

Are Dementia Caregivers Planning
for Their Own Future?

A Needs Assessment and Examination of
Barriers to Services

by

Jeanette L. Suarez

In Partial Fulfillment of the Requirement for the Degree of

MASTER OF SCIENCE

in

The Department of Psychology

State University of New York
New Paltz, NY 12561

May 2021

ARE DEMENTIA CAREGIVERS PLANNING
FOR THEIR OWN FUTURE?

A NEEDS ASSESSMENT AND EXAMINATION
OF BARRIERS TO SERVICES

Jeanette L. Suarez

State University of New York at New Paltz

We, the thesis committee for the above candidate for the
Master of Science degree, hereby recommend
Acceptance of this thesis.

Karla Vermeulen, Thesis Advisor
Department of Psychology, SUNY New Paltz

Tabitha Holmes, Thesis Committee Member
Department of Psychology, SUNY New Paltz

Greta Winograd, Thesis Committee Member
Department of Psychology, SUNY New Paltz

Submitted in partial fulfillment
of the requirements for the Master of Science degree
in Psychological Science
at the State University of New York at New Paltz

ACKNOWLEDGEMENTS

I would first like to thank my advisor Karla Vermeulen, and committee members Tabitha Holmes, and Greta Winograd for offering guidance, insight, and much needed encouragement throughout the whole process of this study. I would like to especially acknowledge and wholeheartedly thank the caregivers of Meals On Wheels & Services of Rockland, where I am currently employed. They were gracious enough to partake in this study during a challenging time in our history. Special thanks to the CEO of Meals On Wheels, Kevin Hardy, and my supervisor, Sharon Martini. Sharon, I could not have done this without you. You have been a great support since day one, three years ago, when I started this process. Thank you! Thank you! Finally, I would like to dedicate this thesis to my husband, Benjamin, whose grandfather had Alzheimer's, and my two children, Ianna, and Elijah. They were a witness to my journey of late nights, long commutes, balancing acts, personal struggles, and final triumph. Ben, you have always been my biggest fan. Thank you for encouraging me when I wanted to give up, and thank you for always pointing me back to a loving God who cares for me.

TABLE OF CONTENTS

Acknowledgements.....	iii
Abstract	v
Introduction.....	1
Dementia Burden.....	2
Needs of Persons with Dementia.....	3
Caregiver Burden.....	4
Needs of Dementia Caregivers.....	6
Hypotheses	9
Method	10
Participants.....	10
Study Design & Procedure.....	10
Measures	11
Results.....	12
Qualitative Analyses.....	16
Discussion.....	19
Limitations/Future Directions.....	22
References.....	24
Tables & Figures.....	29
Appendices.....	38

ABSTRACT

Due to the complex nature of the decline of persons with Alzheimer's and other types of dementia, dementia caregivers are at greater risk of psychological morbidities, which often has an effect on caregivers' own physical health. These caregivers, who are usually family members, experience first-hand the demands of caring for their loved ones. The present research examined how the demands of caregiving (caregiver burden) had impacted decisions regarding their own future care needs in the form of financial and advance care planning. Sixty-six caregivers from Meals On Wheels & Services of Rockland and the SUNY New Paltz community participated in this study. Although caregiver burden did not have an impact on caregivers' view of the financial future, caregivers who scored high in the dimensions of Challenges to Self-fulfillment and Physical Health Challenges had completed more advance care planning steps than other caregivers. Caregivers with a clearer view of the financial future had also completed more financial planning steps than other caregivers. Caregivers over 40 years of age completed the most financial and advance care planning steps. Barriers to financial and advance care planning were also identified and explored.

ARE DEMENTIA CAREGIVERS PLANNING FOR THEIR OWN FUTURE? A NEEDS ASSESSMENT AND EXAMINATION OF BARRIERS TO SERVICES

Medical advancements have helped to improve the life expectancy rates of Americans over the past century. According to a report by the World Health Organization (2011), older individuals are living longer while fertility rates continue to decline, making the aging population a rapidly growing percentage of the total population. The expansion of the aging population is happening on a global level, not just in the United States. The global projected population of people aged 65 and older will reach about 1.5 billion by 2050, with 14 million in the United States. A closer examination of the intricate needs of older individuals has been the focus of the healthcare industry and pharmaceutical companies alike, as they continue to engage the ever-growing aging population.

A decrease in infectious communicable diseases and deaths has given rise to non-communicable diseases in the United States and abroad. Research on chronic illnesses, medication management, and Alzheimer's and other types of dementia has become an ongoing initiative in addressing the health challenges associated with aging. Allowing older individuals to "age in place" or in their homes involves the cost of support services such as formal paid caregivers or a daycare program. Informal dementia caregivers are often at the forefront, coordinating these services, as well as providing direct care to their loved ones. Consequently, many caregivers experience burnout and high stress levels that affect their health and well-being. The dementia burden has long-term implications for informal caregivers (often family members), as it will necessitate continued efforts in meeting the increasing needs of their loved ones, and often at the expense of the caregiver's own needs. The extent to which caregivers are adequately planning for their own long-term care needs is explored in this thesis, which also examines barriers to support services since supports could provide guidance in this process.

Dementia Burden

Alzheimer's, the most common form of dementia, is a type of degenerative brain disease marked by debilitating cerebral changes. These changes result in a decline of cognitive functioning (Alzheimer's Association, 2020). An individual may not show symptoms for a number of years. However, as neurons in the brain become damaged, memory loss worsens, having an impact on daily activities affected by those areas of the brain. Other forms of dementia include vascular dementia, Lewy body dementia, Parkinson's dementia, and numerous others, which exhibit similar cognitive symptoms, with variations of brain cell damage in different areas of the brain. An estimated 43.8 million people were diagnosed with Alzheimer's or another type of dementia worldwide in 2016 (Launer, 2019). In 2019, approximately 5.8 million Americans were diagnosed with Alzheimer's disease (Alzheimer's Association, 2020).

Alzheimer's Disease International published a 2018 World Alzheimer's Report, which estimated a worldwide cost of \$1 trillion in dementia care, which included direct medical care, home care, community programs, and care provided by informal caregivers. The projected growth of dementia cases will inevitably give rise to higher health care costs and exponentially increase that number in the years to come as the population of older adults grows. Adequate and consistent care for persons with dementia aging in place will continue to be a challenge for caregivers who may not have access to sufficient income and assets. Persons with dementia with higher income and savings/assets may eventually deplete their resources to cover the cost of their own care, as adult children are faced with the task of handling their parent's resources. Spouses of persons with dementia, with shared household incomes, will have to balance living expenses as well as allocate funds to care for their spouses. The legalities tied to financial planning for family members with dementia can be an overwhelming and oftentimes, an expensive process.

Long-term care planning may force caregivers to consider applying for Medicaid to help cover the continued costs of in-home aides and adult day care programs when assets deplete or are non-existent. Decisions regarding nursing home placement or memory care assisted living arrangements are often grappled with, as many caregivers try to honor and respect their loved one's final wishes in light of their increasing needs. These crucial decisions are inherently stressful, causing many caregivers to prolong decision-making, especially those of a permanent nature, such as institutional care.

Needs of Persons with Dementia

The range of individual needs of persons with dementia will vary based on cognitive functioning, multiple morbidities, behavioral and psychiatric symptoms, as well as any functional dependencies (Prince et al., 2015). Adequate assessments are imperative in properly identifying these needs. Unmet needs lead to higher risks of falls, caregiver burden, increased comorbidities, increased risk of harm, and even death. Each individual's level of functioning, medical history, status of social support, and availability of resources will necessitate a tailored approach in a care intervention plan. According to the World Health Organization (2017), a gap exists between the needs of dementia patients and existing care plans and services. Being able to zero in on the prevalent and vast needs of persons with dementia would help to influence and guide the types of services being offered. Further needs exploration will contribute to a greater understanding of the characteristics associated with the needs most frequently reported.

A recent meta-analysis and systematic review (Curnow, Rush, Maciver, Gorska & Forsyth, 2019) sought to capture and synthesize some of the most prevalent needs, as reported by persons with mild-to-moderate dementia and their informal caregivers. An initial search of over 2,500 articles yielded a concise list of 24 prevalent needs of dementia patients, as highlighted in

a final six studies (Curnow et al., 2019). The studies utilized approved versions of the Camberwell Assessment of Need for the Elderly (CANE). Responses regarding the 24 prevalent needs were compiled for both persons with dementia and their caregivers. When comparing the effect sizes of the responses of both groups, results were significant in the areas of household activities, memory, self-care, incontinence, psychiatric symptoms, money, alcohol, abuse & neglect, accidental harm, behavior, and daytime activities. These results also showed that dementia caregivers rated the same needs higher than the persons with dementia. Caregivers answering the CANE may have completed the assessment for a loved one with severe dementia, which may have accounted for the higher rates. This meta-analysis demonstrates some of the prevalent needs of persons with dementia, as well as the informal caregivers' assessment of those same needs. The level of caregiver involvement should be considered as care plans are put into place. Understanding the prevalent needs of persons with dementia will help to reduce unmet needs and thereby reduce harm, morbidities, and caregiver burden.

