifelong learning.

Evaluations of the strategies summarized here and in Appendix G, while often promising, are limited, especially in the area of palliative care.

Much is undertaken on the basis of experience and logic. Chapter 10 discusses directions for research to build the knowledge base for effective education in pediatric palliative care.

Patients and Families as Teachers

> *A social worker raised the astounding idea that instead of using actors or social workers, why not have standardized parents be actual parents, who went through the same training about giving feedback [to residents]?*
>
> Deborah Dokken, parent, 2001

At the Lucile Packard Children's Hospital, a six-session seminar in pediatric palliative care for first-year pediatric residents began in July 2001. The seminar runs continuously with the goal of having every resident rotate through and complete the course. During one of the six sessions, volunteer parents who have lost a child talk to the group about their experiences. As one family participant attested: "Now there is some emotion. There is a face. I think they realize their actions stay with these people for their lifetime" (Conlon, G., 2001). In a mentor session, a senior faculty member discusses with the group his or her experience working with children who die and their families. In other sessions, residents discuss their own professional and personal experiences with death and learn about symptom management, spiritual and cross-cultural aspects of care, and practical issues such as death certificates and coroner notification. (The needs assessment undertaken as part of the development of this course is described in Contro et al., 2002.)

One frequently cited effort to strengthen the medical school curriculum is Harvard University Medical School's elective course in "Living with Life-Threatening Illness" (Billings and Block, 1997; Block and Billings, 1998).[2] The approach is to pair students with volunteer patients (sometimes including children) who have a life-threatening medical problem and then use that ongoing relationship as the focus of the course's examination of issues in palliative and end-of-life care. A video and educational guide developed by the Education Development Center, which examines the experiences of students enrolled in the class over a two-year period, is part of an effort to encourage other schools to develop similar programs (Romer and Solomon, 2000). Earlier, Mermann and colleagues (1991) pioneered a similar course at Yale, but that course is no longer taught.

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[2] A range of materials was developed in support of this course by its faculty (Billings and Block, 1997).

Simulated or Standardized Patients or Parents Simulated patients are a well-accepted educational and assessment tool. Recently, the Federation of State Medical Boards and the National Board of Medical Examiners, which jointly administer the national licensing examination for physicians, announced that a clinical skills examination including standardized patients would be added to the examination (FSMB, 2002).

Use of standardized patients is more challenging in pediatric than in adult settings. Lane and colleagues, however, describe the use of child standardized patients in an evaluation of a pediatric clinical skills assessment tool and reported that their use proved feasible for the evaluators, enjoyable for the children, and acceptable to the children's real and standardized parents (Lane et al., 1999). Educators might, however, be hesitant to use child actors or volunteers to portray gravely ill or dying children. If their use was part of research to evaluate the strategy, an institutional review board, which must approve most human research, might object.

Use of standardized family members presents fewer complications (see generally Clay et al., 2000). In a project exploring ways to increase organ donation, Williams and colleagues have studied the standardized families, in this case, people trained to behave as family members being confronted with bad news, decisions about end-of-life care, and requests for organ donation (Williams et al., 2001b; 2002). These sessions were intended to improve the communication skills of physicians, nurses, clergy, and transplant coordinators participating as a team The standardized families did not operate from explicit scripts and the sessions could be interrupted to discuss and even restart "problem" conversations. The families, trainers, and other participants provided feedback. The rate of consent to organ donation requests rose from 25 percent before to 75 percent after the intervention but then fell back with staff turnover (Personal communication, Michael Williams, M.D., Johns Hopkins Medical Institutions, March 11, 2002). The researchers are still preparing their final report and are seeking another grant to study the strategy in two to four community hospitals.

In another project, researchers at George Washington University videotaped and evaluated skills of pediatric residents and emergency department fellows in communicating news of a child's death to standardized parents and then provided feedback to the residents and fellows (Greenberg et al., 1999). During a similar exercise several weeks later, the researchers found improvements in information and counseling skills.

Hospice and Inpatient Palliative Care Experiences As noted earlier, some hospices offer educational programs not only to their own staffs and volunteers but also to health professions students and community providers. Gomez (1996) described one inpatient hospice program that was linked to a community-based home hospice program. It offered educational experiences for residents, medical students, and nurses. As described above, a survey of directors of pediatric residency programs suggests that such experiences are rare, even for clinicians who routinely care for children who die.

Mentors and Role Models One objective of developing a cadre of palliative care specialists is to provide established clinicians and clinicians-in-training with role models and mentors. Mentoring implies a more directed effort to teach and counsel a particular individual rather than to teach by example in group situations such as clinical rounds for medical residents and other trainees. Examples of mentoring strategies (as part of broader educational programs) include matching medical students with community-based physicians known for their attention to spiritual issues in practice and matching first- and third-year medical students to work with chaplain mentors in sessions with patients.[3]

In a controlled trial of an ethics education program, Sulmasy and colleagues (1995) compared groups of house officers, one that received lectures and another that received a more extensive intervention that included a physician ethicist as role model who participated in clinical rounds where he raised ethical questions about patients' care. The trial also included two control groups. Those in the extensive intervention group showed more confidence on procedural issues and noted more concurrent care concerns (e.g., pain management) associated with DNR orders.

Faculty Development Among other goals, a broad initiative to improve end-of-life care in Department of Veterans Affairs (VA) hospitals has aimed to increase the number of "faculty leaders and innovators" in the field and to develop curricula for the VA's internal medicine residency programs (http://www.va.gov/oaa/flp/docFLPFactSheet.asp). The VA does not care for children and no equivalent care system exists for children. Nonetheless, this initiative has an evaluation component that may generate lessons useful for other faculty development efforts.

Projects at Harvard and Stanford also aim at faculty development. In addition to covering palliative care principles and practice, Harvard's program for nursing and medical educators (Harvard Medical School, 2002, http://www.hms.harvard.edu/cdi/pallcare/program.html) examines oppor-

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[3] These examples are included in short descriptions of programs that received awards for education in spirituality and medicine from the George Washington Institute for Spirituality and Health, George Washington University Medical School (http://www.gwish.org/courses/id44.htm). Systematic evaluations of program effects were not described.

tunities and challenges in palliative care education and program development. A one-month program at Stanford aims to provide participants "with background knowledge and seminar leadership skills required to deliver a series of eight 2-hour seminars to their colleagues and to residents at their home institutions" (Stanford Faculty Development Center, 2002, http://www.stanford.edu/group/SFDP/progeol.html). Again, these programs focus on adult care.

Continuing Education Other important initiatives focus on continuing education for physicians and nurses. The Education for Physicians on End-of-Life Care (EPEC) Project (with leadership from the American Medical Association's Institute for Ethics) has developed an education package that includes a mix of didactic sessions, videotape presentations, interactive discussions, and practical exercises (Emanuel et al., 1999). The Decisions Near the End of Life program, which has been used by interdisciplinary leadership teams in more than 230 institutions, includes a series of case-based seminars on ethical issues in end-of-life care (Solomon et al., 1997). Neither of these initiatives focuses on care for children and their families but both recognize the need for age-appropriate care. Both also have a "train-the-trainer" strategy with the objective of more broadly disseminating the resources for education in end-of-life care. The EPEC trainer's guide includes a module on the evaluation of training sessions.

A similar initiative for nurses is the End-of-Life Nursing Education Consortium (ELNEC), a partnership of the American Association of Colleges of Nursing and the City of Hope National Medical Center. The initiative focuses specifically on preparing nurse educators to bring education in end-of-life care to nursing schools and continuing education programs in a variety of settings (AACN, 2002). A pediatric version of ELNEC has been pilot tested (Personal communication, Betty Ferrell, Ph.D., City of Hope Medical Center, July 8, 2002). Other pediatric materials are being developed as part of Initiative for Pediatric Palliative Care described in Chapter 1.

As noted in the introduction to this chapter, major textbooks on palliative medicine, nursing, and psychiatry now include chapters on pediatrics, and a self-study program on pediatric palliative care and other education materials should be available soon. In addition to these resources, other resources include several books and similar materials that discuss concepts, principles, and practical aspects of palliative and end-of-life care for children and their families (see, e.g., Goldman, 1999, ChIPPS, 2001; Armstrong-Dailey and Zarbock, 2001).

DIRECTIONS FOR EDUCATORS

The goal of professional education in palliative, end-of-life, and bereavement care is to build the competence of physicians, nurses, and others who care for people with fatal or potentially fatal medical conditions. Education cannot, however, ensure competent practice. As discussed throughout this report, that requires organizational environments, professional culture, financing policies, and laws and regulations that reward—or at least do not discourage—such practice. Nonetheless, undergraduate, graduate, and continuing health professions education must provide the basic knowledge, skills, and attitudes required for competent practice.

Effective and compassionate care for children with life-threatening medical problems and their families will typically involve a range of health professionals as described in Chapter 5. Thus, education strategies must not only be appropriate to each profession's role but also prepare professionals to work effectively in teams. Further, although educational programs will typically focus on pediatricians and other child health specialists, training is also important for others (e.g., emergency first responders) who are commonly involved in the care of children with life-threatening medical problems or have contacts with family members (e.g., police officers investigating an infant death at home).

Recommendation: Medical, nursing, and other health professions schools or programs should collaborate with professional societies to improve the care provided to seriously ill and injured children by creating and testing curricula and experiences that

- **prepare all health care professionals who work with children and families to have relevant basic competence in palliative, end-of-life, and bereavement care;**
- **prepare specialists, subspecialists, and others who routinely care for children with life-threatening conditions to have advanced competence in the technical and psychosocial aspects of palliative, end-of-life, and bereavement care in their respective fields; and**
- **prepare a group of pediatric palliative care specialists to take lead responsibility for acting as clinical role models, educating other professionals, and conducting research that extends the knowledge base for palliative, end-of-life, and bereavement care.**

Many efforts to improve care for adults and children who die emphasize communication, ethical concerns, and similar issues. The studies reviewed earlier in this report underscore that education in palliative and end-of-life care must also respond to deficiencies in symptom management and other clinical care that permit needless suffering at the end of life. Overall, educators, like clinicians, must be held accountable for the kind of patient care they honor, as evidenced in the curricula, requirements, and experiences they provide for health professionals in training.

No single educational strategy or format will be sufficient to prepare professionals for the intellectual, emotional, cultural, and practical challenges of providing palliative, end-of-life, and bereavement care to children and their families. Likewise, varied incentives will be needed to reinforce educational initiatives including residency program requirements and inclusion of questions in licensure and certification examinations.

> **Recommendation: To provide instruction and experiences appropriate for all health care professionals who care for children, experts in general and specialty fields of pediatric health care and education should collaborate with experts in adult and pediatric palliative care and education to develop and implement**
>
> - **model curricula that provide a basic foundation of knowledge about palliative, end-of-life, and bereavement care that is appropriate for undergraduate health professions education in areas including but not limited to medicine, nursing, social work, psychology, and pastoral care;**
> - **residency program requirements that provide more extensive preparation as appropriate for each category of pediatric specialists and subspecialists who care for children with life-threatening medical conditions;**
> - **pediatric palliative care fellowships and similar training opportunities;**
> - **introductory and advanced continuing education programs and requirements for both generalist and specialist pediatric professionals; and**
> - **practical, fundable strategies to evaluate selected techniques or tools for educating health professionals in palliative, end-of-life, and bereavement care.**

The committee believes that these strategies for health professions education, if implemented and sustained, will be broadly beneficial. That is, they should reduce the suffering experienced by children who survive as well as children who die, and they should improve the support provided to all families who confront a child's serious medical problem or death. To confirm this expectation and refine strategies, educational programs and tools will require evaluation to determine whether they are changing knowledge, attitudes, and behaviors, ideally over the longer term as well as in the short term.

CHAPTER 10

DIRECTIONS FOR RESEARCH

> *Awful as it was, I was given a gift of experience. If I can use it [in research] to help someone else, it makes [my daughter's] life mean something still.*
>
> Bereaved parent (Contro, 2002, p.15)

Among the most common phrases in this report are "research is limited" and "systematic data are not available." Clinicians and parents must often make decisions about the care of children with little guidance from clinical or health services research that documents the potential burdens as well as the potential benefits of medical interventions. For example, parents of infants born more than 14 weeks prematurely are faced with urgent decisions about the extent of life support that they wish for their infant. They frequently must confront unanswerable questions and make their best guesses about what to do with the help and support of neonatolgists and nurses who must often, in turn, rely on their own experience and judgment with limited scientific knowledge to guide them. Neonatologists generally lack validated predictors of very premature infants' risk of death or long-term morbidity, although both outcomes are frequent.

The knowledge base for organizational and policy decisions is likewise limited. For example, organizations considering the creation of a pediatric palliative care program have little research on which to base decisions about services, staffing, outreach, budgets, and similar matters. What information is available relies heavily on descriptive case studies of adult programs. Funding for comparative health services research to test different approaches to organizing adult or pediatric palliative care is minuscule compared to the funding available for clinical research. Even when hospices and hospitals undertake data-intensive internal studies (e.g., for quality improvement projects), they often lack the resources and motivation to produce analyses that meet peer-review standards for publication and wider dissemination.

Researchers, clinicians, and policymakers have recognized shortfalls in clinical research involving palliative and end-of-life care for children and have taken steps to encourage and guide such research, some of which are described later in this chapter. The remainder of this chapter

- briefly reviews initiatives to encourage pediatric research in general and in palliative and end-of-life care specifically;
- describes directions for clinical, health services, and educational research to guide improvements in palliative, end-of-life, and bereavement care for children and their families;
- summarizes the practical challenges of undertaking pediatric research; and
- reviews ethical and legal questions raised by research involving children.

Lessons learned from the kinds of research recommended here should help inform and improve the care of children who survive as well as children who die. It should likewise help all families who experience a child's serious or fatal medical problem.

INITIATIVES TO ENCOURAGE PEDIATRIC RESEARCH

General

Federal policymakers have taken steps to encourage certain kinds of pediatric research. In 1998, following directions from Congress in 1995, the National Institutes of Health (NIH) issued policies and guidelines for including children as research participants (NIH, 1998). Under the policy, children are to be included in all such research funded by the NIH unless their exclusion is justified on scientific or ethical grounds. Exclusion would, for example, be justified when a medical problem does not affect children. For some medical conditions, children's developmental characteristics might suggest the need for a separate, child-only study.

Legislative conference language accompanying the legislation encouraged but did not require the NIH to establish pediatric research priorities (NIH, 1998). The organization has not developed an overall set of priorities, although some individual institutes have developed priorities for certain clinical problems or services including kidney disease (NIDDK, 2001), HIV/AIDS (NIH, 2001a), and emergency medical services (NIH, 2001b). The priority-setting activity related to emergency services was stimulated in part by recognition that more needed to be done to implement the research recommendations in the 1993 Institute of Medicine (IOM) report on emergency medical services for children (IOM, 1993).

In 2000, the Children's Health Act (P.L. 106-310), among its other provisions, created a pediatric research initiative to increase NIH support for research on diseases, disorders, and other conditions in children. The legislation also supported the training of more pediatric researchers to conduct basic and clinical research. Earlier, the Food and Drug Administration Modernization Act of 1997 (P.L. 105-115) provided incentives for pharmaceutical companies to test drugs in children, and Congress renewed that legislation with slight modifications late in 2001 (Best Pharmaceuticals for Children Act, P.L.107-109). Companies that undertake studies on their products' effects on children get six months of exclusive marketing rights for the drugs in return.[1] (A later section of this chapter describes provisions in this and other legislation and regulation related to protection of child participants in such studies.) In addition to the pediatric exclusivity provision, the Food and Drug Administration (FDA) issued regulations in 1998 that allow it to require drug companies to undertake pediatric testing for certain drugs likely to be used in children (63 Fed. Reg. 66632, December 2, 1998, effective April 1, 1999).[2]

In May 2001, the FDA published an updated list of priorities for pediatric drug research that included more than 425 drugs or drug uses (FDA,

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[1] Federal regulations requiring pediatric studies of certain drug and biologic products were proposed in 1997 and issued in final form in 1998 (http://www.fda.gov/ohrms/dockets/98fr/120298c.txt). In 2002, the government announced that it would suspend these rules for two years pending study of the need for them (Connolly, 2002); a month later, it reversed that decision (Kaufman and Connolly, 2002; Landa, 2002). Unlike the legislation, the regulations also cover biologics (e.g., vaccines, blood products, gene therapy products, HIV and hepatitis tests, innovative therapies for diseases such as cancer and arthritis).

[2] In a set of questions and answers about the rule, the FDA has stated (emphasis in the original deleted): "Under the rule, FDA has the authority to require pediatric studies on a drug product for the product's approved indications if there is substantial use in the pediatric population or the product would provide a meaningful therapeutic benefit—and the absence of adequate labeling could pose significant risk (see 21 CFR 201.23(a)). At this time, however, FDA will not require studies of approved drugs except if approved by the Center Director. Instead, FDA will seek to have manufacturers voluntarily submit studies for marketed drugs under the incentives provided by [the legislation] (see 63 FR 66634 Sec II). For those drugs in which voluntary measures fail to obtain necessary pediatric studies, FDA will consider requiring studies" (http://www.fda.gov/cder/pediatric/faqs.htm#the "Rule"; last update: March 8, 2001).

2001b). Of these, about two dozen uses might relate to symptoms of life-threatening illnesses.

In a report on the pediatric exclusivity provisions, the General Accounting Office noted that when the legislation was passed, approximately 70 to 80 percent of drugs were not adequately labeled for use with children. Since then, pediatric drug research has increased substantially and has provided "new and useful information about whether and how drugs work in children" (USGAO, 2001b, p. 6). According to a recent FDA report to Congress, "the pediatric exclusivity has done more to generate clinical studies and useful prescribing information for the pediatric population than any other regulatory or legislative process to date" (FDA, 2001c, p. ii). The FDA report also noted continuing problems in some areas including the irrelevance of exclusivity provisions to certain old, "off-patent" antibiotics and other drugs and to drugs with low volumes of sales ("orphan drugs"). Another problem has been inadequate incentives for studies in neonates and very young children that must follow studies conducted on older children. In addition, following the completion of studies, manufacturers have sometimes been slow to change drug labeling to reflect the results.

The 2001 legislation renewing "pediatric exclusivity" included provisions to encourage timely changes in drug labeling to reflect new research results. It also established an Office of Pediatric Therapeutics within the FDA to coordinate the agency's activities related to children and pediatric practice and provided for the NIH-based Foundation for the National Institutes of Health (formerly the Foundation for Biomedical Research) to collect funds to support pediatric drug research.

Pediatric Palliative and End-of-Life Care

Research to support improvements in palliative, end-of-life, and bereavement care for children and their families constitutes only a tiny fraction of research involving children. Likewise, research involving children and their families occupies a small niche in the world of research on palliative and end-of-life care, which itself is small in comparison to other areas of clinical and health services research.

Some units of the National Institutes of Health are supporting or show a potential willingness to support relevant research (NINR et al., 1997). For example, in soliciting research proposals on emergency medical services for children, the National Institute of Child Health and Development (NICHD) identified the need for research on the biobehavioral aspects of pain, stress, and coping with illness or injury in situations of emergency care (NIH, 2000b). The National Institute of Mental Health suggested research on aspects of emergency medical services delivery (e.g., medical staff communication style, follow-up care) that could potentially identify processes of emergency care that positively or negatively affect the experience of families whose children die.

In addition, as discussed elsewhere in this report and in Appendix H, the Center for Medicare and Medicaid Services (CMS) is funding several demonstration projects that are intended to provide information about the development, operation, effectiveness, and costs of comprehensive programs of palliative care for children and families from the time of diagnosis through bereavement. Although the evaluation designs do not involve controlled comparisons, the evaluations should provide considerable descriptive and analytic detail about the structure of palliative care programs, populations served, and costs.

Foundation-supported studies have been and continue to be particularly important in extending the knowledge base for adult and pediatric palliative, end-of-life, and bereavement care. Two pediatric programs are among 22 projects funded by the Robert Wood Johnson Foundation to test creative strategies for improving palliative care (Promoting Excellence, 2001). One, led by Children's Hospital and Regional Medical Center of Seattle involves the state health department and regional Blue Cross Blue Shield plans in developing innovative ways to extend health plan coverage for palliative care during a child's life-threatening illness. (See also Chapter 7.) The other, led by SSM Cardinal Glennon Children's Hospital in St. Louis, involves support for a statewide network of health care providers ready to care for children at home. The hospital is developing a palliative care consult program to provide 24-hour consultative services, with a palliative care team to educate physicians, hospice providers, and community hospital staff.

Another example of a privately funded initiative is the already-cited project supported by the Nathan Cummings Foundation and the Open Society Institute that is led by the Education Development Center of Boston (Solomon et al., 2001a). It involves eight children's hospitals (Children's Hospital/Dana-Farber Cancer Institute, Boston; Children's Hospital of Philadelphia; Children's Hospital and Health Center of San Diego; Johns Hopkins Children's Center; Children's Mercy Hospital, Kansas City; Lucile Packard Children's Hospital, Stanford University Medical Center; University of California, San Francisco Children's Hospital; and Vanderbilt Children's Hospital). This project has examined clinicians' and parents' perspectives on palliative care and is developing quality improvement models and educational materials to support improvements in care for children with a range of life-threatening medical problems and their families.

Another project involving support from multiple private foundations (including Soros and the Charitable Leadership Foundation) is the Pediatric Advanced Illness Coordinated Care (PAICC) initiative that was discussed in Chapter 6. This effort, being led by the Center for Advanced Illness Coordinated Care of Albany, New York, is now developing, evaluating, and refining a standardized model of communication and care coordination in five institutions (Himelstein et al., 2002; Hilden and Tobin, 2002).

DIRECTIONS FOR FUTURE RESEARCH

General

Throughout its work, the committee has been hampered by the lack of basic descriptive information about death in childhood as well as scant research testing the effectiveness of clinical interventions and organizational processes and structures in providing palliative, end-of-life, and bereavement care that meets the needs of seriously ill or injured children and their families. Studies reviewed by the committee in Chapter 3 describe deficits in care received by children who die and their families. Unfortunately, available research leaves much that is unclear about the extent and causes of shortfalls in care, the number and kinds of children and families who could benefit from palliative and end-of-life care, and the effectiveness of specific strategies to improve the delivery and financing of this care.

> **Recommendation: The National Center for Health Statistics, the National Institutes of Health, and other relevant public and private organizations, including philanthropic organizations, should collaborate to improve the collection of descriptive data—epidemiological, clinical, organizational, and financial—to guide the provision, funding, and evaluation of palliative, end-of-life, and bereavement care for children and families.**

In the 2001 report *Improving Palliative Care for Cancer* (IOM, 2001c), the IOM's National Cancer Policy Board included two recommendations aimed at stimulating palliative care research in designated "centers of excellence" and encouraging such centers to take a lead role as agents of national policy in promoting palliative care. The Board also recommended that the National Cancer Institute (NCI) should add the requirement of research in palliative care and symptom control for an institution's designation as a "comprehensive cancer center." The research activities suggested for such centers included the following:

- formal testing and evaluation of new and existing practice guidelines for palliative and end-of-life care;
- pilot testing of "quality indicators" for assessing end-of-life care at the level of the patient and the institution;
- uncovering the determinants of disparities in access to care by

minority populations and developing specific programs and initiatives to increase access; and

- providing clinical and research training fellowships in medical and surgical oncology in end-of-life care for adult and pediatric patients.

This general strategy should also prove productive in stimulating palliative, end-of-life, and bereavement care research involving children and their families. While by no means discouraging research in other institutions, the committee encourages initiatives that build on federally funded pediatric centers, networks, and similar structures.

Recommendation: Units of the National Institutes of Health and other organizations that fund pediatric oncology, neonatal, and similar clinical and research centers or networks should define priorities for research in pediatric palliative, end-of-life, and bereavement care. Research should focus on care for infants, children, adolescents, and their families, including siblings, and should cover care from the time of diagnosis through death and bereavement. Priorities for research include but are not limited to the effectiveness of

- **clinical interventions including symptom management;**
- **methods for improving communication and decisionmaking;**
- **innovative arrangements for delivering, coordinating, and evaluating care, including interdisciplinary care teams and quality improvement strategies, and**
- **different approaches to bereavement care.**

By organizing multiple sites to investigate a common problem using a common methodology, this strategy should increase the number of children involved in studies and increase the credibility of the findings. It should also stimulate the development of investigator expertise in pediatric palliative care research, encourage the formulation and successful completion of more high-quality research projects, and promote attention to palliative care, end-of-life, and bereavement issues in both pediatric clinical trials and regular patient care. By involving designated institutional participants in collaborative research, a "centers" strategy should also encourage tests of organizational interventions (e.g., random assignment of institutions to test innovations in information systems, training, staffing, or conflict management). The results should benefit children who survive, children who die, and the families of both groups.

The committee recognizes that the infrastructure for biomedical and clinical research varies considerably for different diseases, disorders, and other medical conditions affecting children. For example, the Children's

Oncology Group (COG), supported by the NCI, involves nearly 240 centers (COG, 2001), whereas the Neonatal Research Network funded by the National Institute of Child Health and Development (NICHD) includes approximately a dozen centers (NICHD, 2000; see also http://neonatal.rti.org). Given differences in the research infrastructure and in the conditions that bring death to children, the specific incentives and mechanisms for a center- or network-focused research strategy will have to be flexible and creative. Although the recommendation focuses on NIH-funded centers and networks, philanthropic foundations and other private organizations can also participate in supporting creative projects that are based on these networks but are not limited to NIH priorities.

Flexibility and creativity on the part of both research sponsors and investigators will also be required to extend research earlier into the period following the diagnosis of a life-threatening problem and later into the period of bereavement experienced by the families of so many children with grave medical problems who participate in clinical research. If researchers focus on earlier stages in the trajectory of fatal and potentially fatal conditions, they may be able to increase the number of children participating in research on certain aspects of palliative care (e.g., effective symptom management). They may also be able to develop a fuller understanding of the symptoms and distress associated with serious illnesses (and their treatments) and the benefits and challenges of incorporating aspects of palliative care earlier in the course of a life-threatening condition.

In proposing directions for research to improve pediatric palliative and end-of-life care, the committee tried to focus on the gaps in the knowledge base needed to put the principles set forth in Chapter 1 into practice and to implement the recommendations listed in subsequent chapters. The discussion below focuses on several specific areas for further research including quality of life, symptom measurement and management, bereavement, education, and models for delivering and financing palliative, end-of-life, and bereavement care. At a more general level, a comprehensive research agenda for pediatric palliative, end-of-life, and bereavement care should consider

- the needs of infants, children, and adolescents and developmentally appropriate care strategies;
- a range of causes and trajectories of death including sudden, unexpected deaths, deaths from progressive chronic conditions, and deaths from conditions diagnosed prenatally;
- the effects of uncertainty in diagnosis, prognosis, and treatment on communication with children and families, establishment of care goals and care plans, decisions about interventions, preparation for death, and family perspectives and emotions after death;
- the needs of parents, siblings, and other family members;

- the roles and relationships of different health care professionals and other personnel who are involved with children who may die or who have died and their families;
- the range of care settings and organizations that are involved with children who may die or have died and their families (e.g., emergency first-response units, emergency departments, intensive care units, other inpatient units, hospices, home health agencies, and medical examiners' offices);
- the contribution of family, provider, and other factors to timely or delayed recognition that death is near and to differences in family and physician assessments of prognosis and care options;
- the reports of children and families about their specific experiences with care (preferably concurrent with care rather than after the child's death), not just their global assessments of satisfaction with care;
- the experiences of children and families outside the health care system, including with schools;
- the psychological effects on professionals of caring for children who die and the consequences for their ability to care for children and parents; and
- methods and processes for improving communication and preventing or resolving conflicts among clinicians, patients, and family members.

Much of the research suggested in this chapter is descriptive and qualitative. It involves epidemiological, methodological, behavioral, organizational, and policy studies as well as clinical research. Controlled research strategies, including randomized clinical trials and careful case-control studies, should be encouraged. Such approaches will, however, often be difficult given the small numbers of children who die and the charged emotional circumstances surrounding a child's life threatening illness or injury. Even for relatively narrow clinical questions (e.g., comparison of one pain management regimen versus another), randomized trials are relatively uncommon. Qualitative studies have an important role to play in describing the experiences, perspectives, and values of patients, family members, and caregivers (see, e.g., Sackett and Wennberg, 1997). In devising suitable research strategies, researchers will need to combine creativity, flexibility, and sensitivity both to patient and family burdens and anxieties.

Each research topic suggested here presents different methodological challenges. In general, researchers may encounter problems in defining and recruiting sufficient numbers of research participants, collecting information about subjective experiences from individuals who may be physically or emotionally limited in their ability or willingness to respond to questions, identifying necessary information in medical or other records, and defining measures relevant to patient and family experiences at different stages of life-threatening medical experiences. Epidemiologic and health services research may have to rely on data that is years old by the time it is released. Researchers may also encounter difficulties in getting research approved by Institutional Review Boards, a topic that warrants investigation in its own right.

Research Directions: Quality of Life for Children and Families

To identify practices that affect the quality of life experienced by a child with a life-threatening medical problem requires measurement tools that can reliably and validly reflect the child's experience, particularly when the problem has reached an advanced stage and death is expected or possible in the foreseeable future. Appendix C identifies some of the limitations of current measurement tools (especially those intended for well children) and the complexities of developing better ones. Although improvements in measures relevant for pediatric palliative and end-of-life care can build in a general way on measurement strategies used for adults, much of the work needed will have to be specific to infants, children, and adolescents. Box 10.1 summarizes some important directions for such work.

As discussed in Appendix C, existing pediatric quality-of-life instruments may be generic in nature or they may be disease and condition specific. Either way, such instruments are designed primarily for well or chronically ill children and adolescents. They include items that measure function, problems with physical activities, emotional concerns, cognitive abilities to concentrate on and complete school tasks, and concerns with certain symptoms. Many of these items may not be relevant for a child with advanced illness. The instruments may also overlook some issues, for example, spiritual or existential concerns. In addition, completing an instrument intended for healthier children may be unduly burdensome for a seriously ill child.

BOX 10.1
Directions for Research on Quality-of-Life Measures for Children and Families

- Identify domains of quality of life relevant for children with advanced illness and for their family members.
- Investigate the importance of different domains of quality of life for children and for family members, including how their importance may vary over time.
- Assess the need to adapt measurement instruments to reflect differences in the ill child's stage of development, the nature of the illness, and other child and family characteristics.
- Evaluate the degree and nature of agreement or disagreement between child self-reports and proxy reports by parents or others.

Some instruments also exist to assess quality of life for parents of children who are seriously ill. These focus primarily on elements of caregiver burden and may only incompletely capture the quality of life of the parent of a dying child. The committee is aware of no instruments that assess quality of life for siblings of seriously ill children.

One task for methodologists is to identify specific domains (e.g., physical, spiritual) of quality of life that are relevant for a child with advanced illness. Another task is to determine whether the importance of a domain changes over time as an illness progresses. Methodologists will also have to consider the influence of development stage, culture, and context (e.g., sites of care, nature of the illness, family circumstances) both in the design of instruments and in their application. For example, an instrument may require different formats for young children and adolescents.

Interventions directed toward improving or at least maintaining a dying child's quality of life could also improve the quality of life of family members who suffer with the child. Likewise, interventions to help parents, siblings, and other family members could benefit the ill child. Researchers designing interventions to protect and improve the quality of life of children with advanced illness and their families should consider how they might evaluate these "spillover" effects.

When possible, obtaining the dying child's own report of his or her quality of life is preferred. It may not, however, be possible to identify definitively when a child is dying until illness is far advanced. Also, given the uncertainties associated with predicting time of death, death may come earlier than expected. Thus, some dying children will not be capable of providing self-reports, and the report of a parent or other proxy or surrogate may be necessary. Studies comparing children's self-reports with reports from parents or professionals tend to show low to moderate agreement in ratings of symptoms or other aspects of quality of life (see Appendix C). Comparisons have not been completed for dying children and their parents or health care providers. Another question may arise when dying children experience changes in health care setting (e.g., home to hospital, distant medical center to community hospital) or health care provider (e.g., pediatric oncologist to generalist pediatrician or hospice professional). How such changes might affect proxy reports, especially those of health care professionals, is unknown.

Comparisons of child self-reports and proxy reports will be challenging in the context of a child's advanced illness and will require great sensitivity. Nonetheless, it is important to get a better sense of the degree and nature of agreement or disagreement between the two and of the factors that might increase or diminish agreement (e.g., child's development stage, family culture, location and continuity of end-of-life care). If parents or other proxies tend to overestimate, underestimate, or otherwise misperceive the quality of life experienced by their children, their reports may misdirect efforts to improve care.

Research Directions: Physical and Psychological Symptoms of Serious Diseases and Their Treatments

In 1997, another IOM committee argued that pain research, which has achieved considerable success in illuminating the pathophysiology of pain and developing effective interventions, should be considered as a model for other areas of symptom research. It urged interaction between basic scientists and clinical investigators to direct new intellectual energy to research on significant end-of-life symptoms including fatigue, shortness of breath, nausea, confusion, anxiety, and depression.

This committee agrees with its predecessor that many features of the pain research strategy can be productively generalized to other symptom areas. These features include the following:

- building the neuroscience base for understanding symptoms, for example, continuing to investigate the role of symptom-inhibiting neurotransmitters and receptor-specific opioids that avoid some unwanted opioid side effects;
- encouraging the development and use of more precise descriptive terminology and classification schemes for symptoms to provide a "common language" for researchers;
- continuing the development, testing, and refinement of standard tools for assessing symptoms including their "felt" burden;
- studying the prevalence and severity of symptoms by physiological source or mechanism, medical condition, developmental stage, and other relevant characteristics; and
- investigating potential therapies based on better understanding of both the pathophysiology of symptoms and the patient's reported or observed experience of symptoms.

Research on symptoms has been constrained by numerous factors that have historically limited other pediatric research: small numbers, ethical constraints, complexities associated with outcomes measurement, and lack of financial incentives for the pharmaceutical industry (until recently). The limited research that has been performed has primarily concerned pain management, often in oncology patients only. Problems such as nausea, fatigue, sedation, shivering, anxiety and agitation, depression, seizures, spasticity, constipation and diarrhea, dyspnea, dysphagia, anorexia and cachexia, and dermatologic manifestations of disease and treatment (e.g., itching, mouth ulcers) require attention as well.

Further, although both children and adults have benefited from progress in pain research, many areas for investigation remain in this arena, including identifying the reasons for the underuse of effective therapies to prevent or relieve pain and devising interventions to increase appropriate use of these therapies. The American Academy of Pediatrics (AAP) recently noted the lack of research on the management of pain in newborns with conditions associated with extensive tissue damage or recurrent or chronic pain (e.g., necrotizing enterocolitis, meningitis) (AAP, 2000a). It also noted that the benefits and harms of sedatives and other agents to manage apparent anxiety in neonates have been little studied. Research directions for several areas related to the prevention and relief of pain and other symptoms are summarized in Box 10.2.

BOX 10.2
Directions for Research on Assessment and Management of Symptoms

- Document the prevalence and incidence of children's physical symptoms, in addition to pain, that are associated with life-threatening illnesses or their treatment.
- Document the prevalence and intensity of psychological symptoms in children diagnosed with a life-threatening medical condition.
- Develop instruments to measure pain in selected pediatric populations (e.g., pre- or nonverbal children) and to measure other symptoms in all pediatric populations.
- Develop, refine, and evaluate pharmacologic and other strategies for the effective prevention and treatment of pain and other symptoms in children, including nausea, fatigue, sedation, depression, spasticity, anxiety, and anorexia with priority on the following:
  —Developmental pharmacology
  —Guidelines for use of different interventions
  —Side-effect management
  —Long-term effects on the developing organism
  —Novel routes of administration
  —Procedural sedation and analgesia
  —Behavioral techniques
- Evaluate the effects of strategies to prevent or relieve symptoms on children's quality of life, length of life, and hospital use (e.g., length of stay, rehospitalization rates), and on family functioning and well being.
- Document the effectiveness of alternative and complementary medicine techniques in alleviating symptoms.

Prevalence and Intensity of Symptoms in Children and Families

The prevalence and intensity of physical and psychological symptoms in children, especially symptoms other than pain, is inadequately documented. In particular, the extent and severity of psychological symptoms in children with life-threatening illness—and their parents and siblings—are unknown and probably significantly underappreciated. Depression, anxiety, posttraumatic stress disorder (PTSD), and other psychological and behavioral symptoms can significantly reduce the quality of life for children and their families. They can also compromise the ability of children and families to adhere to treatment regimens.

In addition to experiencing symptoms associated with their medical condition, many children with a life-threatening illness face a barrage of painful or uncomfortable procedures (e.g., aspiration of bone marrow or spinal fluid, drawing of blood, injections of diagnostic or therapeutic agents) that may not be necessary for adequate diagnosis and treatment. Painful or distressing procedures, including demanding chemotherapy or mechanical ventilation, often continue when children are nearing death. Stopping certain life-sustaining interventions for a dying child, for example, mechanical ventilation, can involve physical and emotional distress. Research should investigate the prevalence and intensity of treatment-related distress in children with different medical conditions as well as ways to prevent or relieve it.

Measuring symptoms in infants is a particular challenge. As discussed in Chapter 4 and early in this chapter, pain in infants was not recognized or taken seriously until fairly recently. Now, pediatric researchers are attempting to measure pain, stress, and more generally, distress or comfort in these populations using systematic clinical observations and physiological indicators (see, generally, Schecter et al., 1993; Taddio and Ohlson, 1997; Ballantyne et al., 1999; Stevens et al., 2001).

Measurement of Symptoms

Adequate measurement is the cornerstone of adequate treatment. Without the ability to quantify a clinical problem, it is often impossible to determine if interventions have been effective at ameliorating it. Although many developmentally appropriate instruments are available for most pediatric pain management situations, no uniformly accepted instruments exist for certain subpopulations such as children who are developmentally delayed or intubated. In addition, for symptoms other than pain, easy-to-use, reliable assessment tools are scarce. Treatment of fatigue, shortness of breath, drug-related sedation, spasticity, nausea and other more generalized suffering would all benefit from more uniform, quantified, and validated measurement strategies.

Management of Symptoms

In addition to better documenting the prevalence and intensity of psychological symptoms, research is also needed to refine and compare interventions appropriate for children of different ages and at different stages of a life-threatening medical condition. These interventions include individual psychotherapy, group support, and psychotropic medications.

Most of the pharmacologic agents used for physical and psychological symptoms have not been adequately studied in children. Despite recent incentives for drug research involving children, the developmental pharmacokinetic profile in children of many existing drugs is still unknown and must be established to allow and guide their "on-label" use. Then, evidence-based guidelines can be developed for selecting patients for different drug regimens, escalating or tapering off doses, and managing side effects. Although the negative long-term impact of unrelieved symptoms such as pain is well established, the long-term effects of opioids and other drugs used to ameliorate pain have yet to be established for children with serious, chronic problems that persist for months or years.

To reduce children's discomfort during the administration of medications and to encourage cooperation with uncomfortable treatment regimens, novel routes of drug administration, including transdermal, transmucosal, and regional approaches, must be further developed in addition to better-tasting formulations of existing, orally administered drugs (AAP, 1997a). Development of new agents such as long-acting (e.g., days long) local anesthetics for children experiencing post-operative pain and better treatments for neuropathic and bone pain would also reduce the burden of suffering for many children.

In general, more research is needed both to develop better sedation and analgesic regimens and nonpharmacologic strategies for preventing and relieving procedural pain and to verify the safety and effectiveness of existing regimens. Although not an issue of procedure management per se, the efficacy of intensive, controlled sedation to relieve intractable pain, seizures, or other distress at the end of life also requires continued investigation. Such research is important regardless of one's position on the use of such sedation when a side effect may be hastened death, although that result appears to be uncommon (see Chapters 5 and 8).

As discussed earlier in this report, pain management programs are now a requirement for hospital accreditation and an increasing focus of quality assessment initiatives (JCAHO, 2001). Careful documentation and analysis of sedation failures can improve the quality of care in an institution and also improve the evidence base overall for effective pain management.

Impact of Symptom Control

Documentation of the impact of symptom control on children and families may promote a wider understanding and appreciation of its benefits among patients, families, and clinicians. Even today, some families may believe that severe pain and other physical distress are inevitable and must simply be endured because nothing can be done about them. Likewise, not all clinicians are aware of shortfalls in the management of pain and other symptoms or not all are knowledgeable about the impact on child and family quality of life of proven strategies for relieving symptoms.

Hospital, hospice, and insurance managers may be influenced if further research supports suggestions that better symptom control may shorten hospital stays and reduce rehospitalizations. Given the high cost of certain medications for pain and other symptoms, such evidence may also encourage rethinking of hospice reimbursements so that the appropriate use of highly effective but costly medications is not discouraged.

Complementary Medicine

What are termed “complementary” or “alternative” therapeutic approaches[3] such as acupuncture, massage, therapeutic touch, and aromatherapy may play a significant role in future symptom management. Most of these techniques are noninvasive, and some may be pleasurable for healthy and ill individuals alike. This makes them attractive to children and families facing pharmacological regimens with distressing side effects. The efficacy and acceptability of these techniques for children, especially those with life-threatening illnesses, has not been sufficiently studied to allow routine recommendation of their use. Research in this area could give children and their families, as well as providers, a new array of documented, effective treatment options. Credible research could also alert families to therapies that do not meet the claims made for them.

The benefits of cognitive and behavioral techniques are already well established in the area of pain management (see, e.g., Schechter et al.,

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[3] As described by the NIH’s National Center for Complementary and Alternative Medicine (NCCAM), complementary and alternative medicine (CAM) “covers a broad range of healing philosophies, approaches, and therapies. Generally, it is defined as those treatments and health care practices not taught widely in medical schools, not generally used in hospitals, and not usually reimbursed by medical insurance companies. . . . People use these treatments and therapies in a variety of ways. Therapies are used alone (often referred to as alternative), in combination with other alternative therapies, or in addition to conventional therapies (sometimes referred to as complementary)” (http://nccam.nih.gov/fcp/faq/index.html#what-is). As some of these strategies move into mainstream medicine, they may still continue to be described under the CAM label.

2002), but further research is necessary to demonstrate their efficacy in other symptoms such as fatigue, sedation, and nausea. The use of transcutaneous electrical nerve stimulation (TENs) units has received almost no formal research, yet based on anecdotal reports from patients and clinicians, such units may have a significant role to play in symptom control.

Research Directions: Perinatal Death

More children die in the neonatal period or immediately prior to birth than in any other period in childhood. Recent advances in prenatal diagnosis, prenatal treatment, and neonatal care have led to changes in the timing and nature of decisions that families make when confronted with a fetus or newborn infant with a lethal or potentially lethal condition. Little systematic descriptive information is available concerning the long-term impact on families of these decisions, the perceptions of parents of the benefits and harms of different life-sustaining and palliative interventions, or the best methods for communicating with families faced with these decisions. Likewise, little research has investigated the emotional impact of prenatal diagnosis on mothers and fathers, the effect of perinatal death on surviving or future siblings, and differences in effects on family members related to gender, culture, and socio-economic characteristics. More research in this area (Box 10.3) should help improve the care provided to a large group of bereaved families and should also contribute to a better understanding of decisionmaking about treatment choices (i.e., ending the pregnancy or trying to carry the fetus to term) and the consequences of different choices.

Despite the frequency of perinatal loss, population-based studies of the long-term impact of perinatal loss on parents are not available. Descriptive

BOX 10.3
Directions for Research on Perinatal Death and Bereavement

- Describe quality-of-life outcomes and self-perceptions of parenting skills in a population-based cohort of mothers and fathers up to five years after the perinatal loss.
- Describe gender differences and changes over time in coping mechanisms and parental perceptions of the benefits and harms of life-sustaining and palliative interventions for fetuses or infants with specific, prenatally or postnatally determined lethal diagnoses.
- Assess the long-term as well as the short-term effects on parent outcomes of interventions for parents who have sustained perinatal loss.
- Determine the effect of perinatal death on surviving or future siblings.
- Determine the impact of antenatal ultrasound on parental perceptions of pregnancy and of the prognosis for their baby.

research to assess parents' quality of life and perceptions of their role and skills as parents should follow them for at least five years after a perinatal death.

Because of the differing physical and emotional impact of pregnancy on women compared to men, fathers and mothers may respond differently to information concerning fetal or infant diagnosis and prognosis. They may also differ in the rates at which they comprehend or assimilate information. Such differences may amplify already significant emotional stress or preexisting psychological disorders and may lead to confusion about the wishes of parents for interventions. Obstetricians, pediatricians, nurses, social workers, psychologists, and bereavement specialists would benefit from prospective studies that (1) investigate the coping mechanisms of parents who are confronted by an antenatal or postnatal fetal diagnosis that is potentially lethal and (2) explore parental perceptions of the benefits and burdens of different interventions (including palliative care) stratified by fetal or neonatal diagnosis and by timing of diagnosis.

Several perinatal interventions undertaken in the 1970s and 1980s were reported to benefit mothers during the first six months after a perinatal loss (Giles, 1970; Kennell et al., 1970; Parkes, 1980; Forrest et al., 1981, 1982). No data are, however, available on the long-term impact of these interventions, and no randomized trials have assessed the benefits of specific interventions (Chambers and Chan, 2000). Long-term (one to five years), prospective studies of parents who have received different interventions are needed. They should be stratified by fetal or neonatal diagnosis, reproductive history, and socioeconomic status and cultural characteristics. (See also the discussion below of directions for bereavement research.)

In addition to understanding parental experience with lethal or potentially lethal perinatal diagnosis or death, research attention also should extend to siblings subjected to the stress of perinatal loss and to the grief and parental chaos prompted by such loss. The committee located no longitudinal studies of parental perceptions of surviving siblings, self-perceptions of surviving siblings, or interactions between parents and surviving or later-born siblings.

Although the sensitivity and specificity of antenatal ultrasound diagnosis have been carefully defined (see, e.g., Sabbagha et al., 1985; Brocks and Bang, 1991; Chitty et al., 1991; Ewigman et al., 1993), little research (e.g., Cox et al., 1987; Michelacci et al., 1988; Cromie, 2001) documents the short-term and long-term emotional stress on parents of antenatal ultrasound, including when the procedure leads to a diagnosis of a lethal or potentially lethal condition. More research has focused on prenatal genetic testing and choices about pregnancy termination (see, e.g., Vintzileos and Egan, 1995; Bergsjo and Villar, 1997; Malone et al., 2000; Rillstone and Hutchison, 2001). Given the ubiquitous use of ultrasound and the known impact of emotional stress on pregnancy outcome, prospective studies should evaluate the emotional cost of antenatal ultrasound and the emotional care provided by obstetricians following ultrasound diagnosis of a lethal condition.

Research Directions: Sudden and Unexpected Death

In addition to infant death, the other large contributor to death in childhood is injury, both unintentional and intentional. Despite the development of sophisticated emergency medical services capacities that each year benefit thousands of seriously ill or injured children and their families, little is known about key aspects of the care provided to children who die and their survivors or about the consequences for emergency care providers of their involvement in child deaths. Box 10.4 summarizes several directions for research on sudden and unexpected death, and Appendix F also discusses research needs.

Resuscitation

When resuscitation should be terminated in children who have experienced cardiopulmonary arrest (CPA) is a continual subject of research and debate in emergency medicine. Continued efforts to establish predictors of resuscitation outcomes for out-of-hospital pediatric CPA are warranted to guide prehospital and emergency department care. One particular controversy involves the use of high-dose epinephrine (HDE) following cardiopulmonary arrest in children. The value of this intervention is not supported by

BOX 10.4
Directions for Research on Sudden and Unexpected Death

- Identify predictors of mortality in children during resuscitation in prehospital and emergency department settings.
- Continue to evaluate the benefits and harms of resuscitation measures for children who have experienced prolonged hypoxic–ischemic injury.
- Continue to assess the short- and long-term effects on bereaved parents of being present during attempted resuscitation of a child.
- Investigate the association between acute, sudden, or unexpected death of a child and the development by parents or siblings of more severe grief responses. Consider factors (e.g., nature of the death itself, family characteristics, support offered by emergency personnel) that may affect responses.
- Evaluate the short- and long-term effects of Critical Incident Stress Management or other interventions to lessen stress and emotional trauma for emergency care providers in the short and long term.

clinical research, yet HDE remains a pharmacologic option (Callaham et al., 1992; Dieckmann and Vardis, 1995; Patterson, 1999; Young and Seidel, 1999; AHA, 2000a).

Transient return of spontaneous circulation following prolonged resuscitation can trigger a tumultuous series of events, including admission to the pediatric intensive care unit (PICU) and subsequent decisions about withdrawal of life support, declaration of brain death, and organ donation. Although these events add stress to an already overwhelmingly stressful situation, it is possible that the time spent in intensive care benefits some families, for example, by helping them believe everything possible has been done to save their child. The consequences for families and for clinicians of predictably unsuccessful resuscitation efforts deserve systematic attention.

Several institutional studies have investigated issues related to family presence during attempted resuscitation (see, e.g., Meyer et al., 1998; Guzzetta et al., 2000; Clark et al., 2001). They suggest that families generally favor having the choice and that they tend to report afterwards that being present was helpful. These studies were, however, small, often retrospective, and limited in scope. Nonetheless, emergency medicine professionals are increasingly accepting and even encouraging parental presence, not only during resuscitation in the emergency department but also during other critical care procedures (AHA, 2000a). Given the vulnerability of parents during these high-intensity, often unsuccessful interventions, it seems prudent to undertake additional systematic research on the bereavement outcomes and other consequences of parental presence policies and their implementation. Prospective studies could follow families from the discussion of presence during resuscitation through their decisions, the procedures, and the aftermath, with follow-up during bereavement. The committee did not investigate differences in institutional protocols for family presence (among institutions that allowed or encouraged it), but if different approaches characterize different phases of family experience (e.g., discussion, presence, immediate and later bereavement support), it would be helpful to compare the effects on families and on health care personnel involved.

Sudden Death, Care Outside the Hospital, and Family Support

Each year, before or after a child's sudden and expected death, thousands of families encounter emergency medical personnel, police, staff of medical examiners' offices, and others who may positively support families in time of shock and grief—or whose behavior may unintentionally add to their pain and suffering. The committee identified little research on the aftermath of these encounters (see, e.g., Schmidt and Harrahill, 1995). Although it found examples of educational materials and policies intended to prepare these personnel to support survivors and avoid harm, the actual use and effectiveness of such materials and policies appears little investigated (Jaslow et al., 1997).

The committee recognizes that even retrospective, descriptive studies of the short-term and long-term effects on survivors of prehospital care may be costly and pose other practical and ethical challenges. Nonetheless, it encourages consideration of research on bereaved parents' and siblings' experiences and perceptions as a step toward identifying deficiencies in support and directions for improvement for personnel outside as well as inside the hospital. (Other questions about family experience following a child's sudden death are discussed in the section on bereavement research.)

Critical Incident Stress Management

Professionals who care for children who die suddenly and unexpectedly may also experience serious emotional distress. Critical Incident Stress Management (CISM) is a widely used strategy for providing acute psychological support for emergency medical services (EMS) and other public safety personnel involved in traumatic incidents such as child deaths, multiple deaths, and other especially difficult situations (Everly and Boyle, 1999; Everly, 2000; Lipton and Everly, 2002). Recent reviews of the literature on this strategy concluded that research tends to support the short-term effectiveness of certain critical incident debriefing approaches with emergency and other personnel involved in stressful incidents (Everly and Boyle, 1999; Everly and Mitchell, 2000). Research on long-term effects is limited. More research would be useful in assessing or clarifying the timing of interventions, the criteria for selecting personnel and situations for intervention, the consequences of different levels or types of training for those conducting the debriefings, and the interactions among complementary interventions.

Research Directions: Bereavement Care

As in other areas of bereavement research, the scientific basis for current practices with parents, siblings, or others following a child's death is limited (Stroebe et al., 1993, 2001b). Most studies are retrospective and relatively short term and suffer from the familiar limitations of late recall and abbreviated follow up. Research designs are also often inadequate in other ways (e.g., lack of control groups, small sample sizes), thus raising questions about the validity of the findings (Schut et al., 2001). One complication in intervention research is the relative (and fortunate) infrequency of child deaths in any single community. Possibly, Internet-based strategies can be explored as a means of involving larger numbers of family members.

BOX 10.5
Directions for Research on Bereavement Care

- Develop appropriate, relevant, and culturally sensitive measures of grief and bereavement outcomes for parents, siblings, and the family as a unit.
- Initiate prospective, long-term follow-up studies of bereaved families that begin before a child's death (when it can be anticipated) or immediately thereafter to help better understand common patterns and variations in bereavement and emotional reconstitution and to identify factors that put parents, siblings, and other family members at higher risk of complicated grief.
- Clarify the criteria for diagnosing uncomplicated and complicated bereavement in parents and siblings (taking developmental stage into account).
- Clarify the relationship between bereavement and posttraumatic stress disorder following a child's sudden and unexpected death and the implications for bereavement interventions.
- Identify consequences for bereavement (parent, sibling, other) and the implications for bereavement interventions of (1) site of death; (2) cause of death (e.g., trauma, prematurity, chronic condition); (3) age, developmental status, and birth order of the child who dies; (4) age of parents and age, developmental status, and birth order of siblings; (5) family presence at the time of death and immediately after; (6) parental decisions about curative efforts, life-support interventions, and hospice or other end-of-life care; and (7) behavior of the child's care teams before, at the time of, and after death.
- Evaluate different bereavement interventions, especially immediate interventions, to mitigate the trauma experienced by families and others following a child's sudden, violent death.
- Examine the impact on bereavement of parents' and siblings' attributions of the cause of death (e.g., random fate, God's will, one's own or somebody else's fault).
- Investigate the role of spirituality (as defined by individuals) in bereavement.

The discussions above of perinatal and sudden death have already suggested directions for bereavement research in these areas. Box 10.5 lists additional areas for investigation, including continued refinement of tools for measuring grief and bereavement.

The committee sees a pressing need to develop prospective research that studies over many years the experiences of parents, siblings, and other family members during a child's life-threatening illness and after a child's death (whether sudden or anticipated). Such research should help increase understanding of variations in grief and bereavement experiences, including patterns of complicated bereavement and associated risk and protective factors. Prospective research likewise may increase understanding of parents' willingness or reluctance to participate in bereavement support groups and seek other mental health services for themselves or for their surviving children.

Research also should consider the impact of a child's death as it affects not only parents and siblings individually but also as it affects the parents as a couple, the family as a unit, the extended family, and the family's larger network of support. Measures applicable to individuals (e.g., psychological symptoms) will not necessarily apply to the family unit, and measures of functioning will appropriately vary for parents, young siblings, adolescents, grandparents, and other family members.

As part of a research strategy, the concept of complicated grief or bereavement needs further attention, as do criteria for identifying complicated grief in bereaved parents and siblings. Complicated bereavement has been proposed as a specific mental disorder but is not yet accepted as a diagnostic category (Prigerson and Jacobs, 2001).

The sudden, unexpected death of a child may create symptoms similar to posttraumatic stress disorder in perhaps one-third of surviving family members (Peebles-Kleiger, 2000).[4] The experience of posttraumatic stress after a child's death requires continued investigation, as does the relationship of this stress to complicated bereavement. A better understanding is necessary of the characteristics of individuals (e.g., gender) and situations (e.g., death by homicide, family dysfunction) that are associated with more severe distress or differences in responses. This will help in identifying high-

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[4] As set forth in the guide for diagnosing mental disorders (*Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition [DSM-IV], American Psychological Association, 1994), the criteria for diagnosing PTSD include

1. Exposure to a traumatic event with both of the following elements: experiencing, witnessing, or being confronted with an event involving actual or threatened death or serious injury or a threat to the physical integrity of oneself or another *and* responding with intense fear, helplessness, or horror;
2. Persistent reexperience of the event, for example, in recurrent, intrusive, and upsetting recollections or dreams, in the sense that the event is happening again, or in intense reactions to cues that symbolize or are similar to the event;
3. Persistent avoidance of reminders of the traumatic event as demonstrated by three or more of the following: efforts to avoid thoughts, feelings, or conversations associated with the trauma; efforts to avoid activities, places, or people that arouse recollections of the trauma; inability to remember key aspects of the event; feelings of detachment or estrangement; significantly reduced interest or participation in activities; restricted range of emotions (e.g., to feel love); or sense of a limited future (e.g., loss of expectations related to job, family, life span); and
4. Persistent, new symptoms of increased arousal including at least two of the following: trouble sleeping; irritability or anger, difficulties concentrating; hypervigilance and exaggerated startle responses; duration of symptoms for more than one month; or clinically significant distress or impairment in social, occupational, or other important functioning.

risk individuals in advance for special attention and support and in tailoring strategies to individuals.

More generally, the development of effective interventions depends on better knowledge of the range of reactions to the sudden death of a child and of the factors related to similarities and differences in bereavement experiences and outcomes in parents, siblings, and other family members. Do the same risk and protective factors pertain to adults and children? Some commonly identified or hypothesized risk factors include deaths that are violent, self-inflicted, publicized, or linked to a broader catastrophic event. Hypothesized protective factors include stronger immediate and extended family relationships, relative economic security, religious faith, and absence of past traumatic losses. Research suggests men and women grieve differently. Do they differ otherwise in risk and protective factors?

When death is anticipated, are there factors that predict different outcomes, for example, continuity in relationships with the child's physician or other caregivers, timely and accurate information, or access to psychosocial support services? The research by Wolfe and colleagues (2000a,b, 2001) discussed in Chapter 3 suggests some lines of inquiry. Ideally, these could be pursued using methods that do not depend entirely on after-death interviews with parents. In practice, as discussed elsewhere in this chapter, concurrent collection of information about end-of-life care for children is difficult because the timing of death is often uncertain and because interviews with children or parents during the child's last days or weeks may be unacceptable or infeasible.

