THE RELATIONSHIP BETWEEN CAREGIVER BURDEN AND PARTICIPATION IN SOCIAL ENGAGEMENT ACTIVITIES IN OLDER ADULT CAREGIVERS OF PERSONS WITH DEMENTIA

BY

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THESIS

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ABSTRACT

There are over 55 million individuals with dementia around the world who are supported by a caregiver at some stage. Most persons with dementia (PwD) are cared for by a family member or a friend, referred to as informal caregiver. Thirty percent of these caregivers are over the age of 65 and take on additional responsibilities as the needs of the person they are caring for increase leading to caregiver burden. As the burden of caregiving increases, caregivers experience physical, cognitive, emotional, and social health problems. Social engagement can be a mediating factor to lower caregiver burden and associated health issues; however, there is a paucity of literature on the links between social engagement and caregiver burden especially in older caregivers. Therefore, this study characterized social engagement activities of older adult caregivers of PwD and examined the relationship between caregiver burden and social engagement. Participants included 30 informal caregivers of PwD over the age of 60. These caregivers were recruited from a larger intervention study on social engagement. Data obtained at baseline were used for the purposes of this study. The caregivers completed a comprehensive online assessment that included participant characterization measures, caregiver-related measures, social engagement measures, and a social activity related interview. Results revealed moderate degree of loneliness on the UCLA loneliness scale and a high degree of social isolation on the Friendship scale. Overall, caregivers participated less frequently in group social activities although they rated it as their favorite. Serving as a caregiver for more than 5 years was significantly correlated with loneliness and social isolation. Furthermore, higher caregiver burden was associated with higher levels of social isolation. Healthcare professionals should not only learn about the impact of caregiver burden on social health of caregivers but should educate

caregivers on the importance of finding ways to connect with others socially to minimize the negative impact on their health and well-being.

ACKNOWLEDGMENTS

I would like to thank Elizabeth Lydon, Vincent Mathias, Summer Xia Yu and the Aging and Neurocognition Laboratory for all their help and support during the completion of this thesis. I would also like to thank the RRF Foundation for Aging Grant #2021050 for funding this work.

To my mentor Dr. Raksha Mudar and the Aging and Neurocognition Laboratory

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CHAPTER 1: INTRODUCTION

The health issues faced by caregivers of persons with dementia (PwD) are significant worldwide. There are over 55 million PwD around the world. These individuals are supported by a caregiver at some point (Dementia, 2023). These caregivers are either formal caregivers or informal caregivers. Formal caregivers are professionals who provide care at a cost to PwD (e.g., social workers, therapists, registered nurses). Informal caregivers are family members and friends who provide unpaid care and support to PwD. In the United States alone there are over 11 million informal caregivers providing care to PwD (Alzheimer's Disease Facts and Figures, 2023). Thirty percent of these informal caregivers are over the age of 65 and two in three are women (Alzheimer's Disease Facts and Figures, 2023; Rabarison et al., 2018). Caregiving can be a full-time job with an informal caregiver providing care for an average of 30 hours per week for a total lifetime cost of care of $329,874 (Alzheimer's Disease Facts and Figures, 2023; Jutkowitz et al., 2017).

The number of informal caregivers (henceforth referred to as caregivers) is expected to grow in the US given that the number of people with Alzheimer's disease dementia will reach 13.8 million by 2060 (Rajan et al., 2021). These caregivers play a vital role in providing collaborative care offered by rehabilitation professionals including speech-language pathologists (SLPs) to support aging in place for PwD. Involving caregivers in a patient-centered approach of care is critical. However, it is also important to provide direct support and education to these caregivers given the health consequences these individuals face. For instance, SLPs could educate caregivers on communication strategies (e.g., offering choices, using visuals cues) to improve communication between the caregivers and their care recipients (Bourgeois et al., 2019;

Zientz et al., 2007). Additionally, they can counsel caregivers on approaches to minimize burden associated with caregiving. SLPs are now able to bill Medicare, as of 2024, without the care recipient's presence. This allows opportunities for more direct collaboration to provide high quality of care not only to PwD but also to their caregivers thereby maximizing outcomes (American Speech-Language-Hearing Association, 2023).

Typically, the role of caregiving is taken on by family members or friends before professional caregivers get involved. These caregivers help with activities of daily living (ADLs) such as bathing and dressing (Amato et al., 2021; Balbim et al., 2020; Huang, 2022) and instrumental activities of daily living (IADLs) such as household chores, shopping, providing transportation (Huang, 2022; Lin et al., 2019) and medication management (Balbim et al., 2020; Chiao et al., 2015; Gillespie et al., 2014). In addition, caregivers participate with their relatives in enhanced activities of daily living (EADLs). These activities include leisure activities such as reading, shopping, and volunteering that enhance quality of life (Rogers et al., 1998; Rogers et al., 2020). Caregivers who reside with their care recipients spend the majority of their time at home to ensure the safety of their family members (Nguyen et al., 2020; Nordtug et al., 2021). Often communication between the caregiver and the care recipient can be difficult leading to communication breakdowns and frustration (Hammar et al., 2021). Some may also care for other members of their family (e.g., children), which adds to their stress (Withers et al., 2021). Caregivers take on new roles as the needs of the person they care for increases, leading to increasing caregiver burden.

Caregiver burden is defined as having multiple responsibilities, lack of social activities, and inadequate financial resources (Liu et al., 2020). Neurobehavioral symptoms in PwD such as wandering (Chiao et al., 2015; Grabher, 2018), agitation, aggression (Teri et al., 1992), and

delusions (Chiao et al., 2015; Huang, 2022) can lead to increased caregiver burden especially in older adult caregivers (Tsai et al., 2021; Wang et al., 2022). Additionally, disruptive symptoms in the person they are caring for like irritability and destructiveness are associated with greater stress (Roberto et al., 2019; Zauszniewski et al., 2018). Caregivers caring for older PwD (i.e., > 85 years) experience greater levels of burden and personal strain compared to those caring for a younger PwD (i.e., < 85 years) (Win et al., 2017). Caregiver burden increases overtime (Brodaty et al., 2014; Kim et al., 2012) as caregivers are often not receiving services or support to assist them (Connors et al., 2020). Older adult and spousal caregivers are at an increased risk of caregiver burden (Tulek et al., 2020). With dementia progression, the burden on caregivers increases leading to various health problems (Amato et al., 2021; Chiao et al., 2015; Shulz & Sherwood 2008).

Impact of Caregiving on Health

Physical Health

Increasing caregiver burden impacts the physical health of caregivers. Caregiving can disrupt the sleep cycle causing insomnia and sleep deprivation (Goren et al., 2016; Lippe et al., 2021; Mwendwa et al., 2021). Decreased sleep can lead to multimorbidity including hypertension, heart disease, and diabetes (Liang et al., 2020). In addition, caregivers may need to respond to disruptive behaviors and use their physical strength to move their care recipient or keep the care recipient safe from falls or injuries (Marziali & Garcia, 2011). Spousal caregivers self-reported their health as being poorer with a greater number of years of care provided (von Känel et al., 2019). Given that older adults are already at an increased risk of experiencing chronic health conditions such as dementia (Lopez et al., 2019), heart disease (Khan et al., 2014), diabetes (Sloan et al., 2008), and cancer (Centers for Disease and Prevention 2022; Cinar & Tas,

2015), older caregivers may experience a greater harm to their physical health compared to non-caregivers (Pinquart & Sörensen, 2003).