Caregiver Burden

According to the Alzheimer's Association's latest report (2020), informal caregivers make up approximately 83% of the provision of care to a person with Alzheimer's or other type of dementia in the United States. In 2019, unpaid informal caregivers provided 18.5 billion hours of care, translating into a monetary value of \$234 billion. About one in three caregivers are age 65 or older, with spouses accounting for a large percentage. Spouse caregivers experience unique challenges due to the intimate, committed nature of their relationship. Spouse caregiver burden often results in stress and depression as they face changing roles that they were not prepared for in their marriage (Croog, Burlison, Sudilovoksy, & Baume, 2006). In a study with spouse caregivers of mild to moderate Alzheimer's patients, Croog et al. found that caregiver burden

mainly consisted of anxiety about the future, limitation of social life, personal time restriction, anger-resentment, and feeling the need to do more. Eighty-five percent of caregivers reported anxiety about the future as their main concern or burden. About 45% felt the need to do more, with husband caregivers scoring higher, and 41% reported frequent feelings of anger-resentment toward their spouse, with wives scoring slightly higher. Thirty-two percent scored high on limitation of social life. These caregivers in particular also scored high on a depression-anxiety scale, reporting that limitations on their social life had contributed to greater feelings of depression and anxiety. Understanding the complex dimensions of caregiver burden is an important step in addressing their needs. Helping to relieve some of the burden would allow caregivers a time to refresh, to be able to continue with the daily challenges.

Daily interactions with persons with dementia require constant supervision, prompting, cueing, and redirecting, especially as the disease progresses and functioning declines. The role of the caregiver is often quite different from the original relationship as spouse, son, or daughter. A qualitative study on the roles of dementia caregivers (Lovenmark, Meranius, & Hammar, 2018) revealed that caregivers had mainly described and perceived their roles as an “actor,” “parent,” and/or “survivor.” These roles or subject positions, as presented in the study, had derived from the caregivers’ use of categorization as a way to organize their new reality in their daily interactions with their loved ones. These roles or subject positions were coping strategies they had developed, which were also quite flexible, as context would dictate or influence the appropriate role for the situation or behavior. In their role as actor, many felt they could not share the truth about their feelings, but instead hid them from their loved one. Their role as parent involved direction and assistance with activities of daily living, such as helping with dressing and showering, and addressing behavioral issues. Never having a sense of being “off duty,”

caregivers experienced burnout. As a survivor, caregivers often felt alone in the relationship. They had to be the strong one and cope with living with a stranger. This study sheds light on the emotional burden placed on caregivers as they grieve the loss of the person they once loved, and provide care to a loved one who is no longer able to reciprocate and meet their needs.

Needs of Dementia Caregivers

Services for persons with dementia often cannot be separated from services for the caregiver. Since informal caregivers are usually the main point of contact, who help to facilitate the steps towards services, plans of care will inevitably affect them. As the needs of persons with dementia change, so will the needs of caregivers. Healthcare providers and community programs should offer an assessment of caregivers' needs on a continuous basis. A study by Zwaanswijk, Peeters, Van Beek, Meerveld, and Francke (2013) sought to investigate the problems, needs, and supports of dementia caregivers throughout the various stages of dementia. Zwaanswijk et al. examined the problems associated with the provision of informal care, challenges with the use of professional services by the person with dementia, and the informal caregivers' need for additional support services throughout the stages of dementia. The problems caregivers most frequently reported in all stages of dementia were changes in their loved one's behavior and feelings of dread surrounding the possibility of nursing home admission. Caregivers of persons within the later stages of dementia reported higher instances of loneliness and less contact with relatives than with those in the earlier stages. With regards to professional support services, most of the caregivers expressed a need for additional support, such as guidance with behavioral issues, practical help in the home with chores, emotional support, and information on additional services offered in nursing homes. Identifying the changing needs of caregivers throughout the course of the illness will help to ensure linkages to services on an ongoing basis.

A need that is often difficult to address is the preparation for the eventual death of the loved one with dementia. End-of-life decisions will need to be made, as well as final funeral arrangements. Adding to the difficulty is the emotional stress related to this process. A study with bereaved caregivers of a loved one with a terminal illness (Herbert, Schulz, Copeland & Arnold, 2009) found that the overarching theme of uncertainty had permeated areas involving medical issues and questions, practical information regarding finances and estate planning, psychosocial questions about the impending impact of death on the family dynamic, and religious/spiritual existential concerns for their loved one. Caregivers' life experiences had impacted their level of preparedness. For example, a caregiver with a family member in the medical field had more access to information and therefore felt more prepared regarding the prognosis of her loved one. In contrast, another caregiver expressed how the death of her loved one had caused conflict within her family that she wished she had been prepared for. Herbert et al. found that communication with healthcare providers and other family members is the means through which many have managed some of these uncertainties. Despite this finding, uncertainties specifically surrounding death and dying are often neglected in conversations with healthcare providers. An awareness of the uncertainties mentioned in this study could inform and guide healthcare providers in their discussions regarding end-of-life matters with dementia caregivers.

It is well documented that dementia caregivers experience high levels of depression and anxiety (Coope et al., 1995). They are also at higher risk of being diagnosed with major depressive disorder than non-dementia caregivers (Cuijpers, 2004). Spouse caregivers living with their partner reported lower levels of life satisfaction than non-caregivers in their age group. Level of satisfaction for spouse caregivers was even lower when their loved one resided in a

nursing home (Ask, et al., 2014). Quality of life of dementia caregivers is significantly more affected when compared to caregivers of persons with chronic diseases. Dementia caregivers have reported greater subjective physical complaints with regards to their health (Karg, Graessel, Randzio & Pendergrass, 2018). A study with baby boomer dementia caregivers found a higher prevalence of arthritis and high blood pressure, with dementia caregivers reporting overall poor health in comparison to non-dementia baby boomer caregivers (Moon & Dilworth-Anderson, 2015). Concerning their own needs, another study on baby boomer caregivers found that caregiving had brought a greater awareness of their anticipated future needs, but they were not specifically taking any action to plan for their own long-term care needs, such as applying for Long-Term Care insurance (Finkelstein, Reid, Kleppinger, Pillemer & Robison, 2012).

Informal caregivers, who are usually related to the one needing care, are often stressed in trying to find a balance between caring for their loved one, themselves, and other family members. The reality that a loved one is not cognitively well adds an emotional burden or strain (Brodaty & Donkin, 2009). This is especially true of dementia caregivers given the complex nature of the decline in persons with dementia. A study by Judge et al. (2011) on veterans with dementia and family caregivers examined a care coordination intervention approach to identifying and addressing unmet needs of both patient and caregiver. This care coordination intervention approach was a telephone-based coaching program for caregivers, involving a team of doctors at a Veterans Affairs hospital care system in Texas and their local Alzheimer's Association chapter. Results of the study showed that 29% of caregivers expressed a need for assistance with legal and financial planning for their loved one. This result is of particular interest, since the care coordination model addressing this need could potentially extend to caregivers and their future needs as they age. How does this salience of aging and caring for

someone with dementia affect the caregiver? Is there concern over their own future cognitive health as they age? If so, how has this impacted the way they think about their own future care needs and the costs or steps involved? In light of the research, this thesis examined how dementia caregivers are planning (or not) for their own future while trying to meet the daily demands of caring for the person with dementia. The following hypotheses were investigated:

Hypothesis 1:

- a) Time involved in caregiving will be inversely related to a clear view of the financial future*
- b) Caregiving-related emotional challenges will be inversely related to a clear view of the financial future*
- c) Caregiving-related challenges to one's physical health will be inversely related to a clear view of the financial future*
- d) Caregiving-related challenges to one's own self-fulfillment will be inversely related to a clear view of the financial future*
- e) Caregiving-related challenges to social relationships with family members will be inversely related to a clear view of the financial future*

Hypothesis 2: *The clarity of caregivers' financial view of the future will be positively related to the number of steps taken to financially plan*