Research Directions: Models of Care Delivery

The committee identified a critical need for more systematic information on the organization, delivery, and outcomes of care for children with life-threatening conditions and their families (Box 10.6). After considering written statements from advocacy groups, discussions with parents, research and other literature, and professional experience, the committee identified several consistent themes: confusion about available resources and their quality, fragmentation of services with consequent lack of coordination and continuity of care, uneven and limited access to valued services, and deficits in communication, symptom management, and bereavement care in organizations that care for children with fatal or potentially fatal conditions. The very availability of key services is not well documented. For example, despite the increasing availability of useful information on the Internet, families cannot easily and reliably discover whether a children's hospital has palliative care or pain management teams or which hospices have well-established pediatric programs—much less how that program performs in meeting child and family needs.

BOX 10.6
Directions for Research on Models of Care Delivery

- Identify and describe existing organizations or programs that offer pediatric palliative, end-of-life, and bereavement care, and delineate models of such care, including hospice/hospital partnerships, hospice/home health agency partnerships, inpatient consulting, and direct care programs.
- Conduct community-based case studies of the coordination and continuity of care experienced by children and families and the institutional and other factors associated with more and less positive experiences.
- Describe and assess current processes of care and outcomes (e.g., symptom control, satisfaction with care, preparation for death) in inpatient and home settings.
- Study and compare different modes of communicating with children and families about the diagnosis of a life-threatening illness, prognosis, treatment options (including palliative and end-of-life care), and related issues.
- Define and test strategies for improving coordination and continuity of care including interdisciplinary team care for children with advanced illness.
- Investigate innovative methods to support children, families, and providers in smaller communities and rural areas and promote continuity of local and regional specialty care including palliative, and end-of-life care.

Developing the research base for organizational and system improvement is perhaps the most difficult research challenge identified by the committee. Such research tends to be practically and methodologically difficult, expensive, and not a priority for clinicians, health care managers, or research funders. Recognizing these obstacles, the committee proposes an incremental research strategy that includes both the identification and description of innovative programs and the evaluation of these strategies within and across institutions and settings.

Collecting data on the availability and characteristics of pediatric palliative and hospice care programs is one important step. Another is community-based case studies that describe child and family experiences with care coordination and continuity. Such case studies should help researchers to develop and refine hypotheses about factors that support or discourage coordination and continuity for families receiving services from multiple professionals and providers. Interviews with parents, patients, social workers, and others can generate useful information, but case studies will provide a fuller picture and help refine questions for further investigation.

Concurrently with descriptive research must come the most important step: the definition and testing of discrete, innovative care processes and broader models of palliative, end-of-life, and bereavement care. (For purposes of this discussion, processes of care include activities focused on specific tasks or goals such as symptom assessment and documentation of discussions with parents; models of care include more comprehensive arrangements such as inpatient palliative care consultation services or inpatient hospice units.) Such evaluative research would, ideally, consider outcomes for children (e.g., levels of pain or anxiety, quality of life, continuity of care), families (e.g., satisfaction with care, understanding of diagnosis, prognosis, and treatment options), and providers (e.g., rates of specific problems such as unassessed symptoms).

Given the complexity and expense of organizing multi-site studies, especially in newer areas of investigation, evaluations will often focus on processes and models of care at single sites. Although generalization from single-site studies must be undertaken cautiously, controlled trials and other comparative studies within single institutions can help in the identification of more and less effective ways of providing care. One creative example is the small, randomized controlled trial, mentioned in Chapter 6, of a program providing parents of hospitalized premature infants with an interactive link with the neonatal intensive care unit and also Internet access to other resources.

Notwithstanding the challenges, multi-site, comparative studies are important to replicate and test the robustness of care models in different environments. If, as recommended earlier in this chapter, the NIH promoted research on palliative and end-of-life care based in pediatric cancer centers, neonatal network participants, and similar networks, this could facilitate comparative organizational as well as clinical studies.

Even multi-site studies that are not formally comparative may be a useful step in the development of systematic research initiatives. For example, although not comparative in design, the federally supported Medicaid demonstration projects described earlier in this report should provide individual evaluations of several home care and hospice models and suggest ideas for further investigation. Similarly, although focused primarily on adult care, the quality improvement initiative reported by Lynn and colleagues (2000) suggests opportunities for formal research to improve palliative and end-of-life care for children as well as adults (see Chapter 6).[5] For

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[5] The quality improvement strategies described usually involved the testing of specific, focused organizational changes with small groups of patients during a relatively short period using existing information systems insofar as possible. Based on the results, a change might be abandoned or expanded or considered for more formal comparative research. An important practical difference between quality improvement projects and formal research is that the latter must meet requirements for the protection of human subjects—including special requirements for children—and obtain approval from Institutional Review Boards as described later in this chapter. When CQI projects should be considered research and be reviewed by IRBs is a topic of debate (see, e.g., Casarett et al., 2000, and comments and discussion by Cretin et al., 2000, and Hayley, 2000).

example, studies might compare the outcomes of different processes and structures for assessing, documenting, and managing pain and other symptoms, or they might test different procedures to improve the discussion, documentation, and implementation of care plans for children.

More generally, the research reviewed in Chapter 3 and the ideas and programs described in Chapters 4, 5, and 6 can suggest topics for organizational research into processes and models of care. For example, it would be useful to have additional research comparing outcomes for children and families associated with early versus late discussion of hospice or other options for care at the end-of-life.

Outcome and Performance Measures

One critical issue in organizational research is how to measure performance. For example, to what degree should investigators rely on assessments of patient or family satisfaction with care as indicators of the quality of care? Given the literature it reviewed and members' own experiences, the committee is concerned that families may greatly appreciate the care provided to their children without realizing that more could have been done, for example, to treat a child's pain effectively.

Thus, although it is appropriate to inquire about parents' satisfaction with the care provided to their child and their family and about the help they had making decisions, it is also important to inquire about what the child and family experienced and to continue efforts to develop and use other measures. These measures include valid, reliable, and feasible instruments for assessing physical and psychological symptoms and quality of life. (See also Appendix C and Box 10.1.)

Information and Communication

This report, consistent with other discussions of care for patients with life-threatening medical conditions, stresses the importance of timely and accurate information and communication geared to child and family needs and circumstances. Most studies of communication in this area have focused on adult patients and their families, but many of the findings about barriers to effective communication have broad relevance for child patients and their families.

This committee has stressed the importance of involving children in discussions and decisions about their care, consistent with their development stage and preferences and with sensitivity to family culture and values.

To further such involvement, strategies for communicating with seriously ill children need further systematic investigation. As discussed in Chapter 4, most of what has been written about children's understanding of death involves well children. Because children with advanced illness may have awareness and knowledge beyond their years, findings from studies of communication strategies involving well children need to be used with some caution. Rigorous research on communication with children made vulnerable by serious illness may raise ethical and practical challenges, but if carefully planned, reviewed, and conducted, it has the potential to help the research participants as well as children who follow them.

One persistent theme in statements of parents who have faced a child's life-threatening illness is that shock, fear, and grief interfere with their ability to absorb and process information during initial and subsequent conversations with clinicians. Little or no systematic research is available to guide the timing, pace, or style of communication with these parents. One example of research underway in this area is the PAICC project mentioned earlier. It asks parents about the value and timeliness of information provided through a written manual for parents and other means. The plan is to have 20 parents evaluate the material, revise the manual with that feedback, and proceed again with another cohort of 20 parents.

The usefulness of specific modes of communication with children and parents may vary depending on the purpose of the communication (e.g., giving bad news, developing care objectives and plans), the type of information to be communicated (e.g., medical, administrative), the recipient (e.g., young versus older child), the opportunity for repeated reference to the information, and other factors. Structured, face-to-face communication appears essential for some purposes, but other strategies including written materials, graphics, videos, and Internet-based tools may reinforce such communication and, for some purposes, substitute for it. These expectations are reasonable but should be further investigated.

Interdisciplinary Care Teams

Despite their seeming ubiquity and this committee's judgment of their importance, little rigorous research appears to have focused on the prevalence or functioning of different kinds of pediatric or adult palliative care teams or to have identified factors associated with more or less effective team performance in different contexts. Such systematic research as was identified by the committee focused primarily on primary care and chronic illness care (often as an element of primary care) (see e.g., Campbell et al., 2001; Barrett et al., 2001; Roy-Byrne et al., 2001; Rost et al., 2000; but see also Shortell et al., 1994 on intensive care teams).[6] Team care is, however, often a part of a multi-element intervention in which the individual structural elements or processes are not separately evaluated.[7]

Although problems in coordination and continuity often arise when multiple providers (e.g., hospitals, home care agencies) are involved in a child's care, problems also arise within single organizations (e.g., as shifts change or clinicians from different disciplines interact with parents). As a starting point, it would be helpful to have more systematic information on the structure, composition, environment, and functioning of the lead care teams for children with life-threatening medical conditions and the characteristics of teams associated with better coordination and continuity for the dimensions of care identified in Chapters 4 and 5. In addition, an important question for pediatric palliative and end-of-life care is how care teams relate to each other during transitions in care (e.g., from inpatient to home hospice care) or when additional expertise (e.g., palliative care consultations) is needed.

Regional Programs

As discussed in Chapter 6, access to expertise in pediatric palliative care is limited by geography. Some children who die will be cared for through the end of life at specialized regional centers, but families will take other children home to be cared for by family members and local pediatricians and community hospitals that have limited preparation for and experience in providing palliative and end-of-life care. In Chapter 6, the committee

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[6] Some relevant research may be categorized under related concepts or objectives such as care coordination or quality improvement. For example, team care is often associated with the use of formal clinical practice guidelines and quality improvement initiatives, and some studies suggest problems in the team care component of such initiatives, for example, staff turnover, physical separation, and responsibilities outside the team (Weissman et al., 1997; Hayward et al, 2000; see also Campbell E. et al., 1998).

[7] Some research has focused on the contributions or acceptance of specific categories of professionals (e.g., nurse practitioners, social workers, or genetic counselors) in different environments (see, e.g., Burl et al., 1994; Aquilino et al., 1999; Inati et al., 1994). Research not specifically focused on the effectiveness of multidisciplinary teams has pointed to potential problems for team functioning arising from differences in the views of physicians and nurses about what constitutes clinically or ethically appropriate care at the end of life (see Chapter 3). In its call for grant applications on quality of life for individuals at the end of life, the National Institute of Nursing Research mentioned "multidisciplinary interventions" and noted that research is need to support care systems that include multidisciplinary teams (NIH, 2000).

recommended strategies for supporting these professionals and organizations, including written protocols, family guides, and various forms of telemedicine. The federal government has supported research to investigate the potential of telemedicine to improve care for rural populations, including people receiving care at home for serious chronic illness. (See, e.g., Office for the Advancement of Telehealth at http://telehealth. hrsa.gov.) Although limited, this research can provide a foundation for studies related to pediatric palliative and end-of-life care specifically.

Research Directions: Financing Pediatric Palliative and End-of-Life Care

Chapter 7 has made clear that few systematic data are available to describe the financing of palliative and end-of-life care for children, much less evaluate systematically the effects of different financing policies or practices on that care. Thus, the committee's conclusions and recommendations about financing are based primarily on logic, experience, value judgments, and cautious generalization from studies involving adults. Although the committee believes it is appropriate to move to implement the recommendations, it also recognizes that further research and analysis are important to guide certain changes in financing policies and practices (Box 10.7).

Descriptive Research

More complete descriptive research on financing practices would help providers, managers, and policymakers better understand how care for children who die and their families is financed and how the situation for children differs from that for adults. The first steps should include a state-by-state inventory of variations in Medicaid coverage and reimbursement policies related to the elements of pediatric palliative and end-of-life care discussed in Chapter 7. Although a complete inventory is not feasible for private health plans given their large number, coverage and payment policies should be surveyed for a subset of representative plans or communities.

Next steps should also include some assessment of the extent to which written policies (including early periodic screening, detection, and treatment [EPSDT] policies) match implementation (e.g., whether claims administrators often deny claims for hospice and palliative services covered for children but not adult Medicaid beneficiaries). To be manageable, such an assessment might cover only a subset of states using a survey or case studies or both. Once the descriptive foundation is in place, the next step is to assess the impact of different coverage policies and reimbursement methods on cost, access, and quality of care for children who die and their families.

BOX 10.7
Directions for Research on Financing of Palliative, End-of-Life, and Bereavement Care

- Document variation in state Medicaid and private insurance coverage and reimbursement policies regarding pediatric palliative, end-of-life, and bereavement care:
  —Survey and inventory all state Medicaid programs.
  —Survey a representative sample of private insurance plans.
  —Assess the extent to which written policies match their implementation (e.g., determinations about actual claims for physician, hospice, or home health services).
- Examine the effects of different Medicaid and private insurance coverage and reimbursement policies on access, cost and quality of care.
- Conduct studies to assess the appropriateness for pediatric populations of payment and coding systems created for adult populations (e.g., diagnosis-related groups, resource-based relative value scales)
- Develop diagnosis and severity-of-illness criteria for establishing eligibility for expanded pediatric hospice and palliative care benefits.
- Conduct prospective studies of palliative and end-of-life care to identify and compare costs associated with different care settings and specific interventions.
- Assess hospice access pathways (i.e., hospice referral patterns, characteristics of populations denied access, comparisons of costs and outcomes) and factors influencing those pathways.
- Assess the extent of diffusion of Medicare prospective payment methods for home health care to Medicaid and private insurance plans and the effects on quality of care and family burden.
- Develop a Medicaid hospice cost-reporting system to use in creating a hospice payment outlier system and for research on utilization and costs of hospice care.
- Develop simulation models as research tools that will assist in the estimation of cost and utilization effects of implementing changes in palliative care, end-of-life care, and bereavement benefits. (Note: This research development is dependent on recommendation to create a national data resource on palliative and end-of-life care.)

Payment, Coding, and Severity of Illness Systems or Measures

A number of Medicaid and private health plans have adopted or adapted payment and coding systems originally devised for Medicare (i.e., diagnosis-related groups [DRGs] for hospital care and the resource-based relative value scale [RBRVS] for physician care). Researchers and child health advocates have raised several concerns about the application of these schemes to children, as described in Chapter 7. Further studies are needed to examine whether state and private reimbursement systems based on

DRGs or the RBRVS properly categorize and weigh palliative and end-of-life services for children. Such research could also identify possible adjustments in these systems to correct any problems identified.

Chapter 7 made general suggestions about establishing children's eligibility for certain types of palliative services using diagnosis and severity-of-illness criteria. Analytic work is needed to identify reliable and valid approaches for establishing such criteria for payment purposes and to assess their feasibility, cost implications, and likely consequences for child and family access to palliative care.

Hospice

As discussed in Chapter 7, studies of hospice care for adults have identified serious limitations in Medicare's per diem payments for that care. For example, studies have documented hospice access problems for adult patients with particularly high-cost needs (e.g., those requiring expensive pain medications or other palliative therapies). Research is needed to document the extent of hospice access problems for pediatric patients, examine hospice referral patterns, and identify characteristics of patients who are denied access. To explore these issues, prospective studies using existing clinical networks (e.g., the Children's Oncology Group) for patient identification should be conducted.

In order to implement a payment outlier system for hospices (recommended by the committee in Chapter 7) and to facilitate research on utilization and costs of hospice care for adult and pediatric patients, a Medicaid hospice cost-reporting system should be created. Since many hospices do not currently maintain detailed data on number of hours or types of services provided by staff, Medicaid could begin by creating a cost-reporting system based on high-cost items that hospices are more likely to track (e.g., expensive medications, durable medical equipment).

Prospective Payment for Home Health Care

Because Medicare policies often influence state and private policies, studies are needed to examine how new Medicare prospective payments systems for home health care and other services have diffused to state Medicaid programs and private health plans and how these systems are affecting care for children with life-threatening medical conditions. A first phase of research would involve surveying Medicaid and private plans to assess their adoption of Medicare reimbursement methods. A second phase would investigate the impact of these payment approaches on family burden and quality of care for Medicaid-covered children.

Cost Implications of Family Choices

For reasons discussed earlier in this report, families should have choices about the site of death for children with fatal medical problems. To assess the cost implications of these choices, prospective studies are needed to identify and compare the costs of different home and inpatient care options for children expected to die from congenital anomalies, cancers, progressive neurological disorders, and other serious conditions. Existing studies based on Medicare beneficiaries' use of hospice care cannot be generalized to children and are, in any case, flawed by retrospective research designs that cannot control for selection bias (i.e., differences in preferences and other characteristics of those who choose hospice care).

Although the committee expects that the financing changes recommended in Chapter 7 will involve limited additional costs for the benefits expected, a simulation model would assist in estimating the cost and utilization effects of implementing different options. For example, the cost of eliminating the six-month prognosis requirement could be estimated.

Finally, as noted elsewhere in this chapter, long-term prospective research is needed to evaluate the effectiveness of bereavement interventions for parents and siblings. The estimated costs and long-term cost-effectiveness of alternative interventions should also be investigated if such studies are undertaken.

Research Directions: Educating Health Professionals

Despite several decades of research on methods for educating health care professionals, much uncertainty remains about methods that can be consistently applied to produce changes in knowledge and practice, especially changes that endure beyond the classroom or the continuing education program. One challenge for educators is that the knowledge, values, and actions they teach are not uniformly rewarded or reinforced in day-to-day practice.

Educational research is not always valued within academic departments or by research funders. Long-term follow-up of educational outcomes, in particular, tends to be expensive and logistically complicated. Nonetheless, given the huge investments in preparing health professionals for practice, research is essential to identify the effectiveness of different educational techniques and emphases in creating desired changes in knowledge, skills, attitudes, and especially, behaviors.

The committee expects that much research involving education in pediatric care, adult palliative care, and generally relevant attitudes or skills (e.g., empathy, interviewing patients) would be generalizable to education in pediatric palliative care. Nonetheless, in developing curricula or interventions for pediatric specialists in training or for established pediatric specialists, revisions or adjustments will have to be considered and evaluated to take into account the special emotional and other dimensions of caring for dying children and their families. For example, as discussed in Chapter 8, the use of standardized patients is now a common educational tool, but using child actors or volunteers to depict dying children might encounter practical and ethical obstacles. Standardized families can be used, and systematic research into the effectiveness of this strategy—and of different variants—would be helpful. The projects by Williams and colleagues (2001b, 2002) and Greenberg and colleagues (1993) discussed in Chapter 9 offer examples of how such standardized families might be used to improve skills in communicating bad news and informing family decisionmaking.

Box 10.8 lists several directions for educational research. The involvement of bereaved parents in educational programs should be investigated, both for its impact on trainees and for the consequences for the parents. Conversations with bereaved parents suggest that some have found consolation and strength in presenting their experiences and perspectives, answering questions, and otherwise helping to educate both clinicians-in-training and established clinicians. Self-selection of the most confident or educated parents is, however, a potential concern and should be taken into account in any research about the role of parents as educators.

Because it will take years for newly educated health professionals to dominate health care systems by numbers or other influence, it is important

BOX 10.8
Directions for Research on Educating Health Care Professionals

- Investigate the participation of bereaved parents in educational programs at all levels.
- Identify characteristics of pediatric care systems (e.g., inpatient hospice programs, links to hospice agencies) that promote and reinforce lessons learned about palliative and end-of-life care in all educational contexts, including continuing education.
- Establish priorities and strategies for research on the short-term and long-term effects of education to prepare health care professionals to work in interdisciplinary teams.
- Assess strategies to improve symptom management and increase professionals' awareness of how well their assessments and performance match the experiences and expectations of patients and family members.
- Assess educational strategies to improve physician comfort and skill in compassionately providing patients and families with accurate and complete information about diagnosis, prognosis, and treatment options (including palliative care).

to examine continuing education in pediatric palliative care for established clinicians. Further, research is needed to identify characteristics of pediatric care systems that promote and reinforce lessons learned about palliative and end-of-life care in all educational contexts. As noted above, without reinforcement, educational interventions may manage to create desired short-term results but fail to produce durable changes. Research questions include whether education programs are more effective when institutions have formal relationships with hospices, formal pediatric palliative care consultation programs, formal adult inpatient palliative care services (for institutions serving adults and children), or identified palliative care role models and educators.

This report has stressed the importance of team care to bring multiple clinical perspectives and skills to bear on the complex physical, emotional, spiritual, and practical needs of seriously ill or injured children and families. In addition to research on the performance of pediatric teams in different environments and contexts (including providing palliative, end-of-life, and bereavement care in hospitals or at home), research also should assess methods for successfully educating physicians, nurses, social workers, and others to function as effective members of health care teams.

Also stressed in this report is the importance of adequate and timely information for patients and families. As reviewed in Chapters 3 and 4, studies have suggested that clinicians may be reluctant to provide such information when the diagnosis and prognosis are grim. One study (Lamont and Christakis, 2001) suggested that clinicians may provide patients and families with misleadingly optimistic assessments and that younger adult patients were more likely to receive such misleading assessments than older adults. Another study involving physicians caring for adults found that they dreaded explicit discussion of patient prognosis, usually were not specific, and often waited until parents or families raised the issue (Christakis and Iwashyna, 1998). Other studies of adult and pediatric palliative care have identified discrepancies between physician assessments of care and the assessments of patients or family members (see, e.g., Wolfe et al., 2000b).

A variety of educational interventions—for example, role playing, standardized patients who provide feedback, and parents as teachers—could potentially promote greater clinician self-awareness and more explicit concern for the actual experiences and expectations of patients and family members. Studies of efforts to teach empathy that were conducted in the 1970s suggest strategies to assess and compare such educational interventions (Fine and Therrien, 1977; see also Spiro, 1992; Reiser, 1996; Halpern, 2001).

Finally, the development and evaluation of educational techniques to improve the use of proven symptom management strategies are important if their benefits are to reach children in need. In particular, although cognitive and behavioral strategies have demonstrated effectiveness in reducing pain and improving coping, teaching of these techniques to clinicians generally appears to lack the rigor and uniformity that characterize other clinical domains.

CHALLENGES OF RESEARCH ON PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILES

The paucity of information about palliative and end-of-life care for children and their families has several explanations. Although over 50,000 children die each year, many of these deaths result from severe injuries or sudden infant death syndrome (SIDS). The medical care actually provided to or consciously experienced by these children is limited compared to that of children with chronic medical conditions. For surviving family members, interactions with emergency medical personnel (particularly first responders) or ICU personnel are often relatively brief and poorly documented, which makes it difficult for researchers to use medical records retrospectively to assess the extent and quality of the information and emotional support provided to survivors.

Particularly for deaths involving infants and very young children, a considerable fraction of deaths result from an array of relatively or very uncommon congenital conditions. Even over several years and across multiple medical centers, it may be difficult to identify enough cases for each condition to allow productive prospective or retrospective analyses of the patterns and quality of palliative and end-of-life care for these children and their families. Combining information about children with different conditions may sometimes be a plausible strategy if the symptoms and other characteristics of each condition and the consequences for the children and families are similar. Nonetheless, accumulating enough cases for analysis may still take years.

Even when numbers are sufficient for study, however, retrospective analyses of medical records may be constrained by failures to document relevant aspects of care, for example, whether or not pain and other symptoms were explicitly assessed. Such lack of documentation, in itself, is an important finding with implications for day-to-day clinical practice and quality improvement efforts.

Another constraint is that although Medicare-related databases offer much comprehensive information about the types and costs of care provided to elderly adults, no comparable information is available for younger individuals covered by the 50-plus state Medicaid programs and thousands of private insurance plans. Other information sources, such as government surveys of home health and hospice agencies, may not include enough children to allow meaningful analyses.

Despite many differences, researchers studying end-of-life care and researchers studying children share a common challenge: their subjects are often unable to report directly on the care they have received or on their physical or emotional distress or well-being. Even for children old enough to report reliably, the effects of a life-threatening medical problem or its treatment may render them unconscious, confused, drowsy, fatigued, or otherwise not able to answer questions. As a result, researchers frequently rely on surrogates—usually the parents—to describe their perceptions of the patient's experience and quality of life (see Appendix C). Also, because the time of death is often unpredictable, researchers may be unable to assess patients' status at comparable points before death and may have to rely on the recollections of surrogates about a patient's status during the days, weeks, or months prior to death (see, e.g., Wolfe et al., 2000a,b). Nonetheless, surrogate reports and retrospective reports raise serious questions of validity and reliability, and researchers and research funders should consider alternatives whenever possible.

Another challenge is that research funders, who are accustomed to more stable research situations, measurement tools, clinical end points (e.g., remission, five-year survival), and already-conducted pilot testing, may be reluctant to support research that does not fit these patterns. In the committee's experience, they are also reluctant to fund the kinds of pilot studies that provide an essential base for more rigorous research. This puts researchers in this new and difficult arena in a classic "Catch-22" situation.

In addition, the conduct of medical or health services research involving children faces more stringent ethical and legal constraints than apply to research involving most adults. These are discussed below.

ETHICAL AND LEGAL ISSUES IN RESEARCH INVOLVING CHILDREN

Policymakers, researchers, and ethicists have been working for decades to develop protections for people participating in research, especially "vulnerable" populations including children, prisoners, and those with serious cognitive or emotional problems. The first widely recognized principles for ethical research were the Nuremberg Code's directives for human experimentation, which were developed in 1947 by judges presiding over the trials of Nazi physicians accused of research atrocities (Shuster, 1997). These judges developed 10 principles for research, the first of which stated that it is absolutely essential that human subjects voluntarily consent to participation. The statement did not consider the involvement of children in research.

The 1964 Declaration of Helsinki from the World Medical Association called for parents of child participants in research to give their consent and for children's "assent" to be obtained when possible (WMA, 1964). In the United States, a national commission on protection of human subjects in research likewise proposed in 1977 that parental permission be required as well as assent in some form from children age 7 and over (USDHEW, 1977). Subsequent books, articles, and conferences have continued to explore ethical issues involved in research on children, the boundaries of permissible research, and strategies for protecting child research subjects (see, e.g., Stanley and Sieber, 1992; Grodin and Glantz, 1994; AAP, 1995a; Levine, 1995; Rosato, 2000).

If conducting research presents ethical questions, so does the *failure* to conduct research. As noted by the American Academy of Pediatrics in a statement on drug research, the "lack of studies in children presents the treating physician with an ethical dilemma. The physician must frequently either not treat children with potentially beneficial medications or treat them with medications based on adult studies or anecdotal empirical experience in children" (AAP, 1995a, p. 286).

Federally Funded Research

As set forth in Box 10.9, federal regulations adopted in 1983 and revised in 1991 set forth requirements related to children's participation as subjects of federally funded research (45 CFR 46; USDHSS, 1993). The regulations also provided for institutional review boards (IRBs) to be established by each research institution to review federally funded research that involves human subjects and determine whether proposed research meets federal standards.

Although the regulations and accompanying federal guidance encourage respect for a child's views about participating in research, they make clear that a research project may be approved without requiring that each child provide assent before enrollment (45 CFR 46.408[a]). The IRB must conclude in such cases that the research has the potential to produce an important direct benefit to the child, that such benefit is possible only in the research context, and that provisions are adequate for obtaining informed permission from the child's parents for the research.

The regulations also require that research conform to state laws and judicial decisions including those related to the age of consent for medical treatment. If an adolescent is considered legally competent under state law to consent to treatment, he or she can usually consent to research presenting equivalent risk.

In some situations (e.g., for research on children who have been abused), researchers and the IRB may seek alternatives to or reviews of parental permission for a child's participation in research. If a child is a ward of the state, additional limitations are imposed on his or her participation in

BOX 10.9
Categories of Research Involving Children That May Be Approved for Federal Funding

Research Involving No Greater Than Minimal Risk (46.404)

"The Institutional Review Board (IRB) must find that the research involves no greater than minimal risk to children and that adequate provisions are made for soliciting the assent of the children and the permission of their parents or guardians."

Research Involving Greater Than Minimal Risk That Has Potential to Benefit the Research Subjects Directly (46.405)

"The IRB must find that more than minimal risk to children is presented by an intervention and then must also find that (a) the research may directly benefit the individual research subjects, (b) the anticipated benefit is sufficient to justify the risk, (c) the relation of the benefit to the risk is equally or more favorable as that presented by available nonresearch alternatives, and (d) adequate provisions are made for soliciting the assent of the children and the permission of their parents or guardians."

Research Involving Greater Than Minimal Risk That Has No Prospect of Direct Benefit to Individual Subjects but Is Likely to Yield Generalizable Knowledge (46.406)

"The IRB must find that more than minimal risk to children is presented by an intervention that is not expected to benefit the individual subject directly but that (a) the increased risk is minor, (b) the experiences associated with the intervention are reasonably similar to those inherent in the subject's actual or expected medical situation, (c) the intervention is likely to yield generalizable knowledge about the subject's condition that is vitally important to understand or ameliorate the condition, and (d) adequate provisions are made for soliciting assent of the children and the permission of their parents or guardians."

Research That Is Not Otherwise Approvable (46.407)

"The IRB must conclude that the research does not meet the above requirements but does present a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of children. The research must then be judged by the Secretary of the Department of Health and Human Services (after consultation with appropriate experts and opportunity for public review and comment) to fit one of the categories described above *or* to meet the following conditions of (a) presenting a reasonable opportunity for better understanding, preventing, or alleviating a serious problem affecting the health or welfare of children, (b) following sound ethical principles for research, and (c) including adequate provisions for soliciting the assent of children and the permission of their parents or guardians."

SOURCE: 45 CFR 46 Protection of Human Subjects, Additional Protections for Children Involved as Subjects in Research, Subpart D, Sections 401–409. 56 FR 28032, June 18, 1991 (http://www.med.umich.edu/irbmed/FederalDocuments/hhs/HHS45CFR46.html).

research when the research involves more than minimal risk with no prospect of direct benefit to the child. The research must either be related to children's status as wards or be conducted in settings such as hospitals or schools where the majority of child research participants are not wards of the state (45 CFR 46.409). Also, a special advocate (other than the guardian) must be appointed for a child participating in such research. The committee understands that some states refuse to permit wards of the state to participate in research, even if no alternative treatment exists for the child's life-threatening illness.

Explanations of the proposed research are to be appropriate for the specific child's age, maturity, experience, and medical condition. The National Cancer Institute provides guidance for parents and guardians, including advice that parents not withhold information about the discomforts or risks involved in research and that they monitor whether the child really seems to understand the explanations being provided (NCI, 2001c).

Based on members' experiences and their conversations with other researchers, the committee believes that many IRBs, as presently constituted, may lack the expertise and background to evaluate proposals for research on pediatric palliative and end-of-life care. They may have unwarranted concerns about the potential of such research to cause harm to children and families. As described below, Congress has asked for a study that will investigate the competence of IRBs to assess research involving children.

Some research should soon be available to document positive responses by families to studies investigating their experiences and perspectives (Wolfe, 2001). As noted in a recent report on family perspectives on the quality of pediatric palliative care, "The families who participated in our assessment unanimously expressed gratitude for the opportunity to 'tell their stories' " (Contro et al., 2002, p. 18). Researchers in that study reported, however, that 20 of 63 families they reached declined to participate because it would be too painful.

Privately Funded Research

The regulations described in the preceding section apply to federally funded research involving children. Pediatric drug research promoted by the Food and Drug Administration is generally funded by pharmaceutical companies. As directed by Congress in the Children's Health Act of 2000, the FDA must apply Department of Health and Human Services requirements for federally funded research that involves children to privately funded studies of products regulated by the FDA. (The agency had long required IRB review of drug research submitted to it by private companies [Levine, 1988].)

In April 1, 2001, the FDA issued an interim rule to change its regulations accordingly (21 CFR 50 and 56; FDA, 2001a). The agency invited comment on several issues including children's participation in placebo-controlled trials, the definition of what constitutes a "minor increase over minimal risk" (and ways of measuring minor risk and determining when a minimal risk becomes a major risk), and ways to provide age-appropriate explanations of research to children.

The interim rule differs from the regulations governing federally funded research in certain respects. For research in the "not otherwise approvable" category (see Box 10.8) that is referred to the commissioner of the FDA for consideration, the agency may not be able to offer public review and comment if the research sponsor is unwilling to make public necessary information that is privileged under other FDA requirements.

Research that is neither federally funded nor conducted under the FDA provisions described earlier may be covered by state regulations and institutional policies requiring review of all research undertaken by its employees or students. In general, IRBs apply the same criteria to research proposals without reference to the source of funding.

Continuing Concerns about Children's Participation in Research

Policies about children's participation in research continue to prompt debate. The major issues involve

- the appropriateness of current regulations for children of different ages or intellectual and emotional maturity,
- the ethics of including children and other vulnerable subjects in research that is not expected to benefit these subjects directly,
- the definition of minimal risk,
- the extent of children's and adolescents' comprehension of information about the risks and benefits of treatments and participation in research,
- the potential for conflict between parent and child and the meaningfulness of "assent" or discussions about assent with a child when parents can override the child's wishes, and
- the performance of IRBs in evaluating research involving children.

The legislation reauthorizing the incentives for pediatric drug testing provided for an Institute of Medicine study to examine such issues and review federal regulations relating to research involving children. The results of this report are to be given to Congress by the close of 2003.

CONCLUSION

This chapter has proposed a range of research efforts to strengthen the very limited base of knowledge now available to guide those providing, organizing, financing, and monitoring palliative, end-of-life, and bereavement care for children and families. It has recommended strategies to promote relevant research in federally funded pediatric centers, networks, and similar structures. The intent is to increase the numbers of children and families involved in studies, encourage the development and use of common research methods, and increase the credibility and acceptance of the research findings.

The research directions proposed here focus on children who have conditions that are certain or likely to prove fatal, but investigation of some of the suggested research questions may involve participation by children who survive and their families. In some cases, such participation will reflect the unpredictability of certain life-threatening conditions and the requirements of prospective research designs. In other cases, it will reflect a focus on questions that affect the well being of children and families facing a life-threatening problem, whether or not that problem actually ends in death. In either case, when it is appropriate, including a larger group of children usually has methodological advantages.

Much of the research proposed here thus should provide knowledge that will inform and improve the care of children who survive as well as those who do not—and likewise will help every family that suffers with a seriously ill or injured child. Indeed, all of the recommendations in this report, if implemented, should help create a care system that all children and families can trust to provide capable, compassionate, and reliable care when they are in need.

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APPENDIX A

STUDY ORIGINS AND ACTIVITIES

In Summer 1999, the Institute of Medicine's Board on Health Sciences Policy recommended that IOM undertake a study to investigate care for children who die and their families. With funding from a mix of public and private agencies, the IOM began the study in Fall, 2000. The broad objectives were to 1) develop recommendations to strengthen the knowledge base for compassionate and effective care for dying children and their families; 2) inform health care providers, researchers, medical and nursing educators, state and federal policy makers, insurers, and others about these recommendations; and 3) encourage thoughtful discussion of what constitutes good end-of-life care for children and their families.

The IOM appointed a committee of 14 experts to oversee the study. That committee met 5 times between April 2001 and February 2002. Its task was to develop a report that

- described the major causes and settings of death for children;
- reviewed what is known about 1) the medical and other services provided to dying children and their families and 2) the education of physicians and other professionals who care for gravely ill children;
- assessed the state of knowledge about clinical, behavioral, cultural, organizational, legal, and other important aspects of palliative and end-of-life care for children and their families;
- examined methods for communicating information, determining family and child/patient preferences, resolving conflicts, and evaluating the quality of palliative and end-of-life care as experienced by children and their families; and
- proposed a research and action agenda to strengthen the scope and application of the knowledge base for providing effective and compassionate care for children who die and their families.

The committee arranged for seven background papers, which are readable online (www.nap.edu) as Appendixes B through H. It also conducted a one-day meeting to hear views from family support and advocacy organizations and health care groups, and it invited written statements from additional organizations. In addition, the committee met for a half-day with parents whose children had died from or were living with life-threatening medical problems. Both meetings were open to the public. The agendas and participants are listed below as are additional groups that submitted written statements to the committee.

Public Meeting
Lecture Room, National Academy of Sciences
2101 Constitution Avenue NW, Washington, DC.
Saturday, September 8, 2001
AGENDA

8:30 a.m.	**Welcome and Introductions** Richard Behrman, M.D., Chair
8:40-9:20 a.m	**Panel 1**

The Compassionate Friends, Inc.
Patricia A. Loder

Candlelighters: Childhood Cancer Foundation
Ruth Hoffman

National Organization of Parents of Murdered Children
Jean Lewis

9:20-10:00 a.m.	**Panel 2**

SIDS Alliance
Deborah Boyd

MISS - Mothers in Sympathy and Support
Richard K. Olsen

Hygeia
Michael R. Berman, M.D.

10:20-11:00 a.m. Panel 3

National Tay-Sachs & Allied Diseases Association
Carol and Eric Zimmerman

Support Organization for Trisomy 13/18 and Related Disorders
Kenneth McWha, M.D.

National Organization for Rare Disorders
Diane Dorman

11:00-11:30 a.m. Panel 4

Make-a-Wish Foundation
Michele R. Atkins

1:15-2:00 p.m. Panel 5

American Academy of Pediatrics (AAP)
G. Kevin Donovan, M.D., M.L.A.

Critical Care Section, AAP
M. Michele Moss, M.D.

2:00-2:40 p.m. Panel 6

American Psychological Association/Society of Pediatric Psychology
Daniel Armstrong, Ph.D.

American Board of Pediatrics
Ernest F. Krug III, M.D.

3:10-3:50 p.m. Panel 7

National Association of Children's Hospitals and Related Institutions
Susan Dull, R.N., M.S.N., M.B.A.

National Hospice and Palliative Care Organization
Stephen R. Connor, Ph.D.

National Association of Pediatric Home and Community Care
Dorothy Page, F.N.P., M.S.N.

3:50-4:30 p.m. **Panel 8**

Pediatric Chaplains Network
The Reverend Dane R. Sommer

Child Life Council
Christina Brown

National Association of Social Workers
Mirean Coleman, M.S.W.

4:30 p.m. Adjourn

Additional groups submitting written statements
American Academy of Hospice and Palliative Medicine
American Association of Colleges of Nursing
American Association of Critical Care Nurses
American Board of Pediatrics Program Directors Committee
American College of Emergency Physicians
American Society of Pediatric Hematology/Oncology
Children's Oncology Group End-of-Life Subcommittee
Hospice and Palliative Nurses Association
National Association of State Emergency Medical Services Directors
Organization of Neonatal-Perinatal Training Program Directors

Public Meeting
Room 150, National Academy of Sciences
2101 Constitution Avenue NW, Washington, DC.
Sunday, September 9, 2001

PARTICIPANTS

Winona Kittiko
Atlanta, Georgia

Rose and Gary Conlon
Fremont, California

Les Weil
Milwaukee, Wisconsin

Tina Heyl-Marinueau
Weymouth, Massachusetts

Deborah Dokken
Chevy Chase, Maryland

Rosario and Salvador Avila
Palo Alto, California

APPENDIX B

PROGNOSTICATION SCORES

Murray M. Pollack, M.D., M.B.A.[*]

INTRODUCTION

Decisions about patient care are often based on the prognostic likelihood for outcomes such as death, disability, or toxicity for each potential therapy. For some decisions, the experience and knowledge base of individual clinicians allows good estimates of the outcomes for each therapeutic option. For other decisions involving potential therapeutic options, however, the experience and knowledge base of the individual clinician may be very limited. Decisions involving the likelihood of major disabilities or death, especially for infants and children, are often those for which both the experience and knowledge base of the individual clinician is inadequate. Even more important, the scientific literature is often not helpful in assigning a prognosis to individual patients, especially when the outcome is death or disability in the short-term future.

For these reasons, prognostication, the prediction of disease progression and outcome with and without therapies, remains a critical aspect of clinical medicine. The interest in prognostication tools as potential decision making aids stems from the need to improve prognostic estimates under the conditions of limited clinician experience and limited scientific evidence.

Contemporary developments mainly driven by concerns for adult pa-

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[*] Professor of Pediatrics, George Washington University School of Medicine and Health Sciences; Division Chief, Critical Care Medicine, Children's National Medicine Center; and Executive Director, Center for Hospital-Based Specialties, Children's National Medical Center.

tients are increasing our interest in predicting death and its timing. Patients and families have become more involved in making medical decisions and often need better information about their medical situation and the likely consequences of different treatment options. Meaningful involvement in medical decision making for patients and families implies access to meaningful information about expected outcomes. Meaningful involvement is especially important for those with complex chronic medical problems. Another reason for the interest in prognosis is that laws or regulations make access to some kinds of care contingent on estimates of life expectancy. For example, to qualify for hospice benefits, a Medicare or Medicaid beneficiary must be certified as having less than six months to live. Similarly, Oregon's assisted suicide statute links legal access to prescriptions of lethal drugs to a six-month life expectancy (among other criteria).[1] Statements in "living wills" or advance care directives about preferences for CPR or other life-sustaining interventions may be phrased in terms of expectations about survival or other outcomes (e.g., cognitive capacity). In addition, the development and wide deployment of advanced medical technologies in recent years has prompted concern about possibly futile uses of these technologies for those who die.[2,3]

Pediatric decision making involves special circumstances. The child patient has limited legal autonomy, and capacity to make reasoned decisions that varies with a child's developmental level. Nonetheless, many pediatricians believe that children's views ought to be taken into account, which can present problems, especially in the case of older adolescents. Family and societal values are complex and sometimes incline toward exhausting every life-prolonging option, perhaps without full appreciation of the burdens imposed on the child. Such a decision to continue life-prolonging treatment far beyond the recommendations of health care professionals is also a severe stress to the health care institution and staff when it occurs. Children cannot be left out of the current efforts to insure that people die with as much dignity as possible and that decisions about care be based on the appropriate scientific evidence and clinical experience.

Could prognostication tools and quantitative estimates or scores help clinicians? The following discussion considers the preparedness of physicians to undertake complex life and death decisions, the elements of quantitative prognostic tools and scores, the accuracy of clinicians' estimates, and issues in using prognostic scores to guide decisions about individual patients.

THE LACK OF PREPAREDNESS

Despite the interest in prognostication and its application to end-of-life decisions, educational experiences and resources for health care professionals still provide little preparation in prognostic concepts and methods. Carron et al. surveyed the treatment of 12 diseases in four major textbooks. They found, in general, that helpful prognostic information was rare and that the natural disease progression was described so generally as to lack practical utility.[4] Usually, the course of a disease was only linked to therapeutic options, not to futility. Texts infrequently mentioned death, the dying process or the effects of end-of-life changes on patients and families.

Compared to internists, the experience and training of pediatric clinicians in prognostication sciences and end-of-life rituals is likely to be even more deficient because fewer children than adults die or have life threatening conditions. The effects on families of a child's life-threatening medical problem or a child's death are, however, likely to be even more complex and difficult than the effects of an adult's death.

Similarly, physicians' training in decision-making sciences is limited while the difficulty in making the most informed decision may even increase as information increases. The amount of data obtained from electronic, laboratory and clinical methods has grown exponentially during the past few decades. As the amount of data grows, clinicians will have an increasing difficulty in integrating it to arrive at reliable prognostic likelihood estimates.[5] Humans' short-term memory can use from only four to seven data points or data constructs at one time.[6,7] In data intensive environments such as ICUs, the cognitive limitations of clinicians may be especially restrictive.[8] Attempts to use larger amounts of information simultaneously may lead to ineffective decision making, unjustified variability in clinical practice, and even clinical errors.

There is little information regarding the processes of how physicians learn and practice prognostication, how their experiences affect their practice, or even how frequently they encounter prognostication issues in their practice. In one provocative study, Christakis et al. found that while internists frequently encounter these issues, about 60% find it stressful to assess prognosis explicitly, about 45% wait to discuss prognosis until the patient brings it up, 90% avoid being specific, and almost 60% report inadequate training.[9] Similar data are not available for pediatricians, but it is likely that general pediatricians would demonstrate even less familiarity and comfort with end of life prognostication since relatively fewer children die, those that do die are generally cared for by specialists, and childhood death may be difficult for many pediatricians to face.

What little information we have about pediatric end-of-life decision making suggests that there is substantial variability in how pediatricians estimate prognosis in similar situations. Randolph et al., using a cross-sectional design and several clinical scenarios, surveyed pediatric oncologists and pediatric intensivists. They found a substantial disparity in the prognostic estimates, and of quality of life values as a factor in decisions, and recommended clinical actions between and within these groups.[10] When given the same case scenarios, some physicians chose a full aggressive level of care while others chose only comfort measures. The most significant respondent factors affecting choices were level of training and experience and a self-rated importance of functional neurological status.

ELEMENTS OF PROGNOSTICATION

Prognostication involves the identification of relevant outcomes and clinical data elements that are associated with these outcomes. Statistical methods associate these outcomes and data elements. Choosing the right outcomes and data elements as well as the correct statistical processes is crucial to developing a reliable score suitable for clinical use. Clinicians need to understand the strengths and limitation of these processes to apply these tools.

Relevant Outcomes

Selection of the relevant outcome(s) is central to prognostication methods. Each medical condition has its own relevant outcomes. For example, hearing loss and pain are two serious outcomes for otitis media. For the purposes of this section, survival/death, serious disabilities, and costs will be considered as the most relevant to issues of death and dying. Survival and death are the main outcomes used in prognostication scores because they occur with sufficient frequency, the outcome states are well defined, and they are clearly important. Some have worried that the focus on death in prognostication may cause clinicians to preserve life at the cost of shifting outcomes from death to severe disability. After decades of worrying over this prospect, critics have produced no examples to substantiate a problem. However, other outcomes such as pain and suffering remain serious and important outcomes. Unfortunately, these outcomes cannot be quantified with sufficient accuracy and reproducibility, making objective prognostication very difficult.

Serious physical disability and/or cognitive impairment are also very important in prognostication and in many situations may be more important to patients and families than death. Unfortunately, the use of physical disability and/or cognitive impairment as outcomes in pediatrics has been severely hindered by the lack of summary measures describing disability states in a manner that can be used as outcomes in formal prognostication methods. While extensive neuropsychological testing can define functional states, it is time consuming, expensive, and specialized, limiting its use in developing prognostication scores that may require thousands of patients. One important effort to measure and quantify disability has been the Pediatric Overall Performance Category (POPC) and Pediatric Cerebral Performance Category (PCPC) Scores.[11] These scores are general assessments analogous to the Glasgow Outcome Scale Scores with operational definitions adapted for children. The PCPC and POPC scales quantify overall morbidity and cognitive impairment, respectively. Each is a six-point graded scale of increasing disability from normal function (score = 1) to death (score = 6). They are relatively simpler and quick to use in clinical settings. Qualitative assessments are made by care providers based on very general descriptions of the POPC and PCPC categories. Face and content validities for the POPC and PCPC scales have been evaluated. Differences between baseline and discharge POPC and PCPC scores have been associated with several other indicators of morbidity including length of PICU stay, total hospital charges, discharge care needs and summary measures of severity of illness.[12]

Unfortunately, even though the POCP and PCPC are statistically correlated with the Stanford-Binet Intelligence Quotients, Bayley Mental Developmental Index scores, Bayley Psychomotor Developmental Index scores, and Vineland Adaptive Behavior Scales scores,[13] the correlation of the POCP and PCPC with these tests is not sufficient for use in individual patients. Individuals with the same neuropsychological measure may fall into very different POCP and PCPC categories based on the qualitative assessment of the care giver's assessment of functioning. Therefore, they are unsuitable for use in decision making or prognostication in individual patients. The current use is primarily limited to large group studies where the numbers of patients makes sophisticated neuropsycho-logical testing impractical due to time and cost.

Economic outcome indicators have been popular outcomes in the medical literature because they are easily measured and appeal to those concerned about health care costs, especially costs for care that is futile or of very low probable benefit. While this emphasis has immediate appeal, efforts to define futility and to link it to high medical costs or the need for rationing have not produced acceptance or consensus among clinicians and policymakers.[14] For example, one pediatric ICU study using very broad definitions of medical futility found that relatively small amounts of resources were used for "futile" PICU care.[15]

Development and Validation of Prognostication

Health professionals, administrators, and policy makers interested in the credible and appropriate use of prognostication scores and methods need to understand, in at least a general fashion, several important issues in the development and validation of scores. Many excellent articles and texts have developed the intricacies of the different theoretical and statistical methods and techniques.[16-18] The following is a summary of the central issues.

First, data elements must be easily defined, easily collected, collected with common frequencies, and relevant to the outcome. This is necessary because data obtained in one institution must have the same definitions and be sampled with similar frequencies in another institution if they are to be generalized to other institutions. In particular, it is best not to include variables such as therapies that can be easily influenced by physician behaviors and could be used to "game" the prognostication method. For example, inclusion of FiO_2 in severity scores enables the physician to alter the score by increasing the FiO_2 beyond what might be needed. Issues of pain and suffering which may be very relevant, are similarly difficult to quantify. Second, to minimize observation bias, data elements used to create a score should be selected *a priori* and collected independent of knowledge of the outcome (e.g., prospectively). Third, data should be tested for reliability, usually with one of two methods: intra-observer reliability (consistency of data re-measured by the same person or clinician) or (preferably) inter-observer reliability (consistency of data measured by different people). The kappa statistic is a measure of agreement that is scaled to 0 (chance agreement) and 1 (perfect agreement). Several large multi-institutional studies have collected important and useful data but have neglected to insure reliable data collection, severely limiting the utility of the studies' observations and conclusions, and certainly severely limiting any direct application of the results to individuals.

Individual variables that are candidates for a prognostic model are usually tested separately for statistical association with the outcome (univariate analysis). The set of statistically significant variables from the univariate analyses is subjected to multivariate analysis to assess their *relative* predictive performance, the standard methodology for developing a multi-element index or score. Multivariate logistic regression is most often used when the outcome is dichotomous (e.g., survival/death). Polychotomous logistic regression enables prediction of more than two outcome states. For example, one pediatric ICU study used this technique to predict the discharge states of being dead, comatose, or not comatose.[19] While appealing, very large samples are needed for predicting more than two outcomes. Multivariate linear regression is most often utilized for continuous outcomes (e.g., length of stay); and multivariate linear or quadratic discriminant function analysis is most often used to predict categorical outcomes such as diagnosis.

Care must be taken when developing a score or risk prediction model using multivariate analyses to avoid "overfitting," the creation of a model that is fitted to idiosyncrasies (noise) of the data rather than to their relevant features. Overfitting is most likely to occur when the number of variables included in the score is relatively large compared to the number of study subjects or events. A common rule suggests that there be at least 10 outcome events (e.g., deaths) per independent variable.[20] Single institution studies with small sample sizes often develop very impressive prediction models that fail to perform well when applied to other institutions or new data sets, in large part because the models are fit to the "noise" of the single institution.

All scoring systems should be validated prior to use. Validation of the score in the population from which the score was derived (internal validation) includes data-splitting, cross-validation, or bootstrapping. In data-splitting, a random portion of the sample is used for the model development (training set) and the remainder is used for the model validation (validation set). Cross-validation is repeated data-splitting, generating many training and validation sets. Bootstrapping involves testing the performance of the model on a large number of sub-samples randomly drawn from the original sample. Validation in an *external* sample is the most stringent test and should be performed before any prognostic tool is used to guide decisions about individual patients.

A variety of other less traditional methods have been or could be used for score development. For example, neural networks are designed to mimic the performance of the human brain. While many involve aspects of artificial intelligence, none has performed better than standard statistical methods when applied to prognostication.[21]

Two essential and objective aspects of the validation process are testing for discrimination and calibration.[22] Discrimination, or the ability of a model to distinguish between outcome groups, is most often assessed by the area under the receiver operator characteristic (ROC) curve. The area under the curve (AUC) is an expression of the overall discrimination across the range of risk levels and is a good summary measure of predictive ability. The ROC and AUC are difficult concepts to grasp. The AUC is most easily explained with an example. Image that all the patients who survived were in one group and all that died were in another group. If a patient is randomly selected from each outcome group and their prognostic scores compared, an AUC of 0.90 would indicate that 90% of the time, the prognostic score of those who died would be higher than those who lived. A prognostic score with perfect discrimination would always have the survivor score lower than the scores for patients who died. Thus, perfect discrimination between the scores and the AUC would be indicated by an AUC of 1.0. As the prognostication method's AUC approaches 1.0, it becomes more and more relevant to use in individual patients. Unfortunately, there are no generally accepted discrimination criteria for test use in individual patients, especially if the use is to be involved with decisions of limitations and withdrawals of care. Prognostication methods such as APACHE and PRISM with AUCs between 0.88 and 0.96 have not been accepted into general clinical use for decision making in individual patients, indicating the need for "perfection" if a score is to be generally accepted.

ROC analysis does not evaluate how the predictor performs across the whole range of risk levels, or how well the predictor is calibrated. Calibration assesses the agreement between the predicted outcomes and actual outcomes over the entire range of risk. That is, a valid score or method should be able to reliably conclude that someone with a higher score is relatively sicker than someone with a lower score. To test the calibration of a scoring system, patients are divided into risk groups, usually deciles from 0% to 10% risk, 11% to 20% risk, . . . , 91% to 100% risk. Equivalently, *a priori* designation of patient risk categories can be used. For example, risk categories of low (e.g., 0% to 10%), intermediate (11% to 30%), and high (>30%) can be defined *a priori* and used for the calibration categories. The most accepted method for measuring calibration is the goodness-of-fit statistic proposed by Lemeshow and Hosmer.[23]

Scoring systems or prediction rules should also pass a standard of clinical reasonableness or sensibility.[24] Assessments of sensibility will depend upon the context in which the score is used; for example, a triage score intended for use by emergency medical personnel must be simple, easy to calculate, and not require unstable or irreproducible elements. A mortality risk score such as PRISM is composed of vital signs and laboratory values generally understood to be related to dying. Thus, in the context of critical care where therapies focus on life-support required to treat physiologic dysfunction, a score that uses such variables will more likely be seen as clinically reasonable and sensitive to the user's focus.

A mortality prediction model developed to guide decisions about individual patients needs to meet the most rigorous standards of thorough investigation, which have been noted. Another very important issue in clinical use of prediction methods is continuous updating. As medicine advances, the relationships among clinical variables, therapies, and outcomes will change, requiring updating of the prognostication methods.

One notable potential problem with current mortality prediction models is that they do not allow for the health professional's input into the prediction process. It seems plausible that a health care provider's assessment could improve the model's performance. In particular, health professionals may be better than statistical methods at accounting for uncommon or rare patient characteristics, unique conditions, or unique combinations of events not contained in sufficient numbers in the data set used to develop the prediction method. Incorporating the health professional's estimates into a prediction model could also increase the acceptability of prognostic scores in clinical situations.

Bayesian statistical algorithms have been proposed as a means of combining subjective and objective probabilities and possibly improving both prognostic performance and clinician acceptance.[25] Briefly, Bayesian statistics adjust a predetermined probability estimate (prior probability) with new data and thereby create a new "updated" probability (posterior probability). For example, the analysis might combine a clinician's estimate of a patient's likelihood of survival and the patient's score from a prognostic model. These methods have been applied to current prediction methods, but have not had substantial impact on either performance or user acceptance. Apparently, the addition of subjective elements into prediction instruments has not alleviated the inherent mistrust individuals have of applying scoring systems to individuals.

Computer-based clinical decision support systems (CDSS) have been proposed to help clinicians in a variety of settings. For example, such systems have been used to calculate cure rates for oncology patients and heparin doses for patients needing anticoagulation. Unfortunately, their application to clinical medicine has been disappointing. A recent systematic review found that CDSS's can enhance clinical performance for such activities as drug dosing and preventive care, but there have not been any positive impacts on clinical outcomes.[26]

However, the potential of CDSS systems is tremendous, especially if appropriately large data bases were developed and maintained. For example, if huge data bases could be collected and maintained, analyses could be tailored to the individual patient. Such analyses could focus on the outcomes relevant to the individual patient and be constructed to maximize the accuracy and reliability for a specific person.

EXAMPLES OF PROGNOSTICATION

Scoring systems are a means of quantifying clinical states that are difficult to summarize by other subjective or objective means. These systems are especially valuable in the ICU where subjective impressions of clinical states, severity of illness, and risk of mortality are highly variable.[27-34] In pediatrics, there have been major advances since the development of the Apgar score,[35] which was devised and is still used to quantify the condition of newborns, to current day scoring systems that can provide mortality risk scores for all ages as well as some scores that are useful for defining severity of illness (e.g., severity of respiratory distress) for other diseases such as croup or asthma.

NICU Mortality Scores

For many years, the Apgar score, birth weight, and gestational age served as standard severity of illness measures for newborns with fair success. Unfortunately, the Apgar score may be influenced by region and hospital and has limited use in predicting a newborn's future health. Birth weight and gestational age have also lost favor because the outcomes for infants with similar birth weights and gestational ages may not be consistent across institutions. Scoring systems attempt to control for biologic heterogeneity but they cannot accommodate unreliable variable measurement. Even more important, the rapid advances in neonatal care have made prognostication methods rapidly outdated as the relationships among biologic factors and outcomes change with new advances.

There are currently two established scoring systems for assessing severity of illness and mortality risk in neonates: the Clinical Risk Index for Babies (CRIB), and the Score for Neonatal Acute Physiology (SNAP). CRIB was developed in the United Kingdom for infants with birth weights less than 1500 grams.[36] It is composed of six commonly measured variables collected in the first 12 hours after birth, and the outcome is survival or death. CRIB, however, was developed using data from the pre-surfactant era and in a time when antenatal corticosteroids were not widely used. Both interventions have improved infant survival, altering the relationship of the variables and the CRIB score's outcome. Therefore, the CRIB mortality prediction model should not be used to provide prognostic probabilities for individual patients.

SNAP II is a second generation, physiology-based score for neonatal severity of illness developed from large samples from the United States and Canada.[37] SNAP II has also been modified for use as a mortality prediction model (SPAPPE II) by additional variables including birth weight, small for gestational age, and low Apgar scores.[38] Unfortunately, while SNAP scores have very good discrimination, they have been difficult to calibrate, severely limiting their utility because excellent calibration is a primary validity component that must be present before widespread clinical use.

A recent analysis compared multiple neonatal severity scores in a low birth weight infant cohort from 1994-1997.[39] None of the neonatal severity scores performed well, implying either deficiencies in their development, or advances in neonatology that have made them out of date. Most important, however, the analyses demonstrated that birth weight was still a very powerful outcome predictor if its predictive potential was accounted for with modern statistical techniques.