Cognitive Health

The cognitive health of caregivers is impacted by the level of stress experienced by these individuals. According to Pearlin et al. (1990), primary stressors in caregivers can be categorized into objective and subjective stressors. Objective stressors include the cognitive status of the care recipient, the level of assistance the care recipient needs with ADLs and IADLs, including medication management (Polenick et al., 2018), and the care recipients' behaviors. Subjective stressors include caregiver burnout and the change in relationship between the caregiver and care recipient. Elevated level of stress leads to a decrease in cognitive function in caregivers (Fonareva & Oken, 2014). It has been found that caregivers of PwD perform worse on speed of processing, executive functioning, and delayed verbal recall tasks compared to age-matched controls (de Vugt et al., 2006; Oken et al., 2011; Mallya & Fiocco 2018). There is additional research to suggest that spousal caregivers are at an increased risk of developing dementia compared to their non-caregiving peers (Dassel et al., 2017; Norton et al., 2010; Wu-Chung et al., 2022) with advanced age as an additional factor (Jeffers et al., 2021; Miyawaki et al., 2020).

Emotional Health

Over 40 percent of caregivers exhibit anxiety symptoms, assessed by questionnaires and inventories (Sallim et al., 2015). Caregivers do not usually have formal training to care for their relatives which can create anxiety about their capabilities (Kontrimiene et al., 2021). They may be anxious about their future and the cognitive decline of their care recipient (Goren et al., 2016; Greenwood et al., 2019) and may not have the proper knowledge to provide care (Kontrimiene et al., 2021; Mwendwa et al., 2021). Caregivers are also more likely to experience depression

(Peavy et al., 2022). In particular, caregivers are at risk of feeling depressed and anxious when the person they are caring for exhibits symptoms of agitation, hallucinations and irritability (Wang et al., 2022). Liu (2021) found that spousal caregivers have significantly higher levels of burden and depressive symptoms compared to adult children caring for a parent with dementia.

Social Health

Caregivers are more likely to experience loneliness and are socially isolated given the number of hours they spend providing care each day (Mwendwa et al., 2021; Peavy et al., 2022; Xu et al., 2022). Social engagement, defined as maintaining social connections and participating in social activities (Bassuk et al., 1999), is critical for maintaining social health. Caregivers are less socially engaged with their care recipient, especially as the symptoms of dementia worsens (Peavy et al., 2022). Furthermore, caregivers lose social interactions with others in their community (Waligora et al., 2019) due to their caregiving responsibilities. Hammar et al. (2021) found that older adult spousal caregivers reported wanting to belong and had an overall feeling of loneliness. They felt that they lacked the knowledge to care for their spouse.

Social engagement is important for maintaining quality of life (Delmelle et al., 2013) and may help mitigate negative health outcomes (Xu, et al., 2022). Social engagement can be a mediating factor to lower caregiver burden (Yu et al., 2015). In a recent paper, a framework of social engagement was offered that consists of two domains, social activity and social network (Lydon et al., 2022). Social activity is participation in a task that involves engaging with others. Social network refers to relationships or social connections in one's life. Lydon et al. propose that different contextual factors (e.g., age, race, and environment) as well as health factors (e.g., physical, emotional and cognitive) affect an individual's social activities and social networks.

Research shows that caregiving impacts both social activity and social network contributing to the social health issues in caregivers of all ages (Liu et al., 2021).

There is evidence to suggest that a strong social support network is linked to lower caregiver burden (Socci et al., 2021) and lower levels of depression (Park et al., 2021). The size and structure of the social network differs based on the demographics of the caregiver (Friedman & Kennedy, 2021). Wang et al. (2022) found that spousal caregivers reported weaker social networks when compared to older adult children who care for their parents. Furthermore, in older caregivers, a smaller social network was associated with greater caregiver burden (Keller et al., 2003). In some cases, older adult caregivers do not seek support from their social networks because they want to protect the privacy of the person they are caring for and do not want to burden others in their social network (Dam et al., 2018). Song et al. (2023) conducted a survey of older adult caregiver network properties and caregiver health outcomes. They found that the density of social network was linked to financial hardship.

In addition to the size and density of the social network, the frequency of contact with the network is also an important factor. Park et al. (2021), found that caregivers who had greater frequency of contact with their support network reported lower levels of depression when measured on a 5-point scale (1 = more than once a week, 2 = about weekly, 3 = a few times a month, 4 = monthly, and 5 = less than monthly). However, the type (e.g., talking on the phone, meeting in person) of contact that the caregivers have with their social network and the activities they engage in is not fully understood.

Studies have shown that engaging in social activities can help caregivers create new connections with others contributing to a higher quality of life (Anderson et al., 2017; Morris et al., 2021). There is some evidence to suggest that the needs of male and female caregivers in

terms of social engagement can vary (Lee et al., 2020). Male caregivers who are engaged in satisfying leisure activities show reduced risk of depressive symptoms compared to female caregivers. Female caregivers demonstrate a need for emotional support in addition to higher frequency and satisfaction of the leisure activities (Lee et al., 2020). In a semi-structured interview, Xu et al. (2022) explored the perceptions caregivers had on participating in leisure activities. They found that caregivers participate in leisure activities (e.g., play on mobile phone or tablet devices, watch TV etc.) alone rather than with others. In a recent study, researchers found engaging in a social activity with their care recipients (e.g., attending a community dance class) offered caregivers respite and an increase sense of connectedness (Petts & Urmston 2022). The studies that have explored social activities in caregivers have included caregivers of all ages. Whether the needs of older adult caregivers are different from younger caregivers, given their unique challenges, is not well understood. Also, currently, there is more work surrounding social networks in older adult caregivers rather than the type of social engagement activities they engage in and how it is related to caregiver burden. The goal of my study was to address these gaps in literature.

Study Goals

The overarching goals of this study were to:

(1) Characterize the social engagement activities of older adult caregivers of PwD and examine how engagement varies with time spent caregiving (hours, years) and relationship.

(2) Examine the relationship between caregiver burden and social engagement.

Hypotheses

(1) Social engagement will be negatively impacted with more time spent caregiving and in spousal caregivers.

(2) Increased caregiver burden will be related to increased social isolation and perceived loneliness. This relationship may be impacted by caregiving characteristics (e.g., number of hours of caregiving, age, or relationship).

CHAPTER 2: METHODS

Participants

Participants included 30 informal caregivers of PwD, recruited online through caregiver registries, community outreach, brochures, newsletters, and social media as part of a caregiver intervention study. These 30 caregivers were chosen from a larger intervention study on social engagement. These 30 caregivers were the first to enroll in the larger study. Baseline assessment data from a subgroup of these caregivers will be examined for the purposes of this study.

All 30 caregivers in this subgroup were (i) 60 years or older, (ii) cared for a relative with Alzheimer's disease or other dementia for at least three months, and (iii) fluent English speakers with normal or corrected vision. They were proficient with and had access to a tablet/computer with a camera and had a reliable Wi-Fi connection. Participants who reported a diagnosis of mild cognitive impairment, dementia, other neurologic conditions (e.g., Parkinson's disease), chronic illness (e.g., heart failure), or other major mental health issue (e.g., chronic depression) were excluded.

Procedures

All caregivers underwent a phone screening to determine eligibility for the study. Eligible participants completed a comprehensive assessment online that included participant characterization measures, caregiver-related measures, and social engagement measures.