Hypothesis 3:

- a) Time involved in caregiving will be inversely related to the number of steps taken in advance care planning for the future*
- b) Caregiving-related emotional challenges will be inversely related to the number of steps taken in advance care planning for the future*
- c) Caregiving-related challenges to one's own self-fulfillment will be inversely related to the number of steps taken in advance care planning for the future*
- d) Caregiving-related challenges to social relationships with family members will be inversely related to the number of steps taken in advance care planning for the future*

Hypothesis 4: *Physical health will be positively related to the number of steps taken in advance care planning for the future*

Hypothesis 5: *Number of barriers to planning will be negatively related to number of steps taken to financially plan for the future*

Hypothesis 6: *Number of barriers to planning will be negatively related to the number of steps taken in advance care planning for the future*

METHOD

Participants

A total of 66 dementia caregivers participated in the study. Caregivers from Meals On Wheels & Services of Rockland, and the SUNY New Paltz community were recruited via email, telephone calls, mass mailings, and various social media platforms. The mean age of the participants was 43.34 ($SD=22.75$), with a range of 18-87. Seventy-six percent of the caregivers were female, and 24% male; 71% of the participants were White/Caucasian, 9% were Hispanic/Latino (a), 5% were Black/African-American, 5% were Mixed Race, 2% Asian, with the remaining percentages representing a combination of races and ethnicities. The annual income of participants ranged from less than \$20,000 (17%) to over \$100,000 (30%). Over a quarter of the participants (28.8%) were daughters of a person with dementia; 27.1% of participants who reported “other” as their relationship to the person with dementia were a grandson or granddaughter; 15.2% were spouses, 7.6% were sons, and 4.5% were daughters-in-law. Other relationships were sister, cousin, great grandchild, great niece, and paid caregiver. In terms of frequency of care, 36.4% of the sample provided daily care to a person with dementia; 21.2% provided care 1-2 times a week, 19.7% 3-6 times a week, 16.7% 1-2 times a month, and 6.1% reported “other,” such as multiple times throughout the day, and 2-3 times a month.

Study Design & Procedure

This study was a correlational mixed-methods embedded design, with grounded theory analysis of the qualitative data. A survey (Appendix A) was administered measuring the impact of caregiver burden on financial planning and advance care planning. An online Qualtrics survey, as well as a paper form of the survey, were made available to meet the preference of the

caregiver. SPSS was used to analyze the quantitative data. The qualitative portion of the study explored two questions: “Take a moment to think about your life living with a loved one who has dementia. Describe all the ways in which your life would be different if your loved one did not have dementia” and “Now I’d like you to think about your own future and the things in life that are most important to you. Describe what you would like your life to be like in your final years.” Responses provided examples of emergent themes shared among the caregivers, which either supplemented or confirmed the findings of the survey.

Measures

For the variable *Caregiver Burden*, participants were asked to measure the impact of the demands of caregiving on a five-point Likert scale, from never to nearly always (0-4) within 5 dimensions, utilizing the Multidimensional Caregiver Burden Inventory (Novak & Guest, 1989). Each dimension consisted of five questions, with the exception of Physical Health Challenges, which only had four. The five dimensions were Time-Dependency, which measured time involved in caregiving, Emotional Health, which measured emotional challenges, Physical Health Needs, measuring physical health challenges, Development, which measured challenges to self-fulfillment, and Social Relationships, measuring challenges in social relationships. The caregiver burden subscales were found to be very reliable (α s=.86-.93).

The dependent variable *Clear View of the Financial Future* was measured by a modified version of Hershey’s Retirement Planning Model (2008). Participants were asked to measure financial and retirement planning on a seven-point Likert scale (1-7), from strongly disagree to strongly agree, answering a total of five questions regarding Future Time Perspective, Retirement Goal Clarity, Self-Rated Knowledge of Financial Planning for Retirement, and Retirement Planning Activity. Reliability analysis revealed a good internal consistency (α =.74).

Utilizing a modified version of the ACP Engagement Survey with Barriers (Schickedanz et al., 2009), and the End-of Life Planning Questionnaire-online tool, *Financial Planning Steps* and *Advance Care Planning Steps with Participant-Identified Barriers* were measured. Financial planning questions such as meeting with a benefits specialist, purchasing Long-Term care insurance or life insurance, and prepaying for funeral arrangements followed the same format as the ACP Engagement Survey. A list of barriers to taking these actions, such as “You think you are too healthy” or “You do not have enough information” were answered with Yes or No. An open-ended question, “Are there any other reasons?” allowed for additional qualitative responses. A financial barrier was added to the list of barriers for the financial planning questions. Advance care planning included questions such as choosing a health care proxy, filling out an advance directive and will planning. Participants identified barriers to advance care planning steps and were also given the opportunity to include other reasons in an open-ended format. Since answers to this measure were dichotomous (Yes/No), reliability could not be measured.

RESULTS

Sample sizes, means, and standard deviations of the caregiver burden scale and retirement planning scale are presented in Table 1. Descriptive frequencies for financial planning and advance care planning steps taken are presented in Tables 2 and 3. Mean scores for Financial and Advance Care Planning were further broken down by age groups in Figures 1-3. Next, Pearson correlations were conducted in the analyses of the quantitative data. Missing cases were excluded pairwise in all analyses. Pearson correlation coefficients were calculated to assess the relationship between scores on Clear View of the Financial Future (CVFF) and scores on the five dimensions of the caregiver burden scale (Table 4). Caregiver burden did not have a negative

impact on participants' view of the financial future, Time Involved, $r(63) = -.113, p=.377$; Emotional Challenges, $r(64) = -.009, p=.942$; Physical Health Challenges, $r(62) = .156, p=.227$; Challenges to Self-fulfillment, $r(63) = .183, p=.15$; Challenges in Social Relationships, $r(63) = .042, p=.743$ (Table 4). Although the hypothesis was unsupported, a strong significant positive correlation was found between Challenges to Physical Health and Challenges to Self-fulfillment, $r(62) = .671, p< .001$. Caregivers who felt like they were missing out on life, or who wished they could escape their situation also felt greater physical effects as a result of caregiving. The relationship between CVFF and number of Financial Planning Steps was also explored, revealing that caregivers with a clearer view of the financial future had taken more steps to financially plan, $r(63) = .547, p< .001$. Such caregivers discussed financial planning with a professional, appointed someone as Power of Attorney, purchased Long-Term Care insurance and life insurance, and/or prepaid for funeral services (Figures 4-8).

Pearson correlation coefficients were calculated to examine the relationship between four domains of the caregiver burden scale (Time Involved in Caregiving, Emotional Challenges, Challenges to Self-fulfillment, Challenges in Social Relationships) and Advance Care Planning steps (Health Care Proxy, Advance Directives, Will with Executor). It was hypothesized that caregivers scoring high on these domains would engage less in advance care planning as they would be too busy or stressed to take on these actions. This inverse relationship was not found across the variables, Time Involved, $r(61) = .234, p=.07$; Emotional Challenges, $r(62) = .04, p=.76$; Challenges to Self-fulfillment, $r(61) = .365, p< .004$; Challenges in Social Relationships, $r(60) = -.016, p=.91$ (Table 5). Alternatively, a positive relationship between challenges to self-fulfillment and advance care planning steps was observed, $r(61) = .365, p< .004$, demonstrating

that caregivers with higher scores in challenges to self-fulfillment had completed more advance care planning steps.

Interestingly, a significant positive relationship was also found between Challenges to Self-fulfillment and Physical Health Challenges, $r(62) = .671, p < .001$. Caregivers who felt emotionally drained due to caregiving, or felt that their social life had suffered, also felt greater physical health challenges, such as not getting enough sleep, feeling physically tired, or that caregiving had made them physically sick. Additionally, caregivers scoring high on Challenges to Self-fulfillment also experienced greater Challenges in Social Relationships, $r(62) = .629, p < .001$. These challenges included feelings of resentment towards family members who could help, but chose not to, or feeling under-appreciated by family for their caregiving efforts. The hypothesized positive relationship between the final caregiver burden domain of Physical Health Challenges and advance care planning was supported, $r(63) = .284, p < .05$. Caregivers reporting physical health challenges had taken greater advance care planning steps, such as appointing a health care proxy, completing advance directives, and finalizing a will with an executor. It is likely that these caregivers felt compelled to take action in this area because of underlying health conditions, and/or the challenges associated with caregiving.