Pediatric ICU Mortality Prognostic Scores

Because fewer infants and children die than neonates, it has been more challenging to develop prognostic scores for older children. The two most commonly used severity of illness scores in pediatrics, the Pediatric Risk of Mortality (PRISM) and the Pediatric Index of Mortality (PIM), apply to critically ill and injured children from full-term newborns through adolescents. PRISM is now a third generation score (PRISM III) developed form over 11,000 patients in 32 PICUs.[40,41] It has recently been re-calibrated on over 20,000 patients.[42] Mortality predictions can be made either using the first 12 hours (PRISM III-12) or 24 hours (PRISM III-24) of physiologic variables, and descriptive and diagnostic data such as CPR status, operative status, and the presence of importance diagnoses such as cancer. PRISM III has been used for 4 national studies and is routinely used in over 50 PICUs nationally and internationally to evaluate quality of care as well as case-mix adjust administrative data.

The Pediatric Index of Mortality (PIM) was developed on 5,695 patients from only 7 Australian PICUs and one British PICU.[43] PIM was developed in response to theoretical concerns about lead-time bias, the concept that what precedes the time period of the severity score may create a bias that is not sufficiently accounted for in the severity models. Thus, models such as PRISM III, use data collected over the first 12 or 24 hours after admission, might be affected by pre-PICU management by influencing the amount of physiologic dysfunction. While this concern has no supporting data, it theoretically applies to all scoring systems. For example, the PIM score uses data collected in the emergency department and first hours of PICU care. However, there are at least 3-fold differences in time spent in emergency departments by patients, a potential lead-time bias because the time for stabilization may differ among health care facilities. Another potential lead-time bias for the PIM score involves the competency of the transport team. A recent study of PIM in the United Kingdom claimed adequate calibration, although statistical analysis was not reported.[44] Post hoc statistical analysis demonstrated poor calibration contrary to the authors' claim.

Other Pediatric Scores

In addition to ICU mortality scores, there are a plethora of scoring systems for specific diagnoses. The Glasgow Coma Scale (GCS) score[45] is an example of a score derived from expert opinion as opposed to statistical algorithms. Scores such as the GCS have maintained popularity, despite their only fair statistical performance (construct validity) because their simplicity appeals to users. One respiratory score may be inching its way into clinical use. A clinical croup severity score, after being validated for triage decision making and for measurement of clinical severity, was successfully used to evaluate and implement a critical pathway and to compare outcomes for different croup therapies.[46] Other scoring systems for pediatric asthma, pediatric respiratory failure, and meningococcemia have all been described but have not been consistently valid in external samples.[47-49] The

Pediatric Trauma Score is a widely used trauma score but its use has primarily focused on pre-hospital care and quality assessment.[50]

CLINICIANS AS PROGNOSTICATORS

In general, most clinical predictions by physicians are based on clinical intuition or subjective assessments of complex situations. Unfortunately, clinical intuition is fallible. Several studies have cast doubt on the ability of physicians to judge accurately the probability of a variety of clinically important outcomes based on subjective assessments.[51,52] When clinicians make predictions about complex situations on a subjective or intuitive basis, they are prone to personal biases and other problems associated with heuristics or "rules of thumb." For example, a " value" bias reflects influence by a patient's values (e.g,. social, political similarities) and a "reverse ego bias" reflects a physician's belief that his or her patients will do better than average.[53,54] Physicians often make intuitive judgements using the "availability heuristic" or the "representativeness heuristic." The "availability heuristic" has the weakness of judging the probability of an outcome according to how easily one remembers patients who had this outcome, a judgment process that is biased by both the physician's experience and the physician's recall. The "representativeness heuristic," refers to judging the probability of an outcome according to a patient's resemblance to a previous patient. The "representativeness heuristic" neither accounts for a suitable number of variables nor incorporates the spectrum of possible clinical outcomes.

Physicians' accuracy in estimating mortality risk for patients admitted to ICUs has been variable.[55-58] Generally, clinically experienced physicians perform better than less experienced physicians but there are even discrepancies between physicians of equal clinical experience.[59] Physician prediction performance may also depend upon the patient's disease or severity of illness.[60] Importantly, there are no data about how well physicians can predict the probability of survival for seriously ill patients at the time that triage decisions must be made, for example, when a patient presents to the emergency department. Certainly, the percentages of patients in pediatric and neonatal ICUs that receive only monitoring services is high, implying a lack of precision in estimating severity of illness and therapeutic needs.[61,62]

Single pediatric studies of the prediction performance of nurses and physicians are available for neonatal and pediatric ICUs. Stevens et al. evaluated the performance of physicians and nurses in 544 patients (21 deaths) in two neonatal ICUs.[63] Clinical estimates of severity of illness were done with a 5 point Likert scale from low risk to "virtually certain death, now or delayed." In general, mortality risk increased with increasing clinical estimates of severity of illness. While there was no statistical analysis of calibration, 40% of the physician predictions of "virtually certain death, now or delayed" and 33% of the RN predictions for the same outcome were in error. This tendency for health professionals to overestimate severity of illness was confirmed by comparing a sub-sample of clinical mortality risk estimates to those obtained from the SNAP score. Compared to the SNAP score, the clinicians overestimated mortality risk by 1.5-fold. Discrimination performance of both neonatal physicians and nurses was very good. The ROC for physicians was 0.85, and for nurses was 0.93, equivalent to the SNAP score of 0.94.

Only one study has evaluated the prediction performance of physicians at different experience levels and nurses in a PICU and compared the performance of these health care professionals with the same statistical methods used to evaluate prognostication scores.[64] In this study of 642 patients of whom 36 patients died, predictions were made after the first 10 hours and 24 hours of care by bedside nurses, residents, critical care fellows, and critical care attendings. Because predictions were made after 10 hours, "simple" patients with very short stays either because they were very healthy or obviously dying were excluded. Each health care professional provided estimated mortality risks from 0% to 100%. Agreement among care provider groups was measured with the kappa statistic. Prediction performance for each provider group was evaluated using similar performance criteria as described for quantitative methods. Discrimination was analyzed by the area under the receiver operating characteristic (ROC) curve. Calibration over the entire range of mortality risks was analyzed by the Hosmer-Lemeshow goodness of fit.

The results for the predictions after the first 10 hours are shown in Table B-1 and illustrate a surprisingly good comparison of clinical outcome prediction to quantitative outcome prediction. Discrimination was excellent for all groups as judged by the area under the ROC curve and it was best for attendings and worst for critical care fellows. The discrimination of attendings, residents and nurses approximated the discrimination of PRISM III, and was superior to PIM. These results differ sharply from the neonatal ICU study of Stevens et al. and probably indicate that there is a wide variability of the prediction performance of health care professionals among different institutions. It is also likely that in the study PICU, the same PICU where the PRISM III score was developed, more education and feedback in outcome prediction has taken place than in most ICUs, and this is reflected in the excellent prediction performance of the health care providers.

These data suggest that there is wide variability in the prognostication performance of physicians but that excellent performance is possible. Unfortunately, there are no training programs for physicians to specifically improve their prognostication performance. And personal habits of physicians do not generally emphasize prognostication "learning." For example,

TABLE B.1 Discrimination and Agreement of Health Care Providers

	AUC (SEM)	Kappa (95% confidence interval)
Attendings	0.934 (0.027)	0.565 (0.418, 0.711)
Fellows	0.858 (0.041)	0.495 (0.334, 0.655)
Residents	0.923 (0.033)	0.435 (0.273, 0.598)
Nurses	0.915 (0.034)	0.539 (0.411, 0.667)

AUC = Area under the Receiver Operating Characteristic Curve.
SEM = Standard Error of the Mean.

most physicians do not routinely record their prognostic impressions and then review them after the outcome is known. Therefore, they miss the opportunity to learn from their successes and their mistakes.

Calibration of predictions was good for attendings and fellows but statistically different than predicted for residents and nurses. Agreement as measured by the kappa statistic was *statistically* "good" for all groups (Table B.1); however, the measured kappa statistics indicated a level of disagreement that, if present in a high-risk group, would be sufficiently large to cast doubt on the reliability of the prediction to guide decisions about withdrawals and limitations of life sustaining medical interventions.

Table B.2 shows the sensitivity (correctly predicted deaths/total deaths), specificity (correctly predicted survivors/total survivors), false positives (incorrectly predicted deaths/total deaths), false negatives (incorrectly predicted survivors/total survivors), positive predictive value (correctly predicted deaths/total predicted deaths) and negative predictive value (correctly predicted survivors/total predicted survivors). In clinical scenarios of withdrawals and limitations of life-sustaining medical interventions, the false positives (incorrectly predicted deaths) are the most important error.

False positive error rates were very high. Even attendings, who were the best performing group, had a false positive error rate of over 25% compared to actual outcomes. Residents and nurses had false positive error rates over 45%. The best performance of health care professionals occurred at the highest and lowest mortality risk ranges while the worst prediction performance was in the intermediate ranges. That is, very healthy patients were very reliably predicted and patients easily perceived to be terminal were also reliably predicted. Weighting predictions by the certainty of the prediction (data not shown) improved the prediction performance slightly but not substantially enough to change the performance assessment.

Compared to the first 10 hours, predictions after the first 24 hours were not improved. This is consistent with the finding of others who also

TABLE B.2 Sensitivity, Specificity, False Positives, False Negatives, Positive Predictive Value (PPV) and Negative Predictive Value (NPV) of PICU Healthcare Providers

	Sensitivity	Specificity	False Positives	False Negatives	PPV	NPV
Attendings	48.7	98.9	26.9	3.1	73.1	96.9
Fellows	40.5	98.9	28.5	3.8	71.4	96.2
Residents	45.2	97.1	51.7	3.3	48.2	96.7
Nurses	61.9	96.1	46.9	2.7	53.1	97.3

Sensitivity = correctly predicted deaths/total deaths.
Specificity = correctly predicted survivors/total survivors.
False positives = incorrectly predicted deaths/total deaths.
False negatives = incorrectly predicted survivors/total survivors.
Positive predictive value = correctly predicted deaths/total predicted deaths.
Negative predictive value = correctly predicted survivors/total predicted survivors.

questioned the ability of clinicians to integrate dynamic, time-related data.[65] That is, physicians do not respond quickly to changes in clinical events and incorporate them into revised severity of illness assessments.

As noted earlier, the available studies indicate that physicians find giving prognostic information stressful and they often postpone prognostications until questioned by a patient or family member. One study surveyed internists and found that over 50% reported that they had received inadequate training in prognostication while less than 10% felt that training was deficient in training in diagnosis and therapy.[66] The stressfulness of making prognostic declarations was related to many factors. Physicians who reported inadequate training in prognosis were 60% more likely to find giving prognostic information "stressful" than physicians who rated their prognostication training as adequate. Prognostic certainty did not necessarily alleviate the stressfulness of process; the sense that physicians felt their colleagues would judge them harshly if they made an incorrect prediction was most important in this group. Stress with prognostication was not related to personal characteristics such as sex or years in practice.

Thus, there are important limitations in clinicians' abilities to make accurate and reliable mortality predictions based on either clinical judgment or statistical algorithms. This is especially true under triage situations early in the course of an illness when the clinical course and outcome are not sufficiently defined. Under these circumstances, clinicians, administrators, and policymakers should be very cautious about using mortality predictions to determine whether interventions such as CPR or mechanical ventilation are used or withheld.[67]

Can providers be educated to provide better predictions? Can individual physicians be identified who are better able to evaluate multi-dimensional, data intensive medical situations? This would be analogous to the way pilots are selected in part on their ability to make evaluations in similarly complex situations. No studies have investigated this potential.

At present, the odds are stacked against physicians performing as excellent prognosticators under situations of life and death. Medical schools and textbooks do not provide the appropriate training and information, for example, a grounding in concepts and relevant statistical tools. Physicians are not taught the appropriate skill sets to constantly record and evaluate their performance. For example, physicians do not routinely record their prognostications and review their performance, thus getting immediate and valuable feedback to be used to improve their abilities. They are sometimes rewarded for using heuristics when they are correct, but that is merely a statistical chance, not necessarily a validation of a heuristic. Remarkably, there are few if any reports of educational efforts to improve physicians' prognostication skills, even though it is central to physicians' ability to choose appropriate therapies for physiologic dysfunction as well as to counsel patients and families.

Families are often left with firm opinions by physicians without knowing how much faith to place in these predictions. They may give more credibility to the physician's prediction than is warranted. If proven wrong, their trust in their physician may be reduced. More importantly, when an active decision concerning withdrawals and limitations of care is needed, their trust (or lack of trust) in their physician's prognostic abilities may be misplaced.

UTILITY OF PROGNOSTICATION SCORES FOR INDIVIDUAL PATIENTS

Rationale

There has been an increased interest in the use of outcome prediction models in providing decision support for individual patients.[68-75] In general, these applications have focused on mortality prediction and on resource use for individual patients too healthy to benefit[76] or too sick to benefit[77-80] from intensive care services. Early identification of patients in the ICU for whom further curative, life-prolonging, or life-sustaining therapies are futile or very unlikely to be beneficial could help with difficult decisions, obviate undue patient suffering, and help to direct scarce resources to more cost effective uses.[81,82]

Most individuals and societies have cautiously approached the issue of quantitative prognostication for individual patients with such scores as

PRISM. Most recognize that individual clinicians have the responsibility and accountability for decision making. Prognostication scores can only add information, not dictate decisions, especially decisions regarding withdrawal or limitation of life-sustaining medical interventions. The mystique of a mathematical model developed from tens of thousands of patients cannot substitute for the intricacies of knowing an individual patient. And perhaps most important, the most relevant data, such as cognitive impairment or physical disability, may not be accurately predicted by such a model. It may be seductive to use the information that seems objective and is readily available, even if it is not quite the relevant information. For example, the Society of Critical Care Medicine's Ethics Committee has clearly warned that prognostication scores should be used with caution in individuals, emphasizing that probability of death is only one of the factors pertinent to decision making.[83]

In actuality, we know very little about how decisions are made in ICUs and how objective risk assessments using prognostication scores would serve decision making. Emanuel and Emanuel categorized four models of decision for adult patients that emphasize the roles and relationships among physician and patient dependency, expertise and power: parental model, informative model, interpretive model, and deliberative model.[84] We know little about the use and effectiveness of prognostication scores and methods in adult ICUs,[85] and we know even less about their utility in the context of the decision making models such as those delineated by Emanuel and Emanuel. Our understanding of decision making models in pediatric ICUs is even more limited than adult ICUs. The value of prognostication scores may range from very useful to destructive and their use will require a much better understanding of the of the kinds of decisions and the decision making process.

Studies of Utility in Individuals

Scoring systems may help identify "potentially ineffective care," or isolate patients admitted to the ICU with a negligible chance of survival in whom further care would not be beneficial.[86,87] The utility of objective prognostication scores will depend in large part on the size of the data base, the number of patients in relevant sub-samples, the confidence level or clinical certainty required by physicians for decision making, and the predicted clinical outcome range given the required certainty level, as well as the intended application.

Among pediatric measures, only the PRISM score has received in depth evaluation for use in individuals. One such evaluation demonstrated the problem in using outcome prediction scores to guide care of individual children.[88] First, the numbers of patients isolated by modern prognostication scores such as PRISM III for whom life-sustaining medical interventions are "futile" are very small. In a sample of 10,608 patients from 32 pediatric ICUs of whom 571 died, the observed survivors and sample sizes for the three highest PRISM III scores of PRISM III >28, PRISM III >35, and PRISM III >42 were 10/158, 3/57 and 0/21, respectively. *Thus, in a multi-institutional sample of over 10,000 patients, only one small group of 21 patients (0.19% of the sample) could be detected with zero survivors.* Even though the discrimination power of PRISM III-24 is equal to or better than any prognostication score, it did not isolate a large proportion of deaths in a patient group where all patients died (no false positives).

Second, there are significant unresolved issues of clinical certainty and outcome ranges when predictions for individual patients are based on statistical data. The statistical concepts of confidence intervals and confidence levels must be thoroughly understood in their relationship to the clinical concepts of survival ranges and clinical certainty if they are to help guide for individuals. In a statistical sense, if a model produces a survival prediction with an associated confidence interval calculated at a 95% confidence level, the accepted interpretation is that upon repeated sampling with the same sample size, 95% of the samples will contain the true survival mean within the samples' confidence limits. For most clinicians, this interpretation does not make practical sense. A typical clinician's interpretation of a 95% confidence interval is that there is a 95% chance that the true survival rate is within the stated confidence interval. Consequently, the confidence interval is interpreted as the estimated *clinical outcome range*, the range of actual outcomes estimated by past experience that has a *clinical certainty* of 95%. Thus, both the clinical survival range and the clinical certainty can be evaluated in a statistical sense by the confidence interval and the confidence level. For example, the statistical conclusion that the mortality rate and 95% confidence interval is 80% ± 5% has clinical interpretation of a clinical outcome range of 75% to 85% with 95% clinical certainty.

For individual patients, Marcin et al. asked the question, "What are the survival rates and associated survival ranges (confidence intervals) at different clinical certainty levels (confidence levels)?" for patients in very poor outcome groups noted above.[89] For any given sample size, the analytic preference for increased clinical certainty (higher confidence levels) will be traded off against wider clinical outcome ranges (wider confidence intervals). Conversely, a narrower outcome range (narrower confidence interval) potentially needed for decision making can only be obtained by *decreasing* the clinical certainty (decreasing the confidence level) of the prediction.

This issue was evaluated by calculating the confidence intervals (outcome ranges) at confidence levels (clinical certainty) of 70%, 80%, 90%, 95%, and 99%. Table B.3 illustrates the trading relationship between clini-

TABLE B.3 Maximum Survival Rates at Different Certainty Levels (Maximum survival rate is equal to the upper bound of the exact one-tailed confidence interval based on a binomial probability distribution.) The observed survival rates were 10/158 (6.3%), 3/57 (5.3%), and 0/21 (0%) for PRISM III-24 >28, >35, and >42, respectively.

Certainty level (%)	PRISM>28 (%)	PRISM>35 (%)	PRISM>42 (%)
70	7.9	8.2	5.6
80	8.5	9.5	7.4
90	9.6	11.3	10.4
95	10.5	13.0	13.3
99	12.3	16.6	19.7

cal certainty (confidence level) and survival ranges (confidence interval). For example, although there were no survivors with a PRISM score >42, predicting death with a clinical certainty of 99% (99% confidence interval) would result in a wide survival range of 0% to 19.7%, a very wide potential survival range for a sample with a measured survival of 0% and one with an upper limit of survival that would make clinicians very uncomfortable in withdrawing care. However, if the physician is willing to accept a clinical certainty (confidence level) of only 70%, then the survival probability range is much narrower and lower at 0% to 5.6%. It may seem paradoxical as the table shows that the outcome range is narrower at a certainty of 99% for the PRISM >28 (maximum survival rate of 12.3% versus 19.7%). This occurs because there are more patients in that sample with PRISM III >28 than in the sample with PRISM III scores >42.

Clinical futility, one of the situations in which prognostication scores have been envisioned for use, often requires finding sample or prediction groups where there are zero survivors. Yet, this example illustrates the difficulties in obtaining and evaluating samples or prediction groups where there are zero survivors. In the examples above, most parents and physicians would continue medical care despite the observation that no one had ever survived because there is a substantial statistical probably of survival. That is, in the example given above, there is almost a 1 in 5 chance that the true outcome will be survival if we require a 99% certainty of making that judgment.

Of course, there is a limit to the application of statistical logic to clinical decision making. In statistical analyses, the trade-off between confidence interval width and confidence level is clear. The analogy to the outcome ranges and clinical certainty, while close, is not always logical. For example, imagine trying to start cars that do not have batteries. If after turning the ignition 21 times and finding that none of the engines start, what is the outcome range and certainty level that the next car without a battery will start? Statistically this is identical to the outcome problem illustrated above. With a 99% clinical certainty, the chance of the next car starting could be as high as 19.7%. This, of course, is not the reality. The certainty of the outcome of the next attempt to start a battery-less car is quite clear, and the outcome range is very narrow. This example, which exploits substantial real-world experience, helps define the limits of clinical decision making with quantitative methods.

Some of the confusion concerning the use of prognostication scores for individuals comes from the potential application of prognostication scores to health policy or societal decisions. For example, should insurance coverage be refused for the use of a particular therapy for patients with certain medical characteristics associated with a very low likelihood of benefit? This question is very similar to the problem above, but the results are very different. For this perspective the authors queried the PRISM data base with the "same" question, but from a health policy perspective: "What is the maximum error rate of a health care policy which limits therapies for patients with PRISM III scores exceeding a very high threshold, and how do these maximums (based on confidence intervals or estimates of survival ranges) change as the confidence levels (as estimates of clinical certainty) change?"[89] In this case, the use of a score to guide rationing decisions at the collective level may have more utility because the perspective changes from an error rate for an individual patient to an error rate for *all survivors*. Since the number of all survivors is much larger, the error rate is much, much smaller. This is seen in Table B.4.

At a 95% confidence level (clinical certainty), the maximum error rate was 29 per 100,000 PICU survivors, an error rate of only 0.029% (Table B.4). Changes in the certainty level in this example produce relatively minor changes in the outcome range. Even for a 99% certainty level, the error rate rises only to 46 per 100,000, an error rate of 0.049%. From a health policy perspective, limiting certain interventions for all patients with a PRISM III-24 score of >42 might be viewed as having an acceptable error rate.

From the health policy perspective, the risks of making an error by limiting resources to all patients with a very high PRISM III score are relatively similar to many of the risks of daily living. For example, the risk of dying in an accident in the next year is 36 per 100,000, being murdered in the next 2 years is 20 per 100,000 of dying in a work related accident in the next year is 9 per 100,000.[90]

TABLE B.4 Maximum Error Rates at Different Certainty Levels if All Patients with a PRISM III-24 Score of >42 Were Discharged on Day 2 of PICU Care (Maximum error rate is equal to the upper bound of the exact one-tailed confidence interval based on a binomial probability distribution.)

Certainty level (%)	Maximum error rate
99	46 per 100,000
95	29 per 100,000
90	23 per 100,000
80	16 per 100,000
70	12 per 100,000

CONCLUSIONS: CAN PROGNOSTICATION SCORES BE OF SOME ASSISTANCE IN END-OF-LIFE CARE?

There are many obstacles in applying prognostication scores to end-of-life decision making. This manuscript has tried to examine the major issues based on the available pediatric data and the adult data that can be extrapolated to pediatrics. Extrapolation of adult data to pediatrics is especially uncertain because the decision making models and the ethical constructs may be very different.

Health care professionals need help in prognostication. First, end-of-life prognostication is stressful and physicians often avoid it. Most physicians believe they have had inadequate training and physicians do not routinely self-assess their predictions to improve. Second and most important, pediatric health care professionals make errors. Even in academic neonatal and pediatric ICUs where staff feels the most comfortable with end-of-life decisions and where experience is maximized because of the number of deaths, physicians and nurses make substantial errors in predicting death based on subjective judgment. The false positive rate for predicting death ranges from approximately 25% to 50% in sickest patient groups, clearly a worrisome error rate. This is reflected in the observation that many children in whom care is limited or withdrawn actually live. In a study of withdrawals and limitations of care in 16 PICUs, 7 of 83 patients who had care withdrawn or limited due to "imminent death" survived to hospital discharge. Of these, 5 had do not resuscitate orders, 1 had an additional limitation, and 1 had active withdrawal of care.[91]

Can prognostication scores help clinicians and families? Some families may be ready for better prognostication methods; almost 30% of families of children who died in 3 Boston PICUs after forgoing life-support felt that there was insufficient information concerning their child's chances for survival. Yet the chance of "getting better" was the second most important factor to families, with 78% rating it as very important.[92] While these data suggest that quantitative prognostication could be useful, there has not been a single convincing study that prognostication scores will help in the end-of-life process. And, experience suggests that physicians shy away from generating and using probabilistic data. For example, for adult patients, although objective methods of diagnosis of myocardial infarction have long been demonstrated to be superior to clinical judgment alone, physicians have never gravitated toward using the worksheets and doing the computations required for widespread use of such predictive instruments.[93]

Second, prognostic scores derive their strength from the statistical methodology used to develop and validate them. They are, however, subject to the same limitations as all statistical processes. And, as evaluated above with the concepts of certainty and outcome ranges, there is not always a clear clinical counterpart to the statistical concepts. The acceptance of prognostication scores by health care providers will require a greater understanding of the statistical concepts and how to apply them to clinical situations.

Third, it is not clear that prognostication scores will fit comfortably into physician-patient relationships. The relationship of patient and physician varies greatly depending on the characteristics of individual physicians and individual patients or families.[94] Patient values may range from fixed to changeable, from harmonious to conflicting. The physician's sense of his or her obligation may range from information giver to interpreter to persuader to advocate for the patient or family or both. The patient's sense of autonomy may be very strong to child-like and may change over time, for example, as an illness progresses. Similarly, patients' values regarding the use of life-sustaining care when illness is not far advanced may change as illness progresses. And, the patient-physician relationship may rapidly shift as the medical situation changes. For example, in an emergency situation, the relationship may be paternalistic when decision making is rapid without time for measured consideration of the therapeutic options and then may evolve into one that is more deliberate or informative as more time passes and the decision makers are able to discuss medical issues and get to know the patient's values.

Notwithstanding these cautions, physicians may find prognostication scores useful in some situations. Perhaps they can fit some physicians and patients by providing a measure of objectivity to decision making. Confirming an impression of a poor prognosis by using objective data and a prognostic score may provide help and reassurance to some clinicians.

Routine availability of prognostic information might, over time, somewhat modify the inclinations of some physicians to offer patients and families overly optimistic prognostic assessments that discourage adequate preparation for death. However, for some physicians, patients, and families, prognostication scores may be destructive. Particularly when the patient is a child, physicians or families may require a very high degree of certainty that there is "no hope." For those, a prognostic score will never provide this degree of certainty. A prognostication score actually might serve to legitimize the persistence with care giving because the statistics could offer "some hope" based on the statistical computations never reaching an absolute conclusion.

In any case, the effective use of prognostication scores will remain limited until huge data bases can be collected that have a sufficient number of patients who can be matched or approximately matched to the individual patient. We will need our largest collective experience to serve the individual in issues of life and death decision making. There are a variety of incentives for collecting these databases. They could be used for a variety of purposes including quality a care assessment, and numerous health services and outcomes studies. But their most exciting potential would be to provide a huge objective experience that could be distilled from hundreds of thousands patients and applied to the single individual.

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APPENDIX C

ASSESSING HEALTH-RELATED QUALITY OF LIFE IN END-OF-LIFE CARE FOR CHILDREN AND ADOLESCENTS

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INTRODUCTION

The assessment of health-related quality of life (HRQL) among children is an area that has seen considerable growth over the past decade. Whereas clinicians and researchers have previously decried the paucity of available HRQL screening or research instruments for use with pediatric populations (e.g., Bradlyn, Ritchey, Harris, Moore, O'Brien, Parsons, Patterson, and Pollock, 1996), there have been more recent calls for a moratorium on new instrument development (Feeny, Barr, Furlong, Hudson, and Mulhern, 1999). Generic and disease-specific HRQL instruments are routinely used in certain clinical situations and are now more commonly included as part of pediatric research protocols. However, these HRQL clinical screening or research instruments have not been fully applied in end-of-life care for children and adolescents; thus, their utility and validity in this phase of care are essentially unknown. This is in part related to uncertainty about whether or not the definitions and the instruments of pediatric HRQL that emanate from either healthy or chronically ill pediat-

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ric populations can adequately represent the HRQL of dying children and adolescents. Despite this uncertainty, certain aspects of the HRQL clinical and research work completed in healthy or chronically ill pediatric populations do have relevance to the HRQL of dying children and adolescents.

HRQL is a means by which clinicians and researchers can comprehensively describe the impact of a particular disease or treatment on an individual (or group of individuals), beyond that which is typically conveyed by examination of survival statistics. The purpose of this appendix is to examine the role of HRQL in assessing the impact of end-of-life care with children and to describe the means and methods by which that function may be accomplished. Additionally, in light of the relative novelty of this field of inquiry, we will highlight gaps in the current scientific literature.

Health-related quality of life measurement has emerged as an important focus in clinical trials, clinical practice improvement strategies, and health care services research and evaluation (Fayers and Machin, 2000; Varni, Seid, and Kurtin, 1999a). Although health status, functional status, and health-related quality of life (HRQL) are terms that have often been used interchangeably, a meta-analysis suggests that health status and functional status most commonly are used to refer to the physical functioning dimensions of the broader HRQL construct, while HRQL additionally includes the psychosocial dimensions of emotional, social, and role functioning, as well as related constructs (Smith, Avis, and Assmann, 1999). HRQL instruments must be multidimensional, consisting at the minimum of the physical, mental, and social health dimensions delineated by the World Health Organization (WHO, 1948). While the importance of measuring HRQL in palliative care is increasingly recognized in the adult literature (Paci, Miccinesi, Toscani et al., 2001) the strengths and limitations of HRQL measurement in pediatric palliative care have not been adequately investigated.

WHAT IS HEALTH-RELATED QUALITY OF LIFE?

Numerous definitions have been proposed by investigators; however, most have as their conceptual foundation the World Health Organization's (WHO's) definition of health as "a state of complete physical, mental, and social well-being; not merely the absence of disease" (WHO, 1948). In the adult literature, these dimensions have, at times, been supplemented with dimensions of patient satisfaction and spirituality (e.g., Cella, 1997). In the child literature, clinicians and researchers have noted the importance of considering children's development stage and family impact on quality of life as well. For example, the Children's Oncology Group has adopted the following definition of HRQL: "a multidimensional construct, incorporating both objective and subjective data, including (but not limited to) the social, physical, and emotional functioning of the child and, when indicated, his or her family. HRQL measurement must be sensitive to changes that occur throughout development" (Children's Oncology Group, 2000). Note that HRQL is often described as having both an objective component (e.g., "what were you able to do today?") and a subjective component reflecting patients' perceptions of their situation and abilities.

The definition that is given to HRQL does influence the measurement approach that will be used by investigators. For example, HRQL definitions may refer to an individual's satisfaction with his or her current level of functioning compared to an "ideal" (e.g., Cella and Cherin, 1988; Hinds, 1990; Vivier, Bernier, and Starfield, 1994), which would typically then require clinicians and researchers to assess satisfaction with current functioning on the one hand and ideal or desired functioning on the other. "Calman's gap" has been used to refer to the notion that HRQL is determined by the difference at a particular time between the hopes and expectations of an individual and that individual's current experience—to improve quality of life you must narrow the gap (Calman, 1984). The extent to which children can grasp the concept of comparing actual functioning to ideal functioning is not well understood however. This suggests that for young children in particular, this approach requires further investigation.

Other definitions of pediatric HRQL focus specifically on the impact of an illness or change in health on children or adolescents (Rosenbaum, Cadman, and Kirpalani, 1990), including any effect on their psychological status, social activity, physical symptoms, overall sense of well-being, or opportunity to have control over life choices (Bradlyn, Harris, Warner et al., 1993; Czyzewski, Mariotto, Bartholomew et al., 1994; Keith and Schalock, 1994). Definitions that reflect more psychological processes and states (e.g., Shumaker et al., 1990) typically rely on traditional psychometrically developed psychological measures of satisfaction and well-being.

WHAT IS HRQL IN END-OF-LIFE CARE, PARTICULARLY WITH CHILDREN?

HRQL is perhaps the ultimate outcome of interest in end-of-life care. When a child enters this phase, there is an implicit understanding that the *quantity* per se of that child's life is no longer the primary issue, but that the quality of the remaining time is the focus. Thus, the emphasis shifts when the child has been definitively diagnosed with a life-ending condition to one of the quality of the child's existence. The World Health Organization describes pediatric palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount." Further, the goal of palliative care is "the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient (WHO, 1998).

In a recently released policy paper on palliative care, the American Academy of Pediatrics (AAP) offered a more expansive definition that included an integration of curative treatment and palliation for children experiencing a life-shortening (but not immediately life-threatening) disease from the point of diagnosis forward (AAP, 2000). In adult literature about HRQL and palliative care, the concepts of spirituality, meaning, and life transitions are often included. Their frequent mention indicates that the subjective component of HRQL becomes a more primary focus in end-of-life care. Again, the extent to which this has been empirically studied in the pediatric literature is significantly limited. While acknowledging this limitation, we have chosen to adopt the AAP definition of palliative care as the basis for our comments here on pediatric HRQL and end-of-life care. This definition fits well with the unique aspects of many childhood illnesses (e.g., type, illness trajectory, response to treatment) and the evidence that children are generally treated more aggressively at end of life than are adults, perhaps without sufficient attention to the prevention and relief of distress and suffering.

Most definitions of palliative care emphasize the intent to alleviate disease- or treatment-related symptoms, but as noted by Doyle, Hanks, and MacDonald (1998), symptom alleviation is done to provide “the best quality of life for patients and their families.” Donnelly and Walsh (1996) note that palliative care patients are often multisymptomatic (median number of symptoms for adults is 11), with fatigue and lack of energy being most frequently reported; because of this, HRQL measures must be easy to complete.

Donnelly and Walsh (1996) argue further that HRQL questions need to be highly relevant to end of life and unambiguous in their meaning. Items regarding work and dating (for example) are inappropriate, and this and the overemphasis on the physical domain (rather than “poor” HRQL) may explain the low scores obtained by advanced cancer patients. They note that changes in HRQL need not parallel decline in physical ability and that for advanced cancer patients the frame of reference for evaluating HRQL changes and nonphysical issues emerge and become more important. These authors argue for global (as opposed to multidimensional) assessment—it is simpler and likely allows for increased compliance in those with poor stamina and allows the patient to define the construct.

Of course, short scales with more concrete descriptors do have the capability of being multidimensional. With children this may confer a benefit because we do not fully understand the limits of children’s ability to deal with the more abstract concept of “health-related quality of life.”

For the purpose of this appendix, we are defining pediatric HRQL at the end of life as a multidimensional concept, reflecting physical, emotional, and social functioning of the dying child and his or her family. Our definition emphasizes that clinicians and investigators must take into account and incorporate developmental progressions and family functioning and impact. Finally, pending further empirical investigation, issues that are typically identified as important in general end-of-life care—for example, spirituality and life meaning—should be included to the extent that they are demonstrated to be developmentally appropriate.

MODELS OF HEALTH-RELATED QUALITY OF LIFE FOR DYING CHILDREN AND ADOLESCENTS (CONCEPTUAL IMPLICATIONS)

In the past two decades, several models depicting health-related quality of life in children and adolescents experiencing chronic or serious illness have been proposed. Certain of these models are deduced from those developed with adults (Schipper, Clinch, and Powell, 1990), while others have been inductively derived from patient-specific pediatric groups (Hinds, 1990; Juniper, Guyatt, Feeny et al., 1996; Parsons and Brown, 1998; Testa and Lenderking, 1995). These models tend to reflect the domains of physical, emotional, and social health and the presence and intensity of symptoms; a few additionally reflect spirituality and family influence. Other models focus on the child's or adolescent's ability to function, presupposing that limitations in the abilities to complete role-related tasks or to achieve goals have a negative effect on HRQL (Barr, Furlong, Dawson et al., 1993; Feeny, Furlong, and Barr, 1998; Lansky, List, Lansky et al., 1987; Rosenbaum, Cadman, and Kirpalani, 1990). Yet other models have meaning of the illness experience as central to a child's or adolescent's HRQL (Haase and Rostad, 1994). The domains or components of these diverse models are not given differing weights, implying that the domains affect the child's or adolescent's HRQL equally or that our ability to identify meaningful weightings is not well developed at this time.

There are no published accounts of these HRQL models being applied to dying children and adolescents. This is somewhat surprising because HRQL is highly relevant in end-of-life care for children and adolescents. Determining a dying pediatric patient's HRQL could assist in diminishing patient and family acute suffering (such as that caused by unrelenting pain) as well as later suffering for the family survivors of the deceased child (such as that caused by regretting a treatment-related decision). Assessing the dying child's or adolescent's HRQL may also identify the patient or family who is at particular risk of a complicated end-of-life care situation that might be amenable to professional intervention. Additionally, maintaining a focus on the dying child's HRQL just as this was a focus during the child's earlier curative or life-sustaining care can reassure parents that their child will not receive any less care at this final stage of treatment.

Because HRQL has not been systematically studied in children and adolescents receiving end-of-life care, we do not fully understand the exact type and number of domains in a model of HRQL that would best represent this patient group. However, clinical reports and findings from a limited number of qualitative and descriptive studies suggest that an HRQL model applicable to children and adolescents needs to incorporate both child and family well-being, emphasize the presence and intensity of symptoms, and be sensitive to the duration and individuality of the dying process.

Dying children and adolescents express strong and at times urgent concerns for the well-being of their family members, clearly conveying that their family's HRQL is central to that of their own (Hinds, Oakes, Furman, 2001a; Hinds, Oakes, Furman et al., 2001b). It is hypothesized, then, that knowing their family's well-being is addressed contributes to a more positive HRQL for the dying child or adolescent. Likewise, the profound negative and life-changing effect on a family of a child member's dying and death has been repeatedly documented (Davies, Deveau, DeVeber, Howell et al., 1998; Gilliss, Moore, Martinson, 1997; Martinson, McClowry, Davies, Kuhlenkamp, 1994). Thus, it is reasonable to measure family members' HRQL in its own right.

Adolescents' descriptions of dying and those of parents of dying children convincingly convey the overwhelming ability of an intense and troubling symptom such as pain or nausea to diminish HRQL to unacceptable levels (Hinds, Bradshaw, Oakes, and Pritchard, in press). This latter report also suggests that domains in an HRQL model for dying pediatric patients do not have equal weight or influence. Although it is important to replicate this research, it may be that only one or a limited number of domains (i.e., symptom-related suffering) need to be assessed in critical end-of-life situations when the time and burden required for assessment are constrained. Models of HRQL for dying pediatric patients and their families may need to also reflect the influence of type of death and duration of illness if the death is illness related, parents' satisfaction with their ability to be "good parents" to their dying child, the ability of the family to maintain some degree of normalcy during the dying process, and the influence of family and child development and culture (Goh, Lum, Chan et al., 1999; Lantos, Berger, and Zucker, 1991; Rushton, 1994). Finally, clinical observations suggest that any model of HRQL for dying pediatric patients needs to reflect the fluidity of the dying process and the existence of a continual transition occurring for the patients, their family members, and their health care providers.

RECOMMENDED DOMAINS FOR HRQL IN END-OF-LIFE CARE

HRQL instruments typically reflect either a "generic" or a "disease-specific" approach to measurement. Generic instruments are appropriate for general population studies and for those situations in which disease- or treatment-related difficulties are not areas of primary interest. Disease-specific instruments are believed to contribute additional information that would not typically be collected via generic instruments, such as alopecia or lymphedema (in the case of cancer), or angina or shortness of breath (in the case of cardiovascular disease). While the relative merit of a generic versus a disease-specific approach to measuring HRQL is a matter of empirical inquiry (Patrick and Deyo, 1989), there are advantages to an integrated modular approach (Sprangers, Cull, Bjordal, Groenvold, and Aaronson, 1993; Varni, Seid, and Rode, 1999b). Disease-specific modules may enhance measurement sensitivity for health domains germane to a particular chronic health condition. A generic HRQL measurement instrument enables comparisons across pediatric populations and facilitates benchmarking with healthy populations but may not be sufficient in palliative care.

In addition to the generic physical, emotional, and social functioning domains delineated by the World Health Organization, the dimensions of role functioning and disease-specific symptoms are essential to include in the comprehensive measurement of HRQL in children, including ill children. Role functioning for children includes the ability to engage in the normal activities of daily living of childhood, which may be play, attending school, or participating in sports and recreational activities, depending on the age and developmental stage of the child. Disease-specific symptoms include pain, nausea, fatigue, and other effects of disease and treatment on child functioning.

Conceptually, disease-specific symptoms, which may be targeted for treatment intervention, are hypothesized to directly affect generic HRQL; that is, targeted symptoms are hypothesized to be causal indicators of HRQL. Thus, in structural equation terminology (Loehlin, 1998), disease- and treatment-related symptoms or problems are hypothesized to be causal indicators of the HRQL construct, while physical, emotional, social, and school (role) functioning are hypothesized to be effect indicators (Fayers and Hand, 1997). For example, in recent studies with the PedsQL (Pediatric Quality of Life Inventory), higher levels of pediatric cancer and rheumatology disease-specific symptoms were causal indicators of lower levels of the PedsQL 4.0 Generic Core Scales (Physical, Emotional, Social, and School Functioning) (Varni, Seid, and Kurtin, 2001), which are the effect indicators of generic HRQL (Varni, Burwinkle, Katz, Meeske, and Dickinson, 2002a; Varni, Seid, Smith, Burwinkle, Brown, and Szer, 2002c). For instance, higher levels of pain and fatigue were associated with lower levels of generic HRQL (Varni, Burwinkle, Katz, Meeske, and Dickinson, 2002a; Varni, Seid, Smith, Burwinkle, Brown, and Szer, 2002c).

These findings provide empirical support for the conceptualization that disease-specific symptoms are predictive of generic HRQL and may have implications for treatments designed to enhance HRQL in pediatric palliative care. Stronger causal evidence would result from a treatment intervention study in which an intervention tailored to target specific symptoms such as pain or fatigue results in decreased symptoms and subsequently higher generic HRQL. However, the selection of HRQL measures for an intervention must include those measures that have demonstrated responsiveness to change and, ideally, have been shown to have an impact on clinical decision-making (Varni, Seid, Knight, Uzark, and Szer, 2002b).

The following briefly delineates specific generic and disease-specific domains and symptoms that encompass the broader construct of health-related quality of life within pediatric palliative care based on findings from the pediatric and adult palliative care literature. Although many of the domains are consistent with existing conceptualizations of HRQL in general, the items that make up the scales measuring the domains may differ to some degree in palliative care or may differ at different points in the end-of-life trajectory (Stewart, Teno, Patrick, and Lynn, 1999).

Physical functioning includes general ambulation and mobility, such as walking and running, as well as the ability to engage independently in the normal daily activities of childhood, such as sports and recreation, bathing, chores, self-care, and other physical tasks appropriate for age. *Emotional functioning* includes varying levels or intensity of depression, anxiety, anger, and worry. *Social functioning* includes interactions with friends, classmates, peers, and family members including siblings. *School functioning* involves the work of childhood and includes the ability to attend school, to concentrate at school, to remember what was presented in class, and to engage in homework and other school assignments. If the child is not able to attend school, it includes the ability to engage in school-related academic assignments such as take-home assignments and homework.

Fatigue is a multidimensional construct, and includes general fatigue (e.g., feeling too tired to start or finish things), sleep–rest fatigue (e.g., sleeping and resting a lot), and cognitive fatigue (e.g., hard to think quickly or problems with remembering). Fatigue was the most frequently reported symptom in a study of children with cancer at the end of life (Wolfe, Grier, Klar et al., 2000). *Pain* includes intensity (e.g., mild, moderate, severe), location (e.g., head, stomach), and the qualitative aspects of pain (e.g., sharp, pressing, horrible). *Nausea* includes sensations associated with treatments such as chemotherapy and may result in food not tasting appealing or in lack of appetite. *Dyspnea* or shortness of breath can be one of the more troubling symptoms in palliative care. *Constipation* can be associated with medications and the lack of activity. *Cognitive functioning* includes paying attention, problem solving, and remembering past and current events. *Procedural anxiety* is associated with medical procedures that are perceived as painful or threatening.

Other suggested domains include *communication* with physicians, nurses, and other health care professionals about feelings, questions, or health concerns important not only for parents, but also for children. *Spirituality* includes a belief system in which one attempts to understand the meaning and purpose of life and one's relationship to a higher power or to God. Spirituality may also be conceived as a coping strategy rather than an HRQL domain. For example, praying to God to make the pain and hurt go away may be conceived as a coping strategy (Varni, Waldron, Gragg, Rapoff, Bernstein, Lindsley, and Newcomb, 1996). However conceptualized, spirituality is considered an important construct in palliative care in adults. Whether and how to measure spirituality in pediatrics and how old children must be in order to assess their spirituality beliefs remain to be empirically determined.

Adult Versus Child HRQL Domains

The aforementioned HRQL domains and symptoms represent many of the dimensions that have been delineated in the adult palliative care literature and most from the pediatric palliative care literature (Richards and Ramirez, 1997; Stewart, Teno, Patrick, and Lynn, 1999; Wolfe, Grier, Klar et al., 2000). Not included were domains found in the adult palliative care literature that did not appear applicable to pediatrics, given issues of cognitive developmental stage concerns in children (Thompson and Varni, 1986). For instance, while the importance of the "existential" domain has been demonstrated in adult palliative care (Cohen, Mount, Bruera, Provost, Rowe, and Tong, 1997), the construct requires cognitive development that may be beyond most children.

Table C.1 provides an overview of representative child and adolescent HRQL instruments, with information regarding specific domain content. It can be seen that while most instruments include multidimensional assessment of physical, emotional, and social functioning, some of the "traditional" dimensions assessed in adult palliative care (e.g., spirituality, meaning of life) are generally absent.

Tailoring Assessment to Disease and Disease Trajectory

Particular HRQL domains may be more germane at specific points on the trajectory in the child's life-ending condition. Given the wide variation in both the problems encountered and the HRQL outcomes among pediatric patients during palliative care, computer-assisted tailored assessment may be helpful during different stages of the child's life-ending condition. For instance, earlier in the child's trajectory, peer social interactions and schooling functioning may be important dimensions to measure. However, later in the child's trajectory, pain, fatigue, and cognitive functioning may emerge as more relevant for that stage in the child's illness. Tailoring HRQL assessments may facilitate the individualizing of treatment strategies to maximize efficacy across multiple HRQL domains.

HRQL in children has been assessed in a variety of settings and diseases, including asthma, diabetes, and oncology. However, similar to the history of HRQL with adults, many of the advances have occurred within the framework of pediatric oncology, in particular. In fact, many of the instruments used with both adults and children were developed in the oncology clinical trials setting. It has been noted, however, that because the goals of palliative care are more diverse than those for treating a malignancy, the dimensions included in HRQL in this setting must be broadened beyond physical, emotional, and social well-being (cf., Richards and Ramirez, 1997). Salmon, Manzi, and Valori (1996) posit that a number of factors support the notion that in the face of death, individuals change the criteria by which they evaluate their lives. Questionnaires typically used to assess HRQL of people with poor prognoses are primarily symptom based and do not reflect factors that become important when confronted by a fatal illness (such as the meaning of life and the degree to which life has become enriched by the illness) and therefore are less useful. The extent to which children are able to understand enrichment and the meaning of life is not well understood however.

USES OF HRQL

Richards and Ramirez (1997) identify several potential uses of HRQL information, including (1) clinical management—quantifying symptom severity and functional capacity can enhance the clinical care given to the patient; (2) clinical audit—estimations of the prevalence and severity of specific problems can be accomplished by aggregating patient data, which can then be used to help evaluate the outcomes of an intervention or policy; (3) clinical research—if optimizing HRQL is the goal of palliative care, then HRQL needs to be a primary end point in evaluating new treatments or approaches; and (4) resource allocation—limited resources make it essential that the cost-effectiveness of palliative care be measured and HRQL data provide the means by which treatment impact can be quantified.

In a 1997 Institute of Medicine (IOM) workshop (Teno et al., 1999), four applications of HRQL were noted: (1) clinical assessment, (2) quality improvement, (3) accountability, and (4) research. Each application carries

TABLE C.1 Representative Pediatric HRQL Instruments

Instrument	Type	Domains	Number of Items
Child Health Questionnaire (CHQ-PF50)	Generic	14 domains: physical, role—social–emotional, role—social–behavioral, role—social–physical, bodily pain, general behavior, mental health, self-esteem, general health perceptions, change in health, parental impact—emotional, parental impact—time, family activities, family cohesion	50
Child Health Questionnaire (CHQ-CF87)	Generic	12 domains: physical, role—social–emotional, role—social–behavioral, role—social–physical, bodily pain, general behavior, mental health, self-esteem, general health perceptions, change in health, family activities, family cohesion	87
PedsQL 4.0 Generic Core	Generic	4 domains: physical, emotional, social, school	23
Health Utilities Index (HUI Mark 2)	Utility	9 domains: sensation, hearing, speech, mobility, self-care, emotion, cognition, pain, fertility	N/A
Health Utilities Index (HUI Mark 3)	Utility	6 domains: vision, ambulation, dexterity, emotion, cognition, pain	N/A
Child Health and Illness Profile (CHIP)	Generic	6 domains: activity, comfort, satisfaction, disorders, achievement, resilience	219
Pediatric Oncology Quality of Life Scale	Cancer-specific	3 domains: physical, emotional, treatment-related adjustment	21
PedsQL 3.0 Cancer Module	Cancer-specific	8 domains: pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, communication	27
Diabetes Quality of Life	Diabetes-specific	4 domains: satisfaction with treatment, impact of treatment, worry about future effects, worry about social or vocational issues	62
Diabetes Quality of Life for Youth	Diabetes-specific	3 domains: disease impact, disease worry, life satisfaction	53

	Number of Items	Age Range (years)	Administration Mode	Reference
social– vioral, pain, lth, rceptions, pact— time, sion	50	5–18	Parent proxy report questionnaire, mail or interview	Landgraf et al., 1996
social– vioral, pain, lth, rceptions, vities,	87	10–18	Child self-report questionnaire, mail or interview	Landgraf et al., 1996
al, social,	23	2–18	Child self-report (5–18) and parent proxy questionnaire (2–18)	Varni, Seid, and Kurtin, 2001
g, speech, cognition,	N/A			
n, , pain	N/A			
vement,	219	11–17	Child self-report questionnaire	Starfield and Riley, 1998
al,	21	4–18	Parent proxy report questionnaire	Goodwin et al., 1994
usea, t anxiety, erceived nication	27	2–18	Child self-report (5–18) and parent proxy questionnaire (2–18)	Varni, Katz, Seid et al., 1998
treatment, bout future r vocational	62	Teen–adult	Self-report questionnaire	DCCT, 1988
isease	53	11–18	Self-report questionnaire	Ingersoll and Marrero, 1990

with it a set of assumptions, which may or may not overlap with other applications. For example, quality improvement instruments typically reflect measures of process, while accountability focuses on outcomes.

IMPACT ON CLINICAL DECISION-MAKING

Measuring the quality of care at the end of life may help identify areas of care in which improvement efforts may be directed (Fowler, Coppola, and Teno, 1999). Quality-of-care measures may also be correlated with health-related quality-of-life measures (Seid, Varni, Bermudez et al., 2001). However, an alternative and potentially more direct approach to linking quality of care and HRQL is to investigate the impact of HRQL measurement on clinical decision-making. For example, how is clinical practice impacted by having these data available to health care providers?

The impact of a pediatric HRQL measurement instrument on clinical decision-making can be tested under the working hypothesis that HRQL measurement must occur at the point of service for each individual patient in order to improve health care outcomes (Wetzler, 2000). In pediatric primary care, point-of-service computer-based immunization tracking has been advocated to improve immunization rates (Adams, Conners, Mann, and Palfrey, 2000). In adult primary care, computer-generated feedback of HRQL screening findings, accompanied by problem-specific resource and management suggestions, resulted in subsequent improvements in patient mental health functioning (Rubenstein, McCoy, Cope et al., 1995).

In the absence of standardized HRQL screening information, primary care physicians often fail to recognize problems in patients' HRQL (Calkins, Rubenstein, Cleary et al., 1991). However, previous research with adult patients demonstrated that simply providing primary care physicians with HRQL screening information without specific resource and management suggestions was not sufficient to change either health care provider behavior or patient HRQL outcomes (Rubenstein, Calkins, Young et al., 1989). Thus, a standardized HRQL screening instrument appears to be a necessary but not sufficient condition for enhancing patients' health-related quality of life.

In a study with the PedsQL, families were given the PedsQL as they entered a Children's Hospital specialty clinic (Varni, Seid, Knight, Uzark, and Szer, 2002b). The completed PedsQL instruments were then either placed in the patient's chart or given directly to the pediatric specialist by the family. The pediatrician first went through his or her usual procedures, asking questions about the interim history before examining the child. The pediatrician then asked, "Is there anything else I should know before I look at the PedsQL?" At that point, the pediatrician scanned the completed instruments for "3s" ("often") and "4s" (almost always"), asked about those items and either dealt with them during the clinic visit (with reassurance, confirmation of the problem being true for many other children, acknowledgment of how hard it is, and other simple explanations) or made a recommendation for an intervention. Interventions included having a social worker call the family, making a referral to a counselor, facilitating school accommodations, prescribing problem-specific pharmacological agents, referral to physical therapy, or referral to another member of the multidisciplinary team. Thus, the pediatrician had knowledge of and access to multiple resources and management strategies that are major components of multidisciplinary team care for many pediatric chronic health conditions.

In pediatric palliative care settings, it would be anticipated that a resource referral and management guide might further facilitate the process if the care was not provided in a multidisciplinary setting. Screening for problems in patient-perceived HRQL may also facilitate shared clinical decision-making (Higginson and Carr, 2001). When HRQL measurement instrument scores are available at the point of service, patient and parent perceptions of the child's physical and psychosocial health can inform clinical decisions by the health care provider (Varni, Seid, Knight, Uzark, and Szer, 2002b).

ILLUSTRATIVE MEASURES OF ADULT END-OF-LIFE HRQL

There are a number of HRQL instruments that have been investigated specifically for adults in end-of-life care. We have included a brief overview of several such instruments to illustrate the range of domains assessed and to provide specific examples of the more subjective domains (e.g., meaningfulness) that have gained acceptance in the care of adults.

McGill Quality of Life Questionnaire (Cohen, Mount, Strobel, and Bui, 1995). The McGill Quality of Life Questionnaire is comprised of four, factor-derived subscales: physical symptoms, psychological symptoms, outlook on life, and meaningful existence. The authors note that the McGill is remarkable for several reasons, including the fact that the existential domain is explicitly assessed, that positive contributions to HRQL are measured, and that the scale does not overly emphasize physical functioning and status. The importance of measuring the existential domain was supported by Cohen, Mount, Bruera, Provost, Rowe, and Tong (1997) who reported that the meaningful existence subscale correlated significantly with a single-item rating of overall quality of life. A recent comparison of the McGill to other HRQL instruments in an outpatient palliative care setting reported that patients preferred the McGill because of its comprehensiveness and that the physical symptom and support information gathered by the McGill was a relative strength (Pratheepawanit, Salek, and Finlay, 1999).

McMaster Quality of Life Scale (Sterkenburg, King, Woodward, 1996). The McMaster Quality of Life Scale (MQLS) is a multidimensional scale assessing physical, emotional, social, and spiritual domains. It is comprised of 32 items regarding physical symptoms, functional status, social functioning, emotional status, cognition, sleep and rest, energy and vitality, general life satisfaction, and meaning of life. There is a parallel proxy form to be completed by family and staff; the rating scale includes a "cannot tell" response for proxies and a "does not apply," which can be used for symptoms that may not be relevant for certain patients. Responses to the MQLS are based on a 24-hour time interval to best capture acute changes. The authors report that the scale was reliable and valid with adult palliative care patients, with acceptable intra- and interrater reliability and internal consistency. The mode of administration was found to be important—patients who completed the scale verbally rated their HRQL lower than those who were able to complete it in written format. The scale was found to be sensitive to change and not influenced by age or sex. Although proxy ratings were correlated, systematic differences were found, and the authors recommend that proxy ratings be avoided whenever possible.

Missoula-VITAS Quality of Life Index (Byock and Merriman, 1998). This scale is also focused on an individual's end of life. This 25-item scale is constructed in a manner that allows respondents to differentially weight each dimension and to interpret the items according to their own experiences. The authors report appropriate internal consistency findings and note that total scores correlated with patient-provided global HRQL ratings and another HRQL instrument, although not with observer-rated functional status.

Although the information presented above is representative of investigations with adults only, there are several potentially important factors to consider in future research with children and adolescents. As we have noted throughout this discussion, the extent to which children and adolescents perceive existential and highly abstract domains (such as meaningfulness and spirituality) to be important at this stage of life is largely unknown. While it makes intuitive sense that these domains might have substantial merit among this group of patients, we do not have a good understanding of how to describe and measure them, whether in fact patients describe them as important, or the relationship of these factors to cognitive development.

The adult literature also provides continued demonstration of the difficulties associated with the use of proxy informants. The discrepancy among different proxy informants, as well as the apparent differences between patient and proxy information, underscores the importance of treating these data with caution.

THE HEALTH-RELATED QUALITY OF LIFE OF FAMILIES

This is a potentially significant, but poorly understood, area of inquiry. While we have noted the impact of caring for a dying child on the HRQL of parents and siblings, these investigations are generally at the level of the individual and not at the level of the family as a unit. A review of the existing literature does not reveal any instruments that adequately assess the core dimensions of HRQL as outlined above (i.e., physical, emotional, and social well-being). However, there are instruments that assess family functioning, and one or more of the core HRQL dimensions, to at least some extent. For example, the Quality of Life Index (McCubbin, Olson, Lavee, and Patterson, 1985) assesses the family's overall feeling of satisfaction along a number of dimensions, including schools, health care, and relatives. The Impact on Family Scale assesses the financial burden, social restriction, personal strain, and coping strategies of parents (Stein and Reissman, 1980). However, further investigation is necessary to fully develop a conceptualization and working definition of "family health-related quality of life" as opposed to the more generic concept of "family quality of life."

ISSUES IN THE ASSESSMENT OF PEDIATRIC HRQL AT END OF LIFE

In selecting (or developing) HRQL instruments for pediatric palliative care, an important explicit goal should be to identify (or develop and test) brief measures for the broadest age group empirically feasible, specifically including child self-report for the youngest children possible. Thus, the measures selected to assess HRQL in pediatric palliative care should emphasize the child's perceptions, including the youngest children empirically possible. It is very important that the items chosen for inclusion be initially derived from the measurement properties of the child self-report scales, while the parent proxy report scales should be constructed to directly parallel the child self-report items. This approach helps ensure that the voices of children are heard in matters relating to their HRQL.

