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Proceedings of a Workshop

IN BRIEF

August 2020

Quality of Life, Preventing Elder Abuse, and Fostering Living Well After a Dementia Diagnosis

Proceedings of a Workshop—in Brief

On July 8, 2020, the Committee on Developing a Behavioral and Social Science Research Agenda on Alzheimer’s Disease and Alzheimer’s Disease-Related Dementias (AD/ADRD) hosted a public workshop via webcast. This Proceedings of a Workshop—in Brief summarizes the key points made by the workshop participants during the presentations and discussions and is not intended to provide a comprehensive reporting of information shared during the workshop.¹ The views summarized here reflect the knowledge and opinions of individual workshop participants and should not be construed as consensus among workshop participants or the members of the Committee on Developing a Behavioral and Social Science Research Agenda on Alzheimer’s Disease and Alzheimer’s Disease-Related Dementias or the National Academies of Sciences, Engineering, and Medicine.

¹Presentations, videos, and other materials from the workshop can be found at <https://nationalacademies.org/Alzheimersdecadal>.

SETTING THE STAGE

Committee Chair Tia Powell, Albert Einstein College of Medicine and Montefiore Medical Center, opened this workshop with words of welcome and an introduction of members of the study committee. She also introduced members of the Advisory Panel to the committee—people living with dementia and care partners of people living with dementia—and thanked them for supporting the work of the committee and ensuring the voices of those living with the disease are reflected in the final report. Powell also thanked the sponsors for their support of this study and explained the format of the workshop.

ELDER LAW: ELDER ABUSE AND FRAUD

Julie Zissimopoulos, University of Southern California, and committee member introduced the first panel, in which two pre-senters and a discussant took up topics related to elder law, including financial exploitation and elder abuse.

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FINANCIAL EXPLOITATION, DEMENTIA, AND FINANCIAL DECISION MAKING

The first panelist, Peter Lichtenberg, Institute of Gerontology, Wayne State University, discussed the intersection of financial exploitation with dementia and financial decision making. Lichtenberg noted that while prior experience with managing finances throughout the lifespan can reduce concerns about financial management as a person ages; cognitive decline is associated with difficulty in managing finances, and a general reduction of wealth before diagnosis. Financial concerns such as financial snafus, bounced checks, decreases in bank balances, etc. are often contributing factors that lead families to recognize the severity of their loved one's cognitive decline before receiving a diagnosis. Longitudinal data from the Health and Retirement Study show that people who lost 10–15 percent of their memory across a two-year period also lost 15–18 percent of their total general wealth during the same period (Angrisani and Lee, 2019).

Lichtenberg reviewed the older adult financial exploitation measure conceptual framework developed by Conrad and Iris (2010) and noted that while financial exploitation typically occurs through theft and scams, elder exploitation is most often the result of abuse of trust, feeling entitled to money that would be given to a family member or friend after death anyway (financial entitlement), and coercion. Lichtenberg stated that financial exploitation is easier when the victim has deficits in activities of daily living (ADL) and experiences isolation. A Consumer Financial Protection Bureau (CFPB) report showed that the number of suspicious activities financial institutions reported to the government quadrupled between 2013–2017, and 69 percent of those losses were reported by a person 60 years or older (CFPB, 2019). While the mean loss was \$34,000, 7 percent of the reported cases saw over \$100,000 in losses. Money services businesses such as Western Union saw a larger percentage of scams from strangers, while deposit institutions such as banks and credit unions reported more scams from a person who knew the suspect. The biggest losses reported were from people with a fiduciary relationship with the suspect—averaging nearly \$84,000.

Lichtenberg emphasized that a key question in elder justice has to do with the integrity of financial judgement. He elaborated on this by reviewing underlying aspects of informed decision making that shape a person's financial transactions. These include the person's ability to communicate the choice of what they want to do; an understanding of that choice; appreciation of risks, benefits, and implications of that choice; and ability to associate a reason with that choice (Applebaum and Grisso, 1988). Context matters, Lichtenberg stated, when determining the integrity of financial decisions, which are based on financial situational awareness, psychological vulnerability, and susceptibility. And likewise, he noted, choice, rationale, understanding, and appreciation—the intellectual factors outlined by Applebaum and Grisso—are affected by person's ability to recognize and express financial awareness.

According to Lichtenberg, these factors were taken into consideration when he and his colleagues developed three financial decision-making scales: the Lichtenberg Financial Decision Making Rating Scale (LFDRS), the Lichtenberg Financial Decision Screening Scale (LFDSS), and the LFDRS-I Family and Friends Informant Scale. All three scales were developed around a person-centered approach with the goal of promoting autonomy whenever possible. Being diagnosed with dementia, Lichtenberg noted, does not take away people's need for autonomy.