Barriers

Before delving into the barriers to financial and advance care planning, we gain some knowledge of some of the steps caregivers have taken in these two areas (Tables 2 and 3). Almost a quarter (23%) of the caregivers completed three of the five Financial Planning Steps (Discussed Financial Planning, Power of Attorney, Long-Term Care, Life Insurance, Prepaid Funeral), with 24% completing two of the five steps. In contrast, 29% of the caregivers did not complete any financial planning steps. With Advance Care Planning, 30% completed all three

steps (Health Care Proxy, Advance Directives, Will). However, 42% did not complete any advance care planning steps. It is worth noting that caregivers in the age groups “40-59” and “60 and over” had a clearer view of the financial future than caregivers under 39 years of age (Figure 1). These two older age groups completed more financial and advance care planning steps than caregivers under 39 (Figures 2 and 3), with caregivers over 60 completing the most advance care planning steps. Age seems to be a moderating factor in the three measures. Descriptive statistics identified the top three Barriers to Financial Planning and Advance Care Planning Steps as “Can’t afford it,” “Too healthy,” and “Not enough information” (Table 6). Caregivers were asked to check as many barriers that may apply. The barrier “Can’t afford it” yielded the highest percentages among the financial planning steps, with 42% reporting this barrier for Prepaid Funeral Services, 38% for Discussed Financial Planning, 39% for Long-Term Care insurance, 30% for Life Insurance, and 24% for POA. Additional high-yielding barriers included “Not enough info” and “Too healthy.” For advance care planning steps, Health Care Proxy, Advance Directives, and Will with Executor, caregivers felt they were too healthy (24%, 24%, and 23%, respectively). They also felt like they did not have enough information regarding these end-of-life decisions (17%, 16%, and 23%, respectively).

To explore the relationship between the number of barriers to planning with the number of steps taken to financially plan for the future, Pearson correlation coefficients were calculated. The hypothesized negative relationship was supported, demonstrating that as the number of barriers increased, the number of steps to financially plan also decreased: Discussed Financial Planning barriers, $r(64) = -.638, p < .001$; Power of Attorney barriers, $r(63) = -.556, p < .001$; Long-Term Care Insurance barriers, $r(63) = -.549, p < .001$; Life Insurance barriers, $r(64) = -.606, p < .001$; Prepaid Funeral barriers, $r(64) = -.469, p < .001$ (Table 7). A negative relationship

was also found between the number of barriers to planning and the number of steps taken in advance care planning, once again demonstrating that as the number of barriers to advance care planning increased, the number of steps taken to engage in advance care planning decreased: Health Care Proxy, $r(63) = -.643, p < .001$; Advance Directives, $r(63) = -.598, p < .001$; Will with Executor, $r(63) = -.614, p < .001$ (Table 8).

Qualitative Analyses

Two qualitative questions were analyzed, adding richness to the data. A grounded theory approach of open and selective coding was utilized. Codes were continually assessed and eventually collapsed into emergent themes. A total of 58 caregivers provided responses to the first question (“Describe all the ways in which your life would be different if your loved one did not have dementia”), and 57 caregivers provided responses to the second question (“Describe what you would like your life to be like in your final years”). Less than half (45%) of these caregivers were between the ages of 18-39 years, 21% were between 40-59 years, 22% were between 60-79 years, and 9% were 80 plus years. One-third (33%) of the caregivers were daughters to someone with dementia, and 29% were grandchildren; 40% of the caregivers provided daily care to a loved one with dementia (Table 9).

When asked how life would be different if their loved one did not have dementia, caregivers expressed their answers in a two-fold manner; either focusing on themselves and/or on their loved one. Three major themes emerged: Freedom, Meaningful Connection, and Emotional and Mental Wellness. Interestingly, two sub-themes also surfaced, Cognitive Reappraisal/Active Acceptance, and Resigning Acceptance, representing the present emotional state and internal processes taking place in some of the caregivers at the time of the survey (Table 10). Forty-three percent of the caregivers felt that if their loved one did not have

dementia, they or their loved one would have the freedom to make different choices, would be free from communication challenges, have free time for themselves, have more independence, be free to travel, have financial freedom, and would be free to engage in various activities. In their current circumstances, these caregivers feel tied down or limited by their sense of obligation, knowing that a good portion of their time is earmarked towards the care of their loved one. Another challenge related to caregiving that emerged as a theme is the loss of connection. Forty-one percent of dementia caregivers felt that if their loved one did not have dementia, there would be meaningful connection in the form of new memories together, better communication, celebrations, restored relationship, connection between generations of family members, and a legacy of mutually cherished memories. The antithesis of this is not just loss of connection, but also loss of being fully known, recognized, and received. Caregivers also experience the loss of mutual understanding, expressions of love, and the enjoyment of life together. The loss of meaningful connection and freedom have contributed to feelings of stress, worry, depression, and anxiety. Close to a third (31%) of the caregivers expressed that they would have better mental health, and have less stress and anxiety, if their loved one did not have dementia. Some caregivers used words such as hope, enjoyment, and energy to describe the level of emotional and mental wellness they would have if it were not for the dementia diagnosis of their loved one.

The two sub-themes, Cognitive Reappraisal/Active Acceptance and Resigning Acceptance, represent a percentage of the caregivers (24% and 21% respectively) who either engaged in a meaning-making process, or who seemed overcome by their circumstance. Cognitive reappraisal is the process of changing one's thinking about emotion-eliciting circumstances (Cutuli, 2014). Nearly a quarter (24%) of the caregivers who had engaged in this process were able to identify positive aspects within their negative circumstances. As a result,

they were able to actively accept the negative emotions and events, and deal with them constructively. Active acceptance allows these caregivers to maintain a peaceful emotional state despite the circumstances (Nakamura & Orth, 2005). In their active acceptance, some have learned to cherish the moments they have left with their loved one, or have accepted that love requires sacrifice. In contrast, 21% of the caregivers had engaged in resigning acceptance at the time of the survey, maintaining negative expectations about the future. This is often accompanied by disappointment, sorrow, and a loss of hope (Nakamura & Orth, 2005). A number of these caregivers expressed some level of hopelessness, with a burden that seemed too great to bear.

Rich Quality of Life is the central overarching theme surrounding the second question (“Describe what you would like your life to be like in your final years”), encompassing sub-themes of Community, Positive Emotional Well-being, and Health and Wellness (Table 11). Over half (60%) of caregivers discussed the importance of family, with a desire to be surrounded by loved ones in their final years. Others expressed the hope of having friends nearby as well. Remaining connected to a community of family and friends would help to satisfy the most basic and essential need for belonging, love, care, and acceptance. This was the expressed desire of more than half the sample. About half (51%) of caregivers also stated that they hope to have a stable and healthy internal state in their final years, using descriptors such as happiness, peaceful, comfortable, relaxed, joy, and secure. These descriptors are representative of a positive emotional wellbeing, which cannot be achieved in isolation, but within community. Finally, 40% of caregivers wish to be healthy and of sound mind in their final years. They would like to maintain some measure of independence that only health and wellness would adequately permit them to have. They wish to be free from dementia, but hope to have adequate care by family or a

professional, should they be diagnosed. They also hope to not be a burden to their family. Again, we find an overlap between these sub-themes. Experiencing community decreases the likelihood of loneliness and isolation, which then increases the health and wellness of the individual, as well as their emotional wellbeing. Numerous studies on older adults support this connection, linking social ties to decreased morbidity rates and increased life expectancy (Valtorta & Hanratty, 2012). This rich quality of life might be an ideal concept, but if at all attainable, these caregivers could experience better overall health in their final years.

DISCUSSION

Research has shown that dementia caregivers are at greater risk of psychological morbidities (Judge et al., 2011), which could impact their physical health and increase their own need for care-providing resources later in their own lives. The demands of caring for a loved one with dementia, with all of its complexities, is coupled with an increasing sense of loss. Caregivers have to come to grips with the reality that the attention and care they give will not be reciprocated by the loved one with dementia. The qualitative data reported in this study revealed that though a number of caregivers had found ways to make meaning of their circumstances, an almost equal amount of caregivers felt overwhelmed by a sense of hopelessness. The loss of meaningful connection had also affected the mental wellness of dementia caregivers in this study, leaving a void where joyful memories, shared experiences, and mutual understanding had once existed. Daily stress and worry now fill that void. A good number of caregivers also expressed feelings of constraint tied to the demands of caregiving, lacking the freedom to engage in activities of self-care, personal enjoyment, or self-fulfillment. Concerning their own future, these caregivers hope to have a rich quality of life, within a community of family and friends.

