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## The Association of Burden and Social Engagement with Depression in Caregivers of Adults by Age

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**THE ASSOCIATION OF BURDEN AND SOCIAL ENGAGEMENT  
WITH DEPRESSION IN CAREGIVERS  
OF ADULTS BY AGE**

**A Thesis Presented to the Graduate Faculty  
of the Fort Hays State University in**

**Partial Fulfillment of the Requirements for the Degree of Master of Science**

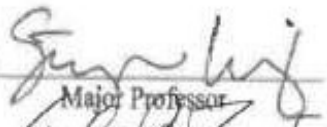
**by**

**Danielle Leigh Forbes**

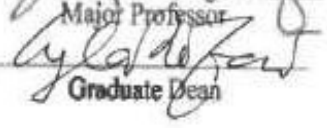
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## ABSTRACT

As life expectancy begins to increase, the need for familial caregivers is growing. The aging of care recipients often means that those providing care continue to get older as well. Previous studies focus little on the differences between older and younger caregivers and rather combine them all into one group. The purpose of this study is to understand whether the caregiving experience is related to the age of the caregiver. Depression, burden, and social engagement, based on the descriptors of leisure, work, and social relationships, were studied in conjunction with the age of the caregivers. This study consisted of 63 caregivers divided by age into groups of individuals under age 65 ( $n = 45$ ) and individuals aged 65 or older ( $n = 18$ ). Data for this project was collected through an online survey which was distributed to individuals in caregiving groups and on social media. It was then analyzed utilizing appropriate statistical measures including Pearson Correlations and multiple t-tests. It was hypothesized that social engagement has a negative association with depression which was found significant. The predictions that younger caregivers and older caregivers would engage in different kinds of leisure activities and have spent different amounts of time in leisure each week were not supported by the data of this study. However, a significant relationship was found regarding the hypotheses between burden and depression in caregivers, as well as between age and burden. The findings of this study imply that to help improve mental health outcomes for caregivers, providers should focus on increasing the amount and quality of social engagement in which caregivers engage. Recommendations for reducing burden and improving outcomes are made based on these findings.

*Keywords:* caregiving; age; social engagement; burden; depression

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TABLE OF CONTENTS

	Page
ABSTRACT.....	i
ACKNOWLEDGEMENTS.....	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES.....	v
LIST OF APPENDICES.....	vi
INTRODUCTION.....	1
Burden.....	3
<i>Risks Associated with Burden</i> .....	4
<i>Moderating Factors</i> .....	6
Social Engagement.....	8
<i>Social Support Relationships</i> .....	9
<i>Peer Support Relationships</i> .....	13
<i>Work and Retirement</i> .....	15
<i>Leisure</i> .....	16
Age.....	18
Current Study.....	21
METHODS.....	24
Sampling and Procedures.....	24
Measurements.....	25
<i>Depression</i> .....	25
<i>Burden</i> .....	26

<i>Social Engagement</i> .....	26
<i>Demographics and Open-Ended Questions</i> .....	27
Analytic Procedures.....	27
RESULTS.....	29
Social Engagement.....	29
<i>Social Engagement and Depression</i> .....	29
<i>Types of Social Engagement and Age</i> .....	29
<i>Time for Social Engagement and Age</i> .....	30
Burden.....	30
<i>Burden and Depression</i> .....	30
<i>Burden and Age</i> .....	30
Caregiver Reports of Needs.....	31
DISCUSSION.....	32
Limitations.....	36
Future Study.....	36
Conclusion.....	37
REFERENCES.....	38

## LIST OF TABLES

Table		Page
A	Demographic Results.....	44
B	Correlations of Depression and Social Engagement.....	46
C	Themes of Caregiver Needs.....	47

## LIST OF APPENDICES

Appendix	Page
A	15-Item Geriatric Depression Scale.....48
B	Zarit Caregiver Burden Interview.....49
C	Quality of Life Enjoyment and Satisfaction Questionnaire.....50
	<i>Work</i> .....50
	<i>Leisure</i> .....51
	<i>Social Relationships</i> .....52
D	Demographic Information and Open-Ended Questions.....53
E	IRB Letter of Exemption.....55
F	Recruitment Message.....56
G	Informed Consent.....57