Participant Characterization Measures

Modified TechSAge background questionnaire (Remillard et al. 2020): Modified TechSAge background questionnaire was used to gather information about demographic, caregiving details, housing and transportation, occupational status, health information, vision, and hearing.

Montreal Cognitive Assessment (MoCA) (Nasreddine et al. 2005): The MoCA is a validated measure for cognitive screening. The MoCA was used for global cognitive screening. An education-adjusted score of 26 and above indicates normal cognition.

Cognitive Functioning Self-Assessment: The cognitive functioning self-assessment is a tool that has been developed in the Aging and Neurocognition Lab. The cognitive functions are self-assessed in the context of daily activities, including attention, word retrieval, comprehension, decision making, task switching, and memory.

Geriatric Depression Scale (GDS) (Almeida & Almeida 1999): The GDS is a validated tool used to screen for mood alterations. There are 15 total questions scored on a scale of 0 to 1. Higher scores indicate higher levels of perceived depression. A score of 0 to 4 is considered normal, a score of 5 to 8 is suggestive of mild depression, a score of 9 to 11 is suggestive of moderate depression and a score of 12 to 15 is suggestive of severe depression.

Caregiver-related Measures

Family Caregiver Identity Scale (FCIS) (Eifert et al. 2021): The FCIS is an assessment tool used to examine the identity of a family caregiver related to five domains including role engulfment and loss of self, loss of shared identity, family obligation and gender norming, extension of former role, and master identity. There are 18 total questions, rated on a scale of 1 to 4 with a maximum score of 72. A higher FCIS score indicates a higher level of caregiver identity.

Perceived Stress Scale (PSS) (Cohen et al 1983): The PSS is a scale used to measure the stress levels in adults related to life events. There are 10 total questions scored on a scale of 0 to 4. Four questions used reverse scoring where a score of 0 equals a 4. Higher scores indicate

higher levels of perceived stress. A score of 0 to 13 indicates low stress, scores between 14 to 26 indicates moderate stress, scores between 27 to 40 indicates high stress.

Zarit Burden Interview (ZBI) (Zarit et al. 1980): The ZBI is a shortened version of the original Zarit burden interview measure. The ZBI is a 22-item survey that measures factors associated with burden which include social health, care recipient dependence on caregiver and other factors. The items are scored on a scale of 0 to 4 with a maximum score of 88. A score between 0-21 indicates little or no burden, a score between 21-40 indicates mild to moderate burden, a score between 41-60 indicates moderate to severe burden and a score between 61-88 indicates severe burden. Higher scores on the ZBI indicate higher perceived levels of burden.

Positive Aspects of Caregiving (PAC) (Tarlow et al. 2004): The positive aspects of caregiving scale is a validated and reliable measure to assess the positive aspects of caring for an individual with dementia. The questions assess feelings of usefulness, importance, and appreciation in caring for an individual with dementia. This assessment includes 9 items that are scored on a scale of 1 to 5 with a maximum score of 45. Higher scores indicate a higher perceived positive view of caregiving.

Quality of Life - AD (QoL-AD) (Logsdon et al. 2002): The QoL-AD is used to assess factors such as physical health, emotional health, and other aspects relating to quality of life. This measure was developed specifically for individuals with cognitive impairment. There are 13 total questions scored on a scale of 1 to 4 with a maximum score of 52. Higher scores indicate higher levels of perceived quality of life.

Social Engagement Measures

UCLA Loneliness Scale – Version 3 (Russell 1996): The UCLA Loneliness Scale – Version 3 is a reliable and validated assessment tool that has been simplified since its previous

versions to measure loneliness. There are 20 total questions scored on a scale of 1 to 4 with a maximum score of 80. A higher UCLA loneliness score indicates a higher level of loneliness.

Friendship Scale (FS) (Hawthorne 2006): The FS is a brief scale that measures the level of social connection in older adults within the past four weeks. The FS consists of 6 items that are scored on a scale of 1 to 4 with a maximum score of 24. Higher scores indicate greater social isolation.

Social Activity Questionnaire (SAQ) (Rogers et al. 2021): The SAQ is a measure that was developed for the Enhancing Neurocognitive Health, Abilities, Networks, and Community Engagement (ENHANCE) study. ENHANCE is a multidisciplinary research center funded by National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) that is dedicated to understanding the challenges and to develop potential technology solutions to support and enhance the independence and community living experiences of older adults with cognitive impairment. There are ten different activities listed that require varying degrees of social interaction. Participants are asked to rate how often during the past year they engaged in each of the activities. The items are scored using a 5-point Likert scale ranging from 1 to 5 with a maximum score of 50. Higher scores indicate greater frequency of social participation.

Social Activity Questionnaire Related Interview

Caregivers also completed a semi-structured interview related to their participation in social activities that was specifically developed for the purposes of this thesis. The *Social Activity Questionnaire Interview* portion was developed to obtain additional information about social activities pursued by caregivers using a semi-structured interview format. The questions for this interview were iteratively revised based on feedback from an expert on caregiving and an expert on dementia. The interview questions were developed to examine both the activities that

caregivers enjoy and the ones they least enjoy. Caregivers were first shown a list of social activities from the social activity questionnaire (See Box 1). Participants were then asked follow-up questions listed in Box 2.

Box 1.

Social Activities Presented

Social Activities:

- Attend a class (training, education, exercise)
- Participate in a club or other social, recreation, or community group
- Visit relatives' or friends' houses
- Talk on the phone
- Go on day trips or overnight trips with others
- Go out to a move, restaurant, or sporting event
- Engage with others over technology (sending email, Facebook, Zoom etc.)
- Attend religious meetings or services
- Unpaid community or volunteer work
- Paid work in the community

Frequency

- Once a year or less
- Several times a year
- Several times a month
- Several times a week
- Every day or almost every day

Box 2.

Social Activity Interview Questions

1. Of the activities you do, which activity is your most favorite?
    a. Who do you participate in this activity with?
    b. What aspect of the activity do you like the most?
    c. How often do you engage in this activity?
    d. How do you generally feel after engaging in this activity?
2. Of the activities you do, which activity is your least favorite?
    a. Who do you participate in this activity with?
    b. What aspect of the activity do you like the most?
    c. How often do you engage in this activity?
    d. How do you generally feel after engaging in this activity?

Transcription Procedures

The participant responses to the social activity interview questions were audio recorded. The audio recordings were uploaded to an automated transcription software (i.e., Otter.ai) and subsequently checked manually to ensure accuracy.

Analysis Procedures

To test hypothesis one, descriptive statistics related to demographics and responses provided on social engagement measures were examined. Content analysis was completed to analyze the social activity transcriptions by coding and categorizing the main themes in the data. To test hypothesis two, Pearson correlations were used to examine the associations between burden and social engagement measures. To examine how different caregiving characteristics (hours, years, and relationship) affected social engagement, within-group correlations were carried out. Groups were defined based on number of hours providing care (less than 20 hours/more than 20 hours), number of years providing care (more than 5 years/less than 5 years) and relationship to the caregiver (spousal/non-spousal).

CHAPTER 3: RESULTS

Participant characteristics

A total of 30 caregivers of PwD (24 female with average age of 67 ± 6.5 years and average years of education was 16 ± 2.1) were included in the study. The caregivers reported an average GDS score of 3.1 ± 3.3 and had an average MoCA score of 27 ± 2.0. Participation characteristics are shown in Table 1. Additional details related to participant characteristics are represented in Figures 1-6.

Table 1.