They also hope to be healthy and of sound mind. So, how has this trickled down to actual planning for their own future, to help increase this likelihood for a rich quality of life?

Results Related to Caregiver Burden

This study surveyed how the demands of caregiving had impacted participants' view of the financial future, as well the steps they had taken to engage in financial and advance care planning. Barriers were also explored. Contrary to the hypothesis, a relationship between Caregiver Burden and Clear View of the Financial Future was not observed, in either a positive or a negative way. This disconnect between caregiver burden and their view of the financial future could be attributed to the fact that over a quarter of the sample (27%) were grandchildren to a loved one with dementia and may not have been the primary caregiver to their loved one, who would normally experience greater burden. It was hypothesized that caregivers scoring high in the four dimensions of the Caregiver Burden scale (Time Involved in Caregiving, Emotional Challenges, Challenges to Self-fulfillment, Challenges in Social Relationships) would complete less Advance Care Planning Steps (Health Care Proxy, Advance Directives, Will with Executor). This was also unsupported. In contrast, caregivers scoring high in Challenges to Self-fulfillment had actually engaged in more advance care planning steps than other caregivers. For the final dimension Physical Health Challenges, caregivers with higher scores had also taken more advance care planning steps than other caregivers, as hypothesized. Challenges to Self-fulfillment and Physical Health Challenges were found to be highly correlated. Caregivers who felt emotionally drained, physically tired or sick might have felt the need to complete some or all of the advance care planning steps in an effort to alleviate stress on their families.

Results Related to Clear View of Financial Future

The hypothesis that caregivers with a clear view of the financial future would be positively related to the number of steps taken to financially plan was supported. However, age of the caregiver seemed to impact these results. Caregivers scoring high in this scale were between 40-59 and over 60 years of age. Top barriers listed for financial and advance care planning steps (“Can’t afford it,” “Too healthy,” “Not enough info”) could also be applied to the retirement/financial planning scale. Someone who feels that they are too healthy (which may correlate with youth) may not see the need to think about their financial future. Or those lacking financial resources may not see it as a viable option at this time, which may be the case with the younger sample.

Financial Planning and Advance Care Planning Steps

Only a small percentage of the caregivers had actually planned for their future. About a quarter (23%) of the caregivers had completed three out of the five financial planning steps. Regarding advance care planning, a little over a quarter (30%) had completed all three advance care planning steps. Once again, age of the caregiver seemed to have impacted the results, with caregivers between 40-59 and 60 and over scoring similarly in financial planning steps, and caregivers 60 and over completing the most advance care planning steps. As previously mentioned, the top three barriers to planning were “Can’t afford it,” “Too healthy,” and “Not enough info”. The number of barriers were negatively correlated to financial and advance care planning steps, as expected. These barriers have broadened our understanding of the decision-making process, providing useful information for further exploration.

LIMITATIONS/ FUTURE DIRECTIONS

The sample size for this study had been greatly affected by COVID19. A number of caregiver services at Meals On Wheels, a key planned source of participants for the researcher, have been on pause since the start of the shutdown with the pandemic. Recruitment efforts were affected, eliminating in-person announcements to active caregiver groups, as well as in-person opportunities to take the survey. As a result, a more modest number of caregivers had participated than originally expected. In addition to the small sample size, missing data were excluded in the analyses, which also could have affected the results of the study. Another limitation is the percentage of young participants versus the rest of the sample. There was a disparity between scores from the younger participants and participants over 40 years of age. Though this was the case, insights into the experiences of younger participants did add value to our understanding of the lifespan developmental factors involved in caregiving.

Concerning the scales, an overlooked variable was length of time as a caregiver. How long the participant has been a caregiver could moderate some of the scores on the various scales. A recent caregiver might experience high stress levels until they accept the “new normal” in their life. Someone who has been a caregiver for many years could have a greater care routine established - or they could experience higher levels of burn out with lack of respite. This would be an interesting factor to explore in future studies.

Since caregiver burden did not seem to play a major role as expected on financial or advance care planning, a closer look at the top three barriers (“Can’t afford it,” “Too healthy,” “Not enough information”) could offer guidance for further exploration. Implementing a gradual plan for financial and advance care planning in accordance with stage of life, health factors, socioeconomic status, and family health history could be a way to bridge the gap between the

desire for a rich quality of life in the final years and taking actual steps to help them towards that goal. This might enable caregivers to some extent, alleviate potential burden for family members, should they develop Alzheimer's or other types of dementia in the future.

Finally, the qualitative data revealed that 24% of the caregivers had engaged in the process of cognitive reappraisal and active acceptance. These caregivers found a way to make meaning of their difficult circumstances, expressing a more positive outlook regarding the negative aspects associated with their loved one's diagnosis. Future research could explore whether this process helps to reduce caregiver burden, compared to caregivers engaging in resigning acceptance or no process at all. This could shed light on who these caregivers are, and any other factors potentially contributing to the engagement of such a process. Identifying these variables could possibly inform interventions and support services addressing caregiver burden.

REFERENCES

- Alzheimer's Association. (2020). *Alzheimer's Disease Facts and Figures*. Washington, DC. Retrieved from <https://alz.org/media/Documents/alzheimers-facts-and-figures.pdf>
- Ask, H., Langballe, E.M., Holmen, J., Selbaek, G., Saltvedt, I., & Tambs, K. (2014). Mental health and wellbeing in spouses of persons with dementia: The Nord-Trondelag Health Study. *BMC Public Health*, *14*, 413. Retrieved from <http://www.biomedcentral.com/147-2458/14/413>
- Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues Clinical Neuroscience*, *11* (2), 217-228. Doi: 10.31887/DCNS.2009.11.2/hbrodaty
- Coope, B., Ballard, D., Saad, K., Patel, A., Bentham, P., Bannister, C., Graham, C., & Wilcock, G. (1995). The prevalence of depression in the carers of dementia sufferers. *International Journal of Geriatric Psychiatry*, *10* (3). <https://doi.org/10.1002/gps.930100310>
- Croog, S.H., Burleson, J.A., Sudilovsky, A., & Baume, R.M. (2006). Spouse caregivers of Alzheimer's patients: problem responses to caregiver burden. *Aging & Mental Health*, *10* (2), 87-100. doi: 10.1081/136078605004924598
- Cuijpers, P. (2004). Depressive disorders in caregivers of dementia patients: a

systematic review. *Aging & Mental Health*, 9 (4), 325-330.

<https://doi.org/10.1080/13607860500090078>

Curnow, E., Rush, R., Maciver, D., Gorska, S., & Forsyth, K. (2019). Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: a systematic review and Meta-analysis. *Aging & Mental Health*, 12 (3). doi: 10.1080/13607863.2019.1695741

Cutuli, D. (2014). Cognitive reappraisal and expressive suppression strategies role in the emotion regulation: an overview on their modulatory effects and neural correlates. *Frontiers in Systems*. <https://doi.org/1.3389/fnsys.2014.00175>

End of Life Planning Questionnaire. (n.d.). Retrieved from www.loveyourlifetodeath.com

Finkelstein, E., Reid, M. C., Kleppinger, A., Pillemer, K., & Robison, J. (2013). Are Baby Boomers who care for their older parents planning for their own future long-term care needs? *Journal of Aging and Social Policy*, 24 (1), 29-45. doi: 1080/08959420.2012.630905

Herbert R.S., Schultz, R., Copeland, V., & Arnold, R. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptoms Management*, 37 (1), 3-12.

doi:10.1016/j.jpainsymman.2007.12.010

Hershey, D.A., Jacobs-Lawson, J.M., McArdle, J.J., & Hamagami, F. (2008).

Psychological foundations of financial planning for retirement. *Journal of Adult Development, 14*, 26-36. doi: 10.1007/s10804-007-9028-1

Judge, K.S., Bass, D.M., Snow, L.A., Wilson, N., Morgan, R., Looman, W.J., McCarthy, C., & Kunik, M.E. (2011). Partners in dementia care: a care coordination intervention for individuals with dementia and their family caregivers. *The Gerontologist, Vol 51 (2)*, 261-272. doi: <https://doi.org/10.1093/geront/gnq092>

Launer, L.J. (2019). Blood pressure control as an intervention to prevent dementia. *The Lance Neurology, 18 (10)*, 906-908.
doi: [https://doi.org/10.1016/S1474-4422\(19\)30288-1](https://doi.org/10.1016/S1474-4422(19)30288-1)

Lovenmark, A., Meranius, M.S., & Hammer, L.M. (2018). That mr. Alzheimer...you never know what he's up to, but what about me? A discourse analysis of how Swedish spouse caregivers can make their subject positions understandable and meaningful. *International Journal of Qualitative Studies on Health and Well-being, 13 (1)*. <https://doi.org/10.1080/17482631.2018.1554025>

Moon, H., & Dilworth-Anderson, P. (2015). Baby Boomer caregiver and dementia caregiving: findings from the National Study of Caregiving. *Age and Ageing, 44*,

300-306. doi: 10.1093/ageing/afu119

Nakamura, Y.M., Orth, U. (2005). Acceptance as a coping reaction. Adaptive or not?