Lichtenberg traced some connections between autonomy, elder justice, and integrity of financial judgement. Both under- and over-protecting older adults can lead to damaging consequences. Under-protection can lead to gross financial exploitation, while over-protection can severely reduce the person's autonomy and control over his/her finances, reducing his/her quality of life and in some instances their longevity.

Currently, Lichtenberg and his team are working on the Wealth Accumulation and Loss in later Life Early cognitive Transitions (WALLET) study, which explores how financial exploitation occurs and whether early detection can be utilized to reduce instances of financial exploitation. He and his team are performing a thorough review of bank records and then interviewing individuals diagnosed with dementia or those who self-report perceived memory impairment over age 60. The goal of this study, he explained, is to develop a financial mismanagement scale based on the patterns that emerge around early detection and reduction of financial exploitation.

LACK OF DECISION-MAKING CAPACITY AND PROSECUTION OF FINANCIAL EXPLOITATION

Catherine Christian, New York County District Attorney’s Office, began her presentation by explaining that she does not use the term “dementia” when describing victims of financial abuse until she has reviewed medical records; instead she notes that they lack capacity. Her office determines whether criminal prosecution is warranted by asking whether the person (victim) understands the actions he/she is undertaking and has appropriate capacity to undertake such actions, such as, for example, giving a condo to a long-lost relative. Christian stated that if the victim has the capacity to make the decision, her office then has to determine whether the person was tricked. If they were not tricked, and they do not lack capacity then there is not a crime. In the majority of her office’s prosecutions for fraud and financial abuse of elderly people, the elderly victims lack capacity.

The victims of financial exploitation, in Christian’s experience, are typically cognitively impaired, have decreased physical health, are trusting of others and/or lonely or isolated, have increased dependency on care partners, and are likely being cared for by someone with a mental health issue or another problem like substance abuse, gambling, or other financial problems. Christian explained that 90 percent of abusers are family members, most often adult children, spouses, or partners. Other abusers can include employee care partners or home health aides; individuals who are the agent of the power of attorney; and bankers, financial advisors, accountants, or guardians.

Christian expressed that the significance of the power of attorney role is understated, even for many lawyers, because the person who is appointed the agent to the power of attorney has the ability to abuse that power. While most agents of a power of attorney do not abuse their power, it can be helpful to have check points in place, such as a bank teller who can spot red flags, so as to ensure that financial exploitation is not occurring.

Christian underscored the importance of such red flags—these signs of financial exploitation include frequent large withdrawals such as daily maximum currency withdrawals from an ATM, uncharacteristic attempts to wire large sums of money, sudden Non-Sufficient Fund activity, and debt transactions that are unusual. Examples of scams include the “grandparent scam” where a predator will call an older person on behalf of a grandson/daughter saying they have been kidnapped, arrested, or in an accident and need money. Christian noted that since the beginning of COVID-19, this type of scam has been more prevalent where she works in New York County.

Victims of financial exploitation are often reluctant to report abuse, Christian explained, because they lack physical and/or cognitive ability to report, they fear retaliation, they may not want to get the abuser prosecuted, or they wish to avoid potential embarrassment. Often bank employees are the ones reporting the crimes, along with adult children who suspect criminal activity when their parent has unexpectedly lost money.

Seniors are targeted, Christian observed, because older people are perceived to have accumulated assets, and they tend to be trusting, polite, and socially isolated. Targeting of this population also occurs because older people are thought of as being unfamiliar with financial matters, and often have cognitive impairments that make them particularly vulnerable to such exploitation.

Christian ended her presentation by highlighting one possible, and potentially powerful, check point: when a lawyer believes that their client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken, and cannot adequately act in the client’s own interest, the lawyer may take reasonably protective action by contacting law enforcement without violating attorney-client privilege.

LIVING WITH AD/ABD IN AN ABUSIVE SITUATION

Cynthia Huling Hummel, member of the Advisory Panel to the committee, served as a discussant for this panel. Huling Hummel began her presentation speaking about her experience as a pastor, and how she learned about the level of control abusers have over their victims. She also shared the Alzheimer’s Association resources outlining the types of elder abuse including emotional abuse, neglect, confinement, financial abuse, sexual abuse, willful deprivation, and self-neglect.