## INTRODUCTION

As medicine and technology continue to advance, the human lifespan increases. According to the National Vital Statistics Reports, the life expectancy of children born in 2020 is 77 years old (Arias & Xu, 2022). However, 25-year-old individuals would expect to have a 53-year lifespan living to age 78. For 50-year-olds the lifespan is 30.4 meaning they would live to 80.4; at 75 an individual would be expected to live another 11.6 years to age 86.6. Finally, if one reaches age 100, they would be expected to live two more years to age 102 (Arias & Xu, 2022). Longer lifespan means greater need for assistance as one ages, resulting in an increased need for caregivers. This need is often filled by familial caregivers. Providence of quality care is important to the health and overall wellbeing of the care recipient, but to provide excellent care, the caregiver must be healthy both physically and mentally. Thus, it is important to understand the needs and concerns of caregivers to provide successful care to the aging population.

Anderson et al. (2013), looked at the demographics of caregivers in the United States. The typical caregiver ranges in age from 50 to 64 years old and is female. The racial group with the greatest number of caregivers is non-Hispanic black. They usually have some college education and are in a married or unmarried couple. Many familial caregivers are the spouse, parent, or child of the care recipient. As the population of care recipients ages, the caregivers will continue to age as well; meaning that in the future, the typical caregiver may be in their late sixties, seventies, or even older when providing care. A great deal of research focuses on understanding the needs of the care recipients and caregivers who are middle aged; however, there is not much known about the older population of caregivers as society moves in this direction.

When compared to non-caregivers the physical and mental health outcomes are worse for caregivers. This is particularly important as the caregiver ages due to health needs that typically accompany aging which may compound with the caregiving role. Furthermore, providence of care may cause a strain in romantic and other relationships for the caregiver due to the time and energy devoted to care. Alshammari et al. (2017) found that 69.2% of family caregivers in Saudi Arabia suffer from depression and mood problems. In the United States, 16.9% of caregivers rank their health as poor or fair, but only 15.8% of non-caregivers fit this category. Caregivers experience more frequent physical distress than non-caregivers, 12% versus 10.5%, and more frequent mental distress, 14.3% versus 9.4%. A higher percentage of caregivers say they are dissatisfied with life than non-caregivers, 7% vs. 5.5%. However, both caregivers and non-caregivers indicate equal amounts of available social support, but this number is low at only 8.5% (Anderson et al., 2013). These statistics should motivate researchers to determine which factors cause poor physical and mental health outcomes for caregivers. Understanding these variables can help create policies and resources to improve health and life satisfaction for those with the difficult role of caregiving.

The purpose of the current review and study is to explore caregivers of adults and the association of burden and social engagement with depression. The continuous growth in the aging population will likely cause an influx of caregivers providing care for their parents, children, spouse, or other loved ones; while at the same time, the caregivers are aging and becoming less able to care for themselves. Therefore, this study will examine young, middle aged, and older adults who function as primary caregivers for adult family members. There are many variables associated with caregiving, causing some difficulty in deciding on which ones to focus. However, this review seeks to understand ways in which burden and social engagement

are related to depression levels in caregivers, and whether the age of the caregiver shows significant differences in these variables. For this study, burden is defined as the amount of strain experienced by the caregiver. This relates to the tasks of caregiving, amount of time spent caregiving, the health factors and needs of the care recipient, and physical and emotional health effects caused by caregiving. Burden can be measured objectively in hours spent caregiving, tasks required, and the like, but it is also important to consider the perceptions of the caregiver when looking at burden. Social engagement for the purpose of this review includes general social and peer support relationships, paid work, and leisure activities. Furthermore, it is crucial to understand whether being a younger caregiver (under age 65) or an older caregiver (over age 65) is related to the effects of burden and social engagement on the mood of the caregiver. Recognizing differences in caregiving for older caregivers is vital as the population of caregivers ages so that appropriate interventions and support systems can be created to meet their unique needs and facilitate high quality care for their loved ones.