Although it is likely that children and adolescents will have different concerns related to their HRQL, the instruments selected should reflect those items that are of universal concern across age groups. Attempts to keep the wording, and thus the content, of items as similar as possible across parallel forms, while being sensitive to developmental differences in cognitive ability, facilitate the evaluation of differences in HRQL across and between age groups, as well as the tracking of HRQL longitudinally.

There are several palliative care situations that should be identified as presenting particular challenges to the assessment of HRQL and many of the issues raised throughout this appendix. Specifically, assessment of neonates, particularly those in the intensive care setting, is an uncharted area of HRQL. Given that the child is clearly unable to serve as a respondent to typical HRQL measures, investigators and clinicians must address the systematic incorporation and applicability of symptom-based scales (e.g., pain observations) and caregiver proxies as critical sources of information to best understand the infant's HRQL.

An additional situation that has received little attention is that of the acute, immediately life-threatening injury (e.g., motor vehicle accident). This situation is particularly problematic in light of the short and immediate time frame for action, the lack of any prior contact and longitudinal understanding of the patient's preferences, and in some instances, the unavailability of a qualified proxy (such as the parents), to provide a historical context to understanding the patient.

Respondent-Related Issues (Child and Family)

Developmental Issues

The cognitive capacity to understand death is generally accepted to be age related (e.g., Stuber and Bursch, 2000). In addition, fears and concerns regarding death are also related to an individual's level of development, with younger children being primarily concerned about separation from the parent(s) and pain, while older children and adolescents struggle with restrictions imposed because of illness and isolation from peers and more philosophical concerns. Issues regarding the loss of previously acquired independence and control over their situation are especially noteworthy for adolescents. The evolving and age-related nature of these issues presents particular conceptual challenges to assessment with these children and adolescents. As we have noted, the extent to which we understand the role of the more subjective HRQL dimensions such as meaningfulness and spirituality for children and adolescents is significantly limited and in need of further investigation.

The serial measurement of HRQL in children in general is methodologically challenging due to a variety of developmental and instrument-specific factors. In contrast to adult instruments where one instrument may be appropriate for individuals from 18 years of age to the elderly, there is no omnibus instrument for children and adolescents. In fact, there may be as many as three or four versions of the same instrument to use for children as they mature (see, for example, the PedsQL). Although crossing these different age thresholds may not be a particular problem in end-of-life care (in that the life expectancy of the child at that point is relatively short), this does create design and analytic problems when investigators attempt to examine the effects of a particular program, for example, that has been applied across a wide range of children and adolescents and therefore includes different measures of the same construct.

Setting and the Role of Parental, Sibling, and/or Caregiver HRQL

HRQL does not exist individually and in a vacuum. Particularly with children, it is likely to affect and be affected by parental and sibling functioning as well.

The setting in which the dying child is cared for has been demonstrated to impact parent and sibling adjustment following the death. For example, parents who cared for the child at home have been described as less anxious and depressed than those who chose hospital-based care (Lauer, Mulhern, Schell et al., 1989; Lauer, Mulhern, Wallskog et al., 1983; Mulhern, Lauer, Hoffman, 1993). From the adult literature, we know that family members who provide care in a palliative setting report significantly lower quality-of-life and physical health scores, compared to those caring for patients who were receiving curative therapy. In addition, patient performance status is strongly related to the caregivers' quality of life—those family members caring for patients with the most impaired performance status were reported to experience lower quality of life. Some argue that "complete and proper" care of the patient therefore must include attention to family members as well (Weitzner, McMillan, Jacobsen, 1999).

Instrument and Technical Issues

Proxy Assessment

Pediatric HRQL measurement instruments must be sensitive to cognitive development and include child self-report and parent proxy report to reflect their potentially unique perspectives. Imperfect agreement between self- and proxy report, termed cross-informant variance (Varni, Katz, Colegrove, and Dolgin, 1995), has been consistently documented in the HRQL assessment of children with chronic health conditions (Czyzewski, Mariotto, Bartholomew, LeCompte, and Sockrider, 1994; Guyatt, Juniper, Griffith, Feeny, and Ferry, 1997; Langeveld, Koot, Loonen, Hazebroek-Kampschreur, and Passchier, 1996; Varni and Setoguchi, 1992; Varni, Katz, Seid, Quiggins, Friedman-Bender, and Castro, 1998), healthy children

(Achenbach, McConaughy, and Howell, 1987) and adults in palliative care units (Brunelli, Constantini, Di Giulio et al., 1998).

The demonstration of cross-informant variance indicates an essential need in pediatric HRQL measurement for reliable and valid child self-report instruments for the broadest age range possible, given the general acceptance that HRQL derives from an individual's perceptions. However, while self-report is considered the standard for measuring perceived HRQL, it is typically parents' perceptions of their children's HRQL that influences health care utilization (Varni and Setoguchi, 1992; Jankicke, Finney, and Riley, 2001). Thus, the imperfect agreement observed between self-report and proxy report supports the need to measure the perspectives of both the child and the parent in evaluating pediatric HRQL since these perspectives may be independently related to health care utilization, risk factors, and quality of care (Seid, Varni, Bermudez et al., 2001). However, in pediatric palliative care there may be circumstances when the child is too ill or fatigued to complete an HRQL instrument. In those cases, parent proxy report is acceptable with measurement instruments that have been demonstrated to show a significant correlation between child and parent report. For instance, the PedsQL has demonstrated a correlation of 0.56 for the total score of the Generic Core Scales (physical, emotional, social, school functioning) between parents and pediatric cancer patients, and correlations between 0.30 and 0.50 for symptoms such as fatigue, pain, and nausea on the Multidimensional Fatigue Scale and Cancer Module (Varni, Burwinkle, Katz, Meeske, and Dickinson, 2002a). Thus, although parent proxy report is less than ideal when used alone, it can serve as a reasonable approximation of child HRQL in circumstances in which child self-report is neither possible nor feasible.

A number of investigations with adults illustrate the difficulties with proxy informants for HRQL. For example, Stephens, Hopwood, Girling, and Machin (1997) examined more than 700 patients and ratings on the Rotterdam Symptom Checklist completed by patients and physicians. There was complete agreement between the two raters (4-point severity scales) in 78 percent of the cases, 18 percent disagreed by one, 4 percent by two, and 1 percent disagreed by three rating levels. The authors reported no change in levels of agreement over time but increasing disagreement with increasing symptom severity, as well as a consistent bias toward doctors' underestimating severity. However, the two methods of collection resulted in similar between-treatment conclusions. Stephens et al. (1997) concluded that in randomized trials, doctors' assessment of key physical symptoms may be sufficient for making between-treatment comparisons. However, the fact that doctors underestimate symptom severity 15 percent of the time underscores the level of caution that must be used in interpreting these data in palliative interventions.

Published reviews of hospital records further document the underreporting of problem areas by the physician. For example, Stromgren and her colleagues (2001) found that pain complaints evidenced the most agreement between adult patient reports and medical record information, but that other symptoms (e.g., psychosocial problems) were reported more often by patients than by their physicians. The authors appropriately suggest that systematic use of questionnaires or other standardized methods may be useful in improving the identification and recognition of symptoms by the physician.

An interesting finding, albeit with adult patients, was reported by Brunelli et al. (1998) regarding proxy agreement. Nurses or physicians caring for the patient completed the Therapy Impact Questionnaire at the same visit that it was completed by patients. The authors report that agreement for physical symptoms was higher than that for psychological or cognitive symptoms and that there was better agreement on the absence (as opposed to presence) of symptoms. None of the sociodemographic data were related to the agreement findings.

Respondent Burden

The impact on the informant of completing the questionnaires (in terms of time, difficulty, and/or distress) is an issue that anecdotally at least, is important. In the acute or long-term care setting, our experiences have been that institutional review boards, in particular, are sensitive to this issue out of concern for protecting the patient (subject) and his or her parents from unnecessary upset or intrusion. In end-of-life care, this is of particular concern, especially given the widespread prevalence of fatigue and pain. There are data to suggest that at least in terms of parent informant measures, parents of chronically ill children do not perceive typical HRQL instruments to be either burdensome or distressing (Harris et al., 1994).

Understandably so, concern exists among health care providers and researchers themselves regarding the potential risks that dying pediatric patients and their families could be exposed to by participating in end-of-life studies. Time and energy to participate are accurately viewed as potential burdens for the patients and their family members. Studies that focus on patients' perceptions of dying could also be considered to be potentially harmful if the topic itself or the study methods cause emotional or cognitive discomfort for the patient. Compounding these concerns is the additional worry expressed by some providers that dying patients and their parents do not have real freedom to decline study participation if they believe that they will receive better care by enrolling in the study or that they risk offending providers important to their child's care if they do not participate. Two important findings from recently completed end-of-life studies on decisionmaking address certain of these concerns. First, 29.8 percent of eligible parents actively (*n* = 6, or 35.3 percent) or passively (*n* = 11, or 64.7 percent) declined participation in the study when asked face-to-face by a study investigator (Hinds, Oakes, Quargnenti et al., 1998). This figure suggests that parents did feel they could decline to participate. Second, all parents who participated in one of the three end-of-life decision-making studies were contacted by a member of the study team who asked the parent to identify (1) what was good about being in the study and (2) what was bad about being in the study. Of the more than 100 parents who participated, only two responded that "nothing was good about being in the study" and both added "but there was nothing bad about being in the study, either." Other parents commented on the unexpected benefits of participating, commenting in particular on the value of being able to describe their reasons for their decisions out loud to a neutral person (the researcher) and feel listened to and respected. Thus, for those parents who chose to participate (and that was less than 70 percent of all eligible), the outcomes were personally beneficial.

A recent investigation with adults (Jordhoy, Kaasa, Fayers, Ovreness, Underland, and Ahlner-Elmqvist, 1999) assesses the issue of compliance with lengthy, multi-item questionnaires. These authors reported that compliance was good up until one month prior to death but that in the final weeks it dropped substantially. Jordhoy et al. (1999) suggested that these relatively longer multi-item instruments should be replaced by simpler methods in the final weeks.

Time Frame

The interval used for reporting is important to consider as well. HRQL instruments currently used with children use an interval ranging from approximately seven days (e.g., PedsQL Acute Version) to one month (Child Health Questionnaire). Adult HRQL instruments ask informants to report on an interval ranging from one day (McMaster Quality of Life Scale) to one week (Functional Assessment of Cancer Therapy). Instruments assessing patient symptoms, such as the Symptom Distress Scale (McCorkle and Young, 1978) often use a brief time frame, such as one day. Because of the dynamic nature of health and symptoms during palliative care, brief time frames are typically appropriate in order to capture the evolving range of symptoms and disease impact.

Attrition

In interpreting research findings, an important issue from an analytic perspective has to do with the loss of HRQL data through subject attrition.

This attrition can occur because of death or because the patient is impaired to such a degree that he or she is unable to complete the required assessments. Data loss is, in general, a critical issue in all HRQL research, particularly because it is necessary that health states such as death be accounted for in the analysis. Failure to adequately account for subjects who have died may have the unintended effect of making an intervention appear to be more effective than it actually is: for example, a larger number of patients may die sooner in one group, but those who continue to survive report relatively higher HRQL than the total surviving population in the other group. By their very nature, preference or utility approaches to HRQL, such as the Health Utilities Index and the Quality of Well-Being Scale, take into account death as a health state by assigning it a value of zero. A number of statistical procedures have been recommended to account for missing data (e.g., Fayers and Machin, 2000; Zwinderman, 1992) and should be consulted during the analysis planning phase.

BARRIERS TO STANDARDIZED HRQL MEASUREMENT

Using standardized instruments to measure the HRQL of children in palliative care may meet with some resistance by clinicians who feel that the completion of these measures represents too great a burden for very ill children and their parents. Oftentimes, a more qualitative approach is sought with the belief that such methods are less burdensome and intrusive than standardized quantitative methods. While understandable, similar concerns have been seen in the past in regards to pain assessment in children and HRQL measurement in children with newly diagnosed cancer. These concerns were met with brief instruments (to reduce respondent burden) developed with focus groups and cognitive interviews (to hear the voices of children and their parents) and by a careful attention to the methodological details involved in establishing the reliability and validity of these instruments. Subsequent to the development, field-testing, and documentation of the measurement properties of these standardized quantitative instruments, clinical trials have been conducted targeting pain management and enhancing HRQL through symptom reduction using these quantitative instruments as outcome measures. Thus, standardized HRQL instruments have the potential to improve the lives of children facing life-threatening conditions by providing the systematic documentation of efficacy of treatment interventions designed for pain and symptom relief. In palliative care, standardized measures have the potential to increase the accountability and the quality of the care provided by allowing comparison of health care institutions or practitioners and utilizing that information to inform consumers and aid quality improvement efforts (Teno, Byock, and Field, 1999).

Clearly, there are challenges to be faced using standardized measures in clinical trials, clinical practice, and quality assurance efforts (Jordhoy, Kaasa, Fayers, Ovreness, Underland, and Ahlner-Elmqvist, 1999). For example, systematically addressing these barriers has the real potential to improve the health-related quality of life of children with life-ending conditions.

Differences among observers also represent a barrier to assessment. For example, Wolfe et al. (2000) found poor agreement between parent retrospective reports of their children's symptoms at end of life and physician reports. Additionally, although fatigue was frequently reported as a source of suffering for these children, it was infrequently addressed by the treatment team. Finally, Wolfe et al. (2000) found that more active involvement by the treating physician was rated with higher parent ratings of their child's comfort during the last month of life. Hilden et al. (2001) surveyed the pediatric members of the American Society of Clinical Oncology regarding end-of-life care. Although few had received formal training in palliative care, the overwhelming majority (91 percent) perceived themselves as competent in managing pain for children at the end of life and felt that most of their patients did not die in pain, providing further support for the lack of synchrony between parent and physician perceptions. A recent survey by Burns et al. (2001) reported that while the majority of providers reported views that were in agreement with consensus positions adopted by national organizations, nurses were less likely than physicians to agree that families were well informed and ethical issues were adequately discussed in their intensive care units. This suggests once again that there may be substantial disagreement among the perceptions of providers from different disciplines and family members.

Other potential barriers to effective end-of-life care were also identified by Hilden et al. (2001). Almost 50 percent indicated that they waited for the family to initiate discussions regarding advance directives and other communication difficulties. This is interesting in light of a finding with adult palliative care cancer patients (Detmar, Aaronson, Wever, Muller, and Schornagel, 2001) that psychosocial issues are the most vague in terms of who should initiate the discussion. Although patients and physicians reported it was important to discuss a wide range of issues, the most comfortable topics were around issues of physical functioning. This suggests that psychosocial issues may be underreported by patients and underidentified by physicians, leading to a degree of unrecognized morbidity.

In 1997, the IOM convened a workshop to review quality-of-care and quality-of-life assessment at the end of life (Teno, Byock, and Field, 1999). At that time, it was proposed that instruments should have clinical meaning, be practical, and possess adequate psychometric properties. Additionally, the instruments should assess dimensions that were important to those facing death, should include both patient and family perspectives, and should examine both process and outcome of end-of-life care. In pediatric HRQL, we have a body of literature that sufficiently identifies instruments that are psychometrically sound and practical, but what is most sorely absent is the clear delineation of domains or topics that are relevant to child and adolescent patients.

Important domains have been identified for adult patients at end of life, however. For example, Steinhauser et al. (2001) surveyed seriously ill patients, recently bereaved family members, and health care providers. They reported that pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a "whole person" were rated as important by all respondents. Several items were significantly more important to patients than providers, including being mentally aware, having funeral arrangements planned, not being a burden to others, helping others, and coming to peace with God. Although there were many items with substantial agreement across raters, it is important to note that there were differences in patient preferences compared to those of health care providers.

CULTURAL ADAPTATIONS AND LANGUAGE BARRIERS

This is a poorly studied area in pediatric HRQL in general and in pediatric end-of-life care in particular. A number of pediatric HRQL instruments are available in a variety of language translations; for example, the Health Utilities Index and the PedsQL are both available in Spanish and French versions. The inclusion of a broad range of eligible patients in HRQL is important for a number of reasons, including the potential generalizability-limiting effects when investigators fail to include non-English-speaking patients in a clinical trial, in addition to the ethical obligation to offer treatment broadly. However, investigators are challenged to provide scales that have been through rigorous forward and backward translation processes in order to demonstrate cross-cultural equivalence and cross-instrument equivalence. The simple "word-for-word" literal translation of concepts related to support and the meaning of life is not likely to successfully convey the conceptual underpinnings of these terms.

METHODS AND IMPLEMENTATION—MEASUREMENT IMPLICATIONS OF A HRQL MODEL FOR DYING CHILDREN AND ADOLESCENTS

In recent years, the recommended approach for measuring HRQL has been to include a generic measure of health status and a disease-specific measure within the same study or trial and to have the patient complete both forms (Scott and Garrood, 2000). This approach has been used as a way to define and address needs of unique patient groups while also producing responses that may be used to compare one patient group with other groups. Results have been used to compare different treatments, including toxicities and survival, to monitor health status over time, and to identify needed health policy changes (see, e.g., Cramer and Spilker, 1998; Levi and Drotar, 1998). Exceptions to this recommended approach are very likely to be made when measuring HRQL of dying children and adolescents because of the concern with patient burden and the need to give priority to those measures that can sensitively detect change in clinical conditions rather than those that yield data for population comparisons. Future research is needed to identify the utility of different assessment schedules and combinations of instruments, for example, assessing generic HRQL monthly in combination with weekly assessment of symptom-specific items.

It must be acknowledged that in certain situations, children may be unwilling or unable to provide the necessary information for an assessment of their HRQL. As noted in the previous discussion regarding proxy reporting of HRQL, the patient's report is far and away the perspective of choice. In many situations, it has been demonstrated that proxy reporting is not equivalent and, in the case of internal states such as mood and pain, may actually underrepresent significant problem areas. Investigators should consider the use of instruments such as visual analogue scales in situations where completion of a longer HRQL scale may be too burdensome.

In those situations in which proxy report is the only information available, a family member or health care provider who has closely observed and interacted with the dying child and who can accurately interpret the child's physiological and behavioral responses may be the most clinically useful source of estimating that child's HRQL acutely and over time. In such cases, strategies should be implemented to maximize the sensitivity of the family member or health care provider to changes in the dying child's status while avoiding fatiguing that person. For example, the sensitivity of health care providers is heightened when the same individuals are regularly assigned to care for the dying child. In addition, their efforts to document and share their astute clinical observations of the child's responses with other staff can further benefit the child for those times when the provider is not available to provide direct care to the dying child.

MEASUREMENT REQUIREMENTS IN PURPOSE OF ASSESSMENT

Any measure of HRQL must be both reliable and valid for the purpose for which it is being used. In general, reliability refers to the stability or accuracy (i.e., extent to which it is free from error variance) of the score(s), while the validity of an instrument reflects the extent to which it actually measures the intended construct. Additionally, HRQL instruments that are used in clinical trial settings must also be responsive to changes in clinical status in order to be considered useful. However, the purpose for which the assessment is being conducted is also important to consider, since there are unique requirements depending upon whether an instrument is being used for program evaluation purposes, for individual patient clinical decision-making, or for policy determinations.

A NOTE ON HIDDEN MORBIDITY IN PEDIATRIC PALLIATIVE CARE

Previous research in pediatric health care investigating psychosocial health as the "new hidden morbidity" demonstrated the continuing under-identification of psychosocial problems in routine pediatric practice (Costello, Edelbrock, Costello, Dulcan, Burns, and Brent, 1988). It seems reasonable to expect that the underidentification of psychosocial health problems demonstrated in pediatric primary care (Costello, Edelbrock, Costello, Dulcan, Burns, and Brent, 1988) and in pediatric tertiary care for children with chronic health conditions (Varni and Setoguchi, 1992) is also true in pediatric palliative care (Wolfe, Grier, Klar et al., 2000).

In adult patients' communication with their physicians during outpatient palliative care visits, it was demonstrated that patients' self-reported HRQL was the most powerful predictor of discussing HRQL issues with their physicians (Detmar, Muller, Wever, Schornagel, and Aaronson, 2001), with lower HRQL patients being more likely to discuss these issues with their physicians than those with higher HRQL. Even in patients experiencing serious HRQL problems, emotional functioning and fatigue were not addressed approximately 50 percent of the time. These findings suggest the value of systematic assessment of HRQL concerns utilizing screening methods akin to laboratory tests. Similar to laboratory tests for biological disease, screening for HRQL morbidity in a patient population requires a standardized test with established reliability and validity (Varni and Setoguchi, 1992).

To tackle this hidden psychosocial morbidity, HRQL measures may serve as standardized screening instruments for identifying physical and psychosocial health concerns from the perspectives of both the child and the parent at the point of service (Varni, Seid, Knight, Uzark, and Szer, 2002b).

Consistent with a serial screening approach is the recommendation from the American Academy of Pediatrics that an integrated model of palliative care include pain and symptom management at diagnosis and throughout the course of the condition, regardless of the ultimate outcome. From this perspective, all children diagnosed with a potentially life-threatening condition should be screened on a regular basis for HRQL concerns and provided with appropriate palliative therapies based on these serial screenings. In this way, all children, regardless of the potential for cure, would be managed with optimal health-related quality of life as a vital and essential health outcome goal.

CONCLUSIONS

Health-related quality of life is the outcome of uppermost concern in end-of-life care for children and adolescents. When children or adolescents begin this phase of care, there is an implicit understanding that the *quantity* of their lives is no longer the primary issue; instead, the *quality* of their remaining time is the principal focus of care efforts. Regrettably, insufficient knowledge is available regarding how children and adolescents die. As health care providers focus more on HRQL of dying children and adolescents through formal clinical assessments and research, medical knowledge and understanding of this phase of care will expand. Physical and emotional care of dying children and adolescents will be improved, and evidence-based justifications for resources that could benefit dying pediatric patients and their family members will be more readily available.

Our purpose in this discussion has been to facilitate the focus on HRQL of dying children by offering a definition of HRQL in dying children, proposing an HRQL conceptual model that includes the well-being of the dying child and the family, and identifying HRQL measurement challenges and strategies. A review of this literature suggests a number of areas in which we have a poor or limited understanding of how to best understand the HRQL of children during this stage of life. In particular, there is limited knowledge regarding how family HRQL should be conceptualized and assessed and the extent to which abstract concepts such as meaningfulness of life and spirituality should be, or are able to be, included in our conceptualization for children. Although researchers will continue to benefit from the work carried out with adults who are dying, it is imperative that our efforts to better understand children who are dying move forward quickly so that children who face this challenge can receive the highest quality of care.

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APPENDIX D

CULTURAL DIMENSIONS OF CARE AT LIFE'S END FOR CHILDREN AND THEIR FAMILIES

Barbara A. Koenig, Ph.D.[*] *and*
Elizabeth (Betty) Davies, Ph.D.[†]

> *"Every medical encounter involves the meeting of multiple cultures."*
>
> Linda Barnes, et al., 2000 [1]

> *"Treatment may be given more as a ritual commitment to the value of fighting death than out of rational expectation that it will help the patients."*
>
> Talcott Parsons, Renee Fox, and Victor Lidz, 1972 [2]

INTRODUCTION

The Relevance of Cultural Difference at Life's End

End-of-life care and palliative care for children and their families encompass key domains of life that are inevitably shaped by cultural context. Understandings of the boundary between life and death and the rituals that give meaning to this key transition vary widely. Is it critical to fight death or should it be accepted as part of life, beyond the control of medicine? What is the meaning and significance of the loss of an infant or child? How do

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parents, the family, and the broader community react to the crisis of life-threatening illness and experience a child's loss? Finally, how should the American health care system incorporate attention to cultural difference in efforts to reform and improve care for children living with life-threatening and terminal illness and their families? To answer these questions we provide an overview of what is known about the relevance of cultural difference in health care for children and families, specifically focused on end-of-life care and bereavement.

When *cultural* difference is considered, we generally think of differences among families from varied ethnic backgrounds. "Ethnocultural" background influences all aspects of health care, nowhere more profoundly than when death is near. Even patients and families who appear well integrated into U.S. society may draw heavily on the resources of cultural background (particularly spirituality) when experiencing and responding to death. When cultural gaps between families and health care providers are profound—accentuated by language barriers and varied experience shaped by social class—negotiating the difficult transitions on the path to a child's death, always a daunting challenge, becomes even more difficult. All domains of end-of-life care are shaped by culture, including the meaning ascribed to illness, the actual language used to discuss sickness and death (including whether death may be openly acknowledged), the symbolic value placed on a child's life (and death), the lived experience of pain and suffering, the appropriate expression of pain, the styles and background assumptions about family decision making, the correct role for a healer to assume, the care of the body after death, and appropriate expressions of grief. When the patient's family and health care providers do not share fundamental assumptions and goals the challenges are daunting. Even with excellent and open communication—the foremost goal of culturally appropriate care—barriers remain. Differences in social class and religious background may further accentuate the profound challenge pediatric palliative care presents to the health care system.

Throughout the latter half of the twentieth century and continuing today, the death of a child has been considered a tragedy of the first order in the United States. For the family, few experiences are as difficult to navigate and to survive emotionally, physically, and economically intact. Significant health care resources have been devoted to forestalling premature death in children and newborns, often with great success, such as in the treatment of childhood cancers. The high cost of intensive care for premature newborns may be lamented, but services are rarely questioned or denied. Some might argue that this devotion to forestalling death in childhood is itself a deeply rooted cultural feature of U.S. society, expressed vividly in the priorities of the political and medical care systems.

The question of whether the loss of a child is experienced in a fundamentally different way in societies with different values or significantly higher childhood death rates is of more than academic interest [3]. Clearly if a family bears eight children and only expects two to survive to adulthood, the experience of death will not mirror that of a United States middle class family whose only child dies, although feelings of grief and loss will be as deeply felt, albeit differently expressed. In resource-poor environments it may not be possible to devote significant means—emotional or financial—to stave off a child's death, even one that is theoretically preventable. One might argue that the U.S. focus on child death as a tragedy is in some ways a feature of affluence. Unlike many countries today and unlike most periods of human history, we have the privilege to focus on extending the lives of children with chronic, life-threatening conditions.[1] Significantly, immigrants to the United States may have markedly different expectations about child death shaped by the experience of severe poverty, health care systems marked by inequality, and war or other catastrophes.

Thus, a key cultural feature of our efforts to improve the care of dying children in the United States is a profound yet generally unspoken background assumption: we believe that death in childhood is "unnatural" and unthinkable, that morally it should or ought to be controllable. Because death in childhood is an unspeakable tragedy, almost an obscenity, we devote nearly unlimited resources to preventing it. A significant consequence of this cultural stance is that the death of infants and children in the United States health care system takes place only after all aggressive efforts to stave off death have failed. Often, death follows an explicit negotiation about the exact moment, location, and mode of dying. Estimates are that a high percentage of deaths in intensive care units (ICUs) (some studies report close to three-quarters) occur following an explicit negotiation or decision-making process [4, 5]. This makes good communication—the core element of decision making—a high priority. In an increasingly diverse society, the goal of excellent communication about palliative care realities, which is difficult under the best of circumstances, becomes a serious obstacle to care.

When the Institute of Medicine (IOM) conducted its first comprehensive assessment of care of the dying in the United States [6], little was

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[1] One of the authors first learned this lesson when she received a letter from a nurse in South Africa following the publication of an early article on the care of dying children in the U.S. The writer stated that Koenig's description of the ethical conflicts experienced by nurses caring for dying children who received aggressive therapy in spite of little hope of survival was of little relevance to her, because most of the dying children she cared for were killed by preventable infectious diseases, such as measles. The issues of economic privilege and social position were highlighted again for the authors during final editing of this manuscript. A front page story in the *New York Times* described a father in war-ravaged Afghanistan who had sold two of his sons to aid the survival of the rest of the family.

known about the impact of increasing cultural diversity on the provision of palliative care services or end-of-life care generally. In 1993, Koenig conducted a review published in the IOM report that described the paucity of research findings to date; the review focused on the importance of unexamined Western assumptions undergirding bioethics practices guiding end-of-life care for adults and emphasized the importance of encouraging a sophisticated understanding of the nature of cultural difference, in order to avoid the harmful effects of stereotyping patients [7]. Since that first report a growing literature documenting the role of cultural factors in end-of-life (EOL) care for adult patients has developed (see a recent review by Kagawa-Singer and Blackhall [8]). Although still incomplete, the research to date reveals the dimensions of cultural difference most salient in EOL care, including the focus on autonomous decision making by individual patients, varying preferences about the intensity of treatment, differential hospice use, disparities in access to pain medications, and concerns about trust in the health care system. By contrast, very little research on cultural issues specific to infants and children has been published.

A Firm Research Base Is Lacking in Pediatrics

An extensive review of the health care, psychological, and anthropological literature conducted by one of the authors (Medline 1990–2001, PsycInfo, CINAHL, and Anthropological Literature) using a variety of keywords in numerous combinations (including but not limited to children, pediatric, culture, ethnic, death, dying, palliative, hospice, illness) documents the lack of published research in this area. We found approximately 20 articles published over the last 10 years that report empirical findings related to cultural issues in families where a child is seriously ill or dying or has already died. Some of those studies included a discussion of cultural issues in palliative care outside the United States. Although of theoretical interest, studies of other societies—when the cultural background of the patient and family match that of the health care team in a homogeneous society—are less germane to the situation of plural societies like the United States. We conclude that a firm research base on cultural dimensions of end-of-life care for children and families is lacking. In particular, how culture affects negotiation about treatment decisions and palliative care in the American context is little studied.

As with pediatric palliative care more generally, and as documented in the IOM report for which this background paper was prepared [9], the research base supporting practice is limited. However, because children are inevitably part of families, much that has been learned about the cultural dimensions of EOL care for adults may be directly relevant to children, although research specific to the unique needs of children is of course necessary. Whether the person dying is a newborn or a revered grandparent, serious illness affects the family as a whole, and decision making about end-of-life care is often a shared responsibility, even for adolescent and adult patients.

Furthermore, structural and other constraints on the provision of palliative and EOL care to certain population groups are likely to be shared across age groups, affecting both children and adults. Differences in utilization of hospice services among U.S. populations, for example, are well known. African-Americans—12.3 percent of the U.S. population—comprise only 8 percent of hospice patients [10]. As a group, minority patients account for 25 percent of the population but only 17 percent of those receiving hospice care [11]. Although the exact reasons for these disparities are unknown, it has been suggested that hospice care may present barriers to underserved populations, those without the economic resources to shoulder the burden of family care giving, or those who lack a stable home for the provision of home-based services. Subtler barriers may be created by the hospice philosophy of open acceptance of and discussion of death. Additional research to investigate this possibility is required.

The Significance of Population Diversity and Profound Health Disparities

There are two primary reasons for the current attention to the issue of ethnocultural diversity in health care. One is primarily political—the recognition and growing acceptance of the United States as a multicultural society marked by inequality; the other is demographic—the increasing diversity of the population.

The task of providing culturally appropriate healthcare services is a daunting one. As widespread disparities in U.S. morbidity and mortality rates are documented and links to varied access to health care services are confirmed, attention to "difference" takes on added significance [12]. Eliminating health disparities across the U.S. population is an established national priority [13]. Recently, as one effort to reduce health disparities, the Office of Minority Health of the U.S. Department of Health and Human Services (DHHS) released national standards for "culturally and linguistically appropriate health services" [14]. It is not always clear, however, how these standards can be applied to improving EOL care for children and what barriers exist to their implementation.

The existence of significant disparities in U.S. mortality rates, for example the continuing excess mortality of African-American males across the life-span [12, 15], complicates the goal of improving EOL care. Figures D.1, D.2, and D.3 compare the rates for leading causes of death in children for African-American males and European Americans at various ages. Differences in cause of death are striking, particularly for violent death and

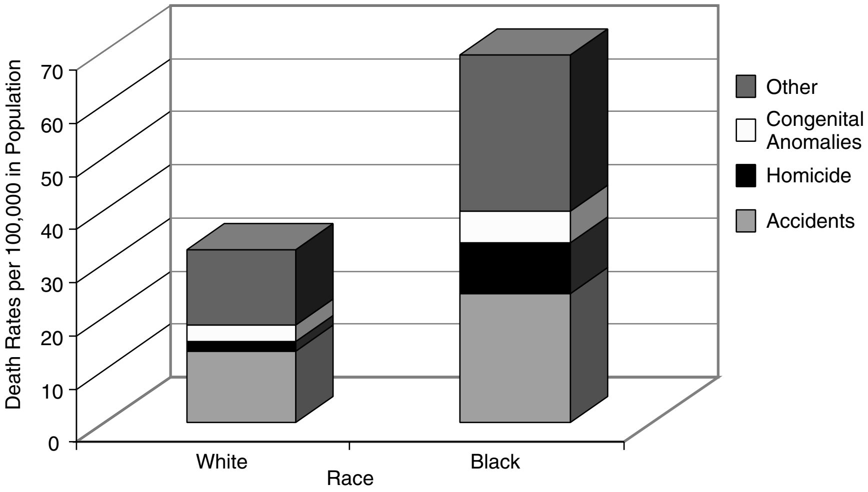

FIGURE D.1 Death rates for white and black males, ages 1 to 4 (1998). SOURCE: Table 8 in Murphy SL. Deaths: Final data for 1998. *National Vital Statistics Reports*, July 24, 2000, 48(11):1–105.

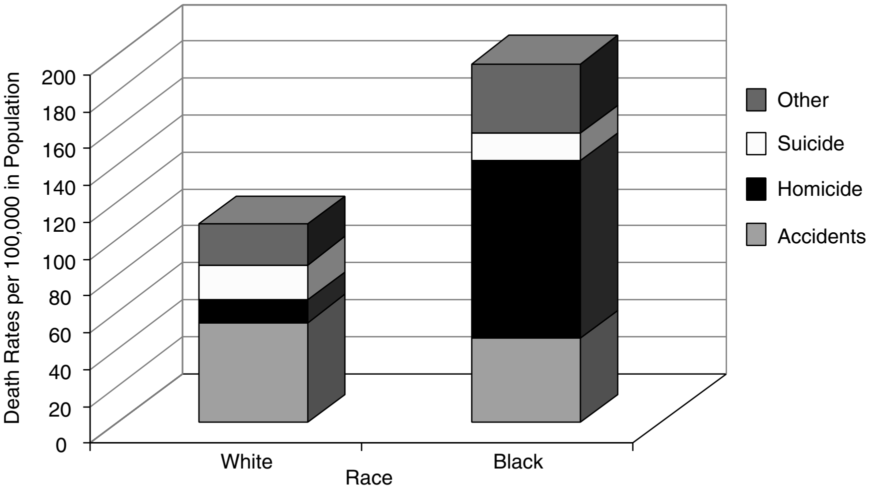

FIGURE D.2 Death rates for white and black males, ages 15 to 24 (1998) SOURCE: Table 8 in Murphy SL. Deaths: Final data for 1998. *National Vital Statistics Reports*, July 24, 2000, 48(11):1–105.

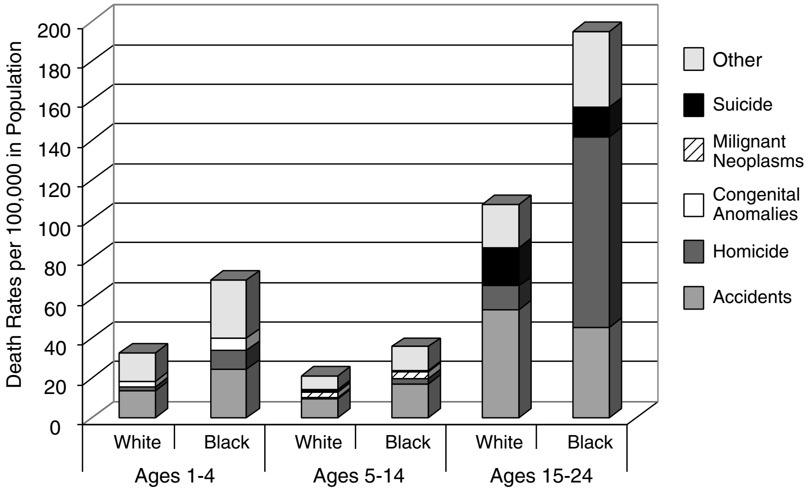

FIGURE D.3 Death rates by selected causes of death for white and black males, ages 1 to 4, 5 to 14, and 15 to 24 (1998)
SOURCE: Table 8 in Murphy SL. Deaths: Final data for 1998. *National Vital Statistics Reports*, July 24, 2000, 48(11):1–105.

accidents. HIV/AIDS does not occur in the "top 10" list for European Americans, while it is included for African-American children from birth through their teens. Excess deaths from preventable causes change the underlying dynamics of care.

Documented health disparities, especially those that reveal higher mortality rates in U.S. populations that have been subject to past racial discrimination, are directly relevant to efforts to improve end-of-life care in the United States, whether for children or adults. Recent studies that reveal differential access to curative services are particularly troubling, such as a lower rate of surgical referral for African-American adults with potentially curable (Stage I and II) lung tumors than for whites [16]. Findings documenting disparities in access to services are less clear-cut in pediatrics. One study found that black children and adolescents with end-stage renal disease were 12 percent less likely to be waitlisted for transplant than whites, even though all were Medicare-eligible [17]. The historical context of lack of access to health care services makes the explicit negotiation of death a particularly charged issue, one likely to be contested [11, 18, 19]. Even if differential access to care and varied treatment outcomes in children prove to be less extensive than those documented in adults, the existence of systematic black/white health disparities will continue to have an impact on the care of infants and children. The prior experience of parental decision makers with their own care, or with the care of other family members, will inevitably shape their interactions with care providers about a critically ill child. African-Americans may now be seeking treatment for their seriously ill child in a hospital that denied care to blacks within the memory of their parents and grandparents.

The attention of physicians to palliative care needs is also affected by historical patterns of discrimination. Physicians practicing in communities lacking access to care may make life-saving technologies—rather than improving care for the dying—a top priority. Focus groups conducted with African-American physicians (including pediatricians), who often care for high numbers of minority patients, in four regions of the United States found that end-of-life care was simply not a priority [20]. The "Initiative to Improve Palliative Care for African-Americans" is a national effort to focus attention on care near the end of life [21]. Strategies targeted to the needs of particular communities are critical.

The diversity of the U.S. population has increased markedly over the past decades. Although most pronounced in states like California and New York, the U.S. population as a whole is more diverse today than at any point in the twentieth century. The 2000 census reveals that 20 percent of the U.S. population, or 56 million people, are immigrants or first-generation residents. Projections suggest that some areas of the U.S. will have no "majority" population by the middle of the twenty-first century; people of color will triple by the year 2050. Due to higher birth rates in some communities and greater immigration rates among the young, the diversity in the U.S. population is greater in the youngest age groups. This means that when one considers the arena of end-of-life care, there is far greater diversity in pediatric than in adult practice. Overall, the majority of U.S. deaths occur among individuals greater than 65 years of age, in the eight, ninth, and increasingly the tenth decade of life. Thus, the typical adult hospice or hospital-based palliative care service will have a population of patients that is considerably "whiter" than a clinic focusing on children; attention to cultural diversity is more acutely needed in pediatrics than in the adult practice arena. Figures D.4 through D.7 compare the U.S. population diversity by age group in three states and for the U.S. as a whole (Figure D.7). In California (Figure D.4), only 30 percent of the population under age 10 are identified as white; in New York (Figure D.5), the figure is 50 percent; and in Ohio (Figure D.6), 80 percent.

The increased attention to diversity is also a strong political and moral commitment, not simply a response to "the numbers." During the early twentieth century, the expectation was that new immigrants would simply melt into the U.S. mainstream. Accepting the health care practices of the dominant society was an explicit element in the "acculturation" process. The fact that certain populations, specifically those set apart by the practices of racism, were excluded from the melting pot was little noticed. Populations do not "melt" with equal rapidity.

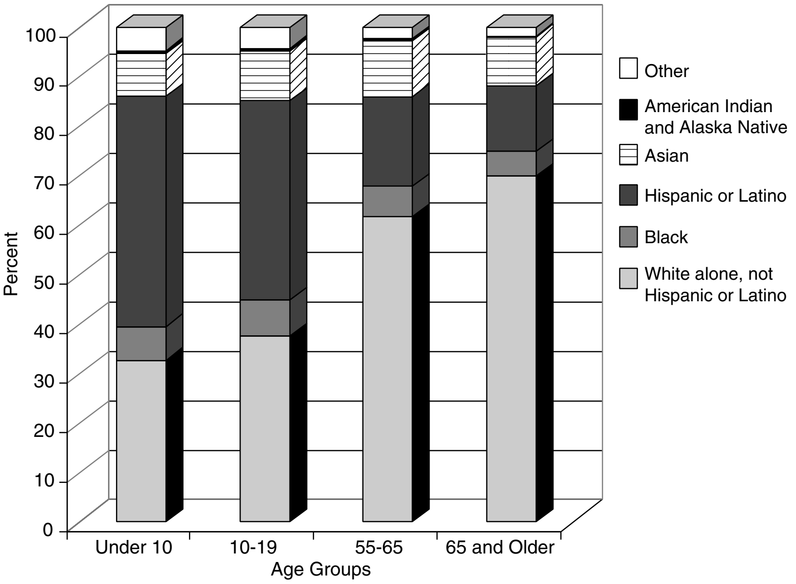

FIGURE D.4 Breakdown of diversity at young versus old ages in California (2000)
SOURCE: United States Census Bureau.

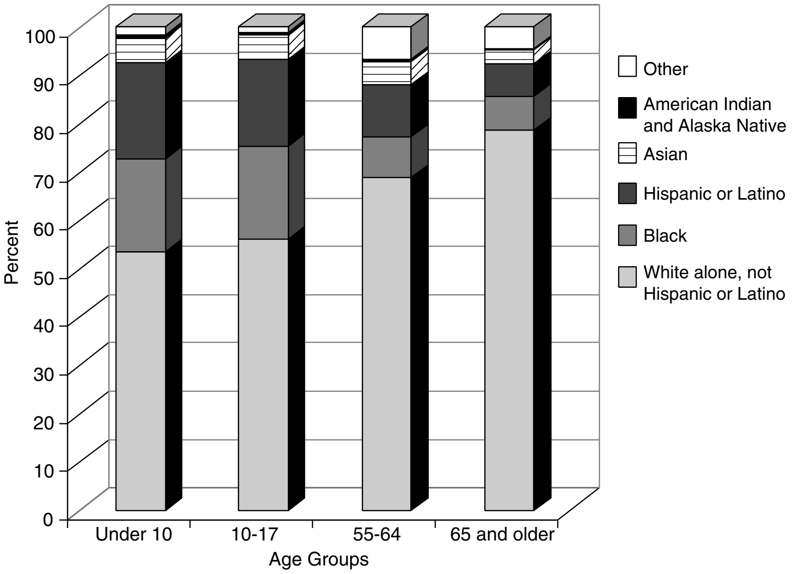

FIGURE D.5 Breakdown of diversity at young versus old ages in New York state (2000)
SOURCE: United States Census Bureau

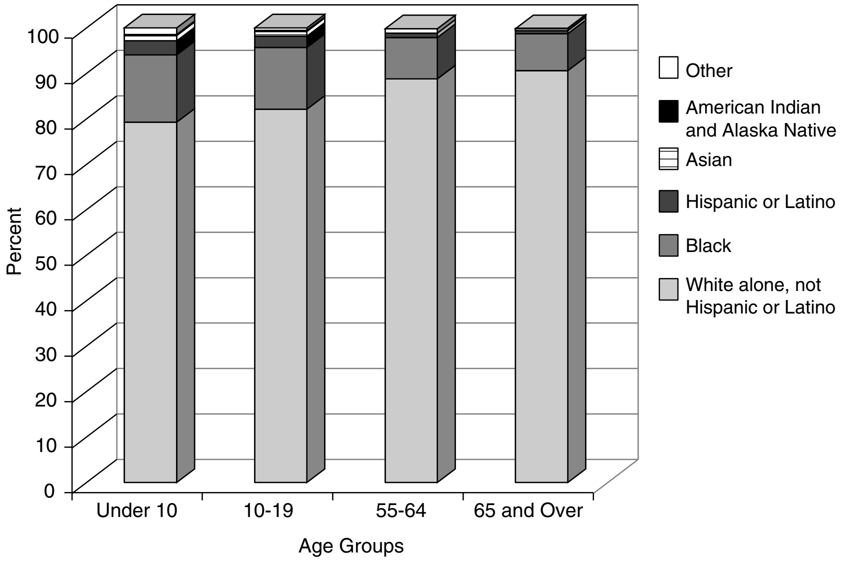

FIGURE D.6 Breakdown of diversity at young versus old ages in Ohio (2000)
SOURCE: United States Census Bureau.

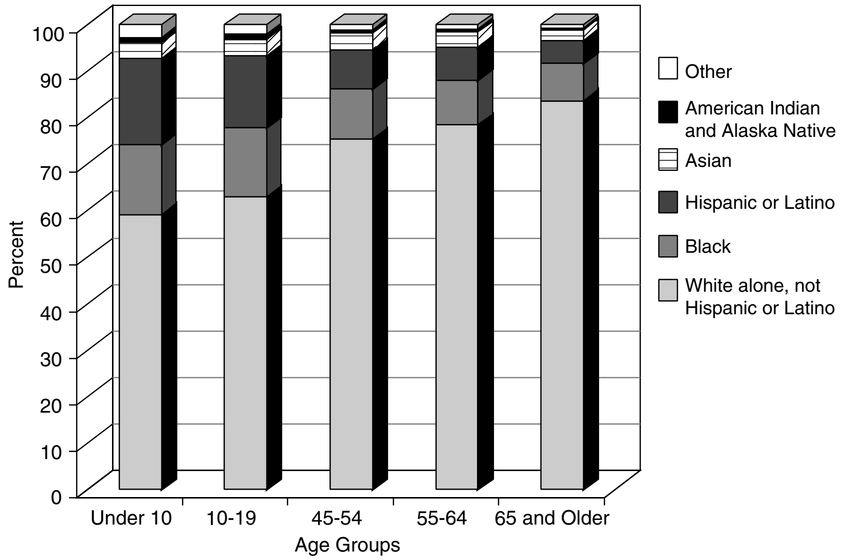

FIGURE D.7 Breakdown of diversity for various age groups in the United States (2000)
SOURCE: United States Census Bureau.

Likewise the idea of "acculturation" has proven to be a poor model of the complex process of accommodation and adaptation occurring in the United States. In a truly multicultural society, all parties in the exchange are transformed—it is not simply a matter of immigrants gradually becoming Americanized while stewing in the "melting pot." In health care for seriously ill children, it is not helpful to consider the absolute level of acculturation of any specific individual or family. Inevitably, families will be varied in their knowledge of and integration into "mainstream" health care practices. A single family may be "multicultural," including grandparents who are very much involved in caring for a child with a life-limiting condition but who are unable to speak English and lack familiarity with the United States' health care system. In the same family the child and his or her siblings may have been born and educated in the United States, leaving the parents caught in between the expectations of their American-born children and their desire to meet the demands of grandparents. Members of the same family may draw on the resources of culture differently; they may embrace different religious faiths or engage selectively in cultural practices.

Increased population diversity is a feature of health care professionals and health care workers in general, not just of patients. Many nursing assistants and home health aids, as well as physicians, nurses, and social workers, are themselves immigrants or self-identify as belonging to a particular ethnocultural group. The varied cultural backgrounds of care providers may influence their expectations about what is appropriate care for seriously ill children. Cultural expectations of nursing home personnel caring for the elderly have been show to be of concern when decisions are made to withhold or withdraw treatment, particularly tube feeding, which may have significant symbolic value [22]. Similar concerns may exist in pediatric long-term care settings if care providers come predominantly from cultural or religious backgrounds where feeding is considered obligatory, regardless of benefit to the patient or the desires of the child or family. Potential conflict in negotiations about appropriate end-of-life care comes to the fore in situations of diversity.

DEFINING THE KEY DIMENSIONS OF CULTURAL DIFFERENCE: INTERSECTIONS OF "RACE," ETHNICITY, SOCIAL CLASS, AND IMMIGRATION STATUS

What Differences Make a Difference?

Considerable research documents the relevance of ethnocultural and religious differences in the experience of death and dying and in clinical approaches to end-of-life care [23, 24]. However, health research in general does a poor job of making clear analytic distinctions among the key *ele-*

ments of difference. When we talk about "cultural" difference, do we mean a patient or family's voluntarily adopted and expressed "ethnic identity," their nation of origin if recent immigrants, their "race" as assigned by a government enforcing discriminatory laws such as segregation, or specific health-related practices such as diet or use of medicinal herbs? In health care research there is considerable confusion in terminology, particularly with regard to the use of the term "race." In a review of articles making comparisons among human population groups published in *Health Services Research*, Williams noted, "Terms used for race are seldom defined and race is frequently employed in a routine and uncritical manner to represent ill-defined social and cultural factors" [25]. Lack of precision—näively conflating race, biology, and culture—makes it impossible to tease out the causes of health disparities between racialized[2] populations and more privileged groups.

The lack of consistency in the use of terminology for concepts of race, ethnicity, ancestry, and culture is manifest in the wide variance in terms used to identify individual and group identities [27]. Terms such as white, Caucasian, Anglo, and European are routinely used interchangeably to refer to certain groups, whereas black, colored, Negro, and African-American are used to refer to comparison groups [28]. Also, white–black comparisons are straightforward in contrast to the confused use of terms such as Hispanic and Asian. Both of these labels, one based on linguistic criteria and the other on continental origin, lump together many populations of people reflecting enormous variability in factors related to health and medical care.

Extensive debates in the biomedical literature focus on the appropriate use of terms such as race, ethnicity, and culture [29, 30]. Much is "at stake" in how these categories of difference are utilized when conducting research or in designing programs to improve the cultural competence of health care providers. In particular, approaches to conceptualizing disease etiology or health outcomes may have moral significance if one naively assumes that culture predicts behavior in a precise way or that something essential or "inherent" in a certain population leads to poor health outcomes or barri-

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[2] The term "racialized" population is preferred by many anthropologists to the use of the term "race." Because human races are socially constructed categories, and not biological or genetically distinct groups, use of the active term makes it clear that different populations are understood as biologically inferior only within particular social and historical contexts. Within U.S. history, for example, certain populations, such as Jews, the Irish, and immigrants from southern Europe were once considered as separate "races," but were later de-racialized. These changes are reflected in the categories used by the U.S. census in describing population differences. See reference 26.

ers to health care access. In the case of black–white differences in infant mortality or homicide rates, for example, how one thinks about causation, and the relative contribution of genes, environment, and social structure, may determine the type of intervention recommended. Meaningful genetic and biological differences do not always map clearly onto social categories of human difference, whether defined as race, ethnicity, or culture. If we talk about "racial" differences about preferences for palliative care services, what exactly do we mean? In the United States efforts to tease apart the independent contributions of "race" and socioeconomic status (SES) when analyzing health care outcomes may be daunting.

Although the dimensions of difference most relevant to EOL care are likely to be social or cultural, biological or genetic variation may also be germane. For example, the field of pharmacogenomics tracks individual and group differences in drug metabolizing enzymes to predict response to medications such as chemotherapy or pain medicines. Although classic understandings of human "races" do not parallel actual genetic variation at the molecular level [31], there may be allele frequency differences among socially defined populations relevant to pharmacogenomics [32, 33]. More sinister applications of genetic reductionism may link excess homicide rates in certain populations to a genetic predisposition to violence. Although this example may seem extreme, it points out the importance of clear thinking about the relative contribution of genetic variation, environment, and social context in thinking about cultural difference in health care. It has been known for decades that there is ethnocultural variation in the expression of pain or painful symptoms [34]; the degree of variation in the actual experience of pain—possibly modulated through the action of pain medicines—remains unexplored.

Immigration status is another key category of cultural difference. Recent immigrants provide challenges to the health care system, particularly in end-of-life care. In much of the world, the American ideal of open disclosure of information about diagnosis and prognosis is not the norm [35, 36]. In fact, patients and families may experience the directness about diagnosis characteristic of U.S. health care as needlessly and aggressively brutal, violating norms espousing "protection" of the ill. Although children may be seen as more in need of protection than adults, much pediatric palliative care literature recommends openness—appropriate to an ill child's age—as preferable to concealment. U.S. bioethics procedures governing end-of-life care may seem unfathomable to those newly in this country, but it is perhaps the assumptions of bioethics that are culturally bound. As Die Trill and Kovalick note, "Those who argue that children always should be told the truth about having cancer must recognize that the truth is susceptible to many interpretations" [37] (p. 203). Parents or other family members who object to sharing the full differential diagnosis with an ill child may be accused of being "in denial" about the severity of their child's illness. Lastly, the experience of those immigrants who are refugees from political violence or war adds another dimension. The effects of multiple losses—on family members, including the death of other children in the family, one's country, one's entire history—are difficult to predict but clearly shape a family's response to the serious illness and threatened loss of a child. Responses may appear to be overly stoic or overly emotional.

In the U.S. context it is especially important to separate analytically the concepts of culture, ethnicity, and race from the effects of SES. Historically underserved populations may have special barriers to EOL care that have little to do with difficulties in communication and are not related to their identification with a certain set of ethnic traditions. In a ground-breaking study, Morrison documented the lack of availability of narcotic analgesics in minority communities such as Harlem; pharmacies simply did not carry the opiates that are "state-of-the-art" drugs for pain control in children as well as adults [38]. The American "drug wars," including the recent battles about the abuse of time-release opiates like oxycontin, are often fought in poor neighborhoods with limited access to legitimate employment [39]. Children from minority backgrounds may not receive adequate pain control if drugs are not prescribed because of fears of theft or abuse by a child's family members. When members of the health care team are hesitant to prescribe narcotics it may be a legitimate concern based on factual information about a particular family's drug history, or it may be the exercise of racial stereotyping. The end result is the same: children may be denied needed pain relief. The experience of children with sickle cell disease, whose pain is often undertreated, is an example [40-42]. Culture thus contributes to inadequate symptom management, but indirectly, through the actions of health care providers. Research in a Los Angeles emergency department documented that Hispanic patients with injuries identical to whites were given less analgesic medication [43].

Strategies: Cultural Competence, Cultural Sensitivity

Within the U.S. health care system, considerable attention has been paid to efforts to improve the "cultural competence" of practitioners, including pediatric care providers [44, 45]. Most recently, national guidelines, including standards for the availability of translation services, have been promulgated [14]. The American Psychological Association has posted guidelines for culturally sensitive end-of-life care on its Web site [46].

In spite of considerable rhetoric, there are no widely accepted definitions of terms such as cultural competence, cultural sensitivity, or culturally appropriate care. We argue below that no one clinician can ever be fully "competent" because it is impossible to learn by memory a full compendium of the world's cultural practices and beliefs. The language of "competence" also suggests that all dimensions of cultural difference are encapsulated within the bounds of the patient–family–care provider relationship, ignoring social forces that inevitably impinge on the most virtuous clinician. In general, we favor the notion of culturally "sensitive" or "appropriate" care, which focuses on specific skills, such as communication, rather than on mastery of cultural traits. It also fosters the notion of respect for diverse beliefs, and self-reflection about one's own cultural background [18].

Major efforts in health professional education in end-of-life (EOL) care have paid attention to the cultural dimensions of EOL care. The American Medical Association's Education for Physicians in EOL Care (EPEC) program and the End-of-Life Nursing Education Consortium (ELNEC) include attention to ethnocultural difference.

A Caution Regarding Use of Language—Ethnocultural Difference

In the discussion that follows, we define culture as the "the conscious and unconscious structures of communal life that frame perceptions, guide decisions, and inform actions. It is the web of meaning in which each person lives" [1]. This *interpretive* rendering of culture has dominated anthropological theories since formulated by Clifford Geertz [47]. We use the term "ethnocultural" difference to refer to patterns of values, beliefs, and attitudes found among individuals who share a common language and may claim the same ancestry, religion, folk or dietary practices, or general world view. The term "ethnicity," when correctly used, is similarly defined.[3] However within biomedicine the term ethnicity has unfortunately been appropriated as a "politically correct" replacement for race. We use the term ethnocultural to keep our analysis focused on the cultural domain, while at the same time avoiding an "essentialist" view of cultural difference. Suggesting that ethnic culture is an essential feature of individuals or families—rather than a complex, dynamic resource, embraced or abandoned and constantly changing—is dangerous and inaccurate. Much naïve work in cultural competence education seems to suggest that culture predicts behavior in a straightforward way. This approach is inherently reductionistic and risks stereotyping individuals and families.

Furthermore, attributing differences in behavior, attitudes and beliefs to race has the potential to reinforce racist stereotypes. Certainly, some U.S.

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[3] The term ethnicity was originally deployed within anthropology to counter the racial determinism of 19th and early 20th century theories of difference among human populations. It was used as a synonym for culture.

populations have been racialized in the past, with groups subject to discrimination based on notions of inherent difference correlated with skin color or national origin. Thus explaining how "race" is relevant to palliative and EOL care is complex; it is most relevant when examining lack of access to services or failure to embrace bioethics practices that demand a fundamental level of trust in the health care system. The term itself must be used cautiously to avoid the implication that inherent, essential differences among human populations exist.

WHAT'S KNOWN; WHAT'S NOT KNOWN

Review of the Research Base on Cultural Dimensions of EOL Care in Adults and Families: Can We Extrapolate?

Progress has been made in understanding the relevance and importance of cultural diversity in end-of-life care for adult patients [8]. The primary clinical implications of that research base are discussed below, with a focus on communication and negotiation about appropriateness of care. Here we ask the following questions: Can we extrapolate from what we know about the cultural dynamics of providing EOL care to adults? Do significant differences exist when the goal is providing culturally sensitive end-of-life care to infants or children with life-limiting conditions and their families?

Negotiations about appropriate care of children unlikely to survive to adulthood are shaped by cultural context. What is the meaning of a child's death for the child, the family, the broader society? Is it an ultimate tragedy, a life-changing event? Or is it taken for granted, deeply felt, but understood as part of life? Because a child's dying is "out of order" in most industrial societies, this relatively rare event is managed very differently in pediatrics than in adult medicine or geriatrics.