As a person living with dementia, Huling Hummel stated that it is hard enough to care for oneself in an abusive situation without dementia, but living with dementia makes leaving an abusive situation more challenging, if not impossible. Huling Hummel reviewed a study from England of 220 carers that found that abusive behavior by family carers toward people with dementia is common, with a third of the group reporting levels of abuse and half reporting some abusive behavior, with verbal abuse being the most common form reported (Cooper et al., 2009).

Approximately one in ten Americans aged 60+ have experienced some form of elder abuse, Huling Hummel commented. However, it is estimated that only one in fourteen cases of abuse are reported to authorities (National Council on Aging, 2020). Recent studies show that nearly half of those with dementia experienced abuse or neglect, and interpersonal violence occurs at disproportionate rates among adults with disabilities (NCOA, 2020).

Huling Hummel observed that individuals living with dementia who are being abused do not have the knowledge about resources available to them, nor do they have access to services and supports. She described a recent phone call she received from a friend who is living with middle-stage Alzheimer's disease. The friend relayed to her that she had locked herself in her bedroom because her husband had been drinking, and “when he drinks he gets ugly” and tells her he is sick of her, threatening to “dump” her at the local nursing home and file for divorce. Huling Hummel recommended calling the local police, but her friend was adamant about staying with her husband who she has been married to for decades. The friend also mentioned that after acting the way her husband does after he drinks, the next day things return to normal and he gives her presents. “Besides, where would I go?” she asked. “The nursing home would put me in the lockdown ward.” Additional knowledge about and access to resources on abusive relationships could be beneficial to others living in similar situations.

Several of Huling Hummel's friends have lost money and valuables to predators, she explained, whether through marketing scams or to members of their family. A few months ago, Huling Hummel recalled that she received a threatening email saying that the person who emailed her knew all of her passwords and unless she sent him \$2,500 in 24 hours, he would release humiliating sensitive information to her family, friends, and business colleagues. Huling Hummel was affected by the message enough to change all of her passwords and run a virus check on her computer and cell phone. The experience was scary for her, and she stated that many older adults are approached in such a threatening manner every day.

The Advisory Panel to the committee put out a call for commentaries to learn more about the perspectives of individuals living with dementia and those providing care for a person living with dementia, Huling Hummel explained. One submission included a note asking for further protection of those living with a disability like dementia whose inhibitions may be loosened due to the nature of the disease. This submission described a dire situation in which the father, who was living with undiagnosed dementia, was about to lose his home because he had neglected to pay the mortgage, but had written checks for tens of thousands of dollars to charities and scam companies. His care partner noticed a change in her father's ability to understand financial documents, and when she and her father tried to resolve the problem, there were no policies in place to help protect her father or anyone with AD/ADRD from experiencing something similar. It is all too common for the hardships of those living with AD/ADRD to go unrecognized by local, state, and federal governments, Huling Hummel observed.

In light of that, Huling Hummel explained, she would like to see additional research about interventions and safeguards most effective in stopping abuse against those living in dementia at home and in care settings, as well as research about the supports available for those with dementia who have been physically, sexually, or psychologically abused. She also stated that she would like to see research considered that would better protect those living with dementia from such abusive situations. She concluded by urging the committee to look into whether oversights are in place that help this population, and to brainstorm how to find additional appropriate partners as a part of a community effort to reduce elder abuse and fraud.

LIVING WELL WITH DEMENTIA

Tia Powell moderated the second panel on living well with dementia.

DISEASE TRAJECTORY, RETAINING COGNITIVE CAPACITIES, AND MAXIMIZING QUALITY OF LIFE

Leslie Chang Evertson, University of California Los Angeles, began her presentation by reminding the committee that dementia is typically a progressive disease with no cure, and symptoms depend on many factors such as the type of dementia diagnosed, the co-morbidities experienced, and the individual's living situation and care they are receiving. She then reviewed the stages of the most common dementia, Alzheimer's disease, and associated difficulties experienced by individuals in each stage. Difficulty with the most complex instrumental activities of daily living (IADLs, e.g., finances, driving, and managing medications), for example, occur the mild stage of Alzheimer's, followed by difficulty with easier instrumental ADLs (simple food preparation, shopping), repeating questions, and possible delusions and agitation in the moderate stage. For those living in the severe stage of dementia basic ADLs like eating and toileting, mobility, swallowing, and verbal output become more difficult. Evertson mentioned that from 2000–2018, deaths related to AD/ADRD have increased by 146 percent (Alzheimer's Association, 2020).