### **Burden**

The statistics from Alshammari et al. (2017) and Anderson et al. (2013) presented above show that the burden of caregiving is a major problem for caregivers of elderly adults. The level of burden has many detrimental factors on the physical and mental health of the caregiver. A study of Saudi Arabian family caregivers found that 30.8% of caregivers experience little to no burden, whereas 42.9% of caregivers experienced little to moderate burden, 20.6% experience moderate to severe burden, and 5.7% experience severe burden on the Zarit Burden Scale (Alshammari et al., 2017). Consideration of these statistics is important as they demonstrate that caregiving has some inherent burden and understanding how burden translates to the wellbeing of caregivers can help improve the lives of both the caregivers and the care recipients.

## *Risks Associated with Burden*

The amount of strain a caregiver experiences is the highest predictor of their quality of life. Those with higher levels of burden report reduced functioning in their physiological quality of life and more depressive symptoms than non-caregivers (Roth et al., 2009). Burden is related to the status of the care recipient, particularly for adult children caregivers of their parents for whom a negative correlation is seen between burden and increased depression in caregivers. (Lin et al., 2012). Better care recipient health has a positive effect on the caregiver's emotional well-being, but for those caring for individuals with greater disability status, burden rates are higher on the caregiver strain index (Garcfa-Domfinquez et al., 2019). Cohabitation with the care recipient also increases negative emotions, strain, anxiety, and stress in caregivers (Stoltz et al., 2004). Furthermore, for some caregivers, role overload is associated with sleep disturbance which may also relate to factors that can increase feelings of burden such as nighttime caregiving duties, mood disturbance, and limited time to focus on personal concerns (Liang et al., 2020). Understanding the effects of burden on caregiving can lead to greater awareness of the causes of depression in caregivers resulting in better sources of support and prevention of negative outcomes.

One source of burden for caregivers is the financial strain which results from becoming a caregiver. There may be several sources of financial difficulties such reduction of work hours and costs related to the healthcare needs of the care recipient. For younger caregivers, who have not had as much time to build financial stability, financial strain adds to the difficulty of caregiving, particularly if the caregiver must quit their job to provide care. For older caregivers, the cause of financial strain is more related to the personal needs of the caregiver. Aging often results in need for more healthcare services, medication, and transportation assistance which

increase financial outflow at a time when income may be significantly reduced due to retirement (Bianchi et al., 2016). Besides financial strain, age is linked to burden in that younger caregivers tend to report higher levels of burden than those who are older (Stoltz et al., 2004). However, this might be due to perceptions that the task of caregiving is more normative in older caregivers, while younger caregivers might not expect to provide care for their loved ones at a young age. While younger caregivers report more burden, older age is linked to more time spent caregiving (Bianchi et al., 2016). This makes sense because older caregivers are likely to care for much older care recipients. Other sources of burden for caregivers include the labor related to care tasks, loss of personal and leisure time, loss of social life, loss of other life pleasures, and the threat of loss of a loved one (Lin et al., 2012). However, it is unclear which sources of burden create the greatest difficulties for caregivers, and whether age is associated with different experiences of burden. Separating factors of burden and determining which are associated with different age groups would create a better understanding of how burden affects caregivers' needs.

Burden and depression are shown to have a positive association, in that the greater the individual's perception of burden, the greater their depression scores (Lin et al., 2012; Roth et al., 2009). Researchers claim causality of burden as a risk factor for psychiatric problems including a moderate risk for depression (del-Piño-Casado et al., 2019). Burden leads to greater feelings of stress and depressive symptoms because caregivers feel that they cannot prevent negative outcomes which leads to poor physical health and increased rates of anxiety and depression (Ramsay et al., 2010; Lin et al., 2012). Finally, the time commitment related to caregiving has effects on depression rates. For adult child caregivers of their parents, depression rates are six and a half times higher for those who have a greater time commitment than for those

who spend a limited amount of time in the caregiving role (Cannuscio et al., 2004). This might mean depression is a greater concern for older caregivers because they spend more time caregiving.