Swiss Journal of Psychology 64 (4), 281-292.

Novak, M., Guest, C. (1989). Application of a multidimensional caregiver burden

inventory. *The Gerontologist*. Retrieved from

<http://gerontologist.oxfordjournals.org>

Patterson, C. (2018). *World Alzheimer's Report 2018, The State of the Art of Dementia*

Research: New Frontiers. London, UK. Alzheimer's Disease International.

Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2018.pdf>

Prince, M., Guerchet M., Wimo, A., Ali, G.C., Wu, Y., & Prina, M. (2015). *World*

Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of

Prevalence, Incidence, Cost and Trends. London, UK. Alzheimer's Disease

International. Retrieved from

https://www.researchgate.net/publication/281555306_World_Alzheimer_Report_2015_The_Global_Impact_of_Dementia_An_Analysis_of_Prevalence_Incidence_Cost_and_Trends

Schickedanz, A.D., Schillinger, D., Landefeld, S., Knight, S.J., Williams, B.A., &

Sudore, R.L. (2009). A clinical framework for improving the advance care

planning process: start with patients' self-identified barriers. *Journal of American Geriatric Society*, 57 (1), 31-39.

doi:10.1111/j.1532-5415.2008.02093.x.

Valtorta, N., Hanratty, B. (2012). Loneliness, isolation and the health of older adults: do we need a new research agenda? *Journal of The Royal Society of Medicine*, 105 (12), 518-522.

Doi: 10.1258/jrsm.2012.120128

World Health Organization. (2011). *Global Health and Aging*. (Publication No. 11-7737). Retrieved from

https://www.who.int/ageing/publications/global_health.pdf

World Health Organization (2017). *World Health Statistics 2017, Monitoring Health for the SDGs*. New York, NY. United Nations. Retrieved from

<https://apps.who.int/iris/bitstream/handle/10665/255336/9789241565486-eng.pdf;jsessionid=7A1131FA DC72B1BB2D58ADC13F99B517?sequence=1>

Zwaanswijk, M., Peeters, J.M., Van Beek, A., Meervald, J. & Francke, A. (2013).

Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Open Nurse Journal*, (7), 6-13. doi: 10.2174/1874434601307010006

TABLES

Table 1. Descriptive Statistics for Caregiver Burden and Retirement Planning

Variables	N	M	SD
Time Involved in Caregiving (on a total scale from 0 to 20)	64	12.67	5.03
Emotional Challenges (on a total scale from 0 to 20)	65	3.95	3.8
Physical Health Challenges (on a total scale from 0 to 16)	63	6.52	4.73
Challenges to Self-fulfillment (on a total scale from 0 to 20)	64	8.84	5.54
Challenges in Social Relationship (on a total scale from 0 to 20)	63	5.8	4.78
Clear View of Financial Future (on a total scale from 1 to 35)	65	20.23	5.96

Note. M and SD represent mean and standard deviation, respectively.

Table 2. Total Financial Planning Steps Taken*

Number of Steps Taken	Number of Participants	Percent of Sample
0	19	28.8%
1	10	15.2%
2	16	24.2%
3	15	22.7%
4	3	4.5%
5	1	1.5%
Missing	2	3.0%
Total	66	100.0

* Options included discussing financial planning with a professional, naming a Power of Attorney, purchasing long-term care insurance, purchasing life insurance, and pre-paying for funeral expenses

Table 3. Total Advance Care Planning Steps Taken*

Number of Steps Taken	Number of Participants	Percent of Sample
0	27	40.9%
1	8	12.1%
2	8	12.1%
3	20	30.3%
Missing	3	4.5%
Total	66	100.0%

* Options included designating a health care proxy, completing an advance directive, and completing a will

Table 4. Intercorrelations among Caregiver Burden Scale and Retirement Planning

	1	2	3	4	5	6
1. Time Involved in Caregiving						
2. Emotional Challenges	.03					
3. Physical Health Challenges	.43**	.41**				
4. Challenges to Self-fulfillment	.24	.44**	.67**			
5. Challenges in Social Relationship	.00	.46**	.46**	.62**		
6. Clear View of Financial Future	-.11	-.01	.16	.18	.04	

Note. N=65. **p<.001

Table 5. Intercorrelations among Caregiver Burden Scale and Advance Care Planning Steps

	1	2	3	4	5	6
1. Time Involved in Caregiving						
2. Emotional Challenges	.03					
3. Physical Health Challenges	.43**	.41**				
4. Challenges to Self-fulfillment	.24	.44**	.67**			
5. Challenges in Social Relationships	.00	.46**	.46**	.63**		
6. Total Advance Care Planning Steps (HC proxy, Adv Dir, Will)	.23	.04	.28*	.36**	-.02	

Note. N=65. **p<.001; *p<.05

	Can't Afford		Not Enough Info		Too Healthy	
	n	%	N	%	n	%
Discussed financial planning	25	37.9%	17	25.8%		
Power of attorney	16	24.2%			16	24.2%
Long-term care insurance	26	39.4%	21	31.8%		
Life insurance	20	30.3%	13	19.7%		
Pre-paid for funeral services	28	42.4%		16.7%	24	36.4%
Health care proxy			11	16.7%	16	24.2%
Advance directive			11	22.7%	16	24.2%
Will with executor			15		15	22.7%

Table 7. Intercorrelations among Financial Planning Barriers and Financial Planning Steps

	1	2	3	4	5	6
1. DFP Total Barriers						
2. Fin POA Total Barriers	.65**					
3. LTC Total Barriers	.53**	.58**				
4. Life Insurance Total Barriers	.50**	.50**	.70**			
5. Prepaid Funeral Total Barriers	.61**	.56**	.51**	.40**		
6. Total Fin Plan Steps (DFP, POA, LTC, LI, PPF)	-.64**	-.56**	-.55**	-.61**	-.47**	

Note. $N=65$. ** $p<.001$

Table 8. Intercorrelations among Advance Care Planning Barriers and Advance Care Planning Steps

	1	2	3	4
1. Health Care Proxy Total Barriers				
2. Advance Directive Total Barriers	.86**			
3. Will with Executor Total Barriers	.70**	.77**		
4. Total Adv Care Planning Steps (HC Proxy, Adv Dir, Will w. Ex)	-.64**	-.60**	-.61**	

Note. $N=65$. ** $p<.001$

Table 9
Demographic Profile of Participants Providing Qualitative Responses (N=58)

Characteristics	Categories	<i>n</i>	%
Gender	Male	10	17%
	Female	48	83%
	Total	58	100%
Age Group	18-39	26	45%
	40-59	12	21%
	60-79	13	22%
	80+	5	9%
	Missing	2	3%
	Total	58	100%
Race/Ethnicity	White/Caucasian	40	69%
	White/Caucasian & American Indian	1	2%
	White/Caucasian & Black/African American	1	2%
	White/Caucasian & Hispanic/Latino/a	1	2%
	Black/African American	4	7%
	Black/African American & Hispanic/Latino (a)	1	2%
	Hispanic/Latino (a)	6	10%
	Mixed Race	3	5%
	Prefer Not to Answer	1	2%
	Total	58	100%
Annual Household Income	Less than \$20,000	7	12%
	\$20,000-\$34,999	5	9%
	\$35,000-\$49,999	9	16%
	\$50,000-\$74,999	10	17%
	\$75,000-\$99,000	6	10%
	Over \$100,000	19	33%
	Prefer Not to Answer	2	3%
	Total	58	100%
Relationship to Person With Dementia	Spouse	8	14%
	Son	4	7%
	Daughter	19	33%
	Daughter-in-law	3	5%
	Grandchild	17	29%
	Other	7	12%
	Total	58	100%
Frequency of Providing Care	Daily	23	40%
	3-6 times a week	11	19%
	1-2 times a week	11	19%
	1-2 times a month	9	15%
	Other	4	7%
	Total	58	100%

Table 10
How Life Would Be Different if Loved One Did Not Have Dementia (N=58)