Evertson then turned to the role of the physician and, particularly, how important it is for physicians to recognize how AD/ADRD can affect other health conditions. She underscored evidence that many physicians are unaware of cognitive impairment in more than 40 percent of their patients which has led to delayed diagnosis and broader health complications (Chodosh, Petitti, and Elliot, 2004), and that 27 percent of primary care providers surveyed reported being only sometimes or never comfortable answering patient questions about Alzheimer's or other dementias (Alzheimer's Association, 2020). An inability to recognize dementia and its impact beyond the diagnosis often means that providers fail to meet the needs of their patients. A study at UCLA's Alzheimer's and Dementia Care Program showed a high rate of confidence in doctors but a low rate of feeling like they actually have help. It found that only 28 percent of those surveyed felt they had a healthcare professional who could help them through dementia care problems, although they noted that 79 percent felt that their doctor understood how memory or behavior problems complicate other health conditions (Jennings et. al, 2015).

Evertson discussed the difficulties that physicians face in supporting both the individual with dementia and their care partner(s). She explained that health care providers need to better equip families with additional support and education around a dementia diagnosis, because even when they do provide information to families, the time allotted for each patient/family is usually not sufficient to allow for the necessary support. Evertson also noted that, when seeking additional sources of support for their patients living with dementia, providers often fail to look outside of the medical model, and so rely heavily on resources they are aware of, when other modes of support might benefit patients and care partners alike. Lastly, Evertson noted doctors are often unable to treat care partners' symptoms of depression and other physical and mental effects of caregiving arise, because they are unable to treat someone unless he or she is a patient. Care partners need to be educated and supported, or else the person with dementia will not receive the care needed, Evertson commented.

There are a number of shortcomings on the provider side, Evertson explained, where practice can be improved to better support individuals living with dementia and their care partners. The Alzheimer's Association found that 50 percent of primary care physicians believe the medical profession is not ready for the growing number of people with ADRD (Alzheimer's Association, 2020), Evertson highlighted. Also, providers are unable to estimate life expectancy since each individual has a unique set of co-morbidities along with their dementia diagnosis, which need to be viewed holistically in order to determine life expectancy. Conversations should be continuous based on the stage of dementia, Evertson urged, as the patient has different needs and desires at each stage. Providers also can improve upon their understanding of what people with a dementia diagnosis can do, since each person experiences his/her own trajectory of the disease.

There are strategies to retain cognitive capacity after the onset of dementia, and number of years of education, Evertson stated, has been shown to lessen the expression of dementia before death, rather than completely protect individuals from getting a dementia diagnosis as was previously thought to be

true (EClipSE Collaborative Members et al., 2010). Other strategies such as cognitive stimulation—a range of enjoyable activities providing general stimulation for thinking, concentration and memory usually in a social setting, such as a small group (Woods B, et. al, 2012)—have shown a benefit for maintenance of cognitive function and self-reported quality of life, but cognitive stimulation needs to be better standardized in order to further explore its benefits.

To effectively sustain activities for people living with dementia, those activities have to be tailored based on preferences and the stage of disease the person is in. Sustaining engagement in activities may be difficult because some people with dementia lack insight about their diagnosis. Access to resources is another important barrier for some—especially during a pandemic—that could stem from transportation needs, finances, and/or availability of activities. Affordability, levels of safety, and other factors are also important to consider when determining how best to sustain the activities someone diagnosed with dementia enjoys.

Maintaining a high quality of life after a dementia diagnosis should be discussed in a provider/patient setting as a reflection of that individual’s values and desires, Evertson suggested. An optimal approach would be to begin by asking the person living with dementia what a high quality of life means for them, Evertson explains, and then ask the same of the care partner and/or family members. Scales have been developed such as the Age Friendly Health Systems Guide (Age Friendly Health Systems, 2019) and the Quality of Life in Alzheimer’s Disease scale (Logsdon et al.,1999), which can be shared with care teams to establish what the person living with dementia values.

Evertson suggested that the committee consider exploring research on how health care providers develop an understanding of the trajectory of dementia, and how that affects interactions with and the quality of life for their patients. Additionally, she stated, more should be done to determine how to educate people earlier in the disease progression—both to the benefit of the person living with the disease and their care partners and loved ones. She also noted the importance of providers continuing to address the changing needs of the individual with dementia as he/she moves through the stages of disease, because the needs for the patient and family will change based on symptoms and severity. Evertson concluded with the suggestion to consider further utilizing goal attainment scaling (demonstrating the extent to which goals have been achieved on a common scale) as an appropriate method of specifying health goals and attainment for individuals with dementia.