Participant Characteristics (n = 30)

†Demographics	
Number of participants	30 (24F)
Age (yrs)	67 ± 6.5
Education (yrs)	16 ± 2.1
†Participant Characterization	
Geriatric Depression Scale	3.1 ± 3.3
Montreal Cognitive Assessment	27 ± 2.0
**Relationship to care recipient*	
Spouse	13%
Parent or In-law	50%
Sibling	3%
Other	33%
**Hours providing care*	
0-10	13%
11-20	27%
21-30	3%
31-40	33%

Table 1 (cont.)

41+	23%
**Years providing care*	
1-3	13%
3-5	43%
5+	43%

†Cells represent mean ± SD; * percent of participants for demographics

Figure 1.

Age Distribution

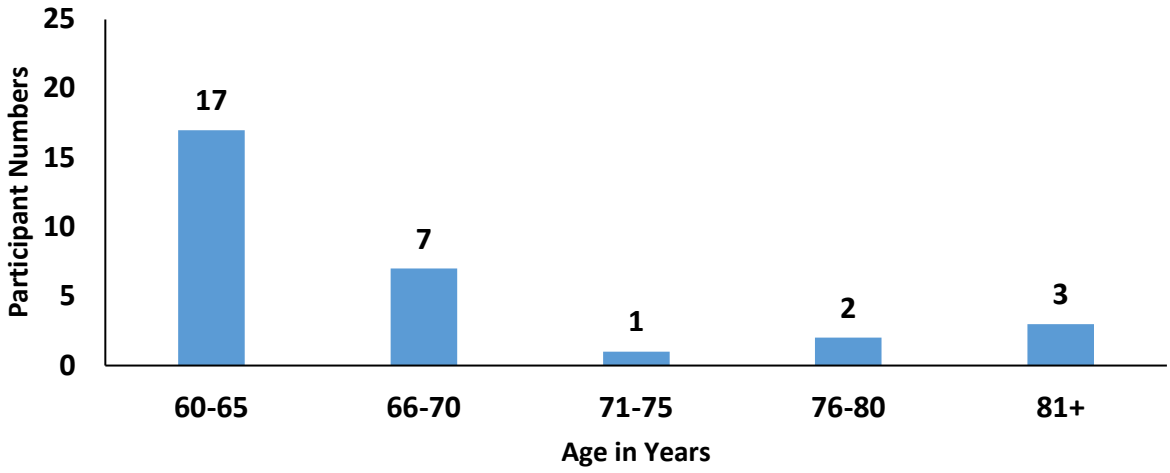


Figure 2.

Level of Education

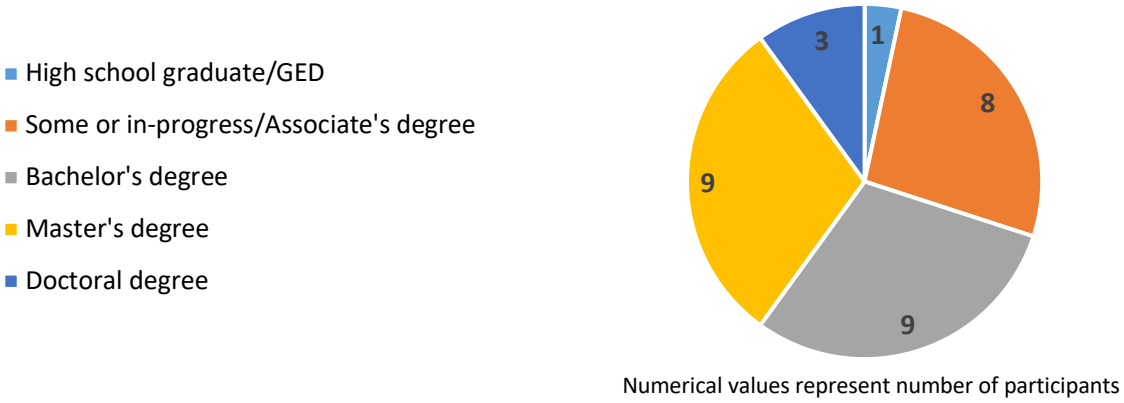


Figure 3.

Relationship to Care Recipient

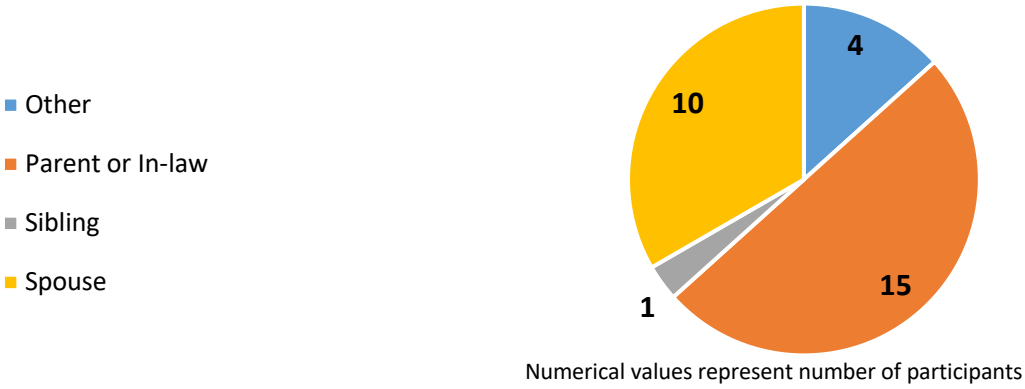


Figure 4.

Number of Years Providing Care

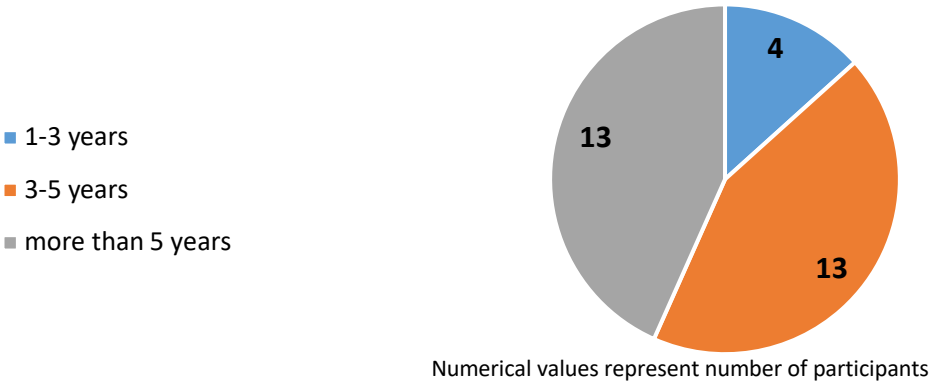


Figure 5.