<i>Themes</i>	<i>N</i>	<i>%</i>	<i>Examples</i>
<p>Freedom (Self-care)</p> <p>(Travel, Independence)</p>	<p>25</p>	<p>43%</p>	<p>I'd have more free time to do things for myself and worry about myself. It's not that I have 0 time for myself, but I do spend the free time I have with worry in the back of my mind (Daughter, age unknown).</p> <p>Could plan travel/trips to visit relatives not living in New York. She could continue doing the things that she had talents for and enjoyed (66 yr. old, daughter).</p>
<p>Meaningful Connection</p>	<p>24</p>	<p>41%</p>	<p>We could do many things together and try to live a good life (87 yr. old, husband).</p> <p>My children would have more significant interaction with their grandmother, I'd be able to reminisce with my mother about my childhood, I'd ask more questions about relatives who have passed on, she would still call me on my birthday and sing to me, we'd enjoy mother-daughter things like going to the spa like we used to, holidays would mean more, time spent with her would be less like work and more enjoyable (52 yr. old, daughter).</p>
<p>Emotional & Mental Wellness</p>	<p>18</p>	<p>31%</p>	<p>I would not be as tired and nervous and anxious all the time. I would not be scared every time the phone rings that it is a call saying my sister has passed as she has Lewy Body dementia which is terminal with an 8-year life expectancy range. I would not have relocated to help her and come out of retirement to work part-time to help out financially (67 yr. old, sister).</p> <p>Our family gatherings would be less stressful, but also my parents would be less stressed, too (21 yr. old, grandson).</p>
<p>Present State/Internal Processes: Cognitive Reappraisal/ Active Acceptance</p>	<p>14</p>	<p>24%</p>	<p>I think that many more moments would fly past if my loved one did not have</p>

Positive Emotional Well-being 29 51%
 (Happy, relaxed, comfortable, etc.)

me. I would like my life now to be less stressful and have good health to be able to see my grandchildren grow to adulthood and enjoy them **(87 yr. old, wife)**.

Staying healthy, being able to enjoy seeing my children, grandkids grow and enjoy all things in life, going on vacations and trips with them **(63 yr. old, son)**.

Happy. Healthy. Loving. Warm **(28 yr. old, granddaughter)**.

In my final years, I want to be comfortable and know that my loved ones will be okay without me (financially, emotionally, etc). I don't want to burden anyone, and I hope to feel like I lived a fulfilling life **(20 yr. old, granddaughter)**.

I hope to be able to be calmer in my future years and not so nervous **(67 yr. old, sister)**.

Health & Wellness & Body 23 40%

Just to be in good health and try to (Mind enjoy what they call the golden years-life is not good today **(87 yr. old, husband)**).

Free of dementia, healthy enough to enjoy my family, not to be a burden on my family if I do end up with dementia and need care, my family not to feel guilty about placing me in a residential facility that can care for my particular needs **(52 yr. old, daughter)**.

I would like to be of sound body and mind. I would love to be able to enjoy my daughter and her children should she choose to have any. I would love to be able to travel and be self-sufficient **(53 yr. old, daughter)**.

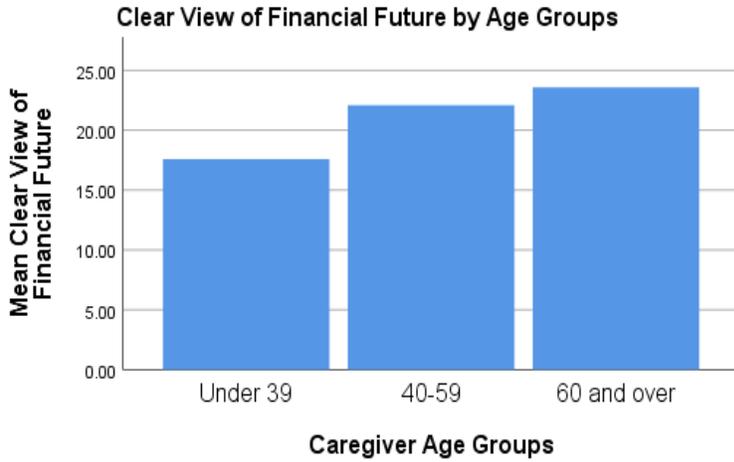


Figure 1. Clear view of the financial future by caregiver age groups.

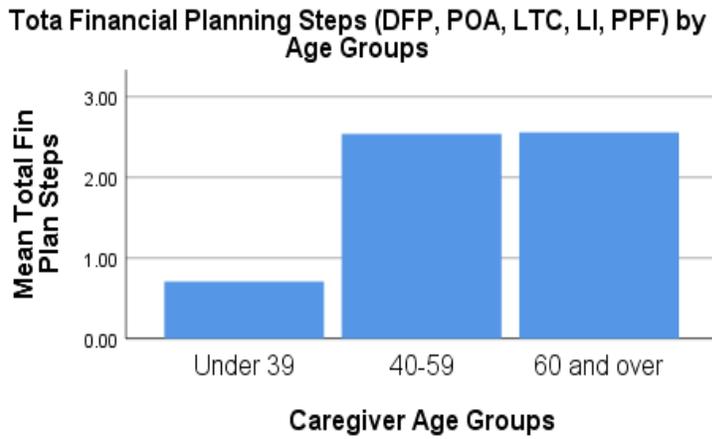


Figure 2. Total financial planning steps by caregiver age groups.

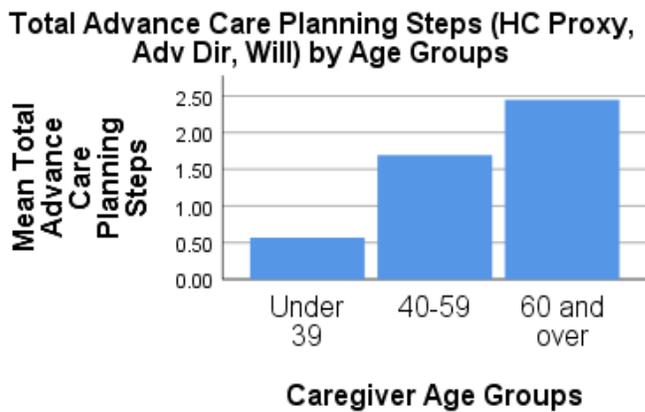


Figure 3. Total advance care planning steps by caregiver age groups.

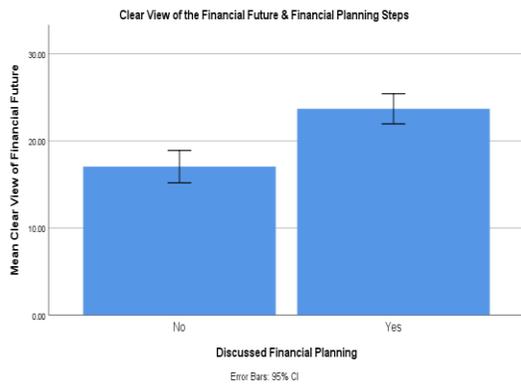


Figure 4. Clear view of the financial future of participants who discussed financial planning.

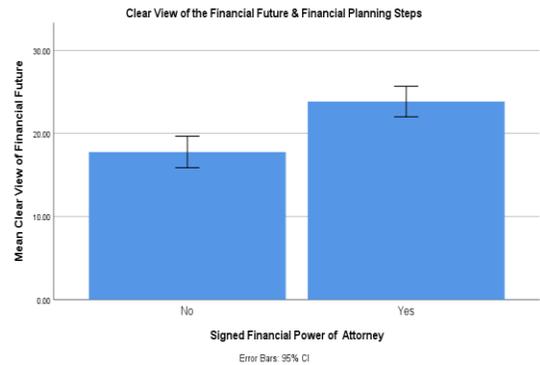


Figure 5. Clear view of the financial future of participants who signed a Power of Attorney.

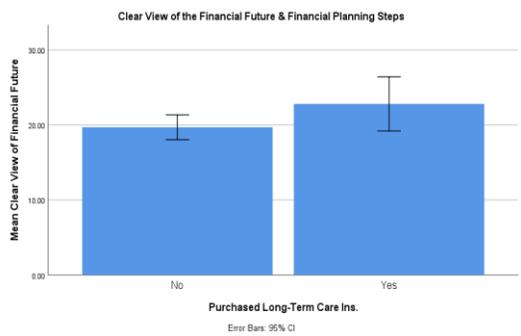


Figure 6. Clear view of the financial future of participants who purchased Long-term care ins.