TWO PERSPECTIVES ON LIVING WITH AD/ADRD

Brian Van Buren, member of the Advisory Panel to the committee, shared a biographical video produced by Dementia Action Alliance. In the video, Van Buren explains that he experienced bouts of depression after his dementia diagnosis and didn’t know how he would continue to live. In the video, Van Buren expressed his love of cooking and sharing meals as a way to connect with people. During his career as a flight attendant, Van Buren traveled to 56 countries and 49 states. He is passionate about traveling, and his diagnosis has not stopped him from doing what he loves. As a recognized advocate for dementia, he uses his passion and purpose to help support others, and he stated that there is no limit for those diagnosed with dementia except the limit that one puts on oneself.

Jim Butler, member of the Alzheimer’s Association’s National Alzheimer’s Early-Stage Advisory Group, explained that before he was diagnosed with Alzheimer’s disease in 2016, he experienced cognitive issues—frequent forgetfulness and confusion while doing tasks that he once viewed as easy. After an experience at an Apple Store where he was flustered and frightened, he shared his concerns with his family who supported his decision to reach out to his doctor with his concerns. Butler noted that after a multitude of visits and tests—neurologist, cognitive testing, MRIs, etc.—he was diagnosed with Alzheimer’s disease, confirmed with amyloid and tau biomarkers.

Butler described the difficulty he and his wife Lisa faced in the first months after the diagnosis and attributed his engagement with a cognitive therapist as the first step in his acceptance of his diagnosis and decision to be proactive in learning how to live well with it. Butler stated that his plan for living well with Alzheimer’s includes three things: making connections, asking for what he needs, and accepting where he is every day. With those goals in mind, Butler listened to doctors about best practices and became involved in Alzheimer’s related groups and activities in his hometown of Chicago. Making connections in

this way, he reported, helped him realize that the best way to work through the diagnosis was to be with people just like him who were dealing with daily challenges of living with dementia. He expressed that speaking with others who understand what he is going through brings inspiration in his life and shows him that he is not alone. Butler's outlook on life has changed since his diagnosis, as he no longer worries about the long-term future but instead stays in the moment. He explained that he takes time to cherish his relationships and enjoys his life.

The second important part of living well, Butler noted, is accessing what he needs from others. He explained that the vast majority of medical professionals he has met with have been supportive and informed and have adjusted their interactions with him accordingly. He stated that while not every conversation goes perfectly, and he sometimes has to ask others to slow down or repeat themselves, sharing that he has a cognitive impairment often leads to deeper discussion about symptoms that the other person or their family members are experiencing, which he views as a gift.

Butler concluded that he does the best he can to not get frustrated with the cognitive issues he experiences every day. He has learned to accept those difficulties and be gentle with himself when they do occur so he can ultimately express himself better. He has learned to accept that there are things he cannot do anymore. With this in mind, Butler expressed that living well with a dementia diagnosis is dependent on how someone lived their life before and how one chooses to deal with what's in front of them. For him, he said, he is happy to have each and every day.

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COMMITTEE ON THE DECADAL SURVEY OF BEHAVIORAL AND SOCIAL SCIENCE RESEARCH ON ALZHEIMER'S DISEASE AND ALZHEIMER'S DISEASE-RELATED DEMENTIAS

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DISCLAIMER: This Proceeding of a Workshop—in Brief was prepared by Molly Checksfield, rapporteur, as a factual summary of what occurred at the meeting. The statements made are those of the rapporteur or individual meeting participants and do not necessarily represent the views of all meeting participants; the committee; the Board on Behavioral, Cognitive, and Sensory Sciences; or the National Academies of Sciences, Engineering, and Medicine. The committee was responsible only for organizing the public sessions, identifying the topics, and choosing speakers.

REVIEWERS: To ensure that it meets institutional standards for quality and objectivity, this Proceedings of a Workshop—in Brief was reviewed by Deborah Blacker, Harvard Medical School, and Tracy Lustig, National Academy of Sciences. Kirsten Sampson Snyder, National Academies of Sciences, Engineering, and Medicine, served as review coordinator.

SPONSORS: The workshop was supported by the Division of Behavioral and Social Research of the National Institute on Aging, AARP, the Alzheimer's Association, the John A. Hartford Foundation, the Office of the Assistant Secretary for Planning and Evaluation, the U.S. Department of Veteran's Affairs, the American Psychological Association, and the JPB Foundation.

Suggested citation: National Academies of Sciences, Engineering, and Medicine. (2020). *Quality of Life, Preventing Elder Abuse, and Fostering Living Well After a Dementia Diagnosis: Proceedings of a Workshop—in Brief*. Washington, DC: The National Academies Press. doi: <https://doi.org/10.17226/25901>.

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