The epidemiology of death in childhood is also significantly different from that of death in older people. Compared with adults, the causes of death in children are more varied and the pathways to death are less predictable (see Chapter 2, "Patterns of Childhood Death in America"). Accidents are more common, and many deaths are the result of genetic or neurodegenerative illnesses and may follow a prolonged period of disability. A large proportion of pediatric death occurs during infancy. There are more commonalities in the cause of death among adults, with the majority succumbing to the major killers, cardiovascular disease and cancer. In children the picture is considerably more complex, making the tasks of prognostication difficult. Christakis has documented the sociological features of medical practice that lead to physicians' routine overestimation of patients' likely survival [48]. In pediatrics, the inherent uncertainty of prognostication is increased by the variability of diagnoses leading to death, contributing to delays in implementation of palliative care even greater than those with adult patients.

CULTURE MATTERS: KEY DOMAINS OF CLINICAL SALIENCE

A basic principle of pediatric palliative care is providing family-centered care that takes into account both the common and the unique needs of families when a child has a terminal condition and is dying [49]. Despite this emphasis, remarkably little attention has been paid to understanding how a family's cultural background influences its experience as it faces this most traumatic event. This seems a remarkable oversight, since it is widely recognized that cultural values, beliefs, and practices play a central role in shaping how families raise and care for their children not only when they are healthy, but especially when they are seriously ill [37]. Watching a child fall sick and die is a crisis of meaning for families, and it is through their cultural understandings and practices that families struggle to explain and make sense of this experience [50].

Extrapolating from the growing literature on cultural issues in EOL care for adult patients and families, and gleaning what has been documented in the more limited pediatric literature, it is possible to identify the key domains of clinical significance in caring for children from diverse ethnocultural backgrounds who are unlikely to survive to adulthood. In general, the cultural challenges of EOL care can be divided into two fundamental categories: those that do, and those that do not, violate the health care team's foundational cultural values, norms that may also be enforced by legal requirements. In the first category are cultural values or practices that call into question the biomedical goal of combating disease and extending life. A family who refused to allow a potentially curative limb amputation for a female child with osteosarcoma because of beliefs about the need to preserve bodily integrity, and a daughter's marriageability, would immediately create consternation for health care team members. By contrast, another family who wished to engage a spiritual healer to pray for a successful outcome to the same surgery would *not* create a cultural crisis, since the family's goals could easily and effortlessly be incorporated into the clinicians' care plan. Generally, issues such as care of the body after death do not provide a fundamental challenge to biomedical values and beliefs; thus customs prescribing particular approaches to post-death care are relatively easy to implement unless they violate laws governing disposal of the body. However, even in post-death care there may be situations that lead to cultural conflict, such as requests for autopsy or organ donation in situations where the wholeness of the body is highly valued. And the domain of grief counseling and bereavement care may or may not elicit conflict. For pediatric specialists focused on cure, less is "at stake" once a child has died and can no longer be saved, but conflicts may still emerge over differing definitions of acceptable grieving practices.

Family Roles and Responsibilities in Shared Decision Making

In traditional bioethical decision making about end-of-life care for a competent adult patient, the decisions are left up to the individual; theoretically the family or broader community is not critical to the patient's choices. In the case of children, where parents become surrogate decision makers, the situation is much more complex [51]. Disagreements about the goals of care, although rare, are emotionally difficult for all. In many cross-cultural situations, the Western view that individual patients (or in the case of a dying child, parents alone, in consultation with their child's physicians) will make decisions about care may be too narrow. In some societies a social unit beyond the nuclear family may also have considerable decision-making authority. Elders in an extended family or clan group may expect to be involved, and parents may desire this. Integrating them into care in a Western hospital or pediatric unit is hard but may be desirable. Gender may play a role as well. In traditional male-dominated societies, mothers may never have experienced the level of decision-making authority automatically granted to both parents in the United States. This may be a source of tension. Similarly, the evolving practice in pediatrics of requesting "assent" to care by older children, especially girls, may create tensions within the family.

A further dynamic may result from the ideal "shared decision-making" model. Tilden et al. have documented stress among family members involved in decisions to withhold treatment [52]. The impact of parental involvement in decisions to terminate treatment has not been studied extensively. Inexperienced clinicians or trainees may present decisions about limiting painful or aggressive procedures—sometimes an opening to a transition to palliative or hospice care—in an insensitive way, making it appear that the parents or other decision makers must give "permission" for futile care to be withheld. Although the parents' role in making decisions on behalf of their infant or child must be respected, few parents, regardless of their cultural background, are able to do this easily. In fact, the resistance to giving up hope and explicitly limiting therapies found among families from diverse backgrounds may be appropriate. Models of care that do not require that curative therapies be abandoned in order to obtain excellent palliative services may ultimately lessen this problem. Parents should never be told that care will be withheld; rather the focus should be on meeting the needs of the child and family.

Varied Understandings of the Role of Health Professionals or Healers

Just as the appropriate role of parents caring for a seriously ill child may vary, the families' expectation of the role played by health professionals may differ. In some societies, healers are expected to make a diagnosis almost magically, perhaps by feeling the pulse without asking any questions. Healers may exert considerable power and authority; they may expect and receive deferential behavior. Patients and families schooled in these traditions may be confused by the shared decision-making ideals of Western practice. They may lose confidence in physicians who do not appear to know unequivocally the correct course of action but instead ask for the parents' views.

In many societies the roles of healer and religious specialist intersect. "Each religious tradition has its own images and ideals of the doctor, in which the individual engaged in healing is defined as enacting some of the highest ideals of the tradition itself" [1]. The healer's role at the end of life may be particularly meaningful, or it may be proscribed to take on the care of those not expected to survive, as in the Hippocratic tradition.

Families who have been denied access to health care providers may also question the trustworthiness of the "establishment" health system, worried that those in power do not have their best interests at heart. The disparities in morbidity and mortality across U.S. populations suggest that often African-American patients receive less intensive care. The irony is that research on end-of-life decision making in adults reveals that minority patients may actually desire more aggressive care near the end of life [53].

Communication Barriers, Need for Translation

Negotiation about the appropriateness of clinical services for children nearing the end-of-life is a complex task when health care professionals and family members share fundamental goals and assumptions. By no means has a successful "formula" for such communication been established. When cultural barriers exist, particularly those created by language, the goal of open and effective communication is exceptionally difficult. Language translators may be available only intermittently, and are often poorly trained. In March 2002, two hospitals in Brooklyn, New York, that routinely serve large numbers of Spanish-speaking patients were sued for failure to provide translation services, examples of a number of such legal actions dating back several decades.[4]

The task of language translation in the arena of ethical decision making and end-of-life care is particularly complex. How does one translate a discussion about a "do not resuscitate" decision to a family with no previous experience of cardiopulmonary resuscitation (CPR), and no prior knowledge of the American bioethics tradition of requiring permission not to offer CPR, even to an infant or child actively dying? What if the language characters representing resuscitation are interchangeable with those suggesting the religious concept of resurrection? Although it sounds silly from the perspective of Western, scientific understandings of death, who would not elect to have their dying child brought back to life if offered the choice

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[4] Congress passed Title VI of the Civil Rights Act to ensure that federal money is not used to support discrimination on the basis of race or national origin in government activities, including the delivery of health care. Title VI states, "No person in the United States shall, on ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Neither Title VI nor the implementing regulations discuss linguistic access per se. However, courts have consistently found a close connection between national origin, which is specifically covered by Title VI, and language. In *Lau* v. *Nichols* [414 US (1974)], the U.S. Supreme Court held that the San Francisco school system violated Title VI by failing to take steps to assist Chinese students. Since *Lau*, a number of lower courts have found that the failure to provide translation services may be discrimination on the basis of national origin.

Although the Hill-Burton act is no longer in force, it had significance in previous standards. In return for Hill-Burton funding support, medical facilities agreed to be bound in perpetuity by provisions requiring "community service." Facilities must make services "available to all persons residing in the facility's service area without discrimination on the ground of race, color, national origin, creed or any other ground unrelated to an individual's need for service or the availability of the needed service in the facility." The Office of Civil Rights (in the DHHS) has consistently taken the position that the community service obligation requires hospitals to address the needs of limited-english-proficiency patients, which extends to providing interpreters.

Some states, most recently Massachusetts, have published their own guidelines for government-funded agencies and hospitals. All include the requirement for translation services if needed. However, many physicians and hospitals oppose these guidelines because they claim the costs of providing interpreters is prohibitive. They also claim that the US Supreme Court, in overturning *Alexander* v. *Sandoval* (99-1908) 197 F.3d 484 (2001), has removed the legal basis for claiming that English-only instructions constitute discrimination on national origin under Title VI. In this recent case, by disallowing private causes of action, the 5-4 split court essentially overruled much of its earlier reasoning in *Lau* v. *Nichols*.

There are also malpractice cases on failure to provide language-appropriate services, in some cases where English speaking staff have not been available. There are fewer cases based on liability or torts in the matter of language translation issues. There are also legal cases involving sign-language and the provision of interpreters in American sign language for deaf people, but those arise under the Americans with Disabilities Act.

in those words? How might medical interventions at the moment of death be understood among practitioners of Buddhism who believe that rituals spoken during the dying process guide the "soul" through dangerous spiritual territory and ultimately determine where and how a person will be reborn? How do you negotiate with a family about the location of death—home versus hospital—against a cultural background where speaking of an individual's death is thought to bring it about or where certain illnesses cannot be named? The use of family members as interpreters—which may be unavoidable—may make discussions such as these even more problematic. Family members may see their primary role as protecting others in the family from harm and thus "shield" them from information viewed as harmful [54].

Furthermore, models of professional translation, such as those employed in courtrooms where relationships are fundamentally adversarial rather than collaborative, assume that language interpreters should function as neutral "machines." Health care providers need to be aware that translation services such as those available by phone from AT&T may be based on legal models of interpretation. This stance ignores the interpreter's potential value in providing information about the family's cultural background, as well as providing language interpretation. When interpreters are engaged as full partners in providing care, they may aid in negotiations about difficult end-of-life dilemmas [55, 56]. When included as part of the health care team—for example, in programs where native speakers of commonly encountered languages are employed as bilingual medical assistants—interpreters can also serve the useful function of explaining the culture of biomedicine to families.

Integration of Alternative and Complementary Medicine into Palliative Care

Parents and other family members may be subject to strong pressures to utilize "ethnomedical" practices and procedures believed to be efficacious. Recent immigrants may utilize products obtained abroad. Practices vary widely, including acupuncture for pain, cupping or coining, dietary prohibitions based on "hot–cold" belief systems, Chinese herbal products, Ayurvedic patent medicines, and full-blown rituals including chanting and the sacrifice of animals. A skilled practitioner creates an open environment in which the child, family, and perhaps a ritual specialist from the community may openly discuss the appropriate blending of biomedically sanctioned medicines and procedures with ethno-medical products. Although some patent medicines and food supplements are known to be harmful and may actually contain potent pharmaceuticals, the health care team is unlikely to obtain a full accounting of all treatments used for a particular child unless a nonjudgmental attitude is maintained. This may be a challenge when a health care provider must compromise his or her own "ideal" care.

The need to integrate alternative and complementary medicine into palliative care is not limited to patients from particular ethnocultural communities. Research documents that a large percentage of Americans have utilized "alternative" medicine in the recent past [57], with prayer being the most widely utilized practice (82 percent of Americans believe in the healing power of personal prayer) [1].

The Meaning of Pain and Suffering for the Child and Family

Palliative care has as a primary goal the relief of pain and suffering. Ethnocultural difference is relevant to pain management in multiple ways. The effectiveness of symptom management may be lessened by economic barriers to medicines or special treatments. Physicians may undertreat patients because of fear that drugs may be "diverted." Cross-cultural research with adult patients has documented differences in the way people experience and express pain. It is likely that the appropriate expression of pain by adults in a family will influence what is considered acceptable for children: Is stoicism rewarded? Are there gender differences in outward discussion of painful symptoms? Spirituality may have an impact on the meaning of suffering and hence on the management of symptoms. A study of infants and children with a rare genetic disease (recombinant 8 syndrome) in long-time Spanish-speaking residents of the American Southwest revealed the complexity of suffering. The experience of affected children in these devout Catholic families was thought to mirror Christ's suffering, providing meaning to an otherwise unexplainable tragedy [58].

Defining the Boundary of Life and Death

Biomedical definitions of death, including the concept of brain death, appear to be clear cut. However, when examined closely considerable ambiguity remains, particularly in pediatrics [59]. Even among biomedical professionals one frequently hears confusion in language when speaking, say, about an organ donor who is technically brain dead, but may appear to be as "alive" as adjacent patients in an ICU. Linguistically, these brain-dead bodies experience a second "death" once organs are retrieved for transplantation and ventilatory support is removed [60]. It is thus not surprising that patients and families can also become quite confused about states resembling death, including brain death, the persistent vegetative state, or coma. Societies such as Japan, which utilize the same biomedical technologies as in the U.S., have not readily accepted the concept of brain death, in spite of the demands of transplant programs for organs [60].

Disputes arise when a child meets the biomedical criteria for "brain death," but the family refuses to allow withdrawal of "life" support. In a masterful essay, Fins describes two clinical negotiations about withdrawing life support from children defined as brain dead [61]. In one case, the hospital team engages the family's orthodox rabbi and other religious authorities in a complex series of negotiations, respecting throughout the family's view that the patient is not truly dead and that only God can declare death. A more contentious case involves an African-American family who maintains a stance of mistrust toward the health care establishment in spite of every effort on the part of the clinical team. The family's past experience shaped its understanding of the team's intentions in spite of great effort to gain their trust. Disputes such as these are the "hard" cases, revealing cultural clashes that cannot be ameliorated simply by motivated clinicians, sensitivity, or excellent communication skills, although clearly those things may keep conflict to a minimum or may keep small cultural disputes from erupting into major pitched battles.

Since the causes of pediatric death are much more varied than those in adult medicine, the need for autopsy to determine an exact cause of death may be more important. In the case of rare genetic disease, autopsies may help establish a diagnosis or benefit a future child. The acceptability of autopsy, or other uses of the body following death, is deeply sensitive to cultural and religious prohibitions [62]. Knowledge about the acceptability of autopsy, or requests for organ donation in the case of acute trauma, cannot usually be guessed by "reading" a family's background.

Furthermore, different ethnocultural groups may have varied understandings of the nature, meaning, and importance of cognitive impairment in a child. In a society where social relationships are a core value, esteemed more highly than individual achievement, disabilities that affect intellectual functioning but do not interfere with the infant's or child's role in the family may be more readily "accepted."

Acceptance of Hospice Philosophy

As mentioned above, utilization of hospice care programs is not identical across racialized U.S. populations. African-Americans (primarily adults) utilize hospice services at a lower rate than do European Americans. There are significant barriers to hospice care for children in general, since many hospices take children only rarely, and few have dedicated programs for children [9]. Thus, the barriers to care for children from diverse ethnocultural backgrounds are likely to be even higher.

Home death is often considered an ideal within the hospice philosophy. A "good death" is often characterized as one that takes place at home, surrounded by family and/or friends, with pain and symptoms under control, spiritual needs identified and met, and following appropriate goodbyes. Traditionally, this ideal good death required giving up curative interventions. At the moment in U.S. history—the 1970s—when hospice care became a viable alternative, aggressive end-of-life interventions were commonplace, and efforts to secure patient participation in decision making were not yet fully realized. Thus, the home became a refuge from the ravages of hospital death. Even though the strict implementation of a six-month prognosis requirement for hospice is changing, it remains more difficult in pediatrics to predict the terminal or near-terminal phase of illness. Acknowledging that death is near may be particularly difficult. Home death may not be valued in ethnocultural groups where it is considered inappropriate, dangerous, or polluting to be around the dead. Among traditional Navajo, the dying were removed from the hogan dwelling through a special door to a separate shed-like room to avoid the catastrophe of a death occurring in the hogan, which would then have to be destroyed. Burial practices were organized to make certain that ghosts could not find their way back to the hogan, and family members did not touch the dead body. This task was relegated to outsiders. These issues remain salient for those practicing in the Indian Health Service [63]. In some Chinese immigrant communities a death at home may affect the value of a particular property on resale [64].

Care of Family After Death; Bereavement Needs

When a child dies, supportive services to aid a grieving family are vitally important and should be covered by institutional protocols and procedures intended to establish accountability for the consistent provision of such services [9]. The cultural background of the family may be particularly salient in planning for and providing bereavement care. Some authors [65] have specifically addressed family bereavement following a child's death, but most research includes primarily European-American families. Most researchers recommend extending the work to include families of other cultures, but very little work has focused on cultural issues and family bereavement when a child has died.

Although findings specific to children in the setting of a multicultural U.S. society are lacking, much is known about culture and bereavement more generally. Cultural heritage helps define how individuals and families react to loss, and provides insight into behavior, the expression of emotion, and understandings of death. Cultural approaches to dealing with loss may be more or less standardized but almost always involve a core of understandings, spiritual beliefs, rituals, expectations, and etiquette. In many cultures, different kinds of deaths are understood differently and dealt with differently. The meaning of death and the rituals called for, the emotions felt, the extent to which others are involved, and how the body is to be disposed of—all may vary depending on such factors as whether the death is a suicide, a drowning, the result of illness, the death of a child, or the death of an elder [66]. Among the Bariba in Africa, certain infants are defined as witches and thus mothers may not be allowed to express grief on their death [67]. Thus, even if one knows something about how a "typical" death is handled in a particular society, one may not be prepared to understand what is going on when a child dies.

In most cultures, it is believed that children should not die before their parents, even though infant mortality may be high. Common sayings attest to this belief. In China, for example, it is said that "black hair should not precede the white hair." A Korean maxim states that if your parents die, you bury them underground; if a spouse dies, they are also buried underground; but when your child dies, you bury the child in your heart. In Western countries, it is often said that when a person's parents die, one loses the past, but when one's child dies, the parents lose their future. The death of a child represents a unique loss. Nonetheless there may be distinctions made based on age, sex, or disability. In many societies a newborn is not afforded the full status of "personhood" until a specified period of time has passed, often 30 days, after which the child is "named" and becomes part of the tribe or group. Bodies of infants who die prior to that period may not be provided with full funerary rites.

In the anthropological literature, significantly more attention has been focused on the rituals surrounding death and the disposal of the body than on the management of death and the dying process [68]. Behaviors and rituals surrounding a child's dying may be understood in the context of beliefs about the transition of dying, a fundamental "rite of passage." Many cultures view death as a transition, often described as involving a journey to some other place or state [69]. In many cases, people understand that the deceased will continue to have an impact on the living and continue to communicate with the living. Rituals around dying therefore may have special significance. From a Korean perspective, for example, a dying person should not be left alone, for to die alone means a lonely journey after death to a new life. For Korean families, therefore, it is particularly important that all efforts should be made to enable family members to be with their child at the time of death.

Rituals can be understood as "defining" events: they define the death, the cause of death, the dead person, the bereaved, the relationships between the bereaved and others, the meaning of life, and societal values [69]. Rituals can help to restore a sense of balance to life; they help to strengthen the bonds that connect family members to others in their community. In many societies, death rituals are often extended over considerably more time than is common in American society. They may require isolation of the bereaved, the wearing of special mourning clothing or special markings, and even actions that seem unpleasant to outsiders, such as tearing at one's own clothing or hair. Westerners who are accustomed to a single funeral ceremony may fail to appreciate the religious, social, and personal significance of such events. Moreover, families from such societies who reside in the Western world may find themselves unsupported during their bereavement, particularly within health care institutions.

If grieving involves engaging in certain rituals and being able to think, feel, and do certain things in a social environment that supports those endeavors, being in an alien social environment can be very difficult for the bereaved. Grief is not an individual response, but a social one. Moreover, proper grieving may require things as well as people, and those things may not be available when one is away from one's home community. In addition, when one is living far from home, a death can set off grief for deaths that occurred at the time the person left his homeland, for the home left behind, for a lost way of life, or for other things related to leaving [69]. Consequently, such individuals may feel overwhelmed by the totality of their losses that have been triggered by the death of their child.

In some cultures, the outward expression of feelings is not always recommended or socially appropriate. One study compared and contrasted the experiences of Korean, Taiwanese, and American families whose child had died from cancer [70]. In Korea, external expression of grief when one's parents die is expected and almost demanded, whereas when a child dies, the expression of grief by crying is more complicated. Internal grief may be more common. Parents may not wish to burden others and especially do not want to add to the burden of their surviving children; therefore, they cry alone or may smile artificially when they wish to cry. However, Korean parents were like Chinese and American parents in wanting to have a certain period of time to externalize their grief feelings, and in appreciating private space and time to do so. Similarities in grief responses were reported in a second study that explored the experiences of bereaved mothers following a child's death from cancer in Canada, Norway, England, Greece, Hong Kong, and the United States [71].

Somatic expression of emotional distress and grief is also reported in a study by Caspi et al., who conducted interviews with 161 Cambodian refugees living in America. An extraordinarily high percentage of these families (43 percent) had experienced the death of one or more children in the previous 10 years, a result of having lived in a war-torn country before emigrating to the United States [72]. While objective measures showed physical and daily functioning to be unaffected by having lost a child, the bereaved parents strongly believed that they were limited in their ability to do simple physical activities like climbing a flight of stairs or going for a short walk. They also felt that they had difficulty accomplishing chores such as doing laundry or going shopping. Bereaved parents were far more likely to be experiencing somatic symptoms such as poor vision, pain, and numbness, as well as culturally defined symptoms such as *bebachet*—translated by the authors as a deep worrying sadness. However, they did not experience more symptoms of psychological depression than the nonbereaved parents.

Similar patterns may exist amongst Mexican families as well, although findings are sparse. Using ethnographic methods, Fabrega described how families respond to the unexpected death of a child in rural Mexico [73]. He found that behavioral and psychological expressions of grief were very common in bereaved mothers, and were understood by the family and the community as manifestations of acute somatic illness. Help was sought from a traditional healer who treated the mother with medicinal herbs and restorative teas.

The question of meaning, and specifically the influence of culture on how families understand the illness and death of their child, has not been adequately addressed in the research literature. However, isolated findings speak to the importance of how families understand the cause of their child's death and the significant role of culture in shaping these explanatory models. Miller, the author of a popular book on culture and bereavement following the death of a child, indicates that parents of all cultures struggle with finding the answer to two questions following a child's death: "Why did my child die?" and "Why has this happened to me"[74]? The answers to these questions, however, may vary markedly across the world. In Brazil, Bali, Sulawesi, West Africa, and India, the answers have one thing in common: they each turn attention from the ones who are grieving to the child who has departed. In these places, parents are asking for information about the child's fate, his destiny, his time, his choice. In other cultures, particularly in the Western world, parents are more often wondering what went wrong and, in many cases, what they did wrong. Guilt seems to be characteristic of all cultures but is more prevalent in some societies. In some cultures, for example, the mother is seen as being most responsible for children, so that when a child becomes ill and dies, the mother reexamines all her behaviors to find the cause of death. Such mothers carry a heavy load of guilt.

Clinical interventions to aid the bereaved must take into account cultural differences. It is critical to acknowledge that Western ways of grieving and disposing of the body are not universally accepted as the "right" way. It is also likely that our theories of grief and mourning, including definitions of "normal," are inappropriately based on Western behavioral norms. For example, a standard way in the West of dealing with grief is to talk—about one's experience, one's relationship with the deceased, one's feelings. But in some cultures, talking may disrupt hard-earned efforts to feel what is appropriate, and to disrupt those efforts may jeopardize one's health or safety. In some cultures, talk is acceptable, but one must never mention the name of the deceased person. In other cultures, talk is acceptable as long as it doesn't focus on oneself. Even in the West, however, not everyone is open to talking. It is important not to label those who do not openly express their emotions as "pathological"[75]. In fact, the concept of pathological grief is primarily a Western construction. A mother in the slums of Cairo, Egypt, locked for seven years in the depths of a deep depression over the death of a child is not behaving pathologically by the standards of her community [76]. There is enormous variation in what is considered appropriate behavior following death. The ideal among traditional Navajo is to express no emotion, while in tribal societies a death may be met with wild outpourings of grief, including self-mutilation [77]. Even in certain Mediterranean societies, widowhood was considered a permanent state of mourning, and mourning clothes were worn for years, if not decades. In a compelling book, titled *Consuming Grief*, Conklin describes how native Amazonians assuaged their grief by consuming the body of their dead affinal[5] kin [78].

Marked generational differences in dealing with death are common. Typically, the older generation seems to be more observant of the traditional rituals, perhaps especially true in immigrant communities. It is important for outsiders who want to help to be sensitive to the possibility of different needs, expectations, standards, and practices in different generations. Moreover, if one's informant about a particular culture is a younger person, the information that is given may not accurately represent an older person's experience.

Expertise in dealing with someone from another society is qualified by the limits of one's experience and knowledge. Even if one has dealt with bereaved people from a given small-scale society, one cannot presume that one's experience will help in understanding the next bereaved person from that society. Moreover, many people in any one country or society may function within a mix of cultural traditions. Therefore, it may be most helpful to assume that whatever grieving families do has meaning and value to them and then to try to understand it as they do. The task of the outsider who wants to help is to understand the cultural realities of the bereaved, not to fit what they do into a framework that makes sense in terms of the outsider's culture. Much remains to be learned from the bereaved themselves.

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[5] Affinal kin are those related by marriage bonds, for example in-laws, as opposed to those family member related by blood ties, such as parent/child or sibling relationships.

IT'S NOT JUST THE PATIENT AND FAMILY WHO "HAVE CULTURE"

Cultural Aspects of Biomedical Practice in Pediatrics

The lack of pediatric palliative care services in the United States is itself a telling cultural statement. One might ask why the United Kingdom has 23 hospices dedicated to providing services to children with life-threatening illness—more than the entire United States [10]. It is not an accident that hospice and palliative care did not originate in the United States. The shape of our current health care system—which privileges research over care and curative efforts over palliation—reflects firmly established national priorities. Making this observation is not an indictment, rather it is an acknowledgment of the profound paradox embedded in our health care system. Our technological successes carry the seeds of our failures. Indeed, our values have led to the development of cures for many pediatric ailments and an increase in the number of children living with serious chronic illness. Paradoxically, the high value placed on children and their care, and the fact that child death is viewed as a particularly profound tragedy, provide the cultural roots of our current lack of palliative care services for children. Biomedical practices express the cultural assumptions of the wider society, in this case supported as well by political and economic forces. Short, episodic illness is well covered by health insurance. But even relatively well-off middle-class families may experience serious economic consequences when a child is ill and dies over a long period of time. One study estimated an average of $140 per week in uncompensated "indirect" costs associated with care [10].

Unexamined cultural assumptions are apparent throughout biomedicine. Even within the subspecialty of pediatrics a single, monolithic culture does not exist. There are significant differences within subspecialties and between professions. Research has revealed that practitioners interpret the exact prognosis of patients with life-threatening illness quite differently. Even diseases that technically have identically poor prognoses may not be considered equally "terminal" [48]. For example, do-not-resuscitate orders are written more commonly for some diseases and conditions, in spite of similar outcomes [79].

Significant differences exist between professions as well, particularly between physicians and nurses, who often view their roles and responsibilities in end-of-life care quite differently. Muller and Koenig found that understanding a patient's status as "terminally ill" was much more salient to the fundamental tasks of nursing than for internal medicine, where the work of diagnosis dominated other activities, often to the exclusion of considering whether a patient's disease trajectory included death in the foreseeable future [80]. (An exception was extremely time-limited trajectories, clearly revealed by physiological deterioration or imminent dying. In those situations the patient's terminal condition was the preeminent consideration.) Anspach has demonstrated how physicians and nurses practicing in neonatal intensive care, a site of many infant deaths, have diverse understandings of their patients' prognoses [81]. She attributes these different assessments to the varied interactions with patients associated with the roles of nurse or physician. Based on situated knowledge, each professional group "reads" the data about an infant's likely outcome differently. These differing assessments complicate efforts to communicate with family members and negotiate withdrawal and withholding of life-extending technologies [4]. Family members may realistically complain they are hearing a different story depending on whom they talk to on a given day.

Recognizing Cultural Differences That Are Easy to Respect in Practice Versus Those That Offer Fundamental Challenges to Pediatric Palliative Care Providers

Respecting cultural difference may offer a profound challenge to health care practitioners' most fundamental values. In perhaps the best "text" explaining the cultural dynamics underlying the treatment of a critically ill child, Anne Fadiman, in *The Sprit Catches You and You Fall Down*, offers a detailed account of how the physicians caring for a young Hmong child with life-threatening, difficult-to-control epilepsy ultimately fail her because of their desire to offer her "state-of-the-art" care identical to that offered to any of their other patients [82]. Through her detailed ethnographic account, Fadiman reveals how in this case the physician's quest for the "perfect" treatment was the proverbial "enemy of the good." The parents of the child, Lia Lee, were refugees from the American war in Southeast Asia, illiterate in their own language, with ideas about the cause of epilepsy and its appropriate treatment that were completely at odds with the views of the Western health care team. They were not, however, the only participants in the exchange shaped by cultural background and context. Fadiman's work documents the culture of biomedicine, explaining with great clarity how the physicians' uncompromising dedication to perfection kept them from negotiating a treatment regimen acceptable to all.

The Need for Clinical Compromise in Order to Improve Outcomes and Care

Often in cross-cultural settings it is imperative to learn to compromise one's own clinical goals in order to meet the patient "halfway." Fadiman's book recounts the profound miscommunication between the pediatricians and family physicians involved in Lia's care, the Lee family, and the broader Hmong community. When her parents are unable to carry out a complex regimen of antiepilepsy drugs, the child is turned over to the state's child protective services agency, provoking a profound and deepening spiral of tragedies. In the end, the physicians wish they had compromised their goals and prescribed a more simple medication schedule. Ironically, the parents' observation that the medicines were making Lia sick proved true in that one of the antiepileptic drugs contributed to an episode of profound sepsis that resulted in Lia's persistent vegetative state. A number of American medical schools assign this book as a required text in cultural sensitivity training. Its brilliance lies in revealing both sides of a complex equation: a Hmong enclave transported to semirural California and a group of elite, Western-trained physicians and health care practitioners caught up in a drama they cannot understand, not because the Lee family's cultural practices are so esoteric, but because they fail to recognize how their own cultural assumptions and deeply held values limit their ability to help the ill child.

The Culture of Biomedicine and Biomedical Death Reflect Features of U.S. Society

National efforts to improve end-of-life care for both children and adults often include the notion that "cultural change" or promotion of "cultural readiness" is essential for reform efforts to be successful [83, 84]. Yet, what this cultural change would look like and what barriers to such change exist are rarely itemized. National public awareness campaigns such as "Last Acts" have used a variety of strategies to change the "culture of dying" in America, including working with the media. For example, one strategy has been to sponsor script-writing conferences to encourage widely viewed television programs, such as "ER," to include realistic stories about patients near the end of life. In fact, a recent episode focused on end-stage cystic fibrosis. Narratives created for television might convey the idea that a comfortable, pain-free death is possible and should be "demanded" by patients and families as an essential feature of a comprehensive health care system. The stories might convey the important lesson that physicians and other caregivers may forgo their most aggressive efforts at cure without abandoning patients. Unfortunately, these efforts at change ignore a fundamental and problematic social fact—a profound cultural resistance to giving up hope for recovery, a problem in EOL care generally that is most pronounced when a family must negotiate the details of a child's dying while simultaneously mourning the loss of that child's future. Difficult for all families and for patients of all ages, this negotiation is particularly troubling if the family has no idea of the cultural "script" being followed by health care providers.

Research by Koenig and her team revealed that adult patients from minority backgrounds, in particular recent immigrants, seemed to lack a sense of the narrative structure of EOL care that English-speaking, middle-class European-American families understood more readily. In particular, the idea that patients and families would make an explicit choice to abandon curative therapy, followed by the "limiting" of aggressive interventions like intensive care and cardiopulmonary resuscitation, did not seem to be a story patients understood. Recent Chinese immigrant patients could not answer questions that presupposed a transition from curative to palliative goals; it was simply beyond their experience [85]. In their experience, doctors do not "stop" treating patients. Efforts to change the culture through engagements with the media—encouraging op-ed pieces in newspapers, script-writing workshops, and so forth—may educate potential patients about existing approaches in palliative and hospice care. Of course, efforts to target media serving different communities speaking different languages would be critical.

However, one cultural barrier is difficult to surmount. Before physicians can recommend palliative care and before patients and families agree to it, in our current system one must first accept the possibility that death is imminent or at least that one's likely survival is seriously limited. Eventually, current reform efforts—most prominent in pediatrics—to introduce palliative care early in a trajectory of disease or illness may decrease the need for patients or families to embrace a clear transition between curative and palliative modalities of treatment. But it is unlikely that the tension caused by the need to balance conflicting goals will ever dissipate totally.

Thus, even if one embraces the narrative of limiting aggressive treatment and adopting comfort care, including attention to spiritual and interpersonal goals, as a good idea "in principle" for children facing death, there still exists the radically difficult and jarring transition itself, the need to imagine your child, your family, as now taking center stage in a particular EOL narrative. It is no longer theoretical but real. The resistance to seeing oneself, and particularly one's child, in this role is considerable and may prove insurmountable for many. A set of powerful cultural narratives operates to feed this resistance and encourage its perpetuation. Consider, as one example, the heroic narratives of successful research and triumphant cure that are much more often portrayed by the media than stories of failed therapy and excellent end-of-life care [86]. The content of public relations materials produced by medical centers and ads published by drug companies convey powerful cultural metaphors that are directly counter to the mundane realities of palliative care, often focused on managing symptoms such as constipation. Hospital ads suggest that it is vital to "keep shopping" and eventually you will find the program offering the experimental or innovative therapy that will cure your child. The heroic search for cure is celebrated in media accounts such as the film *Lorenzo's Oil* or a recent *New York Times Magazine* profile of a family seeking gene therapy to cure their child's severe, life-limiting genetic illness (Canavan disease) [87]. A full analysis of the culture of dying in the United States must acknowledge these powerful counterimages.

It is important to bear in mind that such stories and advertisements are features of a particular political economy of health care. Unlike providing palliative care, administering chemotherapy generates profits even when the likelihood of its success is low. One recent study—in adults, no comparable data exist in pediatrics—documents that curative chemotherapy is often given very close to the end of life, when its use may be futile [88]. This is not to suggest that individual physicians are primarily motivated by financial gain when they prescribe chemotherapy that they know has little chance of success; that is not the case. Rather, it is critical to acknowledge that the economic structure of health care for children creates few barriers for the use of advanced life-prolonging therapies such as chemotherapy or days in an intensive care unit, at least for those with insurance or access to government-funded programs. The most intensive services often generate the highest profits. By contrast, hospice and palliative care programs are often supported by philanthropy; providing excellent palliative care, especially for children, is at best revenue neutral and more often a money loser for medical centers [9, 89]. Thus, the political economy of health care supports what Daniel Callahan has called "technological brinkmanship," or the aggressive use of technology until the last possible moment, often leading to its overuse [90]. Culture shapes the realities of care at many levels.

CONCLUSION

Clinical Implications: What Can Be Done Now?

In spite of the lack of firm research results on palliative care practices in diverse ethnocultural communities, there is much that can be accomplished immediately to encourage appropriate care for children with life-limiting conditions and family members. Since communication is difficult in all pediatric palliative care settings, specific efforts to improve the availability of language translation services are clearly indicated. This approach is consistent with national cultural competency standards that focus on language interpretation as a key goal [14]. Efforts to improve the availability of interpreters should focus on the documented complexities of translating within the context of profound cultural, as well as linguistic differences, and must acknowledge the issues specific to ethically sensitive end-of-life negotiations. Translators must receive specific training to be effective. Many organizations recommend that family interpreters not be used. Since it is unlikely that family members will ever be completely replaced by professional interpreters, it may be more realistic to suggest that health care providers understand the potential dilemmas associated with the use of family members and seek to control or minimize problems.

Enhanced education about the role of ethnocultural variation in improving outcomes in pediatric palliative care is also a reasonable goal. However, the exact content and focus of such educational programs, especially in the complex arena of children who are dying or who will clearly not survive to adulthood, is still unclear. There is a naïve hope that cultural competency training will lead effortlessly to improved outcomes. It may under some circumstances, but significant cultural difference inevitably brings with it true conflicts that may not be resolved, even with ideal, open communication and mutual respect. In some situations, the distance between families and the health care team may be too profound to overcome in spite of considerable efforts by all. Anne Fadiman recounts a physician involved in the care of Lia Lee, who lamented that even if it had been possible to send the Lee family to medical school with an interpreter, the difference in world views separating a refugee Hmong family from mainstream Western pediatrics would remain insurmountable [82].

In addition, many current approaches to "competency" training do not use a sophisticated concept of culture or cultural difference and instead encourage a "cookbook" approach focused on learning the knowledge, attitudes, and practices of specified ethnic groups [91]. This approach is flawed in two major ways. First, it is impossible for any practitioner to memorize a catalogue of the world's ethnocultural groups. And even if such a list of "traits" could be committed to memory or stored in a database, it would still be necessary to verify with each family and even each individual within a family whether he or she adheres to a certain belief or practice relevant to end-of-life care. Intracultural variation is great; cultures change and transform—they are in constant motion. Burial practices or rituals to manage grief may change by necessity following immigration. Laws prohibit certain ways of disposing of bodies or body parts. On the other hand, the time–space compression characteristic of globalization may lead to the preservation of certain practices in spite of significant odds. Chertow describes how Tibetan Buddhist refugees in Chicago preserved key ritual practices conducted at the moment of death, linking to the appropriate religious specialist in the Himalayas via long distance telephone calls [92].

How one thinks about culture matters. A serious flaw in current cultural competency training is a simplistic and unsophisticated account of culture itself [7, 93]. It is almost as if there is a belief that culture codes for—and predicts—behavior in the same way that DNA codes for a certain protein. Reductionist approaches to education in cultural difference will inevitably fail because, at best, they teach a few general clues that must be verified through interaction with a family and, at worst, they model an unsophisticated approach to culture that leads to simple stereotyping, thus doing more harm than good. Educational techniques and programs that emphasize an interpretive approach to understanding cultural difference are more likely to be successful. These often are "case based"; trainees must interpret the relevance of cultural difference for a specific patient and family in a particular social and historical context [94]. This approach also allows for attention to issues such as racism, socioeconomic status, and the ways in which social forces intertwine with ethnocultural difference. Boxes D.1 and D.2, based on previous work by one of the authors, suggest an approach to the role of cultural difference in health care generally and provide a "template" for clinicians to use when assessing the features of cultural difference most relevant in providing EOL care for children and families.

At the level of health policy, there are also innovations that could improve cross-cultural palliative care for children immediately. However, they may not require a focus on ethnocultural difference, per se. Specifically, efforts to integrate palliative care early in the course of diagnosis for chronic or life-threatening conditions would overcome cultural resistance to palliative care that has at its cause the demand that children and families openly acknowledge and accept that a child is dying, as required by some hospice programs. Such integration of palliative care is a major theme of the IOM report on pediatric palliative care [9]. Although this resistance to acknowledging death is often most pronounced among families from certain Asian backgrounds (such as Chinese Americans or Korean Americans) [8], our research and a review of the adult literature suggests that it is found among all U.S. patient groups. In this instance, a change in policy based on research findings with culturally diverse patients and families may benefit all by calling into question the desirability of requiring that patients (and families) embrace death as a first step to receiving excellent EOL care [95]. And requirements that curative therapies—or supportive care that is costly, such as parenteral nutrition—be forgone as a precondition of hospice enrollments are clearly harmful, and may provide an added barrier to hospice care for children and families where cultural expressions of hope for future recovery (or desire for a miracle) may continue throughout a child's dying trajectory.[6] Indeed, the expression of hope for an ill child's recovery is inevitably shaped by religion and ethnocultural background, sometimes in ways that are difficult to predict.

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[6] Public testimony presented to the IOM committee raised this point eloquently.

Box D.1
Cultural Difference in Health Care

Understanding Cultural Difference

- The meaning of ethnocultural difference in health care must be assessed and understood within a particular social and historical context.
- Cultural values and attitudes are fluid, not fixed; individuals may or may not embrace particular beliefs.
- Culture does not predict individual behavior in a straightforward way; it is not a predictive "variable."
- Culture is not simply a feature of ethnically or racially different "others."
- "Cultural" interpretation reveals significant differences among health care professionals.
- Cultural pluralism means diversity among care providers as well as patients/families.

Respecting Difference Without Stereotyping

- Approach the individual first, assess that individual within the context of his or her family.
- Patients and families should never be approached as empty vessels, the "bearers" of a particular culture.
- As with statistical or epidemiological "data" about an individual patient, clinical "hunches" or inferences must be evaluated for relevance to a particular patient/family situation.
- The "dilemma of difference" means that respecting difference may be in conflict with goals of equal treatment.

A Template for Assessing Ethnocultural Variation

Rather than a list of cultural "traits" (specific to different cultural groups) it is more helpful for clinicians to utilize a "template" that describes the range of variation. Each individual and family can be evaluated with this checklist in mind. For end-of-life care, this list might include the elements listed in Box D.2.

We have suggested that the most serious cultural conflicts are likely to arise as disputes about explicit decision making near the end of life. Many accommodations to cultural practices will be relatively easy to implement, such as modifications to protocols for handling the body after death, or allowing healing rituals in the pediatric or neonatal intensive care unit—assuming, that is, that the rituals do not challenge the predominant biomedical approach to the child's care. In these situations, hospitals and home health agencies can implement flexible policies that take account of difference. Community consultation may be helpful in developing shared goals. However, certain bioethics ideals, such as shared decision making with parents, may actually do harm in some cross cultural situations where the parents are looking for explicit recommendations from an authoritative voice within the health care team. When shared decision making is interpreted as requiring that parents must actively *decide* to "allow" their child to die, conflicts may intensify. We do not yet understand the consequences—long or short term—of active parental involvement in decisions to terminate treatment. Similarly, efforts to implement the practice of "assent" to care (or withdrawal of therapy) by older children and adolescents [10], although well meaning, may create difficulties for families unused to the American ideals of self-determination. The situation will be most acute when family members have different levels of familiarly with this ideal and, in fact, may reject it outright in favor of decision making by parents, community leaders, or deference to medical authority.

Suggestions for Future Research: What Do We Need to Learn? What Is the Correct Balance Between Descriptive Research, Normative Analysis, and Policy Research?

Clearly, there is a great need for additional descriptive research documenting the relevance of cultural difference to end-of-life care for children and their family caregivers, including a commitment to asking hard questions about the impact of immigration, poverty, and racism on the experience of families. With the profound, well-documented health disparities in morbidity and mortality found in the United States, it is likely that resistance to accepting excellent end-of-life care may persist in certain communities in spite of our best efforts to educate the public about the importance of palliative care. The legacy of high death rates and lack of access will remain salient into the future. We need to target research toward an examination of cultural resistance, to understand its sources and manifestations. Research focusing on the outcome of improving trust in patient–provider relationships needs to acknowledge the discrimination embedded in the U.S. health care system in the past and the reality that unequal care continues, in spite of our best efforts [12, 96]. Research designs should focus not just on the culture of the patient and his or her family, but on the culture of care providers—and on how the cultural assumptions of biomedicine are embedded in systems of health care delivery.

There is also the need to ask the normative questions that inevitably arise once descriptive research findings about cultural difference are documented. Under what circumstances should specific clinical guidelines be altered to meet the needs of certain ethnocultural groups, if indeed they should be modified? What are the limits to cultural compromise? Who is best suited to make these determinations—courts, ethics committees, individual clinicians? Claims about respecting difference based on religious beliefs are granted a higher status of protection as a constitutional right.

Box D.2
A Template for Assessing Ethnocultural Difference in Caring for Children with Life-Limiting Conditions and Their Families

1. Assess the actual language used by the child and family members to discuss illness and disease, including degree of openness in discussing diagnosis, prognosis, and death itself.

- Can the word cancer be spoken or can other potentially stigmatizing diseases, including HIV or genetic illnesses, be named?
- What is understood as the cause of the illness? What is its likely course?
- Can the high likelihood of premature death be acknowledged openly, or will this be seen as potentially dangerous?
- Is there a desire to keep information contained, or can the family's broader community be involved, such as schools, churches?
- When conducting negotiations or discussions through a language interpreter, whether a professional translator or a family member, consider the emotional significance of the information to be communicated, the appropriateness of a particular individual to convey such information, and the possibility of engaging the interpreter as a source of information about the family's goals and desires.

2. Determine whether the locus of decision-making authority is with the parents exclusively, or includes a larger social unit, such as the family as a whole.

- If the patient is an older child or adolescent, determine whether the child is expected to be a participant in medical decision making, or is seen as needing protection from such a role.
- Determine the family's expectations about the role of the health care team in decision making; specifically, do they value directiveness as opposed to shared decision making, do they have familiarity with the "team approach" characteristic of pediatric palliative care?

3. Consider the relevance of religious beliefs, particularly about the meaning of death, the existence of an afterlife, and belief in miracles.

- Consider the meaning of a child's suffering from the family's point of view, does the suffering of a child or the loss of an infant have particular meaning?

4. Evaluate whether the expression of physical pain (or other symptoms) is allowable or considered a weakness in character or lack of courage.

- How do culturally-shaped gender roles create expectations about symptom control?

5. Assess how "hope" for a future recovery is negotiated within the family and with health care providers.

- Is hope directly correlated with continuing aggressive medical interventions?

- Is hospice referral or the suggestion of care at home (vs. the hospital) seen as an indication that health professionals are "giving up"?

6. Assess the family's degree of fatalism vs. active desire for control of events into the future.

- Does home care increase a sense of control or lead to fears of abandonment?

7. Determine the family's views about "appropriate" supportive care for their child or infant.

- Do parents and other family members wish to participate actively in the physical care, including technical nursing interventions, of their child?
- Do parents and families believe their role is to provide emotional support or tangible services, such as special meals?
- Is the child's independence promoted, or is a dependent role sanctioned as appropriate in the context of chronic, life-limiting illness?

8. Consider issues of gender and power relationships, both within the patient's family and in encounters with the health care team.

- Assess whether traditional gender roles may exclude women or girls from full participation in shared decision making.
- Is the physician or other care provider granted great authority and respect?
- Do family members fear retaliation for expressing their desires?

7. Take account of the political and historical context, particularly poverty, refugee status, past discrimination and lack of access to care.

- Have refugees suffered inordinate losses that shape their response to a child death?
- Do groups that historically have been denied access to health care services suspect that decisions to limit treatment are the result of discrimination, cost control efforts, or possibly the desire to procure organs for others?

8. Determine who "owns" the body and how the body should be approached and handled after death.

9. When planning bereavement services, consider whether it is appropriate to express one's grief openly, under what circumstances, and for how long.

10. To aid the complex effort of "interpreting" the relevance of cultural dimensions in a particular case, make use of available resources, including community or religious leaders, family members, and language translators.

However even in the case of protections of religious freedoms, exceptions are made in the case of minor children when the situation is judged to be life threatening. In pediatrics, the classic example of the limits of parental authority is the use of court orders to provide life-saving blood transfusions to infants and children when the parents are devout practitioners of the Jehovah's Witness faith. Respecting ethnocultural difference in end-of-life care will also require attention to the normative practices of courts and hospital ethics committees. What assumptions undergird their deliberations? The physicians caring for Lia Lee had little difficulty convincing a court that they knew her interests better than her parents. Policies based on a careful examination of the interaction among religious freedoms, parental and child rights, and efforts to implement culturally sensitive care are needed. Excellent descriptive research on ethnocultural difference can inform policy development but will not provide easy answers to the normative questions. Developing policies to guide care for dying children is difficult under the most ideal circumstances [97]. Determining the limits of culturally sensitive care for children with life-limiting conditions and their families will continue to be a daunting challenge in the clinic, in the courts, and for policymakers and legislators.

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APPENDIX E

BEREAVEMENT EXPERIENCES AFTER THE DEATH OF A CHILD

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INTRODUCTION

The death of a child of any age is a profound, difficult, and painful experience. While bereavement is stressful whenever it occurs, studies continue to provide evidence that the greatest stress, and often the most enduring one, occurs for parents who experience the death of a child [1–6]. Individuals and families have many capabilities and abilities that allow them to respond to interpersonal loss and to emerge from the experience changed but not broken. The few studies that have compared responses to different types of losses have found that the loss of a child is followed by a more intense grief than the death of a spouse or a parent [5]. This conclusion must be considered cautiously, however, since these studies have typically confounded sample differences in age and degree of forewarning [7]. Forewarning is important because according to the Centers for Disease Control and Prevention [8], about half of child deaths occur during infancy, most with limited preparation time. Unintended injuries are the leading cause of death in children age 1 to 14 and account for more than half of all deaths among young people 15 to 19 years of age. In addition, while the overall death rate for children aged 14 and younger has declined substan-

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tially since the 1950s childhood homicide rates have tripled and suicide rates have quadrupled [9]. Recent findings suggest that parents of children who die from any cause are more likely to suffer symptoms of traumatic stress and experience more severe problems with emotional dysregulation than occurs with the death of a spouse [10].

Integrating the loss of a child into the life narrative, making sense and new meanings of such a wrenching event, presents a challenge to parents and family [11]. Although once common, deaths of children between the ages of 1 and 14 now account for less than 5 percent of all deaths in the United States; about 57,428 infants, children, and adolescents died in 1996. In contrast to the past when families might have had several children die, death in childhood is now rare. Children are expected to live to adulthood. Conflicting with current life-cycle expectations, the death of a child may be experienced as the death of the parents' future dreams as well as creating a profound change in their present roles and functioning. Increases in the incidence of suicide and homicide in adolescents and random acts of violence in our society have increased the risk of traumatic stress responses for bereaved family members.

Medical advances have prolonged the dying process for children as well as adults, making terminal illness in children longer and more complex, often requiring parents to make difficult decisions about end-of-life care. Preliminary research evidence suggests that family bereavement may be adversely affected by the inability to reduce suffering during the child's dying process [12].

This appendix reviews the unique features of the parent role; the importance of the parents' continuing memory of the child; the impact of variations in atypical, unresolved, and catastrophic deaths; and the special features of parents' loss of an infant, a school age child, and an adolescent, and the impact of a child's death on siblings and other family members. Also reviewed are interventions and research directions.

BEREAVEMENT, MOURNING, GRIEF, AND COMPLICATED GRIEF

Bereavement is a broad term that encompasses the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one [13]. It is widely recognized as a complex and dynamic process that does not necessarily proceed in an orderly, linear fashion [14, 15]. Rather, individuals have concurrent and overlapping reactions that may recur at any time during the family's bereavement process. Bereavement includes the internal adaptation of individual family members; their mourning processes, expressions, and experiences of grief; and changes in their external living arrangements, relationships, and circumstances.

Grief is a term that refers to the more specific, complex set of cognitive, emotional, and social difficulties that follow the death of a loved one [16]. Individuals vary enormously in the type of grief they experience, its intensity, its duration, and their way of expressing it. Mourning is often defined as either the individual's internal process of adaptation to the loss of a loved one or as the socially prescribed modes of responding to loss, including its external expression in behaviors such as rituals and memorials. Taken together, the grief and mourning processes are understood to be a normal and universal part of the natural healing process that enables individuals, families, and communities to live with the reality of loss while going on with living [17, 18].

Complicated grief in adults refers to bereavement accompanied by symptoms of separation distress and trauma [19]. It is defined as occurring following a death that would not objectively be considered "traumatic" (i.e., not resulting from an unanticipated, horrifying event) and requires that the person experience (1) extreme levels of three of the four "separation distress" symptoms (intrusive thoughts about the deceased, yearning for the deceased, searching for the deceased, and excessive loneliness since the death), as well as (2) extreme levels of four of the eight "traumatic distress" symptoms (purposelessness about the future; numbness, detachment, or absence of emotional responsiveness; difficulty believing or acknowledging the death; feeling that life is empty or meaningless; feeling that part of oneself has died; shattered world view; assuming symptoms of harmful behaviors of the deceased person; excessive irritability, bitterness, or anger related to the death). These symptoms must have lasted at least six months and led to significant functional impairment. Because parents of children who die are at greater risk for traumatic stress symptoms and emotional dysregulation, they are at greater risk of complicated grief [10].

Siblings of children who die have also been found to be at greater risk for externalizing and internalizing problems when compared to norms and controls [20-23] within 2 years of the death. Complicated bereavement has been less clearly defined for children but is also thought to include symptoms of PTSD, other psychological characteristics associated with this disorder, and grief. The Expanded Grief Screening Inventory is a 20-item measure developed to assess complicated bereavement in children and adolescents. Factor analysis indicates three independent factors including positive reminiscing, intrusion of PTSD on the grieving process, and existential loss [24-27]. This measure has shown strong psychometric properties and is currently being used to follow the clinical course of such complicated bereavement in children.

THE PARENT ROLE AND LOSS OF A CHILD

The process of conceiving, giving birth, and raising offspring is shared by virtually all living animals. The human experience of this process, however, adds many elements of psychological, social, and meaning construction. At various stages in the life cycle, men and women relate to child-conceiving and child-rearing roles as central to their existence. Of the bonds formed within the family, the parent–child bond is not only particularly strong, it is also integral to the identity of many parents and children [4]. Much has been written about the significance of the parent–child attachment bond as a major organizer of the individual parent's positive sense of self and significant relationships with others [17].

Parents of children and adolescents who die are found to suffer a broad range of difficult mental and physical symptoms. As with many losses, depressed feelings are accompanied by intense feelings of sadness, despair, helplessness, loneliness, abandonment, and a wish to die [28]. Parents often experience physical symptoms such as insomnia or loss of appetite as well as confusion, inability to concentrate, and obsessive thinking [17]. Extreme feelings of vulnerability, anxiety, panic, and hyper-vigilance can also accompany the sadness and despair.

Grieving parents evidence anger as part of the normal reaction to the loss of their child [17, 29–33]. This may be expressed as intense rage or as chronic irritation and frustration. It may be directed at the spouse, at other family members, at the professional staff, at God, at fate, or even at the dead child. Anger may also be directed at the self, creating feelings of self-hatred, shame and worthlessness [28, 34-36].

Children take on great symbolic importance in terms of parents' generativity [37] and hope for the future. All parents have dreams about their children's futures; when a child dies the dreams may die too. This death of future seems integral to the intensity of many parents' responses. Three central themes in parents' experience when a child dies include (1) the loss of sense of personal competence and power, (2) the loss of a part of the self [38, 39], and (3) the loss of a valued other person whose unique characteristics were part of the family system. While guilt and self-blame are common in bereavement, they are especially pronounced following the death of a child. The parent's role competence as the child's caregiver, protector, and mentor is severely threatened by untimely death.

Parents assert that their grief continues throughout their lives, often saying, "It gets different, it doesn't get better." Words such as "closure" can be deeply offensive. The few studies that have followed parents for years after the child's death support the concept of their preoccupation with the loss of children across the life cycle [4, 40–42]. Klass [39] refers to the "amputation metaphor": the vivid sense of a permanent loss of a part of oneself that may be adapted to, but will not grow back. Freud's letter to a friend about the loss of his eldest daughter describes this eloquently:

> For years I was prepared for the loss of my sons (in war); and now comes that of my daughter. Since I am profoundly irreligious there is no one I can accuse, and I know there is nowhere to which any complaint could be addressed. "The unvarying circle of a soldier's duties" and the "sweet habit of existence" will see to it that things go on as before. Quite deep down I can trace the feelings of a deep narcissistic hurt that is not to be healed [43, p.20].

Parents resist the idea that they will recover from their child's death. Rather than "recovery" or "resolution," which suggest a return to pre-loss functioning, "reconciliation," and "reconstitution" have been used to describe the post-death period because these terms more adequately reflect the profound changes that take place when a child dies. They express the reality that even the successful mourning process results in a transformation in the person consequent to the death of a loved one [44]. Despite traditional assumptions that all bereaved individuals must mourn, prospective studies have shown that considerable numbers of bereaved individuals evidence no overt signs of grieving or of the reconstitutive processes associated with grieving (for a review see [1]). The question these findings raise is to what extent this type of resilient pattern may also be found among those mourning the death of a child [27].

CONTINUING BONDS: THE TWO-TRACK MODEL OF BEREAVEMENT

There is little doubt that most persons respond with emotional and physiological distress following loss. Equally apparent is the fact that the bereavement response is predominantly one of readjusting and recalibrating the often covert psychological attachment to, and preoccupation with, the person now deceased. However, most studies have assumed that a reduction of symptoms defines "recovery" and constitutes a successful bereavement outcome. The parent's continuing investment in the relationship with the deceased has often been neglected. In a recent study of parents of infants who died of SIDS (sudden infant death syndrome), the phenomena associated with the bereavement response had a very different time frame and trajectory when the continuing investment in the relationship with the deceased was assessed [4].

The Two-Track Model of Bereavement [41, 42] combines the perspective of both the symptomatic bio-psychosocial response to bereavement and the relationship with the deceased. The bereavement response is understood to unfold along two multidimensional axes or tracks that are generally significant to understanding human adaptation to life demands. The first track focuses on how people function generally, and in the case of loss, it focuses on how functioning is affected following death. The second track focuses on how people are involved in maintaining and changing their relationships with significant others. In the case of bereavement, this relational track focuses on the bereaved parent's emotions, memories, and mental representations as they relate specifically to the deceased. Thus, the human bereavement response is not only triggered by the death of a significant person, but also initiates a degree of a continuing, albeit quite varied and modified, relationship to that person across the life cycle.

The implications of the Two-Track Model of Bereavement are relevant to theory, research, social support, and clinical and counseling interventions. It is important to consider not only the degree of overt function and dysfunction following loss, but also the ways in which memories and thoughts about the deceased are discussed, thought about, and serve an active role in the emotional and mental life of the bereaved. This ongoing connection is most vividly and consistently reported, indeed insisted on, by many bereaved parents in relation to the death of a child.

The two-track model proposes 10 domains for assessment on each of these axes following loss. On Track I, the individual's functioning is assessed in relation to (1) degree of anxiety and depressive responses and triggers of such responses; (2) other affective responses such as guilt and helplessness; (3) somatic concerns and dysregulation; (4) psychiatric symptoms including orientation and mental status, PTSD (post traumatic stress disorder) in both full-blown and partial forms, and suicidal ideation; (5) self-esteem; (6) the individual's ability to work or perform major life tasks; (7) the management of family relationships, including the relationship to spouse or partner, to other children, and to the extended family; (8) the nature and degree of involvement in interpersonal relationships outside the family; (9) the meaning framework or structure in which the bereaved is embedded and its current power; and (10) the degree to which the bereaved is able to invest emotional energy in life tasks and the type of life tasks that are engaged.