Number of Hours per Week Providing Care

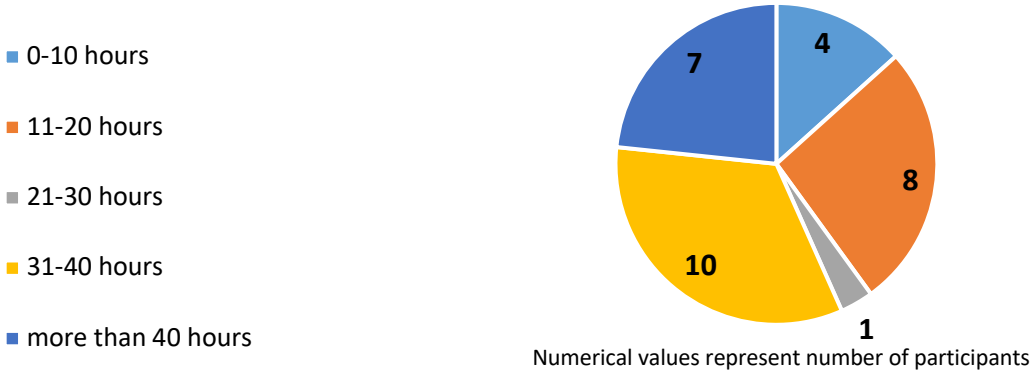
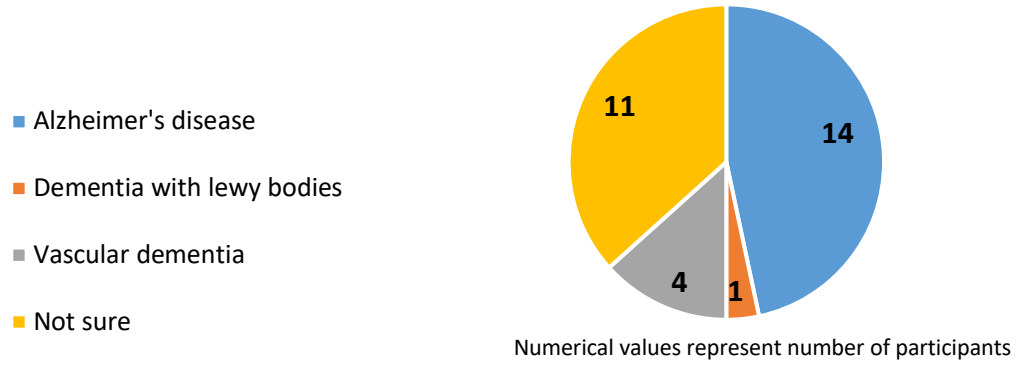


Figure 6.

Care Recipient Dementia Subtype

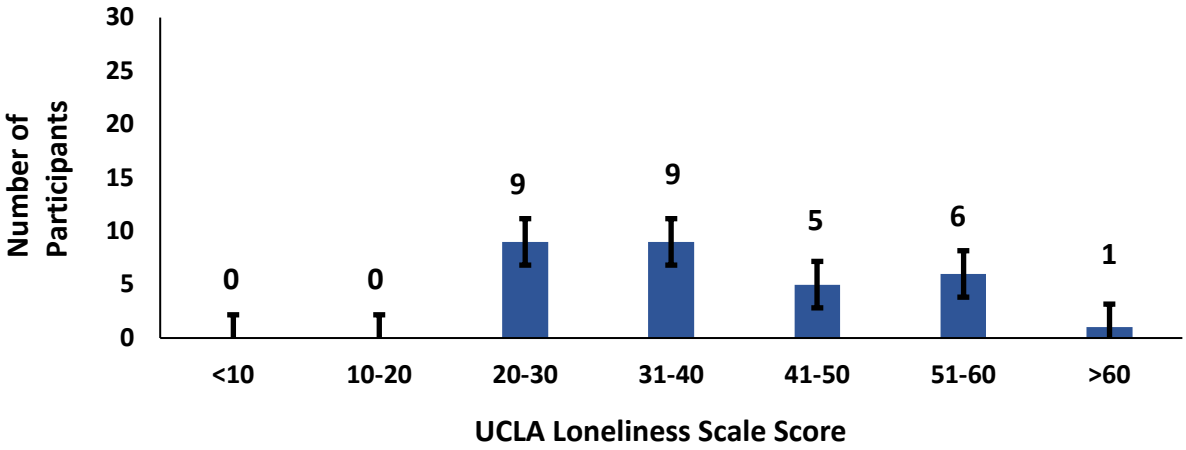


Social Engagement Measures

Caregivers had an average score of 39 ± 12 on the UCLA Loneliness Scale and 19 ± 4.0 on the Friendship Scale. Distribution of scores across participants are illustrated in Figures 7 and 8. Within the social activity questionnaire, caregivers had an average score of 24.4 ± 5.1. The two top activities that they reported doing once a year or less were attending religious meetings or services and doing paid work in the community. They reported visiting a relatives' or friends' house and going on day trips or overnight trips with others as their top two activities several times a year. In addition to going out to a movie, restaurant, or sporting event, they reported frequently attending religious meetings or services, and visiting a relatives' or friends' house several times a month. They reported that they frequently participated in a club or other social, recreational, or community group, talking on the phone, and engaged with others over technology several times a week. Every day or almost every day they reported talking on the phone and engaging with others over technology. Additional responses to social activity questions are shown in Table 2.

Figure 7.

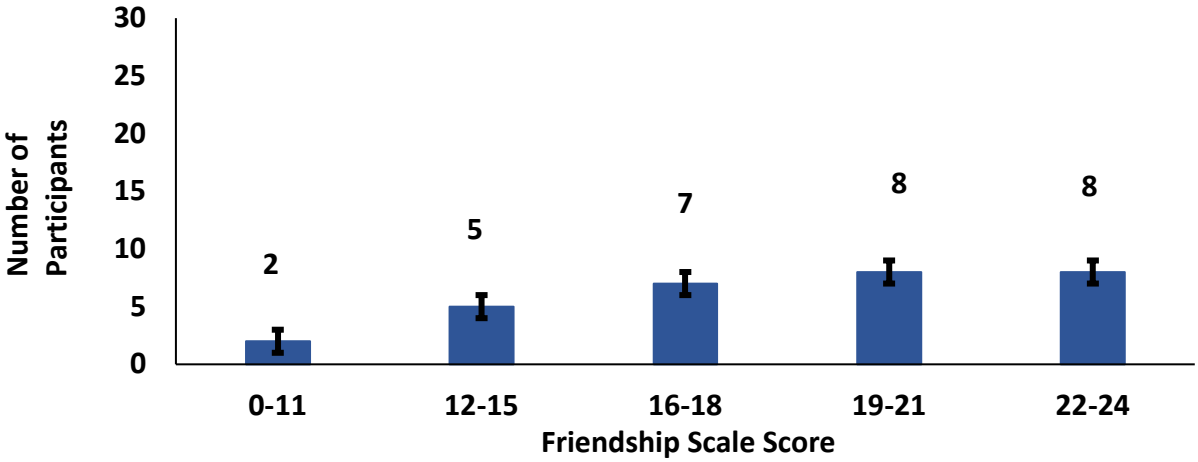
UCLA Loneliness Scale Score Distribution



Loneliness Classification: Low = 20-34; Moderate = 35-49; Moderately High = 50-64; High = 65-80

Figure 8.

Friendship Scale Score Distribution



Friendship Scale Classification: Very socially isolated = 0-11; Isolated = 12-15; Some social support = 16-18; Socially connected = 19-21; Very socially connected = 22-24

Table 2.