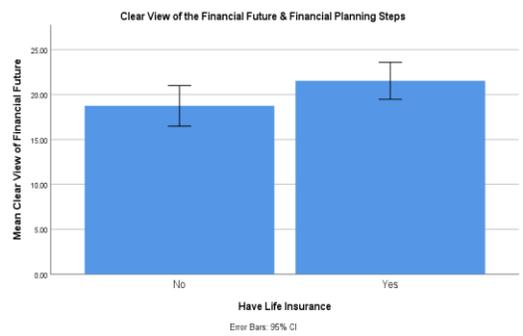


Figure 7. Clear view of the financial future of participants who purchased life insurance.

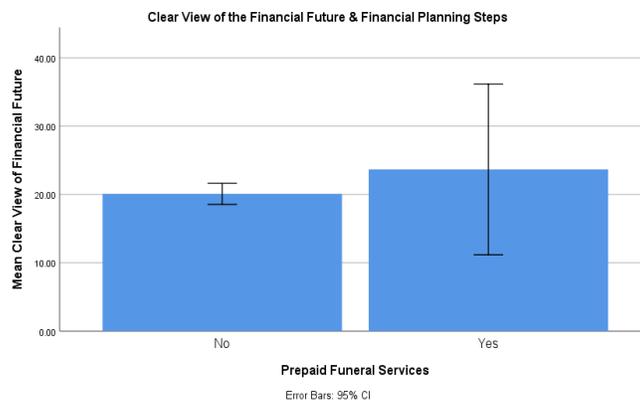


Figure 8. Clear view of the financial future of participants who prepaid for funeral services.

Appendix A
Informal Caregiver Survey
1. How old are you?

2. Gender

Female

Male

Other _____

3. You Identify As

Black/African-American

White/Caucasian

Hispanic/Latino/a

Asian

American Indian

Pacific Islander

Mixed Race

Prefer not to answer

4. What is your annual household income?

Less than \$20,000

\$20,000 to \$34,999

\$35,000 to \$49,999

\$50,000 to \$74,999

\$75,000 to \$99,999

Over \$100,000

5. What is your relationship to the person with Dementia?

Spouse

Son

Daughter

Son-in-law

Daughter-in-law

Other _____

6. Frequency of Providing Care

- Daily
- 3-6 times a week
- 1-2 times a week
- 1-2 times a month
- Other _____

7. As a Caregiver you feel...

Time Dependency Items	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
He/she needs my help to perform many daily tasks					
He/she is dependent on me					
I have to watch him/her constantly					
I have to help him/her with many basic functions					
I don't have a minute's break from his/her chores					

Emotional Health Items	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
I feel embarrassed over his/her behavior					
I feel ashamed of him/her					
I resent him/her					

I feel uncomfortable when I have friends over					
I feel angry about my interactions with him/her					

Physical Health Needs	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
I'm not getting enough sleep					
My health has suffered					
Caregiving has made me physically sick					
I'm physically tired					

Development Items	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
I feel that I am missing out on life					
I wish I could escape from this situation					
My social life has suffered					
I feel emotionally drained due to caring for him/her					
I expected that things would be different at this point in my life					

Social Relationship Items	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
I don't get along with other family members as well as I used to					

My caregiving efforts aren't appreciated by others in my family					
I've had problems with my marriage (or other significant relationship)					
I don't get along as well as I used to with others					
I feel resentful of other relatives who could but do not help					

Financial Planning for Your Own Future

Yes No

8. Are you currently retired?

(skip logic for financial planning questions)

If RETIRED

9. Please rate the degree to which you agree or disagree with the following statements regarding your finances and retirement status

	Strongly disagree	Somewhat disagree	Disagree	Neither agree or disagree	Agree	Somewhat agree	Strongly agree
The financial future seems very vague and uncertain to me							
I pretty much live on a day-to-day basis							
I think a great deal about quality of life in my retirement							

I have met specific goals in saving for my retirement							
I am very knowledgeable about financial planning during my retirement							

If NOT RETIRED

10. Please rate the degree to which you agree or disagree with the following statement regarding financial and retirement planning

	Strongly disagree	Somewhat disagree	Disagree	Neither agree or disagree	Agree	Somewhat agree	Strongly agree
The financial future seems very vague and uncertain to me							
I pretty much live on a day-to-day basis							
I have thought a great deal about quality of life in retirement							
I have set specific goals for how much will need to be saved for retirement							
I am very knowledgeable							

about financial planning for retirement							
---	--	--	--	--	--	--	--

FINANCIAL PLANNING STEPS TAKEN

11. Have you discussed financial planning goals with a professional or benefits specialist? Yes No

(skip logic) IF NO...

You have not discussed financial planning goals with a professional or benefits specialist because...

You think that you are too healthy Yes No

You don't have enough information about your financial planning choices

Discussing financial planning goals would make you sad, nervous, or depressed

You can't afford it at this time

You don't know what financial Planning is

Are there any other reasons? _____

12. Have you signed official papers naming a person or group of people to make financial decisions for you (Power of Attorney)? Yes No

(skip logic) IF NO...

You have not signed official papers granting someone Power of Attorney because...

You think that you are too healthy Yes No

You don't have enough information about your legal choices

Filling out would make you sad, nervous, or depressed

You can't afford it at this time

You don't know what a Power of Attorney is

Are there any other reasons? _____

13. Have you purchased Long-Term Care insurance for any future care needs? **Yes** **No**

(skip logic) IF NO...

You haven't purchased Long-Term Care insurance because...

You think that you are too healthy **Yes** **No**

You don't have enough information about your health or choices for care

Purchasing a policy would make you sad, nervous, or depressed

You can't afford it at this time

You don't know what Long-Term Care insurance is

Are there any other reasons? _____

14. Do you have life insurance coverage? **Yes** **No**

(skip logic) IF NO...

You do not have life insurance because...

	Yes	No
You think that you are too healthy	<input type="checkbox"/>	<input type="checkbox"/>
You don't have enough information regarding various policies offered	<input type="checkbox"/>	<input type="checkbox"/>
Purchasing a policy would make you sad, nervous, or depressed	<input type="checkbox"/>	<input type="checkbox"/>
You can't afford it that this time	<input type="checkbox"/>	<input type="checkbox"/>
You don't know what life insurance is	<input type="checkbox"/>	<input type="checkbox"/>
Are there any other reasons? _____		

	Yes	No
15. Have you already prepaid for your funeral?	<input type="checkbox"/>	<input type="checkbox"/>

(skip logic) IF NO...

You have not prepaid for your funeral because...

	Yes	No
You think that you are too healthy	<input type="checkbox"/>	<input type="checkbox"/>
You don't have enough information regarding funeral packages	<input type="checkbox"/>	<input type="checkbox"/>
Prepaying for your funeral would make you sad, nervous, or depressed	<input type="checkbox"/>	<input type="checkbox"/>
You can't afford it that this time	<input type="checkbox"/>	<input type="checkbox"/>
You don't know what a prepaid funeral is	<input type="checkbox"/>	<input type="checkbox"/>
Are there any other reasons? _____		

ADVANCE CARE PLANNING STEPS TAKEN

Yes No

16. Have you signed official papers naming a person or group of people to make medical decisions for you (Health care proxy, Medical Power of Attorney)?

(skip logic) IF NO...

You have not signed official papers naming someone as your medical decision maker because...

You think that you are too healthy **Yes** **No**

You don't have enough information about your health or choices for care

Filling out would make you sad, nervous, or depressed

You don't know what a Health Care Proxy or Medical Power of Attorney is

Are there any other reasons?_____

Yes No

17. Have you signed official papers to put your wishes in writing about whether or not certain health situations would make your life not worth living? These forms are sometimes called an advance directive or living will.

(skip logic) IF NO...

You haven't filled out an advance directive form or living will because...

You think that you are too healthy **Yes** **No**

You don't have enough information about your health or choices for care

Filling out would make you sad, nervous,

or depressed

You don't know what an advance directive or living will is

Are there any other reasons? _____

18. Do you have a will with an executor?

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

(skip logic) IF NO...

You do not have a will with an executor because...

You think that you are too healthy

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

You don't have enough information about will planning

Making one would make you sad, nervous, or depressed

You don't know what a will with an executor is

Are there any other reasons? _____

The final questions can be answered in any way that is meaningful to you. Please answer in as much detail as you can.

19. Take a moment to think about your life living with a loved one who has dementia. Describe all the ways in which your life would be different if your loved one did not have dementia.

20. Now I'd like you to think about your own future and the things in life that are most important to you. Describe what you would like your life to be like in your final years.