On Track II, the nature of the relationship to the deceased is assessed on 10 other dimensions. These include (1) the degree of preoccupation with memories and thoughts of the deceased; (2) the extent to which the description of the deceased is characterized by an inability or unwillingness to express the personal feelings brought about by the death; (3) the degree of idealization of the deceased; (4) the report of psychological conflict or contradictions in the relationship; (5) the degree and type of positive affect and emotion; (6) the degree and type of negative emotion toward the deceased; (7) the degree of closeness or distance from the relationship and experience of the deceased; (8) the affective experience when discussing the deceased (e.g., a parent who might say, "I always feel guilty thinking about how my son died"); (9) the presence of previously described grief phases of shock, seeking reminders of the deceased, disorganization, and restoration of a coherent life flow; and (10) the manner in which the deceased is memorialized both publicly and within the family. The individual with complicated grief is at greater risk for a variety of psychopathologies and physical illnesses.

ANTICIPATED, SUDDEN, TRAUMATIC, AND CATASTROPHIC DEATHS

The particular circumstances of the death (i.e., whether it was an anticipated death from illness, a sudden death, the result of a natural disaster or a terrorist attack that affects an entire community) also shapes families' bereavement reactions and service needs. When a child's illness is long, arduous, and filled with chronic crises, parents may develop unusual coping skills to sustain themselves and their family over many months and years or they may become worn down and depleted emotionally and financially by the entire process. Therefore interventions that provide practical and emotional support, skills training, and respite throughout the often long and crisis-filled period of the child's illness may aid families' bereavement. Psychological processes that parents have described as helpful include working through the need to assign blame for the disease including self-blame, becoming well informed about the disease and treatment, developing a more realistic assessment of the medical care system and an ability to communicate with professionals, becoming the child's advocate, and focusing on immediate treatment successes while maintaining a long-range perspective.

When the child's death can be anticipated, evidence suggests that effective management of the terminal illness period may also benefit the family's bereavement. In Wolfe's study [12], parents who were informed in a timely way that their child's illness had become terminal, that death was now inevitable, were able to make decisions that lessened their child's experience of pain and suffering. Compared to parents who were informed later, parents informed closer to the time the physician documented the terminal nature of the illness were able to reflect on the death with greater feeling of their own effectiveness in providing their child a peaceful death. With the longer terminal illness period made possible by medical advances, it is important for physicians to recognize and inform families when there is no realistic possibility of significant extension of life so that they can make informed decisions about palliative care or other concurrent model of care rather than curative treatments. Wolfe also found that families may be helped during this highly stressful period by mental health interventions.

Trauma theories and grief theories developed in separate literatures, and only recently has research begun to integrate the findings, concepts, and responses related to these overlapping but distinct conditions [45–48]. There is some evidence to suggest that those bereaved by traumatic deaths may benefit from initial interventions focused on reducing terror, fear, and anxiety about the circumstances of the death—that is, by interventions similar to those typically used for PTSD. Grief therapies have also been found effective in situations of complicated grief, of which traumatic grief is one example [47]. A failure to address the intertwining of these symptoms of trauma and loss early in their bereavement may compromise the individual's capacity to experience optimal recovery. For example, cognitive behavioral interventions suggested for trauma symptoms in a treatment manual by one research team include stress inoculation therapy, gradual exposure, and cognitive processing. Stress inoculation involves such techniques as feeling identification, relaxation techniques, deep breathing, progressive muscle relaxation, thought stopping, cognitive coping skills, enhancing the individual's sense of safety, psycho-education, and understanding the connection between thoughts, feelings, and behaviors [48]. Gradual exposure aims to separate overwhelming negative emotions such as terror, horror, extreme helplessness or rage from thoughts, reminders, or discussions of the death of the loved one. Cognitive processing aims to identify, correct, and challenge thoughts about the death that are unhelpful or inaccurate (for example "my dad must have suffered terrible pain during the explosion in the WTC"). In contrast, bereavement interventions focus on understanding the mourning process including feelings of loss and anticipation of reminders; resolving ambivalent feelings about the deceased, preserving positive memories of the deceased, accepting that the relationship is one of memory and recommitting to present relationships [48]. Nader describes convincingly how trauma prevents reminiscence necessary to grieve by evoking feelings of terror [25, 49]. Conversely, grief can also act as a traumatic reminder to the individual who may be experiencing a sub-clinical response to trauma or meet criteria for a formal diagnosis of PTSD, increasing anxiety in either situation. Those bereaved by deaths seen as nontraumatic are more apt to focus on their relationship to the deceased as an important feature of the experience of loss [44, 50]. Many aspects of parental grief reactions in response to the death of a child have been viewed as overlapping with traumatic symptoms, and indeed even parents whose children have cancer have been assessed to experience high levels of traumatic stress [51].

While the added stresses on families' bereavement related to violent and intentional death have been documented, bereavement interventions or follow-up care have only recently been offered in emergency room settings in a systematic way. Even when offered, families affected by homicide have seldom participated in follow-up bereavement services [52, 53]. Management of the final moments of an intentional or unintentional sudden death of a child continues to challenge professionals. Trauma research consistently supports the benefit of early intervention with traumatized individuals or families close to the time of the death in order to prevent later adverse reactions [54]. However, which interventions are most effective in which situations continues to be debated and awaits further research. For example, a summary of studies of critical stress debriefing in a 2001 review of the effectiveness of psychological debriefing concludes that though debriefing holds potential as a screening procedure, it does not prevent psychiatric disorders or mitigate the effects of traumatic stress. Still, people generally find the intervention of debriefing helpful in the process of recovery [55].

Catastrophic events such as the Oklahoma City bombing and the New York City World Trade Center attacks are very public with broad media coverage. They involve large numbers of deaths and unusual situations that present unique coping challenges during bereavement. Each catastrophic event has important commonalities with other catastrophes, but also important differences. It is these similarities and differences that need to be identified and studied in order to sharpen the ability not only to treat grief reactions, but also to prevent the development of PTSD as well as other forms of complicated bereavement

The World Trade Center attacks involved an attack from an outside hostile enemy that mobilized patriotism and national anger and gave rise to an ongoing war on terrorists throughout the world. Victims, especially firemen, policemen, and rescue workers were hailed as heroes in a war, killed in the act of protecting or saving others. Victims were mostly adults. Particular stresses for survivors include the ongoing search for bodies or body parts and the many continuing reminders related to the ensuing war as well as the many public memorials. For some, finding no remains hinders progress with the mourning process. Early reminders included frequently announced threats of other impending terrorist attacks and other purported enemy acts, such as sending anthrax in letters. The war itself constitutes a reminder interspersed with media reports of investigations about "what went wrong" that permitted the attack and the deaths of thousands.

POSITIVE AND NEGATIVE IMPACT OF A CHILD'S DEATH ON SELF, MARITAL RELATIONSHIP, AND FAMILY

Bereaved parents report a number of potentially positive as well as negative reverberations as a consequence of adjusting to loss. Bereaved individuals discuss their experience of having changed as a result of the loss, of learning to value anew what is really important to them, and of reviewing priorities. Some relationships with families and friends are strengthened, others are found wanting. Perhaps the most important relationship affected by child loss is that of the parents.

The majority of studies on this issue have focused on divorce as an indicator of stress upon the parents. However, there is a great deal of variability across studies regarding the divorce rates following a child's death. A recent review of these studies concluded that some writers give overly high estimates of divorce for which there is no empirical support [32]. On the other hand a substantial minority of couples do seem to experience severe marital distress. Bohannon [33], for example, conducted a longitudinal study of couples' grief responses and marital functioning. In her study, about 30 percent of husbands and wives reported having more negative feelings toward their spouse since the death; 19 percent of husbands and 14 percent of wives felt their marriages had deteriorated since the death. About the same proportion had considered divorce after the death of their child. A major difficulty in doing such research is that the frequency of divorce in the U.S. population is about 50 percent. Separating the "real" contribution of the death of a child from other causes of marital strife in bereaved families is a difficult research challenge.

To address this issue Compassionate Friends, a self-help organization for bereaved parents, recently completed a survey of 14,852 parents who had lost a child. When a Child Dies: a Survey of Bereaved Parents, was conducted by NFO in 1999 and published on the Web site of compassionate friends" (www.doorsofhope.com/grieving-healing/compassionate friends.htm). Its concern was how troubled newly bereaved parents frequently feel when they read or hear about high divorce rates among couples following the death of a child (80-90 percent by some estimates). The survey found that of those who completed it 72 percent of parents who were married at the time of their child's death are still married to the same person. The remaining 28 percent included 16 percent in which one spouse had died, and only 12 percent of marriages had ended in divorce. While acknowledging the potential bias in its sample, the conclusion was that the divorce rate among bereaved parents was substantially lower than is often cited.

Most studies of parent divorce after the death of a child are limited by methodological problems including the lack of a control group, selection bias, and high attrition rates. The highest estimates of divorce seem overstated. Indeed some studies have found that as many as 25 percent of couples experience increased closeness in their marriage [2, 33]. As Rando suggests [56] bereaved couples need to be informed that grief is a very individualized process experienced differently by each partner and reassured that relationships can and do survive after a child's death.

A number of studies have investigated the marital relationship and tried to identify gender differences that may account for conflict and distancing between couples. These and other common problems between parents after the death of a child include the following:

1. Conflict and anger, at times directly or indirectly blaming the spouse for the death, [34, 56] are frequently described as a way of dealing with painful feelings.
2. Breakdown in communication, such as avoidance of all discussion of the death or misunderstandings about it, is often associated with marital distress.
3. Discordant coping is related to differences in grief expression between men and women. Women tend to use more emotional expression as they process discussions to cope with the stress, while men try to control their emotions and cope with them alone, engaging in solution-focused discussions and activities.
4. Incongruent grieving in which father and mother react to the infant or child death with different levels of intensity and for different periods of time—women typically grieve more intensely and for longer periods of time than do their spouses [13]. One study reported continued marital distress from such variations in grief as long as two to four years after the child's death supporting the enduring nature of such stresses [57].
5. Low intimacy in which the combination of incongruent grieving, discordant coping, communication breakdowns, and other misunderstandings, as well as different needs for sexual intimacy are thought to contribute to a low sense of intimacy between parents [58, 59]. Lower levels of intimacy and support from one's partner are associated with greater incidence, intensity, and duration of grief symptoms for both men and women [14, 38, 60-62].

IMPACT OF THE LOSS ON SIBLINGS AND OTHER FAMILY MEMBERS

The death of a child may be one of the most difficult and profound experiences for surviving siblings, grandparents and other family members as well as parents. In the case of an illness such as childhood cancer, the death may have been preceded by months or years of stressful treatments in which family attention and resources were focused on the ill child. In 1981, the title of an article on sibling loss, "Siblings: The Forgotten Grievers" [63], reflected the lack of attention in practice and research to sibling bereavement. Over the past two decades, clinical and research attention to sibling loss, although relatively new, has increased significantly [64]. This development occurred in response to a growing awareness that earlier beliefs of children's inability to grieve were incorrect. In addition, qualitative studies and personal narratives documented the intensity of sibling grief and sometimes lifelong negative consequences of failure to recognize and support siblings in their grief.

Retrospective qualitative studies suggest that surviving siblings may have feelings of isolation and social withdrawal at home and with peers [23, 65, 66]. They have reported feeling different from peers as a result of their experiences and typical peer activities (e.g., interests in fashion, sports) may seem less important after the death. Parents and teachers reported that siblings have significantly lower social competence and higher social withdrawal scores on standardized measures within two years of the death [20, 21]. Siblings themselves describe feeling guilty, anxious, and depressed and parents have noted problems with sleeping, nightmares, anxiety and post-traumatic stress symptoms [22, 23, 67, 68].

Explanations for siblings' distress have focused on the parents' preoccupations with the child who has died and distraction with their own grief causing the neglect of the siblings. Bereaved parents have reported high levels of parenting stress as they are confronted with many new daily responsibilities. Siblings describe a lack of communication, decreased availability and support from parents [23]. Some have suggested bereaved parents may also become closer to and overprotective of surviving children [69].

As understanding of children's capacity to grieve has grown [44, 70] attention has turned to studying the variations in their grief experiences. Research has focused on the development of a measurement tool for assessing sibling bereavement, studied effects of sibling death on younger children and adolescents, identified longer term outcomes of sibling bereavement, and documented the natural history of sibling bereavement [3, 65, 71, 72]. Practice guidelines for interventions with bereaved siblings have also been developed [73].

Few interventions of bereaved siblings have been systematically studied in relation to their effectiveness [74]. However, Davies, in her overview of the literature, suggests a number of principles that have emerged that may inform the structure of interventions and provide helpful thematic foci with the individual child and adolescent [64]. The following principles expand on Davies' discussion.

1. Children of all ages can benefit from validation of the normalcy and appropriateness of a broad range of grief reactions to the death of a sibling. Recognition of their unique relationship to the sibling and their individual responses to the loss of that relationship within their personal and familial situation is fundamental to intervention with bereaved siblings.
2. Context is important and includes taking account of the timing and specific circumstances of the death, the ethnicity and culture of the family. Siblings are likely to benefit from being included in interventions earlier in

the trajectory of the sibling's death and continuing follow up contact over a longer period of time than generally occurs. Children facing the impending death of a parent experience greater anxiety and depression than they do immediately after the death occurs [44]. This finding suggests that the terminal illness period offers the opportunity for family members to prepare for a loss and provides the possibility of preventive intervention. Similarly, facing the death of a sibling gives an opportunity to provide information, education, emotional support, and preparatory actions that can mitigate the adverse consequences of the death. Knowledge of longer term effects of sibling and parent death is limited, therefore interventions need to provide for monitoring of children's and families' functioning over time in order to identify later effects and infuse timely services.

The details of the specific circumstances of the death, (e.g., anticipated, sudden, catastrophic) affect how siblings and family members experience the loss. They may confront more or less traumatic stress, greater or less avoidance of reminders and thoughts about whether the death could have been prevented, and more or less hopefulness about the consequences of the death on the family and their future opportunities in life.

The importance of the family's ethnicity and traditional way of coping with stresses including death is important in intervening effectively with a broad range of diverse family cultures. For example the level of openness in communication of facts and feelings about the loss with both adults and children, the expectations of the length and quality of the grief process, the use of particular rituals and symbolic processes, and decision making patterns can vary enormously and should inform intervention approaches.

3. Developmental attributes are likely to influence how siblings experience and express their loss. For example, young children are more likely to harbor unrealistic fears of their own vulnerability to the illness, injuries, or condition their sibling experienced. Adolescents are more vulnerable to depression in response to the parents' grief and subsequent withdrawal from them as the adolescent goes through normal separation from the family. Knowledge of these differences in cognitive, emotional, and social/ecological capacities should be integrated into intervention approaches and thematic foci.

4. A family and interpersonal focus is essential, whether the primary target of the intervention is the parent or the child. The parents' management of their own grief and construction of the meaning of the loss has an enormous impact on surviving children. The degree to which they blame the surviving children, are able or unable to re-establish a positive relationship to the siblings, to engage in the siblings' growth and view their progress and development as uniquely important as the lost future of the child who died has an impact on the stress of the situation for siblings. Facilitating communication and understanding between parents and their children

about these often unacknowledged dilemmas and management of family communication during terminal illness and after death is an important component of intervention efforts. Similarly the parents' own positive mental health and ability to fulfill important life goals going forward contributes to a stronger support system for surviving siblings.

Empowering a broad range of support systems is also an essential part of an intervention. As children develop, they are affected by an increasing number of social, service, and political systems: e.g. extended family and friends, teachers, coaches, peers, health and mental health professionals, religious groups and institutions, community services, and national and international policies and structures [75]. Influencing these systems through education, dissemination of information, consultation, and support can significantly expand the help available to siblings and other family members.

Qualitative analyses of sibling experiences highlight the following themes as a focus for interventions with siblings.

1. Loss of affection, attention, continuity, and stability within the family due to parental distress and preoccupation with their own bereavement. This can include multiple separations and lack of attention from parents during the ill sibling's terminal illness or unavailability due to parents' traumatic stress responses after the sibling dies. Stresses on the marriage after the death of a child affect the siblings as well.
2. A lack of social validation of siblings' grief experiences. This can be due to lack of understanding of children's grief, underestimation of the importance of the sibling relationship, or fear and lack of knowledge about how to respond to the grief of another child by peers and adults. A student bitterly reported a teacher's question, "Why are you upset, he was only your step-brother?" "But he lived with me all my life," she said to herself. Siblings experience a high level of social constraint in response to their grief.
3. Perceptions of not being good enough to fill the void in the parents' affection. Parents' intense preoccupation with the dead child is interpreted as a lack of love of the surviving sibling—"the wrong child died." The sibling feels devalued, alienated, and isolated from both family and peers.

Davies summaries these themes from the sibling's perspective [64] (pp. 211-216):

1. "I hurt inside" requires comfort, consolation, and validation of the child's unique experience of the loss. This is a particularly challenging task for grieving parents and may be assisted by the use of peer support groups.

2. "I don't understand" requires explanation and interpretation provided at a level appropriate to the child's cognitive developmental level. Concerns about the child's own safety and well being in addition to other facts about the situation should not be overlooked. Resources available to parents and professionals include books that focus on helping children with a broad range of grief reactions and types of losses [76-78].

3. "I don't belong" requires including and involving the child before the death occurs in the case of anticipated loss, during the death and burial rituals, and in the post-death bereavement process. Research continues to support the helpfulness of children's and adolescents' involvement in these processes when they are given adequate preparation for their particular role.

4. "I'm not enough" requires continued reassurance and validation of the unique worth of each child. This response is somewhat unique to sibling loss compared to other types of losses and has at times powerfully affected siblings' adaptation.

IMPACT OF THE DEATH OF INFANTS, OLDER CHILDREN, AND ADOLESCENTS

Infant Death

The deaths of infants, either through miscarriage, stillbirth, newborn death, or SIDS, were until recently regarded even by most professionals as "nonevents" or "non-deaths" affecting unnamed "non-persons" [79]. Greater awareness of the importance of validation and recognition of the significance of the loss of infants to parents has resulted in the development of programs to guide parents in their expression of grief and to encourage them to engage in rituals from their particular religious, cultural, or ethnic background. While there are common issues in bereavement for all infants, each of these circumstances of infant death brings its unique stresses related to the way in which it occurs as well as to the individual parent(s) [80].

Stillbirths. A stillbirth turns an anticipated joyful event into tragedy. Stillbirth can assume two forms. The more common occurs when the baby was viable and then dies during labor or delivery. In the second type the fetus dies in utero and the mother is forewarned of the death days or even weeks before the delivery. Particularly difficult and stressful for the mother is carrying a dead fetus when movement has ceased. Parents often describe these situations as the simultaneous birth and death of the child.

Perinatal Deaths. With the dramatic increase in the survival of low birth weight babies, the death of a very tiny, sick, or deformed newborn is no longer always expected. Parents' hopes may be buoyed with the suggestion of each additional medical procedures, and the added time that the child lives increases their attachment. The advent of new technologies and surgical procedures that might prolong survival but at a price of pain, discomfort, or survival with gross disfigurement or retardation presents new problems to both parent and physicians. A not-uncommon situation occurs when careful diagnostic assessments and open discussions between physician and family have led to a decision not to perform a life-saving operation, with a change of mind by the parent following delivery when the full-blown symptoms of a lifelong disability are only minimally apparent. This situation may engage them in complex legal and ethical issues that intensify the emotional difficulties parents have in dealing with their loss.

Sudden Infant Death Syndrome. SIDS deaths declined by 46 percent from 1983-1996 due to successful education and broadly disseminated ad campaigns. SIDS usually occurs within the first year of life and is the most common form of death after the neonatal period. The particular stress of this type of death relates to the ambiguity about its cause that leads parents to struggle with guilt and whether the death could have been prevented. Family and friends often do not know how to respond and therefore withdraw, inadvertently creating a "conspiracy of silence." Here, health care personnel can make a contribution by providing information about the nature of SIDS that helps reduce ambiguity about the cause of the death.

Grief Reactions to Infant Death

A very common grief reaction after perinatal or SIDS death of an infant is intense preoccupation with thoughts and images of the dead baby. According to several studies, between 65 and 95 percent of mothers and 51 and 85 percent of fathers report problems with preoccupation or irrational thoughts about their dead baby during the acute phase [81, 82]. Many parents report a sense of the baby's presence—of hearing their dead baby cry—and some mothers say they feel fetal movements for months after the delivery. Others report illusions or hallucinations that their baby is still alive. This can be disconcerting to parents and family members; however it is reported in studies of many bereaved parents. Like many other traumatic events, the death of an infant challenges parents' assumptions about their own and their families' safety in the world. Anger and irritability about the injustice and unfairness of losing their child are common grief responses and may be directed toward health care professionals, their spouse, God, or fate. Alternatively, these may be emotions directed inward toward themselves resulting in lowered self-esteem, self-blame, and depression. Parents also experience intense anger and jealousy toward other parents who have living babies.

In general, parents of infants who have died from whatever causes share the experience that their friends and family do not know their infant, that they may not recognize or empathize with the full extent of their loss [83]. Many parents of infants who die report being particularly stressed by people who avoid any discussion of the loss or offer clichés or dismissing statements such as "you can have another child". The advice to have a new child as a way of bypassing or avoiding the pain of loss for the particular child who died remains controversial because findings from research are contradictory [4]. Friends as well as other family members may be impatient about the "slow" rate of parents' recovery from the loss. As in most forms of bereavement, depressive feelings are often present following this type of loss. In fact, bereaved parents have been found to experience elevated symptoms of depression more than two years following perinatal death of their child [57, 84].

Almost all parents search persistently for explanations of the cause of the death following perinatal or SIDS death. Studies suggest that most families believe that it is highly important for them to understand the cause of their baby's perinatal death. Often there is no definite answer or explanation, which they find frustrating. Of interest in one study was the tendency of parents to blame the mother for the baby's death (26 percent of mothers and 13 percent of fathers), despite explanations by their physician to the contrary.

Across studies, mothers consistently report more intense and prolonged grief reactions than fathers except for the area of denial where fathers report greater denial in the immediate aftermath [84]. These differences are reported to cause additional stress and strain on the marriage relationship and to reduce the support available from the intimacy it could provide. A range of theories are suggested to explain differences that could be the subject of future research such as the differences in the bond formed between mothers and fathers and the developing infant [2, 85–87]; general gender differences in reaction to stress; and differences in gender-role socialization involving emotional expressiveness and willingness to acknowledge and report emotions [58, 61, 88–90].

Deaths of Children and Adolescents

Deaths are less common among older children than among infants, with accidents, especially among adolescents, the most frequent cause. Cancer is the leading illness cause of death in children and adolescents. Parents who experience the death of an older child usually have many of the feelings already discussed in relation to infants. However, more is known about the grief of parents of children who die of an illness than about the grief of parents whose children die suddenly by accidents, homicide, suicide, natural, or man-made disasters [91]. One reason for this greater knowledge may be that parents already connected to the health system during their child's illness are more likely to participate in bereavement services after the death as well as having access to services during terminal illness [12]. Retaining parents in need of assistance who have experienced sudden death in formal longer-term bereavement services remains a challenge [92]. At the same time, the existence of self-help organizations focusing on child loss, such as Compassionate Friends, provides alternative avenues for bereaved parents to receive support; yet such organizations serve only 25 percent of bereaved parents. These organizations have been the focus of significant studies on the services they provide to parents [38].

Families' avoidance of formal and informal support services is thought to reflect, in part, avoidance of traumatic reminders. However, the lack of participation in interventions may also reflect inappropriate treatment models that fail to respond to the needs of families who have experienced the sudden death of a loved one [93]. An example of this problem was reported by the William Wendt Center in Washington, D.C., a program developed to provide trauma and bereavement services to families at the time of identification of the body of a loved one who died suddenly from accident, homicide, or suicide [94]. This innovative service established a site in the coroner's office where providers can immediately meet with families upon identification of the body. The center soon discovered that in addition to trauma and grief counseling, case management services were needed to help families with the consequences of such losses (e.g. loss of housing, dramatic loss of income, unsafe living environments, and the loss of support networks) [94]. Longer term follow-up of families affected by such traumatic deaths remains a challenge. With parents of older children, as with parents of infants, the intense nature of their response to the death of their child is thought to be related to multiple factors:

1. the love for the unique child who has died;
2. the special intimacy and strength of the parent–child bond, unlike most other relationships [17, 28];
3. the connection with the parent's hopes and dreams for the future and even immortality [17, 94, 95];
4. the challenge to parental identity as competent protector, provider, nurturer;
5. the social stigma associated with child death [96, 97];
6. the isolation and loss of social support that often follows such stigmatized deaths; and
7. the existential crisis of finding meaning in life without parenting this child.

INTERVENTION APPROACHES

It is important to keep in mind that there are numerous individual, familial, and cultural differences that make responding appropriately to another person's grief anything but a formula. The United States, as most Western countries, has a variety of cultural, religious, and ethnic variations that mediate and modulate the experience of grief and mourning [98]. There is mounting evidence that forms of support that leave room for the bereaved to discuss their thoughts, feelings, and experiences are often seen as the preferred mode of response to bereavement [19, 99, 100]. This is in contrast to approaches that emphasize a more active approach to the bereaved, one that confronts them with models of the "appropriate ways" in which to grieve and expects linear progress along some stage model of grief. It is sometimes surprising to laypersons and professionals alike the degree to which people are willing to educate others about their culture, share elements of their experience, and feel benefited by the experience. What is needed in the listener is an ability to listen with a degree of empathy and patience.

Evidence suggests that parents of newborns, children and adolescents who die benefit from a range of early intervention services [62, 101, 102], yet bereavement programs connected with medical care are only beginning to develop. A small percentage of parents who experience child loss contact self-help organizations. Child death is infrequent in the United States and many parents feel stigmatized by their situation, become isolated, and find outreach difficult. This small number of parents who engage in support programs or participate in research on bereavement following the death of a child has limited knowledge development and innovation. Newer intervention models and interventions described below are promising as they are located at times and in places that are more accessible to parents and they focus on the broad range of needs of parents, siblings, and extended family after a child's death. While additional research is needed to clarify post-bereavement outcomes both short and long term, existing knowledge suggests the following interventions. Those specific to families of newborns who die might include:

1. help parents accept the reality of their loss by gently encouraging them to see, hold, and name their dead baby and to hold and then participate in memorial services;
2. help parents retain important mementos such as photographs and locks of hair, hand and footprints, tangible reminders and "evidence" of the child's presence such as bedding and clothing; and
3. connect families to other parents who have experienced this loss, to

self-help organizations, or to professional counseling or services that address this issue.

Interventions for families of children and adolescents might include:

1. accept a broad range of grief reactions without becoming judgmental or withdrawing—this may include parent's anger, blame, humor, and inability to grieve;
2. provide information in multiple formats (e.g., written, audio/visual, public meeting, broader media programs, Internet based) about the bereavement process including gender differences, expected problems, needs of siblings and extended family, and available services;
3. include information on both trauma and grief responses of children and adults in all education efforts. This is especially important with children as so many children's deaths occur from accidents;
4. create opportunities for families to meet other families facing similar situations that can make the experience less lonely as well as provide a perspective on the loss process. This includes connecting parents to self-help groups, especially those that include siblings and extended family services;
5. make available professional bereavement follow-up counseling for grieving family members, including individual, family, and/or group;
6. create a range of intervention models that address the bereavement process and are accessible to families in time and location. For example services should not be limited to once-a-week psychotherapy for one hour, to a time limited series of meetings, but models may also include less frequent, more intensive meetings offered over a longer period of time. Interventions should also be provided at places convenient to families both geographically (e.g., at home or within local communities) and/or in relation to where the child's terminal condition is treated. Intervention models should address the broad range of families' needs including financial and practical needs;
7. bereavement interventions should begin before the loss when it can be anticipated in order to take advantage of the opportunity for preparation and prevention of later adverse reactions;
8. create models of follow-up care that provide ongoing access and increase knowledge of longer term outcomes;
9. provide family focused interventions that assist parents in connecting or reconnecting with their existing families, friends, and networks of support as a means of re-establishing coherence and meaning as they go forward; and
10. provide specific services and outreach for neglected sub-groups of parents and family members: e.g., parents who have lost an only child,

parents who have lost multiple children, parents whose child died from accident, suicide or homicide, grandparents of children who die.

Interventions for surviving children and adolescents have been addressed in the section on siblings. Suggested models and approaches from the existing literature include the following:

1. provide information in multiple formats (e.g., written, audio/visual, Internet based, group meeting and larger event) for children and adolescents about the nature of grief following the death of a sibling and ways to cope with it;
2. provide information/consultation about ways to help bereaved siblings to parents, extended family, teachers, coaches, religious and social service organizations, hospitals and health care services, emergency services, mental health providers and the media. In this way the knowledge base and social and cultural context in which siblings experience their grief is improved. Information should include the emerging knowledge about the intertwining of trauma and grief, ways to recognize these symptoms and ways to manage them;
3. provide opportunities to receive mementos of the child who died and to participate in memorial services;
4. provide access of bereaved siblings to other bereaved children or adolescents who can share their experiences and reduce isolation. Since sibling death is infrequent in the United States, where possible, integrate children and adolescents who have experienced sibling death into existing bereavement groups and services that include children who have experienced loss from the death of a parent or peer or through divorce. Consider the use of the Internet and teleconferencing as additional ways to form sibling groups and facilitate communication; and
5. increase knowledge of, and provide for the special needs of particular sub-groups of bereaved siblings: those whose sibling died of homicide, suicide, accident or terrorist attack.

Newer intervention approaches have included:

1. Interventions that focus on developing ongoing networks of support within specific geographic, ethnic, or religious communities;
2. Interventions located within service organizations that treat the child's terminal condition and can direct parents early in the bereavement process to appropriate services—e.g., hospitals, emergency services, the coroner's offices, and schools;
3. Interventions that utilize intensive camp/retreat experiences or 1 day work shops with follow-up services in the community;

4. Combinations of professional and self-help leadership in groups; and
5. Novel uses of the Internet and technology to provide group information and on-line discussion groups. A recent qualitative analysis of an online perinatal bereavement group, not professionally led, identified themes of interpersonal connection, memorializing the child who died, and validation of the parent's unique grief experiences. Such technologies can provide important opportunities for access to social support and education.

RESEARCH IN BEREAVEMENT

New intervention models have been developed for specific bereavement situations, some beginning during the terminal illness period [103, 104]. Evidence suggests that this time period offers an important opportunity for preparation and prevention of unnecessary bereavement distress after the death of a child as well as the death of a parent [12]. Other variables that continue to be the focus of research include the role of symptoms of traumatic stress, particular types of child deaths such as suicide, homicide, and deaths from AIDS, gender differences in coping, marital distress and divorce, depressive symptoms, verbal disclosure, emotional expression in the face of social constraints, and the role and function of ongoing memories of and connection to the child who died [4, 105]. Additional research questions include the following:

1. What are relevant bereavement outcomes for sibling, parents, and the family as a whole?
2. What prevention opportunities occur during the child's terminal illness?
3. What are the range of psychological symptoms including traumatic stress experienced by parents and siblings during a child's terminal illness and after a child's death and are they responsive to medical and psychosocial interventions?
4. Do current criteria for complicated grief in adults apply to bereaved parents?
5. Do symptoms and behaviors suggested for complicated or traumatic grief in children differentiate the grief experience of siblings?
6. Most studies of parents' grief for a child who dies have relatively short-term outcome evaluations. Longer term prospective research could improve our understanding of delayed and complicated grief and associated risk and protective factors that occur over time.
7. How is child and adolescent functioning after the death of a sibling affected by family functioning and social support?
8. What are the range of risk and protective factors that affect differ-

ent outcomes such as the parent's decision making about the child's terminal treatment, timely information, and the use of psychosocial support services?

9. How do health professionals differ in their responses to parents during the child's terminal illness from their responses to parents whose children are not terminally ill?

10. Does professional training and skill development in working with bereaved parents and siblings affect outcomes of the experience?

11. Can studies move beyond outcomes such as grief symptoms, depression, and social support to include broader variables of self-esteem, personal growth, and flexibility [4, 105]?

12. What are the barriers to recruitment of research samples in this area and how can they overcome?

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APPENDIX F

END-OF-LIFE CARE IN EMERGENCY MEDICAL SERVICES FOR CHILDREN

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OVERVIEW

End-of-life care in emergency medical services for children (EMSC) seems almost an oxymoron. The instinctive response and clinical objective for providers of EMSC is the preservation of life, sparing no expense or effort in the avoidance of death. However, death is an infrequent but inevitable part of providing care to acutely ill and injured children. Management of the issues and circumstances surrounding sudden and unexpected loss can be particularly challenging and is an underexplored area of EMSC.

This appendix is organized to address the issues germane to the emergency care environment through a contextual comparison and contrast of sudden, unanticipated loss with the more classically described palliative care model of anticipated loss associated with chronic or long-standing illness. This discussion is followed by an examination of the roles of the providers of EMSC vis-à-vis end-of-life issues with recommendations for

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research directions. However, first, a brief historical background and recent perspective are presented.

HISTORY

In 1966, a seminal treatise issued by the National Research Council identified trauma as ". . . the neglected disease of modern society."[1] The publication of this monograph ushered in support for the development of modern-day emergency medical services (EMS) and the idea that patients could benefit from coordinated systems of field triage and organized transport. These systems would not only facilitate rapid transport of ill and injured patients to hospital-based centers for definitive clinical care, but also include rehabilitation, prevention, and research as essential infrastructure elements. The early years of EMS development were focused primarily on field training and hospital coordination to form regionalized networks of care. The care of children in these systems was largely integrated into adult models using principles and approaches extrapolated from adult experience.[2]

Emergence of Emergency Medical Services for Children

In the 1980s, the first subspecialty training programs in pediatric emergency medicine began in Philadelphia, Kansas City, and Washington, DC. Simultaneous to the emergence of these fellowship programs, Senator Daniel Inouye (D-HI), with the help of the president of the Hawaii Pediatric Society, Dr. Cal Sia, was instrumental in focusing congressional attention on the gaps in emergency care for children in this country. In 1984, federal legislation (P.L.-98-555) was passed establishing the Emergency Medical Services for Children program under the Health Resources and Services Administration of the Department of Health and Human Services.[3] Over the past 18 years, the federal EMSC program has maintained a steady appropriation and successfully disseminated grant funding for program development in all 50 states and 6 territories. In accordance with the recommendations of the 1993 Institute of Medicine (IOM) report *Emergency Medical Services for Children*, the programmatic priorities have focused on four areas: (1) education and training; (2) equipment and supplies; (3) regulation and funding; and (4) evaluation and research.[4]

Recent Progress

Summary of the high-priority topics for an EMSC research agenda emanating from the IOM report did not drill down to topics directly related to end-of-life care.[5,6] However, the recommendation "psychosocial support for families of injured or sick children," taken broadly, is certainly inclusive of the issues to be discussed here. A review of the most recently developed federal EMSC five-year plan reveals new objectives related to Critical Incident Stress Management, EMS involvement in the child fatality review process, and a revised objective addressing the special needs of children and families in disaster situations.[7] Despite the absence of specifically articulated recommendations or objectives related to bereavement training or institutional preparedness for dealing with acute loss, federal EMSC, through a funding mechanism entitled Partnerships for Children, has successfully collaborated with the American Psychological Association and the National Association of Social Workers to make important contributions in this area. A recently published body of consensus reports and clinical guidelines in the areas of mental health needs and bereavement practices forms the most comprehensive evidence to date specific to EMSC and EMSC providers.[8-11] This work establishes a foundation upon which meaningful data can be gathered and future research directions built.

Of note, in the education and training arena, the American Academy of Pediatrics (AAP) has introduced a module entitled "Child and Family Interaction" as part of its new Pediatric Education for Prehospital Professionals (PEPP) course, and the latest version of the Pediatric Advanced Life Support (PALS) course has incorporated a new module entitled "Coping with the Death of a Child."[12,13] Also, the Committee on Pediatric Emergency Medicine of the AAP, in conjunction with the Pediatrics Committee of the American College of Emergency Physicians, recently issued an update of its policy statement, supported by a technical report, on the death of a child in the emergency department. In updating its recommendations, the AAP affirms a commitment to family-centered and culturally competent end-of-life care and places the onus of responsibility for organizing and coordinating the response to a child's death on the emergency department (ED).[14,15]

ISSUES IN THE CARE OF CHILDREN DYING SUDDENLY AND UNEXPECTEDLY

The following two vignettes represent actual cases managed at a tertiary care pediatric center and set the stage for the discussion to follow. The scenarios typify the mechanisms, consequential events, and emotions experienced by families and providers alike in the emergency medical services for children arena.

Clinical Vignettes

Case 1: On a warm summer day, the mother of a toddler and 6-year-old child is briefly distracted by a telephone call that she takes poolside in their backyard. When she turns around, the 19-month-old is face down in the shallow end of the pool and requires prolonged resuscitative efforts. Serial head computed tomography (CT) scans demonstrate profound hypoxic brain injury and the child progresses to brain death. Discussions in the intensive care unit (ICU) over the next 24 to 48 hours are complicated by the mother's profound sense of guilt and her inability to participate in decisionmaking.

Case 2: A 14-year-old boy is bicycling home from playing in the park and is struck by a car whose driver was apparently intoxicated. The child sustains life-threatening head and thoracic injuries. As his condition deteriorates, organ donation is discussed with the parents who perceive this as evidence that the medical team is "giving up" and would like to "experiment" on their child.

These scenarios illustrate three important issues in the care of children who die as a result of sudden and unanticipated illness or injury:

1. contextual issues,
2. consistencies with anticipated deaths in children, and
3. contrasts between sudden, unanticipated deaths and anticipated deaths in children.

At the outset, we acknowledge a certain definitional breadth regarding the terms that are used in this appendix. Specifically, we use the term "parents" to refer to the caregivers of the critically ill and dying child. We recognize that family circumstances differ and that for some children this may be a grandparent, an older sibling, or foster mother. Similarly, we refer to "families" but understand this to mean those individuals who love and care for a child whatever their legal or biological relationship. Finally, we focus on death and dying but, as we acknowledge below, for many children there is no clear demarcation between the critical illness and dying. Indeed, one of the chief ambiguities confronted by parents is to understand the child's current medical condition on the continuum between uncertain survival and certain death. Many of the comments here are more broadly applicable to the circumstances of any child who is unexpectedly critically ill or injured. Were we to improve care for the child dying in these circumstances we would actually improve the care of a much larger number of children who survive.

Context

Our society has focused only reluctantly on the death of children, and insofar as we have done so, a palliative care model is most often applied. Therefore, we begin this discussion by emphasizing the context in which it is undertaken: the epidemiologic realities of pediatric death. **It is important**

to recognize that sudden and unanticipated death in children is not the exception, but rather the norm. Basic epidemiologic data clearly demonstrate this point.[16] For children 1 to 4 years of age, at least 43 percent of deaths are due to unintentional causes, homicide, suicide, or brief unanticipated illness. This figure rises to 53.4 percent among children 5 to 14 years old and to 75.7 percent among those 15 to 24 years old.[17] It could be argued that in infancy (children less than 1 year of age) virtually all deaths are unanticipated although some certainly are not sudden, and an additional burden of unanticipated illness occurs in children whose cause of death is attributed to chronic health conditions. That is, even for the child with a malignancy, the rapid development of overwhelming sepsis may be perceived by family members as entirely unanticipated. Thus, among the most important points to be made is that unlike the popular stereotype of childhood deaths in children with leukemia or cystic fibrosis, the majority of children who die do so due to acute processes, most often trauma related. While we recognize the importance to end-of-life issues of palliative care, if the majority of children are to experience "good" deaths and the needs of their family members are to be addressed, there must be broader recognition of the ways in which children most frequently die.

We would also like to emphasize that while the statistics provided above are pertinent to deaths in children, the distress and bereavement discussed below are also found in the larger group of children who survive sudden and unanticipated life-threatening illness or injury.[18] Whether the surviving child emerges cognitively and physically intact or variably disabled, family members, as well as the child, may experience long-term sequelae that need to be anticipated and, as possible, prevented or treated. Unanticipated critical illness or injury can profoundly disrupt the parental sense of caretaking, of secure attachment to the child, and of a predictable family future. For example, children who are critically injured, as well as their parents, experience posttraumatic stress disorder (PTSD)-like symptoms.[19-22]

These epidemiologic and medical considerations create a more complex context for pediatric deaths and dying than is often appreciated. First, the number and type of potentially involved personnel is larger and more diversified. Prehospital providers in EMS, fire and rescue, law enforcement, and public safety, as well as hospital-based providers in EDs, on surgical teams, and in ICUs may have important interactions with acutely dying children and their family members. Each will require appropriate training and resource availability to address the needs of these children and their families. Secondly, as discussed further below, parents confront uniquely difficult circumstances that will shape their ability to continue parenting and advocating for their dying child, as well as affecting the course of the predictably difficult bereavement. Finally, the opportunities for intervention to improve care of the child who dies unexpectedly may be constrained, both by the foreshortened time frame during which the dying child may be cared for and by the unanticipated nature of the illness or injury. Taken together, this suggests that particular attention needs to be paid to the needs of children with sudden and unanticipated deaths and to the needs of their family members.

Consistencies with Anticipated Deaths in Children

We also recognize, however, that the needs of the dying child and family have important similarities whether the death is long anticipated or entirely unexpected. This continuity between issues recognized in traditional palliative care and the circumstances of families we are discussing should be appreciated because it can strengthen care for all children who die. In common with others, we recognize the needs of the dying child to include appropriate medical and psychosocial care with particular attention to symptom management, notably adequate pain relief. Appropriate support, recognition of autonomy, and information must be provided as appropriate to the child's cultural background, development, psychological state, and medical condition.

For family members of any critically ill child, whether due to an anticipated or unanticipated etiology, we recognize the shared need for culturally appropriate and family-focused care that conveys fundamental respect and commitment to shared decisionmaking with the parent. More specifically, all dying children and their families require appropriate (1) facilities, (2) information, (3) support, and (4) involvement in care and decisionmaking. Each of these is discussed briefly here as essential consistencies across all pediatric deaths.

Facilities

Families of dying children need facilities that give them the space and time that they need to be with their child, to have privacy, to include supportive friends and family, and to grieve as they see fit. Also, basic individual needs such as rest, nutrition, and hygiene become secondary priorities for the family in a pre-bereavement state, and institutional accommodations to assist families in addressing these needs become extremely important.

Information

They also need information that is accurate, consistent, and expressed in language they can understand.[23] This information needs to be responsive to their questions and concerns, as well as raising issues of which they may not be aware.[24,25,26] This information exchange may include family members or friends who will help the family sort through what they are hearing and what they want to ask. While "information" emphasizes content, there is also a need to be attentive to the nuances of "communication," or the process by which information is exchanged.[27,28] As emphasized above, all family members of critically ill or dying children need to feel respected and valued. Communication should ideally empower and strengthen their role as parents, rather than marginalizing them or making them feel outside the circle of those caring for their child. Nonverbal details such as eye contact and body language are but the tangible means by which these values are often expressed.

Support

In parallel with communication, parents of dying or critically ill children need support. Whenever possible, this should be provided by those who know the family best and are chosen by the family to be present during this difficult time.[29] On the other hand, the medical context may be unfamiliar or frankly uncomfortable for the family pastor or the child's grandmother. There is a well-recognized and important role for members of the care team that include social workers, child-life workers, chaplains, and the nurses and physicians caring for the child.

Involvement in Care and Decisionmaking

Each of these considerations (facilities, information, and support) is important both in its own right and in so far as these are methods for the appropriate involvement of parents in care and decisionmaking. No "rule" can adequately describe how families might best maintain and express their relationship to their dying child. Nonetheless, it is essential for those caring for the child to support the parents' self-definition as committed, compassionate caretakers through and beyond the experience of the child's death.[30,31,32] Parents remain parents. The death of a child only alters this relationship but does not end it.

Contrasts Between Sudden, Unanticipated Deaths and Anticipated Deaths in Children

Having noted issues that provide continuity between anticipated and unanticipated deaths of children, we now focus on special issues in providing care to the child who dies unexpectedly. As an important starting point, we need to recognize the intense shock and distress of parents who but moments or hours earlier had a healthy child whose future seemed unquestionably assured. This intense emotional arousal quickly includes apprehension and fear, as the severity of the child's condition becomes apparent. In many cases, whether rationally or not, this intense distress will be coupled with a sense of guilt and responsibility. Concerned family members and friends will need to be informed, some summoned for the support they can provide and others held at bay by the distraught parents. Certainly in the first hours after the illness or injury, parents may be relatively isolated as well as overwhelmed.

In this context of intense emotional reactions and potential isolation, parents are now confronting two important tasks: building a relationship with the medical care team and developing the required information to understand the child's care and prognosis. Dealing with physicians they have never met, most frequently at a facility they have never visited, parents are often introduced to a wide and bewildering array of health care providers. The medical caregivers typically represent a variety of levels of individuals from diverse services: nurses, respiratory therapists, technicians, social workers, physicians, surgeons, residents, fellows, nursing clerks, admission personnel, and chaplains. Depending on the complexity of the medical management issues, team members may disagree among themselves regarding the likely severity of the child's condition or the prognosis; there may be inconsistent information about optimal medical and surgical management.[33,34] Furthermore, depending on the circumstances of the facility and the child's need for operative or other procedures, the parents may not be able to see their child for an extended period of time. When they do, the child is often unlikely to be able to speak or even to recognize them and may be seriously disfigured as well as heavily instrumented with what parents often refer to as "all those tubes." The fundamentals of building a relationship to the medical team, of developing trust in its judgment and decisionmaking, and communicating together are extremely problematic in this context. Additionally, parents who have little or no medical background and who are distraught will now be rapidly introduced to complexities such as CT scans, electrolyte results, chest tube drainage, and intracranial pressure monitoring in order to answer their simple question, "How is she doing?"

As if these difficulties were not problematic enough, the pace of the child's death is often considerably foreshortened, so that reactions must be unreasonably accelerated. Some children die in the field, others never leave the ED, most will be admitted to the intensive care unit. In a period of hours or days, the parents will need to progress from their ordinary life to a death vigil. They are likely to be asked to make decisions or at least participate in decisions about their child's care, and about the child's death. Are life supports to be removed, will care be limited, will organ donation be approved, do they want to be present for the last moments, would they want to leave if the child needed to be "coded" (i.e., acutely resuscitated)?[35,36]

The questions are multiple and the answers often complex. Relationships to the medical team may be tentative, and confidence in the ability to understand the issues insecure. Grief under these circumstances can be totally debilitating and incapacitating. This is the context in which parents experience their last hours with a dying child.

Providers of Emergency Medical Services for Children and End-of-Life Issues

The sudden death of a child is a tragic event for both families and health professionals. The unexpected nature of the precipitating event necessarily engages a wide range of professionals who can potentially become involved in care of the child from response in the field, through transport to the emergency department, to management in the intensive care unit or operating room. Death may occur anywhere along the care continuum, with families acutely encountering individuals with differing backgrounds, training, and exposure to this critical aspect of a child's care. It is important to understand the differences in scope of practice and training of emergency and acute care providers, all of whom can potentially provide invaluable services to a grieving family.

Prehospital Providers

While the majority of study on end-of-life care centers on hospital-based practitioners, the prehospital providers play a pivotal role. In the prehospital arena, first responders typically include fire and rescue and EMS personnel who can be grouped into two different categories according to level of training. Firefighters and emergency medical technicians (EMTs) are usually basic life support (BLS) providers. They are trained in basic resuscitation and life support with few procedural skills and very few hours devoted to pediatrics in the training curriculum.[37] Advanced life support (ALS) providers are paramedics (EMT-Ps) who have advanced technical and decisionmaking skills yet who also have little training in pediatrics.[38,39] ALS providers are licensed to administer a variety of medicines and are trained to manage patients of all ages in respiratory or cardiac arrest. Both ALS and BLS providers encounter pediatric deaths in the field and are charged with caring for families in the very early stages of loss.[40] It is estimated that one out of every ten field transports in EMS is a pediatric transport, and of those, one out of every ten pediatric transports will truly be a sick child in need of prehospital intervention.[41] Clearly, pediatric death in the field is a relatively uncommon event; however, the responding

EMS provider frequently has the first and lasting contact with the family. In rural communities, where EMS are typically organized as local volunteer systems, it would not be unusual for providers to be responding to calls involving neighbors, family friends, and relatives.

There has been a paucity of research on EMS providers' experience and training regarding this topic, but from survey data it is clear that providers do not feel that they receive adequate preparation for end-of-life issues in the circumstances of sudden or unexpected death.[42] According to national guidelines, the most highly skilled ALS providers receive only 6–30 hours of pediatric training, and the majority receive no training at all on any aspect of end-of-life care.[43] EMS providers report that they are uncomfortable with this weighty responsibility and indicate that they desire more education and training by their peers in the form of lectures, videos, and roleplaying to prepare them better.[44] Future research directives should include the critical examination of the structural context of the death of a child in the field and the preparedness of those providing care. This may take the form of assessment of educational initiatives for EMS providers on this topic or other more widespread retrospective reviews of EMS participation in pediatric death.

There are certain instances in some jurisdictions where the EMS provider may in fact declare death at the scene and notify next of kin without the presence of other support professionals for the family.[45,46] The patient is not transported to the hospital, and there is no established framework of care for the family in this scenario. Many providers volunteer in the community in which they live, and consequently their patients are likely to be known on a personal level. This can be both helpful and difficult. Oftentimes it is easier for an individual known to the family to deliver the news of the child's death, but this can also be difficult for the provider due to feelings of guilt or fear that the family will "blame" the provider for not saving the child. Stress on the provider is enormous, and only recently has there been widespread integration of Critical Incident Stress Management (CISM) initiatives to ensure that EMS providers can work through their own feelings of despair, guilt, and anger.[47,48,49] There is much opinion but virtually no evidence regarding the efficacy of CISM.[50-53] More work needs to be done to better understand the contribution of CISM and how best to optimize its use for on-scene providers.

Emergency Department Personnel

If a patient is transported to an ED and death occurs there, a larger matrix of professionals is in place to provide support to the family and to the rest of the staff. Codified bereavement plans have been written in which doctors, nurses, social workers, and in some cases, clergy all work together to ensure that such a tragic event can be managed as smoothly as possible. What is clear from published data is that a well-handled counseling session with family members of the deceased can have a dramatic impact on that family's grieving process and ultimate recovery and coping.[54-57] There is still, however, a growing need for further understanding of the natural history of acute loss bereavement across the broad spectrum of cultural and ethnic diversity in this country. Future research needs to include cultural sensitivity as a principal outcome measure in investigations involving death management.

When a patient in extremis is transported to the ED, often it is not the nursing or physician staff who first greets the patient's family. The patient is typically brought directly to the resuscitation bay where medical care continues and the family is greeted by the ED social worker, a clergy member, or patient advocate. Most EDs have a "quiet room," or similar private area removed from the rest of the activity and fast pace. The social worker or equivalent then remains with the family and acts as a liaison to the rest of the staff, keeping the family up-to-date with clinical events and helping to prepare the family for the death notification process. This may include making telephone calls to other family members and providing general comfort and support. Current bereavement care guidelines for social workers include encouraging family members to talk about the patient and the events that led to the child's being brought to the ED, assessing the family's strengths and weaknesses, and explaining the basic roles of the various team members. If there is a family presence policy, the social worker also prepares the family for entering the resuscitation bay.[58-61] After death notification occurs, this individual is then charged with managing the aftermath, from reassuring the family that everything possible was done to save the child to explaining autopsy and funeral procedures.

This professional is typically the one person who will remain with the family for the duration of its stay in the ED. Families are encouraged to go see their deceased child, and she or he typically accompanies the family into the resuscitation bay. Once there, family members are encouraged to hold the child's hand, comb the child's hair, or in the case of an infant death, give the baby one last bath. All these suggestions are offered in accordance with local medical examiner procedures. Many hospitals have parental kits with plastic molds for an imprint of the child's hands and/or feet and a ziplock bag to store a lock of the child's hair. The social worker typically sees that these steps are completed, and parents surveyed months and years after their child's death have found these small mementos helpful in attaining closure of the tragic event.[62]

The social worker or equivalent professional ultimately should let the family decide when to leave and provide them with follow-up telephone numbers if they have questions in the future. In some instances, the social worker will also contact the family at designated intervals after the child's death again to offer support to and connection with the family. While there has been much written on the theoretical components of the bereavement process in the social work literature and elsewhere, there is little in the way of evidence-based information on the efficacy of such programs.

Emergency department nurses and physicians must bridge the difficult gap between acting as the emotionally detached clinical decisionmakers and the emotionally charged messengers of the actual news of death to the family. The relationship with the family is a difficult one because the first meeting is typically the death notification conference. Physicians receive very little training in medical school and residency on the appropriate manner in which to inform family of a loved one's death and describe themselves as ill at ease with their ability to do so.[63,64,65] Some residency training programs are instituting multidisciplinary educational techniques designed to increase physicians' comfort and effectiveness with this difficult part of practice. The methodology of one such type of program includes role playing with objective, standardized "family members," in which residents are given a scenario where they must inform the "family" of a loved one's death and then manage its questions and emotions. They are taught the importance of using the words "dead, death, and died." They learn how to react to hostile, stoic, and grief-stricken parents, and are evaluated through direct feedback from the standardized family members. Residents report that these sessions are instrumental in increasing their confidence and sense of preparedness for this eventuality.[66,67,68] It must be noted that these types of educational programs have only been introduced relatively recently and were therefore not a part of the postgraduate curricula of the majority of practicing physicians. It is also notable that most of these educational programs have been aimed primarily at adult internal medicine and emergency medicine residents. Clearly, more research attention needs to be paid to the evaluation of these programs and how they may be beneficial, particularly as families become increasingly present during resuscitation.

Emergency nurses also play an important role, since much of their training emphasizes family-centered care.[69] In some instances, nurses share the social worker's role as described above and may be the best qualified to explain the clinical events to the family in understandable terms.[70] Pediatric nurses can be particularly instrumental in helping siblings of the deceased child, because they have some understanding of cognitive developmental stages and can help a child of any age understand what death really means.[71] While this facilitation can be difficult in the ED due to time constraints and logistic pressures, the pediatric intensive care unit (PICU) nurse is in a more optimal position to care for family members as he or she has often had more time to observe the family dynamic and develop a relationship with family members.

Pediatric Intensive Care Unit Staff

When an unexpected death occurs in the PICU, the issues can be potentially more complicated for several reasons. First, the family may have developed a "glimmer of hope" if the child has survived the resuscitation bay and consequently may have false expectations of outcome. Second, difficult ethical issues may arise surrounding the issues of brain death and withdrawal of support.[72] It is important for all members of the staff to keep the family abreast of all clinical details and to meet regularly over the course of hours and, in some instances, days to talk about these issues and to prepare the family for potentially difficult decisions. Some hospitals have ethics committees that can guide staff as they grapple with complex cases. In addition, the developing presence of hospital-based palliative care consultation teams can be a valuable resource in this setting. [73]

In the PICU, families do have more opportunity to develop a relationship with staff, and it is important that the minimum number of individuals feasible be assigned to the patient. In this way, the family will have, as much as possible, a defined number of staff with whom to interact.[74] Typical "rules" in the PICU—for example, number of visitors and hours of visitation—are frequently stretched at the end of life. In cases of withdrawal of support, families are allowed whenever they desire to be at the bedside and to exercise, within reason, whatever rituals they desire. Staff are taught to respect these wishes and, if they feel comfortable doing so, to participate with the family if requested.

Training in end-of-life care for PICU staff is scant and similar to that of ED personnel. There may be individualized in-service presentations at certain centers, but the formal training that nurses and physicians receive, if any, is in undergraduate professional or postgraduate training and not specific to the ICU environment. The principles that apply to sudden and unexpected death in the PICU are similar to those that apply in the ED.[75]

Other Out-of-Hospital and Community-Based Professionals

In most jurisdictions, the sudden and unexpected death of a child occurring in the field or in the emergency department is considered a coroner's case requiring an autopsy by the local medical examiner in the jurisdiction of death pronouncement. In cases involving pediatric trauma, for instance, it would not be unusual for the victim to be transported to a facility well outside the local community in a regionalized system of care. The family may not be present at the receiving facility at the time of death, and early loss and bereavement care may actually be shifted to the medical examiner's office. Therefore, when death notification occurs, it is important for prehospital or hospital-based providers to let families know that the coroner process is required by law and that funeral arrangements can be made only after the case has been released by the medical examiner.

In the wake of increasing media attention to youth violence, the global disaster of September 11, 2001, and other mechanisms of sudden death that may involve children and adolescents, schools and communities are forced to face the issues of unexpected loss head on. Crisis and grief counselors with specific training have been routinely brought in to schools to help students and families cope with loss. It is uncertain as to how well survivors are served by community-based bereavement and mental health services, but increased media exposure to the events of a high-profile and/or catastrophic acute loss accentuates the need for appropriately trained individuals and support personnel to be available at a community level.

SUMMARY AND RESEARCH DIRECTIONS

Regardless of provider type, from first responder in the field to attending physician in the ED or PICU, there appears to be a lack of decisive evidence regarding how well families of children who die are served, and there is clearly a need for more formal training for all staff at all levels. While the subject matter is certainly a difficult one to study, the ultimate outcome for the families is certainly influenced by a well-organized, managed death and bereavement process. In the interest of providing a solid continuum of care, a systemic commitment must be made to the education of those who must interface with the family of a child who dies and to the subsequent evaluation and improvement of emerging educational programs and existing services.

Our discussion has been framed around what historical data are available and what new information is being developed. We have made reference throughout the manuscript to those areas of end-of-life care in EMSC in need of investigation and evaluation. Below are several research ideas framed around an important question and categorized by topic.