Responses to Social Activity Questions

	Most frequent activity	**Second most frequent activity**
Once a year or less	Do paid work in the community (80%)	Attend religious meetings or services (53%)
Several times a year	Visit a relatives' or friends' house (63%)	Go on day trips or overnight trips with others (50%)
Several times a month	Go out to a movie, restaurant, or sporting event (33%)	(i) Visit a relatives' or friends' house (27%) (ii) Attend religious meetings or services (27%)
Several times a week	Talk on the phone (27%)	(i) Participate in a club or other social, recreational, or community group (20%) (ii) Engage with others over technology (20%)
Every day or almost every day	(i) Talk on the phone (50%) (ii) Engage with others over technology (50%)	Participate in a club or other social, recreational, or community group (7%)

Note: numbers within parentheses represent % of participants who choose the activity

Content Analysis of the Interview Data Related to Social Activities

Older adult caregivers reported that their three favorite social activities to participate in were (i) participating in a club or other social, recreational, or community group, (ii) visiting a relatives' or friends' house, and (iii) going on a day trip or overnight trip with others. Details of the frequency of chosen activities are listed in Table 3. They reported that the connection, new learning, and laughing associated with these activities are what they enjoyed. Caregivers mentioned that they participated in their favorite activities with family and friends. After participating in their favorite activities, they reported feeling energized, refreshed, and accomplished. Caregivers mentioned that they felt a "sense of accomplishment", "refreshed, renewed, full of energy", "rejuvenated and just grateful", and "always have a fun time and yeah, always feel really good". Caregivers reported their least favorite social activities related to attending religious meetings or services, followed by engaging with others over technology and talking on the phone. After participating in their least favorite activities, they reported feeling frustrated, exhausted, and anxious to get home due to obligation, difficulties with technology, and anxiety from the activity. Caregivers mentioned that they felt "down", "depressed", "frustrated". Caregivers also mentioned that when using technology to communicate they felt "it is nice, but … things can actually be misinterpreted".

Table 3.

Frequency of Most Favorite and Least Favorite Social Activity

Social Activity	Favorite	Least Favorite
Attend a class	10%	3%
Participate in a club or other social, recreational, or community group	23%	3%
Visit a relatives' or friends' house	17%	10%
Talk on the phone	0%	13%
Go on day trips or overnight trips with others	17%	3%
Go out to a movie, restaurant, or sporting event	10%	3%
Engage with others over technology	10%	13%
Attend religious meetings or services	7%	40%
Do unpaid community or volunteer work	7%	3%
Do paid work in the community	0%	7%

The shaded cells above represent the top three activities that the caregivers listed as their favorite and least favorite activities.

Relationship between Social Engagement and Caregiving Characteristics

When different caregiving characteristics (hours, years, and relationship) were examined in relation to social engagement using within-group correlations while controlling for age, only serving as a caregiver for more than 5 years was significantly correlated with the UCLA loneliness score and the FS score (See Table 4).

Table 4.

Correlations between Social Engagement Measures and Caregiving Characteristics

	Hours		Years		Relationship	
	< 20 n = 12	> 20 n = 18	< 5 n = 17	> 5 n = 13	Spousal n = 10	Non-Spousal n = 20
Social-Engagement						
UCLA Loneliness Scale	r = -.01 *p* = .97	r = .30 *p* = .25	r = -.13 *p* = .63	r = .62* *p* = .03	r = .26 *p* = .50	r = .20 *p* = .41
Friendship Scale	r = -.32 *p* = .35	r = -.41 *p* = .11	r = -.17 *p* = .53	r = -.72* *p* = .01	r = -.28 *p* =.47	r = -.43 *p* = .07
Social Activity Questionnaire	r = -.20 *p* = .55	r = -.23 *p* = .37	r = .06 *p* = .84	r = -.49 *p* = .11	r = -.15 *p* = .70	r = -.29 *p* = .22

**p*-value <0.05; The shaded cells above represent statistically significant findings.

Caregiver-related Measures

The caregivers had an average score of 37 ± 13 on the ZBI indicating mild to moderate caregiver burden. The average score on FCIS was 54 ± 6.2 on the FCIS, with average score of 11 ± 2.4 on Role Engulfment, 12 ± 2.5 on the Loss of Shared Identity, 7.2 ± 2.3 on the domain of Family Obligation, 10 ± 1.3 on Extension of Former Role, and 13 ± 1.7 on Master Identity. The caregivers had an average score of 32 ± 9.5 on Positive Aspects of Caregiving, 14 ± 7.3 on the Perceived Stress Scale and 40 ± 6.1 on the Quality of Life – AD scale. Distribution of scores across participants are illustrated in Figures 9-12.

Figure 9.

Family Caregiver Identity Scale (FCIS) Score Distribution

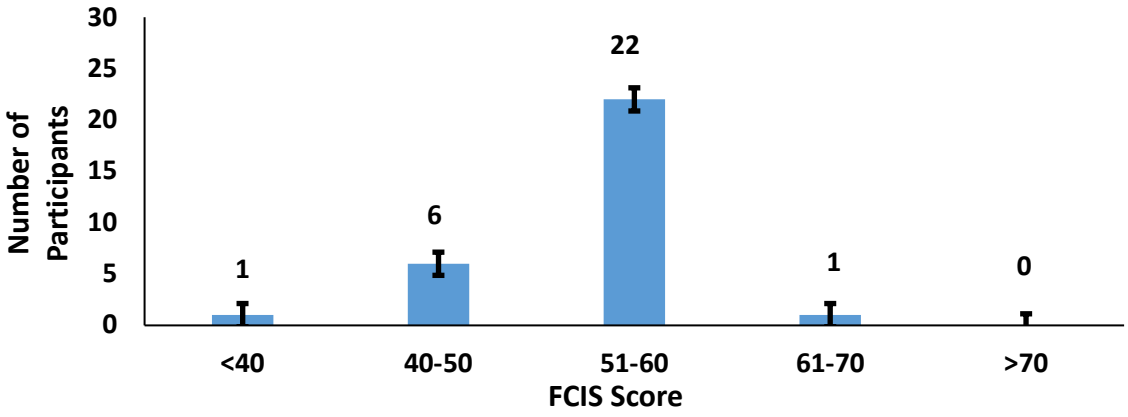


Figure 10.

Zarit Burden Interview Score Distribution

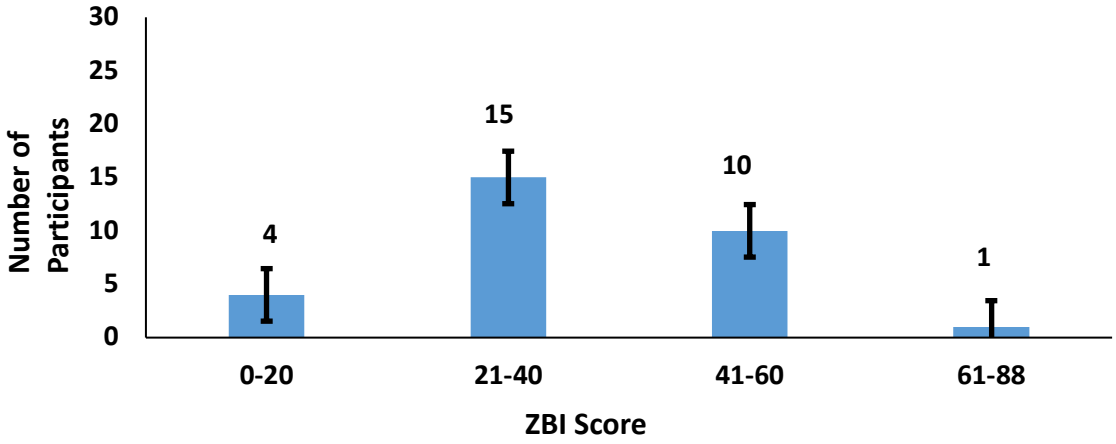


Figure 11.

Positive Aspects of Caregiving Score Distribution

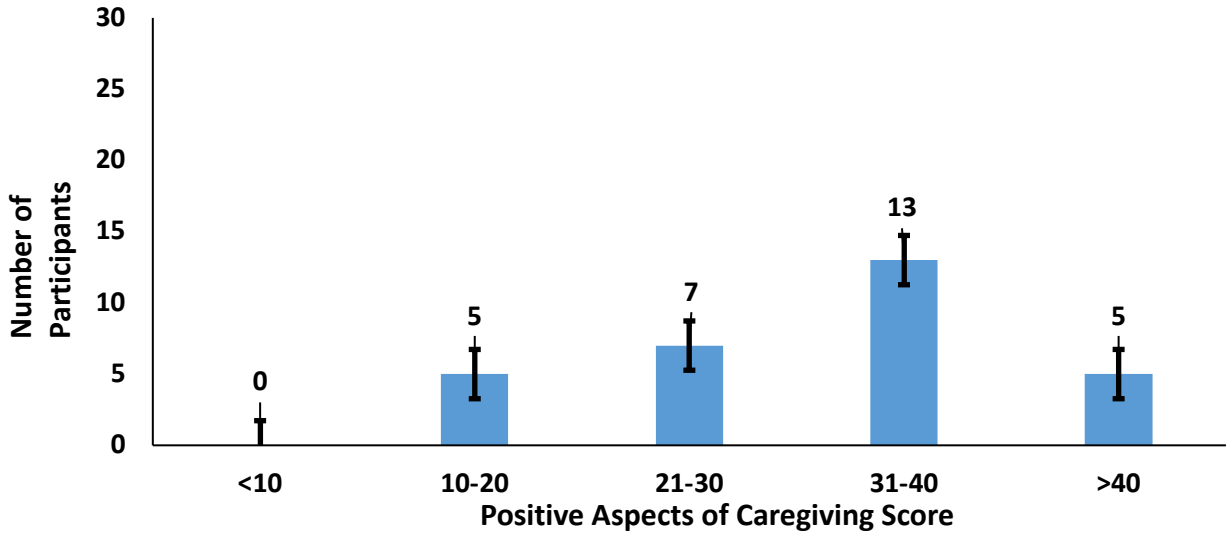
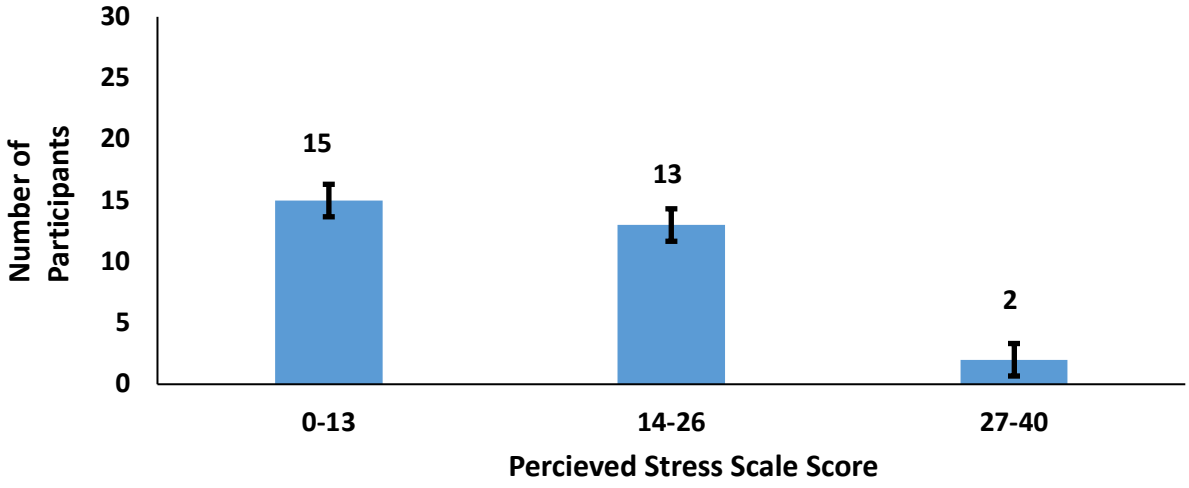


Figure 12.

Perceived Stress Scale Score Distribution



Correlations between burden and social engagement

Pearson correlations were done to examine the relationship between caregiver burden assessed using ZBI scores and social engagement measures. ZBI scores significantly correlated

with the overall scores on FS (r = -.409, p = .025, see Table 5, Figure 13) but not with UCLA loneliness scale. For the social activity questionnaire, analysis was only conducted for the top 3 most frequently engaged in activities by participants. ZBI scores significantly negatively correlated with the activity of participating in a club or other social, recreational, or community group (r = -.390, p = .033, see Table 6). Partial correlations were carried out to examine the relationship between caregiver burden and social engagement measures while controlling for age. The significant relationship found between ZBI score and overall score on FS changed to trending indicating that age is an important factor (see Table 7).

Table 5.

Correlations between Burden and Social-Engagement

	r value	*p*-value
Social-Engagement		
UCLA Loneliness Scale	r = .237	p = .208
Friendship Scale	r = -.409	p = .025*
Social Activity Questionnaire	r = -.153	p = .418

*p-value <0.05

Table 6.

Correlations Burden and Social Activity

	r value	*p*-value
Social Activity		
Participate in a club or other social, recreational, or community group	r = -.390	p = .033*
Visit a relatives' or friends' house	r = -.227	p = .229
Go on day trips or overnight trips with others	r = -.070	p = .714

*p-value <0.05

Table 7.

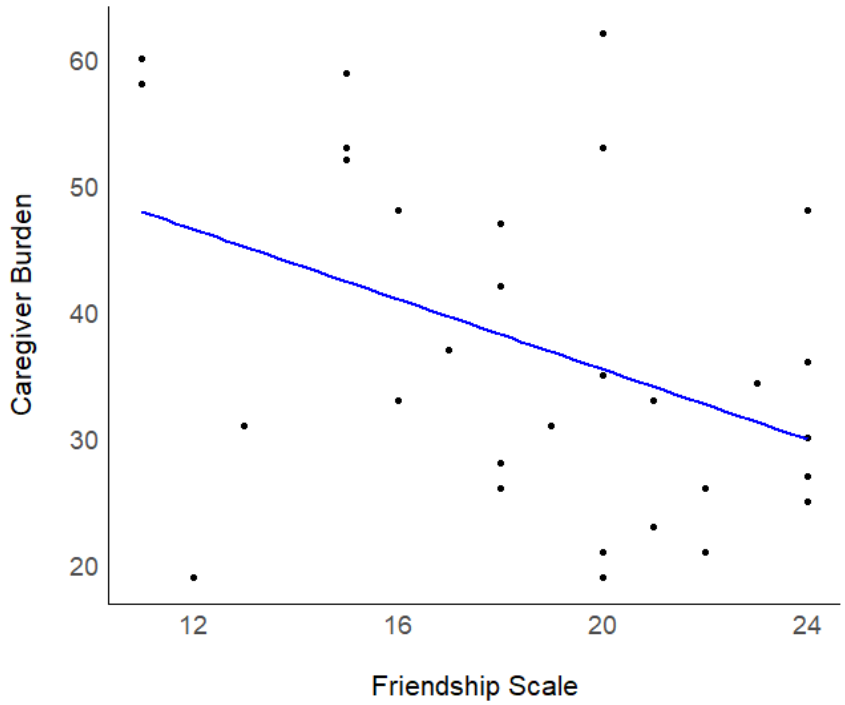
Correlations between Burden and Social-Engagement Controlling for Age

	r value	*p*-value
Social-Engagement		
UCLA Loneliness Scale	r = .203	*p* = .406
Friendship Scale	r = -.425	*p* = .070*
Social Activity Questionnaire	r = -.294	*p* = .221
Participate in a club or other social, recreational, or community group	r = -.410	*p* = .081

*trending

Figure 13.