Bereavement

What is the association of acute, sudden, or unexpected loss with the development of posttraumatic stress disorder? In the context of acute and unexpected loss the bereavement process has been hypothesized to be associated with the development of symptoms not dissimilar from those of PTSD. Pilot work in this area suggests that nearly 30 percent of family members who have experienced the acute loss of a child can go on to exhibit PTSD symptomatology.[18] Research to characterize and elucidate this relationship is necessary in order that specific approaches and interventions can be developed and tailored when the route of loss is sudden and unexpected.

What is the impact on the bereavement process of parental presence during the attempted resuscitation of a dying child? There have been several institutional studies addressing the issue of family presence in the resuscitation bay.[36,60,63] Despite a paucity of conclusive evidence, there is a growing trend towards encouraging parental presence not only during resuscitation in the emergency department, but during critical care procedures as well. The impact of this practice on parents, their perceptions, and their long-term coping has not been elucidated and needs to be addressed as a research issue.

Critical Incident Stress Management

How does Critical Incident Stress Management affect emergency care providers in the short and long term? What are the important outcomes to evaluate? CISM is the most widely used model of acute psychological support of emergency medical services and other public safety personnel.[11,48,50] CISM has been institutionalized as a formal crisis intervention methodology for both large-scale and individual loss in many fire and rescue and EMS services across the country. Yet there is a paucity of evidenced-based information about the short-term and, importantly, the long-term efficacy of CISM. Useful outcome measures need to be identified and qualitative instruments for their evaluation need to be developed.[47]

Clinical Research—Resuscitation

What are the predictors of mortality during resuscitation in the prehospital and emergency department arenas? Is it beneficial to exercise extraordinary interventions in the resuscitation of children who have experienced prolonged hypoxic–ischemic injury? There is a modest evidence-based literature addressing the effectiveness of high-dose epinephrine (HDE) as a treatment modality for children who have suffered cardiopulmonary arrest (CPA).[76-79] The data show little evidence to support benefit from the return of spontaneous circulation (ROSC) in children resuscitated using HDE. Poor and irreversible neurologic outcomes are the overwhelming norm. Resuscitating the heart in an otherwise brain-dead child can generate a cascade of unalterable events for families and providers including transport to a pediatric intensive care unit and decisionmaking about issues such as withdrawal of support, declaration of brain death, and organ donation. Conversely, the time window that a short PICU stay may afford may positively impact the bereavement process for families. A critical examination of this issue is warranted.

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APPENDIX G

EDUCATION IN PEDIATRIC PALLIATIVE CARE

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OVERVIEW

Despite advances in medical care, many children still die throughout the world, making education in pediatric palliative care a universal need. Lack of provider and patient–family education has been cited as a major barrier to children and families accessing skilled palliative care [1].

The purpose of this review is to address the current state of the art and state of the science in pediatric palliative care education. A review of current knowledge in palliative medicine education in general is beyond the scope of this manuscript; the previous Institute of Medicine (IOM) report [2] outlined a detailed analysis and recommendations for change in palliative medicine education. Rather, this review addresses the potential application of available educationally relevant content and methods to the care of the life-threatened child.

Clear definitions of the educational objectives in pediatric palliative care hinge upon a clear definition of pediatric palliative care itself. As suggested by the American Academy of Pediatrics [3], throughout this review the theme of broader definition, earlier access, and a continuum of

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educational opportunity throughout many stages of professional development are highlighted.

> Palliative medicine is the art and science of child-focused, family-oriented, relationship-centered medical care aimed at enhancing quality of life and minimizing suffering. Palliative care is a model of caring for patients and their families who suffer from life-threatening illnesses. Palliative care focuses on alleviating pain and other symptoms of suffering but also attends to the spiritual, emotional, psychosocial and physical needs of both the patient and the family. Palliative care aims to improve the quality of life of seriously ill children and their families throughout the disease experience and recognizes that helping patients achieve a peaceful death is one of the most important and rewarding services that a healthcare professional can provide. Palliative care completes the developmental circle of competent, compassionate care from birth to death, neither hastening nor prolonging death. Inherent in this definition is the possibility of delivering palliative care in partnership with curative care for children with life-limiting illness, or for children who may not die. [4]

Several authors suggest that many of the skills required to provide good quality palliative care are "generic skills that are fundamental to the practice of medicine in any clinical sphere . . ." [5]. In his critical review of palliative care education, MacDonald [6] comments that palliative medicine is often

> . . . listed in the litany of special interest groups that have worthy issues that should be discussed, but for which there is little room in the curriculum. But the principles of palliative care mirror the perceived changes in medical education which deans generally support. For example, who would disagree that our medical students should
>
> - Spend more time in the community and in the homes of patients
> - Develop a sense of whole person care and move away from a single minded interest in the biology of disease
> - Learn to work in health care teams
> - Develop improved skills in communication, and
> - Consider medical issues in ethical terms
>
> Viewed in this light, palliative care education does not provide the student with information on a "special interest"; rather, the student has the opportunity to work in an environment fulfilling most of the goals of basic medical education. Palliative care is not a competitor, but rather a means to reinforce common ideals.

It is within a broad framework that the future of pediatric palliative care education must be viewed.

DEFICIENCIES IN AND BARRIERS TO PEDIATRIC PALLIATIVE CARE EDUCATION

There are clearly many health professionals already involved in pediatric palliative care. This review will largely focus on healthcare professionals involved in the care of life-threatened children and to a lesser extent on allied health professionals.

Physicians in Practice

Pediatric oncologists have been viewed by many as role models in the care of the dying child. A survey of pediatric oncologists sponsored by the American Society of Clinical Oncology [7] demonstrated that 10 percent of responding pediatric oncologists reported receiving formal courses in pediatric terminal care in medical school, and only 2.2 percent reported a rotation in a palliative care or hospice service. Most alarmingly, the most common method reported by pediatric oncologists for learning about end-of life (EOL) care was "trial and error," and many reported anxiety about having to work with dying children.

These data echo those reported earlier by Raney et al. [8]. As part of a global effort to improve cancer education in medical school, a survey was performed of identified cancer educators at all U.S. medical schools. Palliative care was identified by pediatric oncology and family practice educators as needing more undergraduate medical curriculum hours, but it was not on the list of the five cancer topics identified as most important by all respondents (these were early detection, diagnostic methods, tumor biology, cancer prevention, and natural history). Among those surveyed, 34 percent of pediatric oncologists and 28 percent of family physicians also indicated a need for new materials in palliative care (this was the fourth highest ranking area in need of new materials, after patient education material about cancer, nutrition, and epidemiology).

Single-institution studies (e.g., [9]) have also demonstrated deficits in medical school instruction, resident and fellowship training, and continuing education in palliative care pediatrics. For example, in one such study the majority of assessed residents, fellows, and attending expressed a need for further support in dealing with death and dying.

Primary pediatricians also have a critical role in palliative care, as described by the eloquent commentary of Morris Wessel [10] or the case discussion of O.J. Sadler [11]. Primary providers not only care for dying children, but also may care for a dying child's siblings or, even more commonly, children of dying adults. Further study about how to educate hospital and primary care physicians on how to maintain communication in the care of the dying child and how to keep primary physicians in practice up-to-date in the latest developments in the specialty of palliative medicine is needed.

Educational opportunities in palliative care are scant for family practitioners and general practitioners. Efforts have been reported to improve EOL skills and knowledge for family practice residents [12] and for general practitioners in practice [13, 14] using didactic and experiential techniques. Troller [15] published a survey of rural general practitioners in New South Wales. Although a majority (95.2 percent) had treated patients with terminal illness, only 18.9 percent felt that they were adequately trained in palliative care when they entered general practice.

Millar [5], in a study of Scottish general practitioner trainees, found that trainees were getting clinical experience in palliative care in their curriculum. MacLeod [16] found a similar interest in palliative care education in Bath District House Authority in the United Kingdom, and Lloyd-Williams reported a similar receptivity to expanded experiences in hospice as well as a similar curricular paucity in palliative care [17]. These authors also addressed the interest of practicing generalists in increasing palliative care training and experience.

Nurses

Though nurses have been central to the development of the international hospice movement, educational opportunities for nurses are still rare. [18]. Ferrell et al. [19] describe, for example, the project “Strengthening Nursing Education to Improve End of Life Care” funded by the Robert Wood Johnson Foundation. This project, in response to the 1997 IOM report, has as its goals improving the content regarding EOL care in nursing textbooks, ensuring the adequacy of content in end-of-life care, as tested by the NCLEX exam (National Council of State Boards of Nursing), and supporting key organizations in their efforts to promote nursing education and practice in end-of-life care. A survey of nursing school deans and faculty listed “goals of palliative care” as the weakest curriculum component. Efforts to create performance standards in palliative nursing are also published [20].

Pharmacists

A recent survey of close to 4,000 hospices demonstrated that only 10 percent of hospices trained pharmacy students, despite the fact that pharmacists may play an important role in interdisciplinary EOL care [21].

Patient and Family

The work of Collins and Wolfe demonstrate that children with cancer and other life-threatening disorders are suffering, and that physicians and families differ in reporting symptoms, with families always reporting more symptoms than physicians. Large gaps in communication with patients and families regarding prognostic information and other important therapeutic information have also been demonstrated [22, 23].

Physicians in Training

Surveys of medical education in Europe, Canada, the United Kingdom, and the United States continue to demonstrate shortfalls in palliative care education, including great variability in the availability of palliative care courses, curricular hours, and faculty positions in palliative care [24–29]. Curricular content, approach, or efficacy cannot be evaluated in such surveys [30]. Student survey data from the Liaison Committee on Medical Education (LCME), Association of American Medical Colleges (AAMC), and the American Medical Association (AMA), indicated that "while most medical schools reported including the content in the required curriculum, many medical students considered the education that they received to be inadequate [31]." Single-institution studies support these survey data (e.g., [32]).

The 2001 Medical School Graduation Questionnaire from the Association of American Medical Colleges (http://www.aamc.org) demonstrated that approximately 70 percent of students agree or strongly agree that biomedical ethics was adequately covered in the first and second years of medical school; 72 percent of students agree or strongly agree that professionalism was adequately covered, and 53 percent felt cultural competency was adequately covered.

In 2001, end-of-life care instruction was felt to be appropriate by 64.3 percent of students surveyed and inadequate by 34.5 percent. Palliative care instruction was felt to be appropriate by 64 percent and inadequate by 35.2 percent of the students, compared to 59.3 percent and 39.9 percent, respectively, for 1999. Pediatric palliative medicine was not included as a question in this survey.

The survey included an evaluation of medical student instruction in several areas of clinical medicine, some of which are relevant to palliative medicine and end-of-life care. Of students surveyed, 88.2 percent believe that their education on physician–patient communication skills was appropriate, and 84.2 percent felt that they received appropriate instruction on how to work as a member of a team with other health care professionals. Of interest, only 43.3 percent of medical students in 2001 felt that their instruction on pain management was appropriate, compared with 37.5 percent of students in 1999. 77 percent of these students felt their education on ethical decisionmaking was appropriate, compared to only 44.6 percent who felt that their education on legal issues was appropriate. Only 45.4 percent of students felt that their education on complementary and alternative medicine was appropriate.

Regarding communication skills, 75 percent of students agreed or strongly agreed that they felt confident discussing treatment options with a woman with end-stage breast cancer, and 83.9 percent felt confident in their ability to initiate discussion of do not resuscitate (DNR) orders. Professionalism issues were evaluated by this survey. Most students noted that they learned aspects of professionalism, such as compassionate treatment of patients, respect for the privacy and dignity of patients, valuing honesty and integrity, and major ethical dilemmas in medicine (end-of-life care), during their clinical years.

Pediatric Resident–Program Director Survey

In order to assess the educational experiences of pediatric residents on palliative medicine and end-of-life care and to determine how these can be incorporated as part of their residency curriculum we conducted a survey of pediatric residency program directors and pediatric residents in training (J. Kane, C. Torkildson, C. Olney, B. Himelstein, manuscript in preparation). Fifty-five (22.4 percent) of 246 program directors and 98 (42 percent) of 235 pediatric residents responded to our survey. Key findings included the following:

- Thirty-seven (67.3 percent) program directors state that their residents were involved in end-of-life care situations.
- Directors in 23 (41.8 percent) programs believe that their pediatric residents receive direct palliative care education.
- Palliative care as a competency is considered "somewhat" to "very important" by 78.1 percent of the program directors surveyed.
- The overwhelming majority of program directors say that clinical competency to address physical (99.7 percent), psychosocial (98.2 percent) and spiritual distress (73.6 percent) is "somewhat" or "very important" in pediatric residency education.
- Residents believe that it is "somewhat" to "very important" that physicians provide pain and symptom management (99 percent), and psychosocial (99 percent) and spiritual support (76.6 percent) for their patients; 99 percent of residents reported participation in end-of-life care of at least one pediatric patient and 84 (85.7 percent) were actively involved in the care of a dying child. Hospice care is offered as a scheduled resident

rotation in only one (1.8 percent) of the programs surveyed and few had any hospice experience.

- Scheduled or elective palliative care experiences are rarely available.
- Many residents noted being exposed to palliative care experiences in their general pediatric ward, hematology–oncology, pediatric, or neonatal intensive care and emergency room rotations.
- Issues in pain and symptom management and on how to communicate bad news are among the most common lecture topics available for residents.
- Forty (72.2 percent) program directors believe that there is at least one faculty member with experience in palliative medicine and end-of-life care, and 15 (27.3 percent) believe that they have no such faculty in their programs.
- Only 38.2 percent of program directors believe that their graduating residents are competent in pediatric palliative care.
- According to program directors, learning of palliative medicine and end-of-life care is best when delivered informally at the bedside of patients and during rounds.
- Eighty-two percent of directors believe that palliative care education should be continuous throughout their residency education.

It should be noted that with a response rate of only 22.4 percent, there is no way to control for reporting bias. It is tempting to speculate that programs with stronger palliative care programming would be more likely to respond. However, given the limited response rate, these results should not be considered conclusive or necessarily representative.

Experts in the Field

Editorials, reviews, and commentaries abound suggesting the need to improve teaching of physicians and other health care providers about end-of-life care [33–50], in particular following the publication of the IOM's first report in 1997 [2]. Some also discuss the need for patient education in the conflicted culture in which death should be accepted as natural but in which youth is celebrated [51], some address the needs of children [52], and others bemoan the lack of "tangible investment" in and low prioritization of palliative care issues in the curriculum [25]. As Doyle notes and Overton confirms [53, 54]:

> One fact seems indisputable, namely that only countries where palliative medicine has really become established and made much impact on professional education and clinical practice have been those countries where

doctors chose to work full-time in this field, whether or not they were accorded specialty status.

Joint Commission on Accreditation of Healthcare Organizations

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is an independent, not-for-profit organization that is the nation's predominant standards-setting and accrediting body in health care. Although JCAHO standards do not directly address health care professionals' education, they may have a significant impact upon how health care organizations approach professional education.

Standards from the Consolidated Accreditation Manual for Home Care (CAMHC, 2001-2002 edition) and from the Consolidated Accreditation Manual for Hospitals (CAMH, 2002 edition) relevant to care of the dying and age-specific care were obtained by request from JCAHO (Paul M. Schyve, M.D., Senior Vice President of JCAHO, personal communication, 12/19/01). Although there are no specific standards addressing pediatric palliative care in hospitals, home health, or hospice, end-of-life issues and age-specific care are addressed separately. For example, the CAMH "Assessment of Patients (PE) chapter" lists standards such as:

PE.1 "Each patient's physical, psychological, and social status are assessed."
PE.5 "The assessment process for an infant, child, or adolescent patient is individualized."

The "Patient Rights and Organization Ethics" (RI) chapter addresses requirements for hospitals to address ethical issues, patient involvement in care and care decisions, advance directives, withholding resuscitative services, forgoing or withdrawing life-sustaining treatment, and care at the end of life. Standard RI.1.2.8 states that "the hospital addresses care at the end of life." In the description of intent, hospitals are required to address care issues such as pain and symptom management; respect for values, religion, and philosophy; involving the patient and when appropriate family in every aspect of care; and "responding to the psychological, social, emotional, spiritual, and cultural concerns of the patient and family."

Home health and hospice-specific assessment guidelines appropriately require that "the assessment and reassessment of infants, children, and adolescents are appropriate to the care or services provided" (PE.7). Although standards for care, treatment and services (TX) state that "the care of the dying patient optimizes his or her comfort and dignity" (TX.3.1), no specific standards exist addressing the unique needs of children.

New pain management standards are also available (http://www.jcaho.org/standard/pain.html). The discussion of these standards also includes other aspects of palliative and end-of-life care.

EDUCATIONAL CONTENT AND DOMAINS FOR PEDIATRIC PALLIATIVE CARE

Papadatou [55] describes seven challenges in training health professionals in pediatric palliative care:

1. definition of educational objectives,
2. selection of teaching methods and content of training,
3. definition and teaching of emotional involvement,
4. support of training participants,
5. promotion of interdisciplinary collaboration,
6. evaluation of the training process and its outcomes,
7. background and skills of educators.

She also outlines the necessary domains of the educational approach:

- *Cognitive*: "acquisition of information and knowledge";
- *Affective:* "acknowledgment and exploration of personal feelings triggered by the interaction and involvement with young patients and family members";
- *Behavioral:* "development of specific skills"; and
- *Social:* "the actual provision of health services within a specific social and cultural context."

A multi-institutional or multispecialty needs assessment in pediatric palliative care has not been performed. Single-institution assessments in adult palliative medicine have been reported (e.g., [56]); there is one published on pediatric palliative care [57] for residents. The Educational Development Center has also performed a needs assessment in several institutions; this work to date has not been published.

Significant overlap with principles of adult palliative care is apparent. For the child patient, however, many of these topics have important distinctions. For example, legal issues in children may involve lack of decision-making capacity of children or misinterpretation of "Baby Doe" regulations. Related to the child as he/she changes through normal or abnormal development, there will be a changing knowledge and skill base regarding communication issues, understanding the experience of death and dying, symptom assessment and management, quality of life, and school and community issues. Knowledge of the changing physiological responses to pharmacological intervention is also required.

In addition to the cognitive, affective, behavioral, and social domains, several authors have attempted to categorize another important domain. Coles [46] discusses the need in palliative care to teach "professional artistry," emphasizing the dilemmas and uncertainties of professional practice, a model of professionalism that may be mutually exclusive of the "technical rational" approach that involves technical competencies and expertise.

Corr [58] suggests a "valuational dimension" that "refers to the identification, articulation, and affirmation of one's personal values in relation to life and death." Concepts such as altruism, compassion, humanism, and empathy fall under this category—what are personal attributes and values that impede or propel learning in pediatric palliative care, what constitutes good "bedside manner?" This dimension also addresses the "hidden curriculum" in medical education, the ways in which "knowledge and behavior get constructed, outside the usual course materials and formally scheduled lessons" [59].

We reviewed the AMA's Education for Physicians in End-of-Life Care (EPEC) Curriculum, the UNIPAC self-study program produced by the American Academy of Hospice and Palliative Medicine (AAHPM), the Children's International Project on Palliative/Hospice Services (ChIPPS) Compendium of Pediatric Palliative Care, sponsored by the National Hospice and Palliative Care Organization (NHPCO); the End-of-Life Nursing Education Consortium (ELNEC) curriculum; the Toolkit for Nursing Excellence at End of Life Transition (TNEEL); and additional literature references including reports of parent-identified educational domains [11, 45, 60–63]. The following list of palliative care topics and aspects was generated:

1. Principles of palliative care
2. Death and dying
3. Epidemiology of death in childhood
4. Home care and hospice care
5. Assessing goals of medical care
6. Advanced care planning such as DNR or advanced directives
7. Communication of bad news
8. Futility
9. Withholding or withdrawing of treatment
10. Assessment and management of symptoms
11. Grief and bereavement
12. Cultural sensitivity
13. Self-care
14. Legal and ethical issues

15. Interdisciplinary team care
16. Spiritual care
17. Psychosocial care
18. Practical post-death issues (death certificates, morgue, medical examiner)
19. Quality improvement and research methodology in palliative care
20. Compassion, humanity, humility, and altruism
21. Health care delivery issues including reimbursement and regulation
22. Complementary and alternative medicine
23. School and community issues
24. Depression and mental illness

EDUCATIONAL METHODOLOGIES AND OUTCOME MEASURES

Educational Methodologies

A wide variety of teaching methods can be found in the adult palliative care literature, including didactic sessions, supervised clinical practice, computer-based learning, sensitivity groups, journal keeping, mentoring, role play, simulated/standardized patients, video or film viewing, small group discussion, clinical case discussion, interdisciplinary teaching, hospice and home visits, portfolio learning, and psychological training such as cognitive-behavioral methods [64–67]. There are few published data comparing these methods or combinations of these methods. A comprehensive review of educational techniques in general is beyond the scope of this review. What follows are some examples from the literature of current thought regarding educational techniques in palliative care:

Strictly didactic or strictly experiential learning methodologies in palliative care may fail unless personal meaning is achieved in a cognitive framework. According to Papadatou [61],

> Therefore a challenge for educators is to define a theoretical and conceptual framework to support instructional strategies that combine both didactic and experiential approaches in order to allow participants to acquire knowledge that becomes personal and shared."

Standardized Patients

Greenberg reported an initiative to use standardized parents to improve crisis counseling skills surrounding pediatric death in the emergency room setting [68, 69]. Pediatric residents and fellows were videotaped and observed twice while communicating bad news about a child dead on arrival to standardized parents. A content checklist was developed by survey, and standardized assessment measures were used to examine interpersonal skills. Feedback was provided immediately following the first session, and residents were re-rated with a different standardized parent 4–10 weeks later. Improvement in addressing content categories and in counseling skills was demonstrated; durable changes and the need for reinforcement of skills were not explored.

Other models of standardized patient use in teaching delivery of bad news, pain assessment skills, or end-of-life skills have been published [70–72]. An impartial observer should be considered a part of standardized patient evaluations [73]. A recent publication describes the creation of a standardized family with 16- and 20-year-old children to teach interpersonal skills, interviewing, communication, counseling, and history-taking skills for medical students [74]. One recent report describes the successful use of children as standardized patients [75]. Standardized approaches to teaching differences between communication with adult patients versus adult family members with life-threatened children could not be found.

Interdisciplinary Teaching and Learning

Wallgren-Pettersson et al. performed one of several early trials in the use of interdisciplinary teaching, in this case surrounding the care of chronically ill children. The seminar course, combining medical, nursing, and social work students, was well received overall; however, outcomes designed to measure any changes in students' behavior following the seminar were not performed [76].

Programs specifically designed to improve the function of learners in interdisciplinary teams are also reported widely in the literature (review in [77–79]). Examples of educational approaches include the Geriatric Interdisciplinary Team Training (GITT) program [80], courses or miniresidencies [81, 82], and approaches such as the "Party Planner" more akin to teamwork development programs in the business world [83]. Few objective data, however, are available to demonstrate the efficacy and durability of such programs in changing learner behaviors.

Computer-Based Learning

Reed-Thompson et al. [84] explored the efficacy of a multimedia CD-ROM cancer pain management module. Although effective in meeting some of its educational objectives, the authors appropriately caution that getting physicians to use the CD-ROM may be a significant challenge.

Mentoring or Supervised Experience

Sulmasy et al. [85] demonstrated the efficacy of an ethics education initiative in changing physician behavior in a large urban residency program. The program included didactic and experiential components; an ethicist was added to the care team in the intensive intervention arm of the study. The researchers documented changes in the rate at which concurrent care concerns (such as use of antibiotics, nutrition, and spiritual needs) were addressed in patients with DNR orders. Durability of these changes following the intervention was not explored.

Home Health or Hospice Experience

Changes in resident attitudes, knowledge, supervisory assessment, and patient reactions to home visits were demonstrated in a second- and third-year family practice resident home health rotation [86]. Faculty needs for committed time to program development, further needs to refine evaluative tools, and the difficulty inherent in scheduling home visits for hospital-based residents were noted. Similar programs have been described elsewhere [87, 88].

Portfolio Learning

Finlay et al. [89] described a randomized trial of portfolio learning in cancer education. The project aimed to give students a "holistic understanding" of disease and treatment impact on patients and families as well as of the natural history of disease. In this method, students are assigned one-on-one to a patient, and their experience, commentary, readings, press cuttings, and photographs are recorded in a self-formatted portfolio. Study participants also had faculty mentorship. In OSCE (Objective Structured Clinical Examination) evaluations performed at the end of the course of the intervention, students in the intervention group showed trends toward improved factual oncology knowledge as well as performance in role play; durability of change was not assessed at later time points.

Psychological Approaches

Razavi et al. [65–67] performed a well-designed, executed, and evaluated trial of a brief psychological intervention group for health care professionals. Although short-term results were promising in several aspects such as attitudes toward death or self-concept, particularly for those subjects starting out with the most negative attitudes, durable results were not demonstrated.

Family Caregivers as Educators

No references specifically addressing the utility of family members and/or caregivers as educators in end-of-life or palliative care could be found.

Empathy Training

The question of whether or not empathy can be taught is debated [90]. Several published reports demonstrate effective educational approaches to teaching empathy [91–93]. Although empathic ability in medical students does decline over time following specific training, durable effects can still be demonstrated up to three years later [94].

Outcome Measurements

Outcome measures for educational interventions are widely available. For example, the Accreditation Council on Graduate Medical Education (ACGME) Outcomes Project and the American Board of Medical Specialties (ABMS) recently reviewed and compiled a group of these measurements in the "Toolbox of Assessment Methods," which outlines appropriate evaluative measures for a variety of teaching methodologies. A copy of the toolbox is available at the Web site http://www.acgme.org/Outcome/. Important educational outcomes include both short-term and long-term improvements in knowledge (cognitive objectives), attitudes (affective objectives), and behaviors (psychomotor objectives). Measurement of patient and family outcomes resulting from educational intervention is also important.

CURRENT RESOURCES

Textbooks

Several recent reviews of nursing texts [95–98] and general medical texts [99, 100] for content regarding palliative and end-of-life care have demonstrated significant deficiencies, especially regarding information about social, spiritual, family and ethical issues. Pediatric texts were not significantly different from those of other specialties.

The *Oxford Textbook of Palliative Medicine* [101] contains several chapters on pediatric palliative care, including pain control, symptom control, psychological adaptation, family adjustment and support, special services for children, the development of pediatric palliative care, and ethical frameworks. There are also several chapters devoted to education, including education of social workers, clergy, and volunteers. *Principles and Prac-*

tice of Supportive Oncology has a chapter on pediatric palliative care [102], and a new text devoted exclusively to pediatric palliative care is in preparation (B. Carter and M. Levetown, personal communication) with several chapters devoted to advocacy and education. The *Textbook of Palliative Nursing* [103] has two pediatric chapters, one on hospice care and one on inpatient and ICU (Intensive Care Unit) care. *Palliative Medicine Secrets* [104] has a pediatric chapter with basic information presented in a question and answer format. The *Handbook of Psychiatry in Palliative Medicine* [105] has two pediatric chapters, "Psychiatric Care of the Terminally Ill Child" and "Psychotherapy with the Dying Child"; bereavement care and other psychospiritual needs of children of dying cancer patients are briefly addressed in other chapters.

Several resources are available specific to pediatric palliative care. Examples include the *Compendium of Pediatric Palliative Care* from ChIPPS [106] and *End-of-Life Care for Children* published by the Texas Cancer Council [107], a concise and thorough review of essentials of pediatric palliative care including psychospiritual issues.

Published Curricula and Guidelines

Tools specifically designed to assess curricular content in palliative care are scant. Sellers [108] and Meekin [109] report on successful strategies for assessing curricular content, the latter with more attention to the "hidden curriculum" discussed above.

The Education of Physicians on End-of-Life Care Curriculum (EPEC), an initiative of the American Medical Association's Institute for Ethics (1999), is a physician-directed program developed "to provide education for physicians in the core competencies in end-of-life care." [110] Some age-appropriate language is found throughout. It was designed as a "train-the-trainer" curriculum that trainees could adopt for their own organizational needs. VanGeest [111] demonstrated that EPEC was meeting the needs of physician educators in providing topics relevant to care of dying patients and that the curriculum by learner report would change practice behaviors. However, EPEC trainees did not feel sufficiently prepared to teach EPEC to others.

The Canadian Palliative Care Curriculum, published as *Palliative Medicine: A Case-Based Manual* [112]; the International Workgroup in Death, Dying and Bereavement [113]; the American Association for Cancer Education [114]; the National Consensus Conference on Medical Education for Care Near the End of Life [115]; and the European Association for Palliative Care [116] have minimal if any pediatric content.

The American Academy of Hospice and Palliative Medicine has produced a series of educational materials in EOL. A self-study program consisting of a series of monographs called UNIPAC is available. Each follows a self-instructional learning format with objectives, pre- and post-tests, reading material, and clinical scenarios requiring knowledge application. "UNIPAC Eight: The Hospice/Palliative Medicine Approach to Caring for Pediatric Patients" is in field-testing currently [117]. AAHPM has also produced other materials including the *Palliative Care Pocket Consultant* [118] and the *Primer of Palliative Care* [119]; neither has pediatric-specific content. The *Hospice and Palliative Medicine Core Curriculum and Review Syllabus* has a pediatric chapter [120].

The End-of-Life Nursing Education Consortium (www.aacn.nche.edu/elnec) project has been developed to prepare nurse educators to provide end-of-life education for nursing students and practicing nurses together with resources to facilitate education, based upon the recommendations in "Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care" (www.aacn.nche.edu/Publications/deathfin.htm). Pediatric content is integrated into the teaching modules, and a pediatric ELNEC curriculum is under construction (B. Ferrell, personal communication).

REVIEW OF ACCREDITATION STANDARDS

Requirements for licensing or certification of professionals and accreditation of programs from independent organizations were evaluated. The method of search was primarily Web based, but in some cases, telephone contact and/or personal interview with a representative member of the agency confirmed the information in question. The evaluation in this review included, when available, the agency's mission and position statements, curriculum outline, and/or certification criteria.

The accreditation and licensing or certifying requirements and/or curriculum were reviewed for the presence of palliative care content containing the following:

- Death and dying
- Death and dying in adults
- Palliative care
- Palliative care for children
- End-of-life care
- End-of-life care for children
- Hospice care
- Medical ethics
- Goals of care
- Communication (bad news)
- Withholding and withdrawing treatment

- Medical futility
- Pain management
- Symptom management
- Psychosocial support
- Grief and bereavement
- Grief and bereavement in children
- Child's concept of chronic illness
- Child's concept of death
- Child's emotional and cognitive development
- Spirituality and religion
- Spirituality and religion of children
- Concept of care of chronically ill
- Concept of family-oriented care
- Concept of quality of life

Accreditation Standards: Allied Health Disciplines

Pastoral Care

National Association of Catholic Chaplains (NACC)
3501 South Lake Dr., P.O. Box 07473, Milwaukee, WI 53207;
(414) 483-4898; http://www.nacc.org

NACC is an organization of Catholic priests, religious, permanent deacons and laity engaged in professional health care and related institutional ministries.

Association of Professional Chaplains (APC)
1701 East Woodfield Road, Suite 311, Schaumburg, IL 60172;
www.professionalchaplains.org

APC is an interfaith professional pastoral care association of providers of pastoral care endorsed by faith groups to serve persons in physical, spiritual, or mental need in diverse settings throughout the world. APC provides pastoral care through education, research, standards of care, certification, and support of members and promotes public support for skilled spiritual care.

American Association of Pastoral Counselors (AAPC)
9504 A Lee Highway, Fairfax, VA 22031;
(703) 385-6967; http://www.aapc.org/index.html

AAPC is an international organization of ministers, priests, rabbis, and religious-oriented professionals. AAPC promotes the development of pastoral counseling ministry. It establishes standards and provides certification for competent practice and training of pastoral counselors and accreditation for pastoral counseling centers and training programs.

Association for Clinical Pastoral Education (ACPE)
1549 Clairmont Rd., Suite 103, Decatur, GA 30033;
(404) 320-1472; http://www.acpe.edu

ACPE is an interfaith organization that fosters training in pastoral care and counseling through clinical pastoral education (CPE). ACPE establishes CPE standards, accredits CPE centers, and certifies CPE supervisors.

Aspects of clinical pastoral education are consistent with a palliative care approach to patient care, including emphasis on relational skills; students' understanding of how their own attitudes, values and assumptions affect their clinical work; spiritual assessment, coping with suffering, grief, and loss; and interdisciplinary functioning. Pediatric exposure and expertise is dependent upon training sites. There is no unifying curriculum; individual pastoral organizations offer certification for their members.

Social Work

The Council on Social Work Education (CSWE)
1725 Duke Street, Suite 500, Alexandria, VA 22314-3457;
(703) 683-8080; http://www.cswe.org/

CSWE is a nonprofit national association representing more than 3,000 individual members as well as 158 graduate and 453 undergraduate programs of professional social work education. CSWE is recognized by the Council for Higher Education Accreditation as the sole accrediting agency for social work education in the United States.

American Board of Examiners in Clinical Social Work (ABECSW)
414 First Street East, Suite 3, Sonoma, CA 95476;
(888) 279-9378; http://www.abecsw.org/

This organization sets national practice standards in clinical social work.

National Association of Social Workers (NASW)
750 First Street NE, Suite 700, Washington, DC 20002-4241;
(202) 408-8600; http://www.naswdc.org/

NASW is a professional organization of social workers that establishes standards to define and describe professional practice. NASW has written a position paper on hospice, and also lists end-of-life care in several sections of its standards for social work in health care settings"

Clinical social workers have no requirements for structured training in pediatrics, palliative care and/or EOL care. Some schools have courses and/or seminars regarding these topics. Many of the educational objectives of social work, however, are consistent with a palliative model of care, including understanding of the reciprocal relationships between human behavior and social environments, understanding the range of social systems in which people live and suffer and the ways social systems promote or deter people in maintaining or achieving health and well-being; identifying issues, problems, resources, and assets and planning for service delivery, and enhancement of communication skills.

Through the Project on Death in America/Open Society Institute Social Work Leadership Development Award Program (http://www.soros.org), several innovative educational programs in palliative and end-of-life social work education have been funded. Examples include a collaborative social work/clergy graduate curriculum (Katherine Walsh-Burke and John Linder, http://www.soros.org/death/newsletter8/socialnewsletter.html); a statewide social work curriculum project in West Virginia (Jim Keresztury and Doris Nicholas, http://www.hsc.wvu.edu/chel/wvi/events/leadership.htm); a social work textbook review and curriculum development project at University of Wisconsin, Madison (Betty Kramer and Lori Pacourek, http://polyglot.lss.wisc.edu/socwork/phdfacultyresearch2.html); and a pilot curriculum from the Social Work End-of-Life Educational Program (SWEEP, Ellen Csikai, http://www/sfasu.edu/orsp/rr0201/csikai.htm). A program directed by Barbara Jones at Albany Medical Center, specifically geared toward social work education for psychosocial providers for children with cancer, was also recently funded.

Child Life

Child Life Council (CLC) and the Child Life Certifying Committee (CLCC)
11820 Parklawn Drive, Suite 202, Rockville, MD 20852-2529;
(301) 881-7090; http://www.childlife.org/main.htm

The CLC is the professional organization for child-life specialists who use play, recreation, education, self-expression, and theories of child development to promote psychological well-being and optimum development of children, adolescents, and their families.

The educational background of child-life specialists is based primarily on the child and family needs with a focus on enhancing normal growth and development of infants, children, and youth. Child-life education recognizes the diversity of individuals' and families' strengths and needs and promotes individual and family integrity and well-being. Child-life embraces palliative care principles such as the concepts of family-centered care, relationship-based practice, and communication across settings. It also emphasizes application of child development theory and interdisciplinary professional collaboration. Students cover areas that include separation and loss, stress and coping, bereavement support, and interventions. Certification requirements, however, do not indicate specific training in the care of dying children and their families.

Psychology

American Psychological Association (APA)
750 First Street NE, Washington, DC 20002-4242;
(202) 336-5979; http://www.apa.org

The APA is the accrediting body for educational programs in psychology. The Ad Hoc Committee on End-of-Life Issues of the APA issued a "Resolution on End-of Life Issues and Care" promoting end-of-life care research and training within psychology programs, supporting efforts to increase funding for EOL care research, and encouraging psychologists to obtain training in the area of ethics as it applies to end-of-life decisions. The APA advocates for access to hospice and professional mental health services for seriously ill individuals and their families (specific recommendations can be found at http://www.apa.org/pi/eol/activities.html).

Psychology education emphasizes clinical roles in assessment, intervention, advocacy, and interdisciplinary service delivery, all relevant to palliative care. Training stresses development of competence in evaluation of mood and anxiety disorders, pain, family and caregiver interactions, psychological and cognitive functioning, and existential concerns. There are no accredited postdoctoral residency training sites in palliative medicine or EOL care available for psychology doctoral graduates.

Grief and Bereavement Counseling and Therapy

There are currently no generally recognized national standards for training providers of grief and bereavement support services. Individual organizations, however, do offer training and accreditation, such as the American Academy of Bereavement (http://www.bereavementacademy.org), the Dougy Center for Grieving Children (http://www.grievingchild.org), and the American Academy of Grief Counseling (http://www.aihcp.org/aagc/htm). The Association for Death Education and Counseling (ADEC; http:/

/www.adec.org) offers the certification categories "certified grief therapist," "certified grief counselor," and "certified death educator." The Bereavement Professionals Section of the National Hospice and Palliative Care Organization and National Council of Hospice and Palliative Professionals is preparing guidelines for publication entitled "Guidelines for Bereavement in Hospice" with specific recommendations for education and competency in this area (Barbara Bouton, Director of the Bridges Center, Louisville, Ky., personal communication, 12/08/01).

The Education Work Group of the International Work Group on Death, Dying and Bereavement published a statement of principles regarding education about bereavement [121]. Descriptions of the normal grief process are widely available (e.g., [122]). Principles relevant to the care of grieving children and their families have also been published [123, 124]. Several textbooks of bereavement and grief counseling do address pediatric issues [125–127]. Descriptions of workshops and training programs are also available, but their impact on family bereavement is unknown [128, 129].

Accreditation Standards: Nursing

National Council of State Boards in Nursing (NCSBN)
676 North St. Clair Street, Suite 550, Chicago, IL 60611-2921;
(312) 787-6555; http://www.ncsbn.org//public/about/about_index.htm

The mission of the NCSBN is to lead in nursing regulation by assisting member boards, collectively and individually, to promote safe and effective nursing practice in the interest of protecting public health and welfare. NCBSN develops the NCLEX-RN and NCLEX-PN examinations, performs policy analysis, and promotes uniformity in relationship to the regulation of nursing practice, disseminates data related to the licensure of nurses, conducts research pertinent to NCSBN's purpose, and serves as a forum for information exchange for members.

National League of Nursing Accreditation Commission (NLNAC)
61 Broadway, 33rd Floor, New York, NY 10006;
Phone: 800-669-1656 or 212-363-5555; Fax: 212-812-0390
http://www.nlnac.org/

NLNAC is responsible for the specialized accreditation of nursing education schools and programs, both post-secondary and higher degrees (master's, baccalaureate, associate, diploma, and practical nursing program).

National Board for Certification of Hospice and Palliative Nurses (NBCHPN)
Penn Center West One, Suite 229, Pittsburgh, PA 15276;
(412) 787-9301; http://www.hpna.org/nbchpn/hpar.asp

Certification is a voluntary process through which the NBCHPN validates an individual registered nurse's qualifications and knowledge in the specialized area of hospice and palliative nursing practice. Candidates who successfully pass the certification examination for hospice and palliative nurses are eligible to use the registered designation CHPN (certified hospice and palliative nurse).

American Association of Collegiate Nursing (AACN)
One Dupont Circle, NW, Suite 530, Washington, DC 20036;
Phone: (202) 463-6930; Fax: (202) 785-8320
http://www.aacn.nche.edu/ContactUs/index.htm

AACN is the national voice for America's baccalaureate- and higher-degree nursing education programs. AACN's educational, research, government advocacy, data collection, publications, and other programs work to establish quality standards for bachelor's and graduate degree nursing education, assist deans and directors to implement those standards, influence the nursing profession to improve health care, and promote public support of baccalaureate and graduate education, research, and practice in nursing. AACN found that although nursing was felt to be the leader and expert in end-of-life care, "after reviewing accreditation standards, licensure criteria, and curriculum content it became clear that end-of-life education and training is inconsistent at best and sometimes completely neglected within nursing curricula" (http://www.aacn.nche.edu/Publications/deathfin.htm).

National League for Nursing (NLN)
61 Broadway, New York, NY 10006;
Phone: (800) 669-1656; Fax: (212) 363-5555
http://www.nln.org

The National League for Nursing advances quality nursing education that prepares the nursing work force to meet the needs of diverse populations in an ever-changing health care environment. NLN goals include nursing education, faculty development, education research, data collection, assessment, and evaluation.

Nursing programs are accredited by either the National League for Nursing Accrediting Commission (NLNAC) or the Commission on Collegiate Nursing Education (CCNE). NLNAC accredits all undergraduate and master's nursing programs, and CCNE accredits baccalaureate and graduate nursing programs.

Many basic nursing competencies are relevant to the practice of palliative care. Nursing programs emphasize scientific knowledge, characteristics of reasoning, ethical and clinical judgment, decisionmaking, and interpersonal and technological skills, all of which are integral to nurses' clinical expertise and roles. The opportunity to practice nursing in a variety of health care settings offers a unique ability for the nurse to practice direct comfort care in addition to coordination, management, and planning of patients' treatment with a focus on integrating care across multiple settings. In addition, nurses have a unique opportunity to help with the identification, formulation, and evaluation of possible solutions to a broad range of society's needs in relation to end-of-life care in the United States, that are problematic, uncommon, or complex. Nursing is focused on "integrating the influence of the human experience," and communication is a core competency throughout all curricula. Nursing curriculum guidelines reviewed demonstrate a lack of pediatric palliative or EOL care-relevant content.

Accreditation Standards: Medical Disciplines

General and subspecialty pediatric residency education was reviewed; some residency requirements for adult specialties were examined for comparison. A detailed review of the accreditation standards and, when available, the content outline for certifying examinations for each specialty was performed for the following:

- Pediatrics
- Subspecialties of pediatrics including:
    - child neurology
    - child and adolescent psychiatry
    - neonatal–perinatal medicine
    - pain management
    - anesthesiology
    - cardiology
    - critical care
    - emergency medicine
    - endocrinology
    - gastroenterology
    - hematology–oncology
    - pulmonology
    - nephrology
    - rheumatology

    - sports medicine
    - surgery
    - adolescent medicine
- Neonatal–perinatal medicine
- Pediatric hematology–oncology
- Pediatreic pulmonology
- Pediatric cardiology
- Pediatric neurology
- Pediatric surgery
- Pediatric psychiatry
- Family practice
- Subspecialties of family practice

Program requirements for residency education in pediatrics and its subspecialties are notably deficient on issues related to the care of children suffering from chronic, life-threatening, and terminal illnesses. Palliative care, comfort care, end-of-life care, pain and symptom management, relevant end-of-life ethical issues, and interventions to improve quality of life are notably absent from most ACGME requirements. Skills required to provide "care" to children and their families at the end of life are not addressed. New core competencies outlined by ACGME and ABMS may facilitate the introduction of child-focused, family-oriented care aimed at the relief of suffering and achieving the best possible quality of life for sick children and their families.

Accreditation Council for Graduate Medical Education
Suite 2000, 515 North State Street, Chicago, IL 60610-4322;
Phone: (312) 464-4920; http://www.acgme.org/

ACGME is a private, professional organization responsible for the accreditation of nearly 7,800 residency education programs. ACGME accredits residency programs in 110 specialty and subspecialty areas of medicine, including all programs leading to primary board certification by the 24 member boards of the American Board of Medical Specialties, and completion of an ACGME-accredited residency program is a prerequisite for certification in a primary board. ACGME Residency Review Committees (RRCs) develop curricular guidelines for training programs. Specialty boards or subboards produce the content outline for the certifying examination.

Graduate medical education (GME) comprises the second phase of the formal educational process that prepares doctors for medical practice. GME is required for all medical school graduates to obtain licensure and board certification in a medical specialty or subspecialty. GME is conducted primarily in the clinical setting. Sponsors of GME programs (teaching hospitals, medical schools, regional consortia) have ultimate responsibility for the management and quality of all GME-related activities. Sponsors must comply with the institutional requirements promulgated by ACGME. These requirements are specialty specific and represent the medical profession's consensus as to the minimum levels of oversight and support required for GME programs to meet expectations.

Program Requirements for Residency Education in Pediatrics

End-of-life care skills of pediatricians are listed under the behavioral–developmental experience and include assessment of the impact of chronic diseases, terminal conditions, and death on patients and their families. The scope of training for pediatricians includes relevant areas such as medical ethics including confidentiality, consent, relationship to physicians and patients, "issues of life-sustaining treatments," communication and interpersonal skills, emotional and cognitive stages of human development, psychosocial support of the seriously ill child, and interdisciplinary care

Absent are educational experiences related to quality of life, spiritual care of the dying child, the child's perception of illness or death, grief and bereavement, medical futility, pain and symptom management, assessment of goals of care, communication of bad news or advanced care planning, uniqueness of the child and family as a functional unit, and palliative care or hospice.

Program Requirements for Residency Education in the Subspecialties of Pediatrics

The curriculum includes developing the skills required for dealing with "complications of death" as a general statement for all pediatric subspecialty training. Specific palliative care competencies are addressed in some subspecialties:

- *Child neurology*: "The resident must receive instruction in appropriate and compassionate methods of terminal palliative care, including adequate pain relief, and psychosocial support and counseling for patients and family members about these issues."
- *Emergency medicine*: "There must be an emphasis on developing a compassionate understanding of the stress associated with sudden illness, injury and death so that the resident may be responsive to the emotional needs of the patients, their families, and the staff of the emergency depart-

ment. Discussion and appreciation of the many ethical issues involved in pediatric emergency medicine should be part of the educational program."

- *Hematology–oncology*: "The subspecialty resident should participate in the activities of the tumor board and in the provision of comprehensive care to the child with cancer and should have experience in support of the patient, family, and staff in dealing with terminal illness. Residents should be guided in the development of skills in communication and counseling, including the recognition and management of psychosocial problems in pediatric patients."

Required training in palliative medicine, EOL care, and relevant end-of-life ethical issues is notably absent in other pediatric subspecialties with a high number of pediatric deaths such as pulmonology, critical care medicine and neonatal care.

Program Requirements for Residency Education in Family Practice

Family physicians are expected to assume responsibility for the total health care of the individual and the family, taking into account the "social behavioral, economic, cultural, and biologic dimensions." Residents are also expected to have experience in all patient care contexts including outpatient, inpatient, home, and long-term care facilities but hospice care is not listed as a requirement. Experiences in the care of chronically ill patients are required. "End-of-life issues" and "coping with serious illness and loss" are required, but no specific requirements exist in palliative care. Ethics regarding end-of-life care are not addressed.

The subspecialty of family practice geriatric medicine includes many relevant content areas, including experience with home visits and hospice care including continuity of care with an assigned panel of home or hospice care patients as well as management of patients in long-term care settings, including palliative care, knowledge of the administration, regulation, and financing of long-term institutions, and the continuum from short- to long-term care.

The American Academy of Family Physicians (AAFP) position paper "End of Life Care" does not mention children (http://www.aafp.org/policy/issues/e-endposition.html).

Program Requirements for Residency Education in Psychiatry

ACGME requirements for psychiatry residents describe compassion and respect as a medical skill. The documents includes as part of the didactic curriculum the "biological, psychological, sociocultural, religious/spiritual and family factors that influence development throughout the life cycle" but death and dying, end-of-life care, and palliative care are not listed as specific requirements. Hospice care or exposure to patients at the end of their lives is not required for accreditation. Spirituality is mentioned in the context of the totality of the individual. The concept of chronic illness is mentioned in term of psychiatric conditions. The concept of quality of life is not documented.

The content outlines for the certifying examination by the American Board of Psychiatry and Neurology outline pain pathways, treatment of acute and chronic pain, and analgesics as elements of pain management. Death and dying are listed as topics of interest as is the concept of normal grief versus depression. Developmental milestones are also listed. Ethical issues at the end of life and spirituality are not listed in the content outline.

The subspecialty of pain management (psychiatry) lists relevant content areas including "principles and techniques of cancer pain management, including death and dying, and the ethical principles involved in hospital, hospice, and home care," as well as "other services including vocational, nursing, pharmacy, dietary, pastoral care, end of life care, as well as liaison with hospice and abuse services."

Program Requirements in Other Subspecialties

Anesthesiology pain management, a subspecialty of anesthesiology, and neurology pain management, a subspecialty of neurology, list similar content areas to pain management (psychiatry). General program requirements for residency education in neurology include "instruction in appropriate and compassionate methods of end-of-life palliative care, including adequate pain relief and psychosocial support and counseling for patients and family members about these issues."

Obstetrics and gynecology requirements list "compassionate patient care" as one of the goals and emphasize "interpersonal and communication skills and adherence to ethical principles." Palliative care or EOL care and pain management are not listed as requirements for certification.

For comparison, the program requirements for internal medicine include: end-of-life care, "instruction in the principles of palliative care for terminally ill patients, including the role of the health-care team," and "it is desirable that residents participate in hospice and home care."

Competency-Based Medical Education

The ACGME and ABMS have approved a new set of competencies for medical education in six areas. Programs must define the specific knowledge, skills, and attitudes required and provide educational experiences as needed in order for their residents to demonstrate such competencies:

1. patient care that is compassionate, appropriate, and effective for the treatment of health problems and the promotion of health;
2. medical knowledge about established and evolving biomedical, clinical, and cognate (e.g., epidemiological and social–behavioral) sciences and the application of this knowledge to practice-based patient care;
3. learning and improvement that involves investigation and evaluation of their own patient care, appraisal and assimilation of scientific evidence, and improvements in patient care;
4. interpersonal and communication skills that result in effective information exchange and teaming with patients, their families, and other health professionals;
5. professionalism, as manifested through a commitment to carrying out professional responsibilities, adherence to ethical principles, and sensitivity to a diverse patient population; and
6. systems-based practice, as manifested by actions that demonstrate an awareness of and responsiveness to the larger context and system of health care and the ability to effectively call on system resources to provide care that is of optimal value.

American Board of Medical Subspecialties
1007 Church Street, Suite 404, Evanston, IL 60201-5913;
(847) 491-9091; http://www.abms.org

Blueprints for subspecialty certifying examinations prepared by the American Board of Pediatrics (ABP) and its subboards were reviewed. None of the outlines listed the care of the dying child in terms of palliative care or end-of-life care. Death and dying was mentioned in hematology–oncology as “fatal illness.” In critical care medicine, the concept of death was listed as “determination of brain death” and “organ and tissue donations.” Death and dying was not mentioned in pulmonology, cardiology and neonatal–perinatal medicine. The most extensive list of issues related to death and dying in children was seen in behavioral and developmental pediatrics. Ethical issues appeared to be listed primarily in the critical care medicine outline, but the concept of withholding treatment is described as “withholding care.” Pain management and analgesics appear in the content outline of only critical medicine and hematology–oncology but non-pain symptom management is not addressed. None of the outlines reviewed except for behavioral–developmental pediatrics contained topics related to psychosocial support. None of the outlines list religion and spirituality.

Accreditation Standards: Undergraduate Medical Education

Requirements for undergraduate medical education lack standards regarding palliative and end-of-life care for children. Although LCME has a new content requirement in EOL care, there is currently no standard by which LCME can determine whether training programs are, in fact, meeting the new requirements (D. Weissman, personal communication).

Liaison Committee on Medical Education (LCME)
American Medical Association
515 North State Street, Chicago, IL 60610;
(312) 464-4933

Association of American Medical Colleges
2450 N Street, N.W., Washington, DC 20037;
(202) 828-0596; http://www.lcme.org/

LCME is a joint venture of the AMA and the American Association of Medical Colleges (AAMC) that accredits U.S. medical schools. Recent revisions to accreditation standards from LCME include a standard on end-of-life care, but it is very broad in its scope: "Clinical instruction should cover all organ systems, and must include the important aspects of preventive, acute, chronic, continuing, rehabilitative, and end-of-life care."

Additional content guidelines do fit within the broad principles of pediatric palliative care, including "ethical, behavioral, and socioeconomic subjects pertinent to medicine"; "broad-based clinical education programs that equip students with the knowledge, skills, attitudes, and behaviors necessary for further training in the practice of medicine"; "the need for students to be concerned with the total medical needs of their patients and the effect on their health of social and cultural circumstances"; "an understanding of the manner in which people of diverse cultures and belief systems perceive health and illness and respond to various symptoms, diseases, and treatments"; and "the LCME encourages experimentation that will increase the efficiency and effectiveness of medical education."

Council on Medical Student Education in Pediatrics (COMSEP)
American Board of Pediatrics, 111 Silver Cedar Court,
Chapel Hill, NC 27514;
(919) 942-1993; http://www.unmc.edu/Community/comsep/

COMSEP fosters excellence in undergraduate medical education in pediatrics. Functioning under the auspices of the Association of Medical School Pediatric Department Chairmen (AMSPDC), COMSEP is the official organization of North American educators with administrative responsibility for undergraduate medical education in pediatrics. It promotes the development, dissemination, and evaluation of curricular materials and educational resources through interinstitutional collaboration. It advocates for research in pediatric medical education. COMSEP has produced a "module curriculum" for pediatric clerkships. Despite discussion of such conditions as trauma, congenital and genetic disorders, and chronic illness, there is no mention of palliative, end-of-life, or hospice care as core competencies or learning objectives.

Other Educational Standards or Programs

Fellowship Training Standards

The American Board of Hospice and Palliative Medicine has created training guidelines for fellowships in palliative care (available at www.aahpm.org, submitted for publication) as part of the process of seeking ACGME certification for the field. Several academic centers now sponsor fellowship training programs in palliative care [130], and the U.S. Department of Veterans Affairs has also established a six-center "Interprofessional Fellowship Program in Palliative Care" (http://www.va.gov/oaa/flp/hubsite_announcement.asp). However, specific fellowship training programs and standards for pediatric palliative care do not currently exist in the United States. Some age-appropriate language was inserted in the current draft of the training standards to affirm the need to educate adult providers in the care of life-threatened children, but a specific track for pediatric palliative care graduate training was not created in the initial guideline iteration. Abroad, a Pediatric option exists for the diploma in palliative medicine as well as the master in science in palliative medicine program, a one-year academic course offered at the University of Wales College of Medicine.

Courses and Clerkships

The literature is replete with examples of interesting courses and programs in palliative care. Most of these reports could not be analyzed for pediatric content. No peer-reviewed reports of clerkships dedicated to palliative care for children could be located, although they certainly exist. In some cases, goals, objectives and evaluations are described. Examples of targets for education include home care agencies [131], undergraduates [132, 133] and medical students [60, 134–143].

The health care delivery environment has a clear impact on the type of education in end-of-life care necessary. For example, Bascom et al. make an interesting observation that in Oregon, where hospice utilization is higher than in many other parts of the country, the acute care hospital is no longer a major site of death. Surveyed medical students demonstrated that many have limited exposure to death, with 42 percent of graduating students never having witnessing a death [144].

House Staff and Specialty Training

At the house staff level, reports are published regarding elective experiences and courses in hospice or palliative care (e.g., [145, 146]). Von Gunten et al. [147] created a hospice/palliative medicine rotation for fellows training in hematology–oncology. Improvements in fellows' skill in pain and symptom management and understanding of hospice and palliative care were reported.

Practicing Physicians and Continuing Education

Latimer et al. [148] described 10 years' experience with an interdisciplinary (faculty and learner) five-day palliative care course for practicing health professionals. The course attracts primarily nurses and physicians, but also social workers, physical or occupational therapists, and clergy. A wide variety of learning techniques are offered; pediatric issues are clearly outlined in the course curriculum. Evaluations have been positive in course satisfaction and in the likelihood of causing practice change.

Emergency Medical Services, Prehospital Personnel

In addressing the needs of prehospital personnel, a 50-minute educational module entitled "Coping with the Death of a Child" has been created by an interdisciplinary team piloted as part of the Pediatric Advanced Life Support (PALS) curriculum. The module met its educational objectives in pilot work, but changes in knowledge or skills, or long-term retention of curricular content, were not assessed [149].

The Pediatric Education for Prehospital Professionals (PEPP) course, sponsored by the American Academy of Pediatrics, is a comprehensive, innovative, and highly visual pediatric course for both basic life support (BLS) and advanced life support (ALS) providers, with case-based lectures, live action videos, hands-on skill stations, and small-group scenarios (http://peppsite.com). This course has been specifically designed for first responders, emergency medical technicians (EMTs) and paramedics. The one-day BLS course is geared toward EMT-basic, and the two-day ALS course toward EMT-intermediate and paramedic providers. A review of the outline materials for this course did not demonstrate content in pediatric end-of-life or palliative care.

Pharmacy

The Faculty of Pharmacy and Pharmaceutical Sciences at the University of Alberta, Canada, has created an elective experience—the "Pain Module”—for final-year pharmacy students. The course includes both traditional and newer educational formats including computer-mediated conferencing (CMC) and home or hospice visits. Evaluation was performed by survey and focus group, demonstrating not only favorable reviews of the educational techniques, but also something rare in the medical education literature, correlations between learning styles and preferred educational formats [150].

INTERNET RESOURCES

VandeKieft et al. [151] performed a comprehensive review of end-of-life care Web sites, screening for clear ownership or sponsorship, clear authorship, contemporary accuracy, readability, and ease of use. Attempts were made to evaluate privacy, conflicts of interest, goals of the site, date of last update, and availability of downloadable materials including PDF files. Established review criteria for health-related Web sites were noted to be absent. Depending upon the search engine and search strategy, millions of Web sites were identified; several quality end-of-life Web sites were identified. In their article, a selection of key sites meeting criteria was found.

The End of Life Physician Education Resource Center (EPERC) is a central repository for educational materials and information about EOL issues (www.eperc.mcw.edu). The purpose of EPERC is to assist physician educators and others in locating high-quality, peer-reviewed training materials. This web site supports the identification and dissemination of information on EOL training materials, publications, conferences, and other opportunities. There are several pediatric-specific resources available, and the “Fast Fact” series of fact sheets about EOL topics has addressed some pediatric issues.