Correlation between Burden and Friendship Scale



CHAPTER 4: DISCUSSION

The goals of this study were to characterize the social engagement activities of older adult caregivers of PwD and to examine the relationship between caregiver burden and social engagement.

Social Engagement Activity Characterization

Caregivers reported a moderate degree of loneliness on the UCLA loneliness scale and a high degree of social isolation on the Friendship scale. These findings are consistent with other caregiver studies that have found moderate degrees of loneliness in older adult caregivers (Peavy et al., 2022) and mild to moderate degree of loneliness in caregivers of all ages (Bramboeck et al., 2020). The correlation results between caregiver variables and social engagement measures revealed that those who were caregiving for five years or more were more lonely and socially isolated in our sample, consistent with other studies (Li et al., 2021; von Känel et al., 2019). When responsibilities of caregiving increase over the years, presumably due to dementia progression in their relatives, caregivers appear to feel more alone and less socially connected. As the symptoms of dementia become more severe, evidence suggests that the relationship caregivers have with their care recipient begins to change and becomes less socially rewarding (Peavy et al., 2022). Also, caregivers lose interactions with their social network as they spend more time providing care, making them more socially isolated (Waligora et al., 2019). This finding suggests that the more years older caregivers provide support, their social wellbeing is poorer.

When we examined social activities of caregivers, the caregivers reported engaging in a variety of social activities. Depending on the social activity, the frequency of participation varied. Caregivers utilized technology to engage with others on a daily basis such as talking on

the phone. They reported going out to connect with others on a monthly basis (e.g., going to the movies). They also reported pursuing a more involved social activity that required planning such as going on a trip a few times a year. Social activities pursued by caregivers on a daily basis (connecting with others individually on the phone) are similar to what has been found in the literature for older adult non-caregivers (Fu et al., 2018). However, our caregivers engaged less frequently in group activities such as participating in a club or other social, recreational, or community groups compared to the literature. For example, in Fu et al. (2018) study, participants reported participating in sports groups or hobbies almost daily (Fu et al., 2018) and another study found that older adults participated in playing sports at least once a week (Ide et al., 2023). Also, our caregivers did not volunteer regularly which is a commonly pursued activity by older adult non-caregivers (Fu et al., 2018; Ide et al., 2023). Perhaps social engagement group programs that are easily accessible remotely would fill this gap. Technology has shown potential to support EADLs if the technology is accessible and easily usable (Rogers et al., 2020). Additionally, a potential way for caregivers to engage in some social activity is to incorporate it into their daily schedule (Lai et al., 2020). For this to happen, caregivers need to be educated about the importance of self-care and respite.

In terms of the most favorite activity pursued, caregivers rated participating in a club or other social, recreational or community group as their top choice. One caregiver said, “I like the camaraderie, and I enjoy the [ex-] brain exercise”. Caregivers reported that their least favorite activity to engage in was attending religious meetings or services. A caregiver said, “the thought of sitting in a building to meditate or to converse with God has never really appealed to me.” Caregivers mentioned that they did not enjoy engaging in formal activities (e.g., attending religious services) or activities that required a scheduled time because of their inconsistent

caregiving schedule and responsibilities. Rather, they enjoyed informal activities (e.g., visiting friends or relatives house) or activities that were flexible similar to what others have found (Petts & Urmston 2022; Xu et al., 2022). An interesting finding from this study is that the activities caregivers mentioned they frequently engaged in happens to be the activity they did not always enjoy (e.g., talking on the phone), whereas activities that they enjoyed were the activities they did not participate in as frequently (e.g., participating in a club or other social, recreational or community group). They might engage in certain daily activities such as talking on the phone to get by their day-to-day needs that are not particularly enjoyable, such as updating a family member on the status of their care recipient. Studies have found that while caregivers report a common theme of 'no time for me' (Ploeg et al., 2020), participating in social activities (e.g., dance class) allows caregivers to feel fulfilled and gives them a sense of accomplishment (Petts & Urmston, 2022). Our caregivers reported feeling energized, refreshed, and accomplished when they engaged with others. Our study findings suggest that offering respite from caregiving responsibilities to participate in various social activities that caregivers enjoy might minimize their feelings of loneliness and social isolation.

Caregiver Burden and Social-Engagement Measures

Higher levels of caregiver burden on ZBI significantly correlated with lower scores on the Friendship Scale suggesting that those with higher levels of caregiver burden felt more socially isolated. These findings are consistent with other studies involving caregivers (Mwendwa et al., 2021; Peavy et al., 2022; Xu et al., 2022). These correlations changed from being significant to trending when age was accounted for suggesting that age plays an important role in this relationship. Studies have found that older adult caregivers are more likely to experience higher levels of burden (Tsai et al., 2021; Wang et al., 2022). Li et al. (2021) also

found that spousal caregivers (majority older than 65 years old) experienced greater levels of social isolation compared to adult and children caregivers (majority between 45 to 54 years old). Additionally, spousal caregivers report higher levels of burden when their care recipient is presenting with increased neuropsychiatric symptoms. (Cheng 2017). We did not examine whether the relationship between burden and social isolation was different between spousal and non-spousal caregivers, which should be examined in future studies. We did not ask caregivers details about the nature of care they provide; future studies should also examine if caregiver burden in those who support ADLs is more related to social isolation compared to those caregivers who provide less involved support.

This study had other limitations as well. We did not collect information on the dementia characteristics that their care recipients were presenting, or the nature of care provided. Future studies should carefully examine how social engagement differs in caregivers who are caring for someone with neuropsychiatric symptoms. Additionally, the study sample was very small and predominately white. Future studies should recruit participants from a variety of cultures and racial backgrounds.

Clinical Implications

In summary, the results of this study revealed a moderate degree of loneliness and a high degree of social isolation in our older caregiver group. Overall, the caregivers participated less frequently in group social activities although they rated it as their favorite. Serving as a caregiver for more than 5 years significantly correlated with increased loneliness and social isolation. Furthermore, higher caregiver burden was associated with higher levels of social isolation. It is important for rehabilitation professionals including SLPs to understand the impact of caregiving and develop approaches to educate and support the needs of caregivers of PwD. SLPs are now

able to bill Medicare when offering skilled services to caregivers in order to improve patient outcomes even without the presence of the care recipient. This is hopefully the first step to expanding the scope of services to caregivers. SLPs should collaborate with caregivers by educating and counseling them on their caregiver role, the impact of caregiving on their health as well as the quality of care they provide to their care recipients. One way, SLPs can support caregivers is by developing programs and sharing resources on the impact of caregiving. They can offer social engagement opportunities to allow caregivers to connect and engage with others beyond the support groups. As caregivers connect with others, they can begin to build a network of people to support them. Caregivers can begin to engage with the people in their network socially as a form of self-care to potentially lower levels of caregiver burden. A viable solution for easy access to socializing with others is using a video-technology platform (e.g., zoom). This can allow caregivers to engage with others socially from the comfort of their home without having to leave their care recipient alone and meet the needs of their social health. As one of the caregivers in our study said, after engaging in their favorite activity they felt “refreshed, renewed, full of energy and ready to take on the day again”. Such positive social engagement opportunities are key to supporting social health and wellness in caregivers of PwD.

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