From the patient or family perspective, there are no published data regarding availability and appropriateness of Internet end-of-life or palliative care content. Berland et al. recently performed a study to examine accessibility, quality, coverage, and accuracy, as well as reading grade level, for Internet resources regarding breast cancer, depression, obesity, and childhood asthma. They found that less than 25 percent of a search engine’s first pages of links led to relevant content, less than half of English and less than a quarter of Spanish Web sites contained more than minimal clinical coverage, and all English and most Spanish Web sites required a greater high school reading proficiency. These results, although not specific for end-of-life care, suggest that efficient access to understandable health-related Internet content is a nontrivial matter [152].

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APPENDIX H

PROGRESS IN PEDIATRIC PALLIATIVE CARE IN NEW YORK STATE—A DEMONSTRATION PROJECT

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In May of 2000, the Health Care Financing Administration (HCFA) announced the initiation of a demonstration program in pediatric palliative care. The program was the result of several years of discussion, advocacy, and negotiation involving representatives of government, focus groups, and task forces, led primarily by Children's Hospice International (CHI). The primary goal of the demonstration program is to promote the implementation and testing of the "PACC model." "PACC," which stands for Program of All-Inclusive Care for Children, is the pediatric palliative care model developed by CHI. The PACC model is described in detail in several CHI publications (e.g., Children's Hospice International, 2002) and on the CHI web site (http://www.chionline.org). The PACC model may be considered a descendant of the PACE model (Program of All-Inclusive Care for the Elderly) (Department of Health and Human Services, 1999). The PACE model was developed and tested under the auspices of HCFA in the 1980s. Both models include comprehensive, interdisciplinary support for people with life-limiting illness, but the PACC model includes critical features specific to the pediatric population.

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The initial appropriation for development and testing of the Program of All-Inclusive Care for Children was $1 million for fiscal year 2000. Five states submitted proposals that were ultimately accepted for funding: Florida, Kentucky, Utah, Virginia and New York. In 2001, a second request for proposals was released, resulting in continuation of funding for the original five projects along with the addition of a project in Colorado. It is anticipated that a third year of demonstration project funding will be available in 2002. The demonstration projects have common goals of developing model programs in their states; identifying and overcoming administrative, technical, political, and other barriers to implementation; and providing evidence of cost-effectiveness. The demonstration projects may explore a range of public and private options for program financing, but development of Medicaid waiver applications that will support expanded coverage of services will be attempted by all of the projects.

New York state's PACC demonstration project builds on a long-standing and well-regarded program in pediatric palliative care, the Essential Care program (ECP). The ECP is administered by the Center for Hospice and Palliative Care (CHPC) in Buffalo, New York, and has been providing end-of-life (EOL) care for children and families since 1988. The Essential Care program was viewed as a strong starting point for a demonstration project in the state of New York in that the strengths of the program could be documented while adding to the knowledge base both locally and in the field.

BRIEF DESCRIPTION OF THE ESSENTIAL CARE PROGRAM

The history of the Essential Care program has taken place under three administrative structures: an inpatient hospice, a children's hospital, and currently, a more comprehensive hospice that includes a home care agency. This history reflects the complexity of sustaining an organizational base for a population that has often "fallen between the cracks." The program has faced repeated challenges in financing but has also accumulated a wealth of clinical and administrative experience. The initial clinical experience generated some important insights about the needs of the population.

Among the key experiential lessons was the observation that parents did not want to admit their child into "hospice" and wanted to maintain hope for extended longevity. It was also evident that children and families wanted to be at home as much as possible but needed a unique network of support services to do so. Those services included counseling and other support for the well children in the family. Returning the locus of family life to the home meant that "normalization" of family life could become a realistic goal.

Physicians' views were equally clear: They would not in most cases certify that a child had a life expectancy of six months or less, and they were hesitant to abandon all curative treatment. They wanted to remain as active caregivers to these children and not relinquish care to a hospice physician.

It was evident that an ideal program should include all the benefits and services consistent with the hospice philosophy, without the Medicaid rules related to life expectancy and forgoing curative treatment. Thus, the need for Medicaid waivers and other approaches to creating earlier and more flexible access to palliative-type services was apparent to the Essential Care team. In the absence of substantial insurance coverage, financial support has until now included an emphasis on foundations, grants, and local fund raising. Program growth in recent years has been accompanied by parallel challenges in supporting program activities that are not reimbursed under current regulations. An upper limit on nonreimbursed costs may be imminent, threatening continued growth of the program, and might be discouraging to anyone studying the feasibility of beginning new programs in the current economic environment.

In the last three years, the average daily census has increased 85%. The current average daily census is 45, with about 30 new children admitted per year with an average length of stay of approximately 8.5 months. The average number of deaths per year is about 13, with 80% occurring at home, as most families prefer. In the 14-year history of the program, more than 350 families have been cared for. If a child's disease goes into remission and home care services are no longer necessary, a graduation ceremony ensues. Approximately 25% of admissions eventually graduate, and half of those are readmitted and cared for until death. Thus, about one of every eight children served by the Essential Care program ultimately experiences long-term remission and cure.

While in the program, each patient receives nursing, social work, and child-life services, in addition to support from the primary physician or physician specialist. A variety of supplementary services are available, tailored to individual family situations. An overview of each care specialty is given in Addendum H.1. This set of services is quite consistent with the PACC model specifications (CHI, 2002, p. 42).

Third-party payers have played an important part in recognition of this program model. Partnerships with two local health maintenance organizations have been established since the inception of the program. In Table H.1, a breakdown of insurance coverage over the last three years is presented. Blue Cross and Blue Shield and the Independent Health Association have recognized the importance of this program model. Throughout the years they have been very generous in approving nursing visits to accommodate patient needs in the home. They recognize it is cost-effective to keep patients home and out of the acute setting. They have also been the first to approve counseling and other support services for the parents and siblings

TABLE H.1 Essential Care Pediatric Program Primary Insurance Mix in Past 36 Months ($N = 124$)

Primary Insurance	No. of Patients	Percentage
Blue Cross/Blue Shield	41	33.06
Commercial	21	16.94
Independent Health Association	39	31.45
Medicaid	35	28.23
Total	136[a]	109.68

[a] There were 12 primary insurance changes during this period, accounting for 136 primary insurance cases in the 124 families.

in the home. Traditional CHHAs (certified home health agencies) do not readily approve social work visits in the home, and child life is not recognized anywhere in the country as a reimbursable discipline. Both of these health maintenance organizations recognize the importance of the expertise in pediatrics and supportive needs of parents and siblings. They are reimbursing child life under the social work code and giving our program approval for home visits. This does not account for all of the home visits that both of these disciplines make, although it is a start.

NEW YORK'S DEMONSTRATION PROJECT IN YEAR ONE

New York's approach to the demonstration project builds on the Essential Care program but also involves a network of statewide partnerships. These include the parent organization of the Essential Care program, the Center for Hospice and Palliative Care (CHPC), as well as the New York State Department of Health (DoH), and the Hospice and Palliative Care Association of New York State. The co-principal investigators of the grant are program officers in the Department of Health. The DOH has also provided consultation on many program planning and grant activities and has taken a leadership role in the study of costs and the creation of the Medicaid waiver application. The state hospice association has been very involved in coordinating advisory group activities and the statewide conference. The network of cooperation has extended to many other organizations through the New York State Advisory Group on Pediatric Hospice and Palliative Care. Establishment of the advisory group was one of the first-year goals of the project. Other objectives of the demonstration project in the first year were to

1. evaluate the cost of services and develop a methodology to calculate service costs on a statewide basis;
2. add necessary program components to complete the PACC model within Essential Care;
3. conduct a needs assessment in New York state; and
4. conduct a statewide education program in collaboration with the New York State Hospice Association on how to develop a comprehensive pediatric palliative care service, thus stimulating the generalization of the PACC model in the rest of the state.

A chronology of demonstration project activities is provided in Table H.2. The table includes basic information on events leading to the demonstration project and a detailed list of project activities in year 1 followed by a summary of goals for the second year.

TABLE H.2 Chronology of the New York State PACC Demonstration Project

Year	Event	
Pre-Demonstration Project Events		
1988	Essential Care program established	
1997–1999	PACC model created by CHI Task Force	
1998	Essential Care program becomes part of the Center for Hospice and Palliative Care	
Demonstration Project Events		
2000	Demonstration Project Grant application submitted	
	November	Grant activities commence
2001	January	New York State Advisory Committee formed
	January	CHI demonstration project conference
	March	Listserv established for advisory committee
	April	Quality-of-Life measure collaboration initiated
	March–December	Cost assessment designed and conducted

TABLE H.2 Continued

Year	Event	
	June–August	Web-based needs assessment with professionals
	June–July	Annotated bibliographies developed on communication regarding life threatening illness and QoL.
	July	Seminar on communication held with Essential Care program staff
	July–August	Communication study conducted
	July–August	Videotaped case studies with families conducted
	September–November	Conference on Development of Pediatric Palliative Care Programs held in Albany, NY[a]
	November	Preliminary cost analysis suggests need for actuarial consultant
Anticipated Project Events		
2002		Expand needs assessment sample to include children and families.
		Develop standardized needs assessment for community and family level assessment
		Develop 1115 Medicaid waiver application
		Continue development of methods for generalizing the Essential Care program to other areas in the state
		Continue collaboration on development of QoL measures

[a] The conference was begun as scheduled on September 11, but rescheduled and held on November 1 because the day's events precluded completion of the conference.

PROGRAM COSTS AND MEDICAID WAIVER APPLICATION DEVELOPMENT

The development of a federal 1115 Medicaid waiver is one of the expected outcomes of this demonstration project. The underlying logic for such a waiver is to remove the "six months until death" regulation and thus get children with life-threatening diseases into palliative care at a much earlier stage of their disease. The demonstration, however, must illustrate that the costs associated with children in the program are not generally expected to be higher than the costs of those children receiving traditional program services.

Health Department staff collaborated with CHPC staff to develop a methodology for comparing Medicaid costs of children in the CHPC program with the costs of children outside the program. Because the health problems of chronically and terminally ill children are complex, our initial attempts at cost comparisons were inadequate. Building upon our experiences in year 1, we intend to devote our efforts in year 2 to developing a methodology for calculating costs in a much more sophisticated manner. To support this effort in the second year of the project, an actuarial firm has been consulted and will develop the financial analysis and models needed to support the waiver application in 2002.

The primary goals of the actuarial analyses will be to calculate the cost of care for Medicaid children with life-threatening conditions in the most accurate way possible and to compare the cost of care for Medicaid children in the Essential Care program with the costs of care of a clinically matched group of Medicaid children outside the Essential Care program. In order to achieve these goals, the actuarial organization will obtain Medicaid claims data that will include claims histories for children who died with selected diagnoses. These claims histories will include service utilization, dates of service, and diagnostic and clinical detail that will enable the analyst to develop cost estimates for these children at various stages of their disease. Using these data and comparable data from the Essential Care program, the analyst will be able to precisely compare the costs of care for children treated within the Essential Care program with those of clinically identical children outside the program at various stages of their illness.

COMMUNICATION

Communication in the context of palliative and hospice care for children is at once extremely important and extremely challenging. In the absence of a program of all-inclusive care such as Essential Care, discussions within families and between families and care providers about issues related to a child's condition are typically rare and conducted under the most stressful of circumstances around a medical crisis. A hallmark of the Essential Care program is regular discussion of issues related to the child's and family's well-being with trusted professionals throughout the course of care. The extensive experience of the Essential Care program staff results in communication that balances complex issues and dynamics related to family and individual functioning, disease status, and prognosis. The approach might be characterized as similar to Bluebond-Langner's (1996) recommended strategy of "shuttle diplomacy," in which care is taken to assess the readiness of family members for discussion of topics. The goal of this strategy is to find a balance between respecting the individual's and family's desire to carry on normal life by focusing on topics other than illness and the potential benefits of open discussion of critical issues.

Since the demonstration project in New York is based on an existing program, goals were developed to document communication within the program and to compare Essential Care communication practices with models available in the literature. Our literature review on the topic of communication of threatening information in both medical and nonmedical circumstances was followed with a presentation to the Essential Care team. An annotated bibliography was then made available for members of the team. Based on this review, as well as a review of evaluation research methods, it was concluded that case studies would be productive both in advancing understanding about communication within the Essential Care program, and in documenting the nature of communication as an outcome of the demonstration project.

Two levels of case study have been conducted in the first year, and described in the following:

1. *Chart Reviews*. A coding form to analyze the frequency of communication about ten key issues was developed. The coding form was based on the analysis of literature on communication as well as the clinical expertise of the Program Director and grant researcher. The fifty most recently closed cases were chosen for study. Two trained doctoral students in psychology who had been hired to assist with the project over the summer of 2001 reviewed each chart. The range of EoL conversations in this sample was zero to 51, with a mean of 15.5. The three most frequent topics were prognosis, fear of future, and death/dying/grief. The frequency of discussion of the ten topics is shown in Figure H.1. Additional results of the review were presented at the educational conference and will be included in a separate manuscript.
2. *Video Case Studies*. The first aspect of Tobin's (1999) model is recognition of "the individuality of the disease and choice." Video documentaries may be one of the most effective means of capturing the individuality of the child and family. Videotaped interviews with patients, family members and staff members involved in one ongoing case and one closed case were conducted. The tapes were transcribed and studied by a committee that included the program director, the grant researcher, the director of public relations at the CHPC, a CHPC graphic artist, and an experienced television producer. The goal of the video case studies was to capture the individual story of the patient, family, and program interaction. The tapes

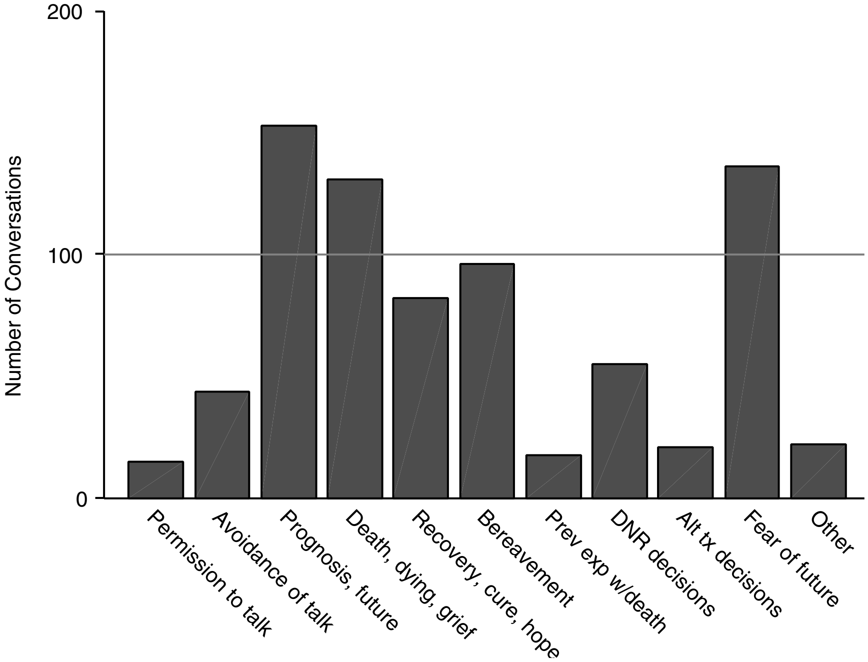

FIGURE H.1 Relative frequency of various topics documented in Essential Care charts.

will be used in professional education and in local program marketing efforts.

Another application of the video case studies is to code segments by the items in the needs assessment and then create interactive concept maps in which the needs statements are illustrated by video clips. For example, the following comment could be used to illustrate the importance of home-based care. This comment was made by the mother of a 2-year-old boy who died at home with the support of the Essential Care program. She was commenting on her perception of how the program helped her and her family:

> The biggest difference I would have to say is the week that we had him home. They made it possible. That week was the most precious week we had with him. They made it possible for him to have time at home after a couple weeks in the hospital with all of the hustle and bustle there—to come home, have a quiet home, special family time. They made it possible to have these pumps available here—to have that family together again one more time. Because Bryce knew we weren't going to have it anymore.

> And it was so important to get out of that hospital setting . . . to have him home, and they made it possible.

Two case studies were completed in the first project year; additional studies may be completed depending on funding. One case involves a family whose young child died after battling an aggressive form of cancer (cited above). The second involves a family with two children diagnosed with incurable neurologic disease that follows a relatively slower course. The interviews include patients, parents, and staff members, and include specific focus on communication in the context of care.

The case studies may be continued in a variety of ways. One way in which the chart study might be continued would be to identify how economic costs might be affected by communication as well as direct quality-of-life (QoL) benefits. The video case studies could be extended to other cases illustrating other issues in pediatric palliative care. We hope to create a set of 10 cases or so that would provide excellent material for research as well as training of palliative care professionals.

PATIENT AND FAMILY NEEDS ASSESSMENT

As of this writing there are no comprehensive, quantitative reports of needs assessments of children or families of children with life-limiting illness in the available literature. Contributing factors may include the complexity of the issues, the traditional focus in health care on adult problems, and perhaps the fact that this is an area that has generated more emotional than behavioral (action) responses in our country. The New York state demonstration project included provisions for a needs assessment to be conducted in conjunction with the cooperating stakeholder groups: the Essential Care program; the New York State Advisory Committee on Pediatric Palliative Care and its parent organization, The Hospice and Palliative Care Association of New York State; the New York State Department of Health; other experts invited by the advisory committee; and families who are currently caring or have previously cared for a child with a life threatening illness.

The specific goals and methodology of the needs assessment were developed in a series of meetings and Listserv discussions with representatives of all stakeholder groups. The discussion that follows outlines the methods and preliminary results of the needs assessments along with discussion of the limits of the analysis and follow-up plans.

Methodology

The grant team reviewed numerous possible approaches to needs assessment. The following issues were identified as critical in the planning of the assessment: (1) scope of needs assessment, (2) sample and participants, and (3) fit of method to scope and sampling.

The scope was defined as the needs of children with life-limiting illness and the families of children with life-limiting illness in New York state. The sampling strategy of the study was defined at three levels:

1. the New York State Children's Palliative Care Advisory Group,
2. the professional networks of experts in children's palliative care needs beginning with the advisory group and extending to colleagues throughout the state, and
3. the children and families who have experienced treatment for a life-limiting illness. (This third level of the assessment is to be undertaken in 2002.)

The statewide scope and sampling considerations lead to consideration of Web-based assessment methods with the ultimate choice of a method known as Concept Mapping (Trochim, 1989).

Briefly, Concept Mapping (CM) is a systematic approach to tapping the shared expertise of a group and constructing statistically based graphic models of the areas examined by the group. There are typically six steps in the process, and they are described in detail by Trochim (1989). Compared with focus group methods, CM provides a more rigorous statistical basis for modeling needs, including multidimensional scaling and cluster analysis. The statistical procedures guide the analyst in producing the most valid and reliable representation of the data. Human judgment is not removed from the process, however, and is critical in the cluster analysis and the interpretation of the resulting maps. The CM analysis may typically include a variety of follow-up studies, several of which are being planned presently in New York. The present discussion of the needs assessment is intended to stimulate and support the efforts of new groups as they consider the issues involved in conceptualizing and measuring the complex needs of children and their families.

Procedures

Phase 1: Brainstorming on Child and Family Needs

The first phase of the study was accomplished by the use of two Web pages, one devoted to brainstorming the needs of children with life-limiting illness, and the second focused on the needs of the families of children with life-limiting illness. Initially, the members of the New York State Advisory Committee were invited to participate in the brainstorming. This was followed by invitations to colleagues of advisory committee members. The same procedure was followed for the family needs assessment.

Phase 2: Structuring the Needs Statements

The statements generated in the brainstorming phase were edited for the occurrence of duplicates and for clarity. The statements were then added to a database on the Concept Systems server, and new Web pages were constructed. The members of the advisory committee were assigned user names and passwords in order to participate in the sorting and rating of the statements. Committee members were instructed to log on to the site and first complete a free sort of the items. The sorting allowed each person to establish piles of similar items and to name the piles.

Following the sorting, committee members were asked to rate each item as to relative importance and feasibility. The importance was rated on a 1 to 5 scale of which 1 represented "relatively unimportant" and 5 represented "extremely important." The feasibility ratings also ranged from 1 to 5, with 1 representing "not feasible" and 5 representing "already being done."

They were also asked to complete demographic items identifying their professional specialty, years of work with the population, work setting, county of residence, and whether or not they had ever had a child member of their immediate family diagnosed with a life-threatening condition. Twelve members of the committee contributed usable data by completing all of the tasks. The needs rating phase was then extended to colleagues, just as the brainstorming in Phase 1 had been.

Results[1]

The brainstorming on children's needs resulted in 74 unique needs statements contributed by 50 experts in pediatric palliative care. The complete list of children's needs is presented in Addendum H.2. The brainstorming on family needs produced 63 unique statements from 40 individual experts in pediatric palliative care throughout New York state. The list of family needs statements is given in Addendum H.3.

The statistical analysis proceeded in two major steps. The first step was to submit the sorting data to a two-dimensional nonmetric multidimensional scaling (MDS) analysis. (All analyses were completed using The Concept System, Version 1.751.) The MDS analysis combined all of the

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[1] The complete results of the needs assessment will be published separately. Only the results of the children's needs assessment are presented here.

separate sorts, resulting in a two-dimensional representation of all of the statements. An *X–Y* value for each statement defines its position on the map, with items closer to one another representing more similar constructs and those further apart reflecting less similar ideas. The MDS results were then examined in a hierarchical cluster analysis. The cluster analysis involved an iterative process in which each possible solution from 20 to 3 clusters was examined for interpretability and statistical indicators of adequacy of the solution. In the following section, the results of the concept mapping of children's needs are presented.

Children's Needs

Of the 17 possible solutions examined, several provided interesting arrangements of the children's needs, but the five-cluster solution appeared best in terms of interpretability and parsimony. The five-cluster map includes the following needs: (1) dignity–respect; (2) physical comfort; (3) psychological support; (4) family support; and (5) system access and delivery. The five-cluster map, with the individual items labeled by statement number is presented in Addendum H.4.

1) Dignity–respect. The central cluster in the concept map of children's needs includes such items as, "honesty," "maintaining a sense of self," "to be valued as an individual by having preferences solicited and acted upon to the extent reasonable," "privacy," "confidentiality," and "culturally sensitive care." These items reflect core aspects of human dignity, which are often included in humanistic accounts of end-of-life processes such as Tobin's, *Peaceful Dying* (Tobin, 1999) but are rarely if ever included in QoL measurement models. The relatively central location of the cluster is also significant because it indicates that this cluster is the one that is most closely related to all other clusters. Thus, the dignity–respect cluster is informative not only in suggesting core needs of children, but also in a theoretical sense. This map suggests that dignity and respect deserve attention from program planners and evaluators as central aspects of a child's life that should receive explicit attention in program planning and evaluation.

2. Physical comfort. Meeting the physical comfort needs of children with life-limiting illnesses is widely acknowledged as a primary goal of palliative care. In fact, the definition of the term "palliation" or "palliative care" suggests this set of needs more than any other. In the New York state assessment, the two items with the highest importance ratings were "effective pain management" and "consistent pain assessment" (the average rating for both items was 5.0 on a scale in which 5 indicated "most important"). Other items in this cluster reflected needs for information related to such care and to active patient participation.

3. *Psychological support.* In our statewide study, more than one-third of the needs statement generated by the experts reflect psychological functioning. The items included a number of important needs that all children have, such as "love," "access to peers," and "fun." The majority of statements were specific to children with life-limiting illness such as "to be reassured that he or she is important and will be remembered" and "pleasant distractions from the situation." The items in this cluster also included those needs related to spirituality, such as "prayers" and "spirituality in their care." In practice, program planners may want to consider these as a separate dimension in the assessment of individual child and family needs.

4. *Family support needs.* The fourth cluster included needs related to maintenance of family functioning, including home-based child-life services and sibling support. There were also a number of items that reflected the need for the child's access to family when hospitalized and for as much care as possible to be delivered in the home. This set of needs will vary with the individual family circumstances (e.g., geographic proximity to treatment, number of siblings). One item called for "family-focused care," which might also serve as a general theme for this cluster of needs.

5. *Service system access and delivery.* One of the prime motivations of all of the demonstration projects is to contribute to the expansion of service system access and delivery. It was not surprising to find that one of the clusters of the needs assessment involves these same issues. Among the items included in the assessment were those related to access policies ("access to palliative care benefit from the time of diagnosis without a time constraint" and "reduction of barriers imposed by the six-month limit of the hospice benefit") and more programmatic issues such as "ability for nurse practitioners or doctors to make home visits," "ability to transition in and out of the hospital as needed," and "competent pediatric-trained professional caregivers." Thus, new programs must consider system factors in terms of who will have access under what circumstances and what services shall be delivered in which settings.

Children's Needs Importance Ratings

The next step in the analysis involved examination of the statement and cluster ratings. Ratings were completed by 40 professionals in pediatrics, including members of the state advisory group and colleagues invited personally by members of the advisory group. Of the 10 highest-rated individual needs statements, four were in the comfort needs cluster, two were in the dignity–respect cluster, two were in the psychosocial cluster, and two were in the service system access and delivery cluster. The analysis of the importance ratings revealed a limited response range, with most of the needs statements being rated at the high end of the scale. This finding suggests that all needs are at least somewhat important, and the task of discriminating relative importance in this area is a difficult one at the population level. Individual differences may still occur in the assessment of children and family needs on a case basis, however.

In addition to the relative importance of each need statement, experts were asked to rate the feasibility of meeting each need given current policies and resources. As with the importance ratings, the highest rated items in terms of feasibility reflected dignity–respect and comfort needs (Addendum H.4). This may be seen as good news, in that dignity–respect and comfort needs are highly rated in terms of importance. However, at the other end of the feasibility scale are many of the system delivery and access needs. This is not surprising, since it is difficult to change systems, and indeed the justification for the demonstration projects has much to do with generating data to support system changes.

Pattern matching is an analysis that allows comparison of two rating scales. In order to identify the degree to which importance and feasibility are congruent, a pattern match graph was generated (Addendum H.5). The graph shows that comfort needs are both highly important and highly feasible in terms of service delivery. Other clusters in the ladder graph show less congruence, resulting in an overall correlation of 0.35. Future applications of pattern matching include analysis of the degree to which needs are perceived as having been met by palliative programs.

In the second year of the demonstration project, the needs assessment will be extended to include responses from children and families. The sampling of children and families is intended to first assist with validation of the needs model and items. Secondly, we will test interview and self-report versions of the needs assessment. When the assessment has been piloted with families, it will be made available throughout the state and to other demonstration projects.

Longer-term uses of the needs assessment data include integrating the results into a descriptive program model and a testable program theory. The descriptive model will be used to illustrate the relationship of needs, services, and outcomes within the Essential Care program. The program theory will include testable propositions about the effectiveness of specific program activities in meeting the needs of the population. The needs model may also be adapted for use in studies designed to estimate the number of children and families, as well as the greatest areas of need, to be included in expanded Medicaid coverage. This could be accomplished by creation of a survey that could be conducted in local communities or statewide with the support of an organization such as the Hospice and Palliative Care Association of New York State. In addition, the needs assessment could be part of a program evaluation design. Finally, the assessment can be translated into clinical practice via development of a standardized assessment instrument used in treatment planning.

QUALITY OF LIFE

Assessment of health-related quality of life has been one of the fastest growing areas in heath psychology and medicine. Yet most of the activity in this field has focused on adult populations. In the pediatric area, there are as yet no well-accepted measures of quality of life for children and families in pediatric palliative or hospice care. Measurement of patient and family satisfaction is already standard practice in the Essential Care program; thus, the focus of the research activity has been patient and family quality-of-life.

We conducted a literature review and found that there are no currently available measures of QoL for the population. We also identified the leading research teams in the world in pediatric QoL assessment. One of the most active and productive research teams is the group led by Jim Varni, Ph.D., at the Center for Child Health Outcomes in San Diego (Varni et al., 1999a,b; 1998). The team has produced a well-developed measurement system known as the PedsQL. Dr. Varni's research team is currently developing a module for assessment of quality of life for children in palliative care, to be known as the PedsQL Palliative Care Module. We have agreed to collaborate in the development and testing of the measure. At this writing our San Diego colleagues are in the process of obtaining institutional review board approval to collect data with the pilot module. We will then coordinate pilot testing of the measure with colleagues throughout the state via the advisory committee.

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ADDENDUM H.1
DESCRIPTION OF SERVICES PROVIDED BY ESSENTIAL CARE PROGRAM BY DISCIPLINE

Nursing

- Oversees coordination of disciplines and patient care in the home
- Provides skilled nursing visits, case management in the home, coordination of home visit schedules
- Shares on-call responsibilities

Social Work

- Works directly with the parents or the child's primary caregiver
- Addresses concrete social issues, financial issues related to the disease; offers community resource referrals
- Serves as a patient and family advocate
- Provides counseling related to parenting and spousal communication
- Facilitates empowerment in parents and family, advocates for choices in caregiving
- Addresses anticipatory loss and grief issues, assists with funeral planning, and transition to bereavement program
- Facilitates spiritual care resources (pastoral care or coordinating with the family's community spiritual support)

Child Life

- Assesses responses and needs of children to health care experiences
- Attempts to minimize stress and anxiety for the sick child and siblings in home
- Prepares children for health care experiences such as medical events or invasive procedures
- Provides experiences to foster growth, development, self-esteem and independence
- Facilitates developmentally appropriate play and interaction at home and in the acute care setting

Physicians

- Physicians are available for consultation on an outpatient basis and will conduct home visits when necessary
- The Essential Care medical director provides consultation services, including

—Attendance at weekly team meetings
—Program admission consultation
—Consultation and liaison to child's primary physicians
—Availability for home visits when necessary

Pastoral Care

- Pastoral care is offered in the hospital and is available at home.

Art and Music Therapy

- This is available on a per diem basis at home for children.

Psychology

- Consultations are available on an outpatient basis.

Allied Therapy

- Physical therapy, occupational therapy, speech, and nutrition consultation are available at home and in the acute setting.

Home Health Aides

- Utilized as needed to supplement home care services

Volunteers

- Utilized to support the family and program staff through a variety of activities including baby-sit siblings, cook and clean for families, run errands, provide transportation for clinic visits or for families to visit the child while he or she is hospitalized

Ancillary Services

- Services include outpatient lab blood work done in the home setting and pharmacy services at home
- Durable medical equipment and supplies are available as needed
- Physical therapy, occupational therapy, speech, nutritional counseling are available at home

Supplementary Services

- *Day care*. Essential Care does not provide day care, however, volunteers do provide families with babysitting and short-term respite at home, and community resources are accessed for longer term arrangements
- Support groups are available for children and their families who are facing the impending loss of a loved one and for those children who have suffered the death of a sibling, parent or grandparent
- *Long distance needs*. Ronald McDonald House and/or Kevin Guest House (Buffalo, New York) are available and utilized when necessary for family traveling into Buffalo from out of town
- *Respite*. Comprehensive respite services may be developed as part of the demonstration project in future years.

ADDENDUM H.2
CHILDREN'S NEEDS STATEMENTS WITH IMPORTANCE RATINGS

28)	Effective pain management	5.00
31)	Consistent pain assessment	5.00
10)	Comforting atmosphere with pain control	4.91
32)	Quality of life	4.91
26)	Prayers	4.73
43)	Love	4.73
69)	Accurate assessment and effective treatment of pain and non-pain symptoms	4.73
74)	Reduction of barriers imposed by the six-month limit of the hospice benefit	4.73
1)	Access to palliative care benefit from the time of diagnosis without a time constraint (such as the hospice regulation)	4.55
3)	Honesty	4.55
14)	Clear, developmentally appropriate explanations of care options, benefits and burdens	4.55
29)	To maintain a sense of self	4.55
51)	The right to say no	4.55
60)	Comfort	4.55
73)	To have a say in the treatment plan	4.55
19)	Unlimited access to family, as desired by the child	4.45
20)	Fun	4.45
24)	To be reassured that he or she is important and will be remembered	4.45
53)	Family-focused care	4.45
9)	To be clearly valued as an individual by having preferences solicited and acted upon, to the extent reasonable	4.36
15)	Opportunities to be cared for by loving family	4.36
21)	Sense of control over life or some aspects of it	4.36
47)	Competent pediatric-trained professional caregivers	4.36
49)	As much time at home as possible (and as little time in the hospital)	4.36
63)	Parents who are mentally healthy and functional under stress	4.36
2)	Coordinated health care provided in a timely, convenient, and pleasant environment	4.27
6)	Consistency in professional caregivers throughout the illness, including the end stage	4.27
11)	Talk about their feelings and fears	4.27

33)	Flexibility to receive care wherever it is safe	4.27
48)	Assessment of personal goals of care	4.27
52)	Knowing he or she won’t be forgotten and will still be loved, talked to, and visited even after death	4.27
68)	Being able to remain in familiar surroundings with familiar people	4.27
71)	Continuity of “normal life” within their family, school, faith or social community, and circle of friends	4.27
7)	To address fears with a competent professional	4.18
8)	Not spending hours and hours in clinics and waiting rooms	4.18
17)	Translators if the child’s first language is not English	4.18
34)	Access to peers	4.18
37)	Parents who are receiving sufficient support so that they can focus on the child and siblings as much as possible	4.18
39)	Privacy	4.18
46)	Child-life intervention in the home	4.18
65)	Confidentiality	4.18
5)	Developmentally appropriate activities and information	4.09
25)	Understandable information about supportive and palliative and hospice care to reduce anxiety and unknowns	4.09
27)	Pleasant distractions from the situation	4.00
30)	Stimulation (via school activity, play, family activities, etc.)	4.00
36)	To acknowledge the sadness of the child and those who love him or her about the illness and possibility of death	4.00
41)	Spirituality in their care	4.00
45)	Focus on the child’s hopes and dreams, including assistance when their hopes and dreams will likely not be met	4.00
62)	Care for the health care provider so that they can care for the children in a more caring and nurturing way	4.00
66)	To have the critical nature of the illness and possibility of death acknowledged	4.00
67)	Regular contact with peers	4.00
16)	Assessment of perceptions of burdens and benefits of care	3.91
40)	The ability to transition in or out of the hospital as needed	3.91
35)	To be physically touched and soothed (e.g., massage)	3.82
42)	More nurses/home health aides who are pediatric trained	3.82
58)	To not feel that the child has caused many other losses for the family (e.g., financial struggles)	3.82
59)	People, things, activities that make the child smile and laugh	3.82
12)	Nonjudgmental love, touch, long talks, looking out a window, feeling the sun	3.73

18)	Being able to give home blood transfusions, especially platelets so the child does not bleed out at home	3.73
56)	Alternative therapies such as art and music	3.73
61)	Nutritional support in the home	3.73
64)	To create a personal legacy	3.73
4)	Laughter for release (e.g., visiting clown programs)	3.64
23)	Culturally sensitive care	3.64
54)	Play therapy that focuses on illness-related topics	3.64
70)	Ability to share with children having same illness in a safe, encouraging environment	3.64
72)	Help with the visual part of the illness so that the child feels as good as possible about his or her body and appearance	3.64
13)	Assessment of preferences and goals for social interaction and facilitation of those preferences and goals	3.55
44)	Peer support groups	3.55
50)	Networking with other children experiencing a similar illness, treatment, etc.	3.55
55)	Assessment of concerns around meaning, loss, and spiritual issues and effective means of addressing these	3.55
38)	Ability for nurse practitioners and doctors to make home visits	3.45
22)	Self-relaxation skills	3.09
57)	Access to a child-friendly Web site for information, chats, etc.	3.00

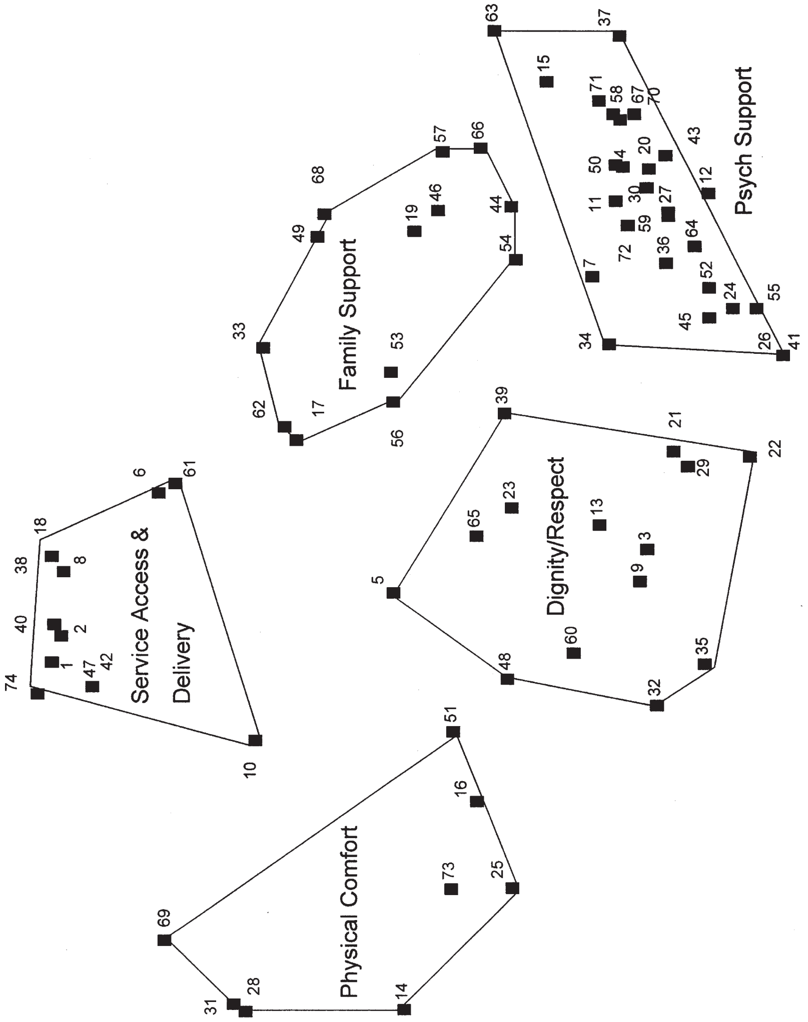
ADDENDUM H.3
CHILDREN'S NEEDS STATEMENTS WITH FEASIBILITY RATINGS

26)	Prayers	4.78
43)	Love	4.78
35)	To be physically touched and soothed (e.g., massage)	4.33
5)	Developmentally appropriate activities and information	4.22
15)	Opportunities to be cared for by loving family	4.22
24)	To be reassured that he or she is important and will be remembered	4.22
28)	Effective pain management	4.22
60)	Comfort	4.22
61)	Nutritional support in the home	4.22
31)	Consistent pain assessment	4.11
36)	To acknowledge the sadness of the child and those who love him or her about the illness and possibility of death	4.11
65)	Confidentiality	4.11
3)	Honesty	4.00
12)	Nonjudgmental love, touch, long talks, looking out a window, feeling the sun	4.00
13)	Assessment of preferences and goals for social interaction and facilitation of those preferences and goals	4.00
20)	Fun	4.00
27)	Pleasant distractions from the situation	4.00
29)	To maintain a sense of self	4.00
30)	Stimulation (via school activity, play, family activities, etc.)	4.00
39)	Privacy	4.00
41)	Spirituality in their care	4.00
53)	Family-focused care	4.00
73)	To have a say in the treatment plan	4.00
7)	To address fears with a competent professional	3.89
11)	Talk about their feelings and fears	3.89
25)	Understandable information about supportive and palliative and hospice care to reduce anxiety and unknowns	3.89
40)	The ability to transition in or out of the hospital as needed	3.89
48)	Assessment of personal goals of care	3.89
51)	The right to say no	3.89
52)	Knowing he or she won't be forgotten and will still be loved, talked to, and visited even after death	3.89
54)	Play therapy that focuses on illness-related topics	3.89
59)	People, things, activities that make the child smile and laugh	3.89

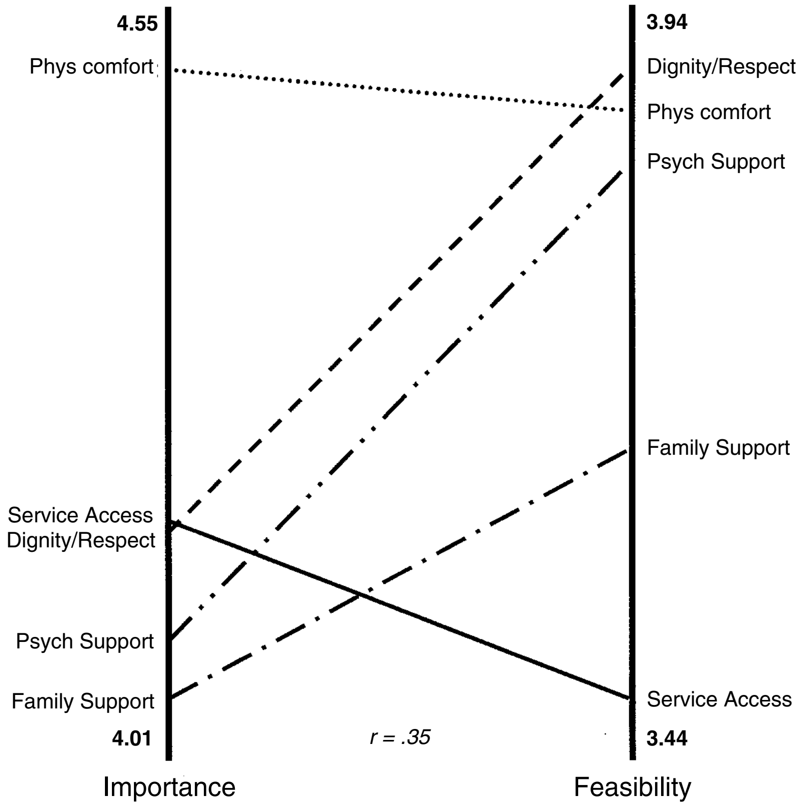
69)	Accurate assessment and effective treatment of pain and non-pain symptoms	3.89
4)	Laughter for release (e.g., visiting clown programs)	3.78
14)	Clear, developmentally appropriate explanations of care options, benefits, and burdens	3.78
21)	Sense of control over life or some aspects of it	3.78
32)	Quality of life	3.78
34)	Access to peers	3.78
37)	Parents who are receiving sufficient support so that they can focus on the child and siblings as much as possible	3.78
58)	To not feel that the child has caused many other losses for the family (e.g., financial struggles)	3.78
9)	To be clearly valued as an individual by having preferences solicited and acted upon, to the extent reasonable	3.67
10)	Comforting atmosphere with pain control	3.67
19)	Unlimited access to family, as desired by the child	3.67
22)	Self-relaxation skills	3.67
33)	Flexibility to receive care wherever it is safe	3.67
45)	Focus on the child's hopes and dreams, including assistance when their hopes and dreams will likely not be met	3.67
47)	Competent pediatric-trained professional caregivers	3.67
49)	As much time at home as possible (and as little time in the hospital)	3.67
55)	Assessment of concerns around meaning, loss, and spiritual issues and effective means of addressing these	3.67
56)	Alternative therapies such as art and music	3.67
68)	Being able to remain in familiar surroundings with familiar people	3.67
2)	Coordinated health care provided in a timely, convenient, and pleasant environment	3.56
17)	Translators if the child's first language is not English	3.56
46)	Child life intervention in the home	3.56
66)	To have the critical nature of the illness and possibility of death acknowledged	3.56
67)	Regular contact with peers	3.56
70)	Ability to share with children having same illness in a safe, encouraging environment	3.56
72)	Help with the visual part of the illness so that the child feels as good as possible about his or her body and appearance	3.56
1)	Access to palliative care benefit from the time of diagnosis without a time constraint (such as the hospice regulation)	3.44
16)	Assessment of perceptions of burdens and benefits of care	3.44

23)	Culturally sensitive care	3.44
44)	Peer support groups	3.44
50)	Networking with other children experiencing a similar illness, treatment, etc.	3.44
57)	Access to a child-friendly Web site for information, chats, etc.	3.44
62)	Care for the health care provider so that they can care for the children in a more caring and nurturing way	3.44
64)	To create a personal legacy	3.44
63)	Parents who are mentally healthy and functional under stress	3.33
8)	Not spending hours and hours in clinics and waiting rooms	3.22
18)	Being able to give home blood transfusions, especially platelets so the child does not bleed out at home	3.22
38)	Ability for nurse practitioners and doctors to make home visits	3.22
71)	Continuity of “normal life” within their family, school, faith or social community, and circle of friends	3.22
6)	Consistency in professional caregivers throughout the illness, including the end stage	3.11
42)	More nurses/home health aides who are pediatric trained	3.00
74)	Reduction of barriers imposed by the six-month limit of the hospice benefit	3.00

ADDENDUM H.4
FIVE-CLUSTER MAP OF CHILDREN'S PALLIATIVE CARE NEEDS



ADDENDUM H.5
PATTERN MATCH OF IMPORTANCE AND FEASIBILITY RATINGS OF CHILDREN'S NEEDS



APPENDIX I

COMMITTEE BIOGRAPHICAL STATEMENTS

Chair

Richard E. Behrman, M.D., J.D., is Executive Chair, Federation of Pediatric Organizations, Education Steering Committee. He serves as Consultant to the Lucile Packard Foundation for Children's Health and Sr. Advisor for Health Affairs at the David and Lucile Packard Foundation. He is also Clinical Professor of Pediatrics at Stanford University and the University of California, San Francisco. He previously held positions as Chairman of the Boards of Lucile Packard Foundation for Children's Health and the Lucile Packard Children's Hospital and Director of the Center for the Future of Children. Prior to holding these positions, he served as Vice President of Medical Affairs and Dean of the School of Medicine at Case Western Reserve University. Dr. Behrman also served as Professor and Chairman of the Departments of Pediatrics at Case Western Reserve University and at Columbia University. His areas of special interest include perinatal medicine, intensive and emergency care of children, the provision and organization of children's health and social services, and related issues of public policy and ethics. Dr. Behrman has published extensively in critically reviewed scientific journals and is Editor-in-Chief of *Nelson Textbook of Pediatrics* and the journal, *The Future of Children*. He is a member of the Institute of Medicine (IOM) and has served as chairman of two IOM committees concerned with child welfare.

Grace H. Christ, D.S.W., is an Associate Professor at Columbia University School of Social Work and has clinical and research interests in the fields of psychosocial oncology, end-of-life care, social work education and research, and childhood bereavement. Among other publications, she is the founder of the *Journal of Psychosocial Oncology* and author of *Healing Children's Grief*, published in 2000 by Oxford University Press. She is currently a

Senior Faculty Scholar with the Project on Death in America and is a recipient of the National American Cancer Society's Distinguished Service Award. She was formerly Director of Social Work at Memorial Sloan Kettering Cancer Center.

Francis Sessions Cole, M.D., is Director of Newborn Medicine, Vice Chair of the Department of Pediatrics, Park J. White M.D. Professor of Pediatrics, and Professor of Cell Biology and Physiology at Washington University School of Medicine, St. Louis, Missouri. His research interests focus on the molecular basis of the susceptibility of the newborn infant to infection and, more recently, on the contribution of genetic variation in the surfactant protein B gene to risk of respiratory distress syndrome in newborn infants. He has produced more than 70 publications on these topics. Dr. Cole is also committed to excellence in education and has received numerous teaching awards including Clinical Teacher of the Year Award and Washington University's Distinguished Faculty Award. He has facilitated the formation of community outreach programs for medical students including the Perinatal Project and Students Teaching AIDS to Students (STATS). He is a member of the Society of Pediatric Research, the American Society for Clinical Investigation, and the American Pediatric Society.

Harvey R. Colten, M.D., is VP and Senior Associate Dean for Translational Research at Columbia University Health Sciences, and previously served as Chief Medical Officer at iMetrikus, Inc., a health services company that provides Internet-based, interactive health management solutions for patients with chronic illness. In the past, he has served as Professor of Pediatrics at Harvard Medical School and Chief of the Division of Cell Biology, Pulmonary Medicine, and Director of the Cystic Fibrosis Program at Children's Hospital Medical Center, Boston; Chair of the Department of Pediatrics and Professor of Molecular Microbiology at Washington University School of Medicine, St. Louis, Mo.; and Dean of the Medical School and Vice President for Medical Affairs at Northwestern University. He is also a Fellow of the American Association for the Advancement of Science, the American Academy of Allergy and Immunology, and the American Academy of Pediatrics. He is a member of the Institute of Medicine and is a past Vice-Chair of its Council.

Joanne Hilden, M.D., is currently Chair, Department of Pediatric Hematology/Oncology at The Children's Hospital at The Cleveland Clinic. Dr. Hilden was formerly the Director of Oncology Research and Children's Oncology Group (COG) Responsible Investigator at Children's Hospitals and Clinics, St. Paul. She founded and co-chairs the COG Task Force on

End-of-Life Care. She is involved in clinical care and teaching medical trainees about end-of-life care and the delivery of bad news. Dr. Hilden is a member of the American Society of Clinical Oncology (ASCO), and served on the ASCO Subcommittee on Cancer Care at the End of Life which produced the group's position statement on care of the dying and carried out a survey of the country's oncologists regarding end of life care. She is a Faculty Scholar of the Project on Death in America. Dr. Hilden is also a member of the Minnesota Commission to Improve End-of-Life Care and she is a certified trainer for the American Medical Association's EPEC project to educate physicians about end-of-life care. She is a Fellow in the American Academy of Pediatrics and a member of the American Society of Pediatric Hematology/Oncology. She led the preparation of a paper on end-of-life issues in pediatric oncology that was included in the 2001 IOM report *Improving Palliative Care for Cancer*.

Pamela Hinds, B.S.N., Ph.D., is the Director of Nursing Research at St. Jude Children's Research Hospital in Memphis, Tennessee. She has expertise in the care of children with cancer and in developing effective team care to meet immediate and long-term needs of children and their families. Her research focuses on decision-making in pediatric oncology, coping and adolescents, and the experience of pediatric oncology nurses, among other topics. Among other publications, she authored the chapter on "End-of-life decision-making by pediatric oncology patients, their parents, and their health care professionals" in the *Oxford Textbook of Palliative Nursing Care* (Ferrell and Coyle, editors). She is co-chair of the Nursing Research Committee for the Children's Oncology Group and is co-chair of the Palliative Care Initiative at St. Jude Children's Research Hospital. She also serves on the Institutional Review Board and the Pain and Symptom Management Committee at St. Jude and is member of the Oncology Nursing Society.

Angela R. Holder, LL.M., is currently Professor of the Practice of Medical Ethics at Duke University Medical Center. Ms. Holder was formerly Clinical Professor of Pediatrics (Law) at Yale University School of Medicine, where she taught a required first-year medical school course on law, medicine, and ethics entitled, "Professional Responsibility." Her primary research interests involve legal and ethical issues of children and adolescents in the health care system, but she has also studied issues of human subjects research, malpractice, confidentiality, and legal and ethical issues in human reproduction. She served on the IOM Committee on the Effects of Medical Liability on the Delivery of Maternal and Child Health Care which produced the report *Medical Professional Liability and the Delivery of Obstetrical Care* (1989).

Haiden A. Huskamp, Ph.D., is an Assistant Professor of Health Economics in the Department of Health Care Policy at Harvard Medical School. Her primary areas of research are: 1) the economics of mental health and substance abuse (MHSA) treatment; 2) the economics of the pharmaceutical industry; and 3) the financing of end-of-life care services. Dr. Huskamp recently served as principal investigator for a study funded by the Robert Wood Johnson Foundation to study the impact of Medicare financing methods on the provision of services to patients at the end of life. Her teaching areas include health care policy and health economics. She received her Ph.D. from Harvard University.

Robert Kliegman, M.D., is Chairman of Pediatrics at the Medical College of Wisconsin and has interests in general and community pediatrics, pediatrics education, neonatology, and public health. He completed residency training in general pediatrics at Babies' Hospital in New York, New York; and he completed neonatology and metabolism fellowships at Case Western Reserve University in Rainbow Babies and Children's Hospital. He is the co-editor of *Controversies in Perinatology* and *Nelson Essentials of Pediatrics*. Dr. Kliegman has been a child advocate working with the American Academy of Pediatrics, municipal, state, and federal governments, and the George Washington University Health Policy Institute-Packard Foundation Roundtable for Children. He served on the IOM committee that produced the report *Approaching Death: Improving Care at the End of Life* in 1997.

Marcia Levetown, M.D., works as a Pain and Palliative Care Education Consultant in Galveston, TX. She also serves as a Clinical Associate Professor of Pediatrics and Internal Medicine at the University of Texas Medical Branch at Galveston. She received her medical degree at the Medical College of Virginia, completed a pediatric residency at Baylor College of Medicine in Houston, and a fellowship in Pediatric Critical Care at Children's National Medical Center in Washington, D.C. Her experience in the PICU led her to establish the award-winning Butterfly Program, a program designed to meet the needs of children living with life-threatening conditions and their families. She is a Project on Death in America Faculty Scholar and Chair of the Children's International Project on Palliative and Hospice Services. She is the Principal Editor of the *Compendium of Pediatric Palliative Care* and author of numerous articles, chapters and curricula on pediatric palliative care issues. Dr. Levetown is a member of the ethics committees of the American Academy of Pediatrics, the National Hospice and Palliative Care Organization and the American Academy of Hospice and Palliative Medicine. She is also a founding board member of the Texas Partnership for End-of-Life Care.

Neil L. Schechter, M.D., is Director of the Pain Relief Program at the Connecticut Children's Medical Center, and Professor of Pediatrics and Head of the Division of Behavioral and Developmental Pediatrics at the University of Connecticut School of Medicine and St. Francis Hospital. His clinical and research experience covers the entire range of pain experience and treatment in children including pain during routine pediatric care and pain of children with advanced illnesses. He was one of the pediatric representatives on the AHCPR Clinical Guideline Panel on Acute Pain Management and was a member of the WHO Expert Committee that developed guidelines on cancer pain and palliative care for children. He is the senior editor of the major textbook on pain management in children. He is the chair of the Special Interest Group on Pain in Children of the Ambulatory Pediatric Association and has been a member of numerous committees at the local, state, and national levels which advocate for pain control and behavioral medicine research including the Supportive Care Committee of the Children's Cancer Study Group, the Executive Council of the Society for Developmental and Behavioral Pediatrics, and the Task Force on Pain in Children of the American Pain Society, among others. In 1998, he received the Jeffrey Lawson Award for Advocacy in Children's Pain Relief of the American Pain Society.

Barbara Sourkes, Ph.D., is the first Kriewall-Haehl Director of Pediatric Palliative Care at the Lucile Packard Children's Hospital and Associate Professor of Pediatrics and Psychiatry, Stanford University School of Medicine. Dr. Sourkes was previously at the Montreal Children's Hospital and McGill University, and at the Boston Children's Hospital and Dana-Farber Cancer Institute of Harvard Medical School. She has published three books: *The Deepening Shade: Psychological Aspects of Life-Threatening Illness* and *Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness* (1982, 1995, University of Pittsburgh Press); and *Les enfants en deuil (Bereaved Children)* with Michel Hanus, M.D. (Frison-Roche, Paris, l997). She was the recipient of the Charles A. Corr Award for Literature from Children's Hospice International in 1999. Dr. Sourkes, a child psychologist, has consulted nationally and internationally on the psychological aspects of pediatric life-limiting illness, palliative care and bereavement. In addition to her clinical activities, research, publications, committee and board memberships, Dr. Sourkes is on the editorial boards of the *Journal of Clinical Psychology in Medical Settings* and *The American Journal of Hospice & Palliative Care* and has served as consultant for films on children with life-threatening illnesses.

Lizabeth H. Sumner, R.N., B.S.N., has been involved in hospice care for over 22 years and is currently the Children's Program Director of San Diego

Hospice. She created the regional Children's Program for terminally ill children in 1987 in partnership with San Diego Children's Hospital / Health Center. The program includes several components such as an "Early Intervention Program" Perinatal Hospice, an innovative program that supports parents through pregnancy and birth of babies diagnosed with life-threatening conditions. The Children's Program also provides services such as counseling and play therapy to support healthy children grieving the loss of a parent, sibling, or classmate. Ms. Sumner has consulted statewide and nationally with other hospices developing programs for dying and bereaved children. She has spoken at numerous local, national and international meetings on the topic of end-of-life care for children. Ms. Sumner has published both academic and popular articles and book reviews in nursing journals, textbooks, and newspapers, as well contributing as an expert resource for various publications. Most recently, she authored the chapter "Pediatric Care: The Hospice Perspective" in the *Textbook of Palliative Nursing* (Ferrell and Coyle, editors), and has a chapter in *Hospice Care for Children* (Armstrong-Dailey and Zarbock, editors). She is a member of the ChIPPS (Children's International Project on Palliative and Hospice Services) workgroup, serves on the Ethics Committee of the San Diego Children's Hospital, and participates in other collaborative initiatives.

Joseph Wright, M.D., M.P.H., is Medical Director for Advocacy and Community Affairs at Children's National Medical Center (CNMC) in Washington DC. He is also an Associate Professor of Pediatrics, Emergency Medicine, and Prevention and Community Health at the George Washington University Schools of Medicine and Public Health and practices pediatric emergency medicine in the Emergency Medicine and Trauma Center at Children's. Administratively, Dr. Wright is founding Director of the Center for Prehospital Pediatrics in the Division of Emergency Medicine at CNMC, and also serves as the State Medical Director for Pediatrics within the Maryland Institute for Emergency Medical Services Systems. His major areas of academic interest include injury prevention and health services research, and he is currently developing a comprehensive program of pediatric prehospital research in the District of Columbia. He has received recognition for his advocacy work throughout his career including the Shining Star award from the Los Angeles-based Starlight Foundation acknowledging his outstanding contributions to under-served communities, and induction into Delta Omega, the national public health honor society. He has authored and co-authored many publications, serves on several national advisory boards, including the American Academy of Pediatrics Committee on Injury, Violence and Poison Prevention, and lectures widely to professional and lay audiences.

INDEX*

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*Index does not include Appendices.