Perceived support is another factor related to burden and depression in caregivers. In the case of adult child caregivers, they often perceive that they give more instrumental support to their parents, which is likely due to other time commitments. However, the parent care recipients perceive reception of less instrumental support from their children. (Klein Ikkink et al., 1999). Managing the dissonance of feeling like one is giving more support while the care-recipient perceives they are not giving enough and feeling as though the caregiver is the only source of social interaction for their loved one may be another source of burden. Loneliness may be a factor causing care recipients to believe they get less care; a homebound individual may feel that they need more time with their caregivers because it may be the only social interaction they get on a regular basis. The caregiver, regardless of age, still wants to please their loved one to the point where they overextend themselves and spend less time engaging in self-care. Not getting adequate rest, nutrition, exercise, and the like may cause both physical and emotional dysfunction in the individual making it more difficult to provide quality care. However, there is little research indicating how strain related to the time and effort perceived in caring is related to the age of the caregiver. It would be beneficial to understand how different age groups engage in self-care to provide appropriate support to the different age groups.

### *Moderating Factors*

While burden can cause negative outcomes for caregivers, there are factors that can moderate poor mental health. For example, caregivers with little strain have better mental health

outcomes than non-caregivers (Roth et al., 2009). This might be due to feelings of accomplishment from helping a loved one. Caregiving can provide a sense of coherence when the caregiver feels they are doing a good job. The caregiver can find greater meaning in their life despite the arduous task of caregiving which gives them a sense of purpose in their day. This might be particularly true for a caregiver who is retired. Furthermore, the ability to manage their environment may make the caregiver feel stronger and more competent about life in general leading to perceptions of self-efficacy (Stensletten et al., 2016).

Age is an important variable to consider when seeking to understand burden in caregivers. Being older may also help improve mental health outcomes. First, older caregivers tend to expect that they will have to care for their loved ones; the experience feels more normative which may help moderate their perception of burden and depressive symptoms. Furthermore, older caregivers show more psychological resilience in comparison to younger caregivers on burden scores. This may be due to having greater access to coping resources such as spirituality (Bianchi et al., 2016). However, for younger caregivers, other roles may mitigate the effects of burden. Bastawrous et al. (2014) found that engaging in multiple roles is not associated with increased strain, depression, anxiety, or burden. Rather, proficiency in roles such as at work, parenting, or in a spousal relationship can help reduce feelings of burden and role overload. Feelings of competency in one aspect of life lead to the confidence to master the new role of caregiving.

It is important to understand that the positive and negative aspects of caregiving do not fall on a single spectrum where one end is all good and the other is all bad. Rather, the good and bad qualities of the caregiving experience are on different spectrums. Caregivers can feel good with the role of caregiving while still experiencing the burden and elevated levels of stress

caused by it (del-Piño-Casado et al., 2015). Burden in caregiving is shown to have negative effects; however, there are altruistic rewards for caregivers too. The correlation between burden and depression is evident in research, but it is unclear whether the age of the caregiver increases or moderates perceived burden and whether age is related to positive perceptions of caregiving. Understanding the effects of caregiving on different age groups can help create better programs to support caregivers and reduce their burden; ideally this would reduce negative consequences for caregivers and improve the quality of care for the elderly.

### **Social Engagement**

Social engagement is an essential aspect of positive mental health outcomes for all individuals, but it is particularly meaningful for individuals in the role of caregiver. Acquisition of a new role often leads to loss of time and energy to give to other roles; for many people, the first areas which they choose to let lapse are social and leisure time. Many caregivers express concern about social isolation and loss of relationships related to the loss of freedom which occurs due to the role of caregiving (Stoltz et al., 2004). One study found that 40% of caregivers do, in fact, struggle with isolation from friends and family members because of caregiving (Alshammari et al., 2017). This demonstrates the importance of focusing on social engagement in research. Social engagement can take on several forms. For this review, four aspects of social engagement are explored, experiences of social support in relationships outside of the caregiving relationship, relationships with peers in similar caregiving situations, engagement in paid work, and time spent completing leisure activities.



### *Social Support Relationships*

Several studies have been done to investigate the impact of social support relationships on caregivers. Wasilewski et al. (2017) asked whether relationships with peers created better support relationships. They found that receiving social support from a variety of sources can have many benefits for caregivers and is linked to better mental health outcomes. Another study by Liang et al. (2020) looked at the relationship between social engagement in dementia caregivers and its effect on role overload and sleep. They concluded that social engagement has been shown to have moderating effects on burden and improves problems with sleep maintenance insomnia; however, this is only found to be significant when the support is instrumental help with caregiving activities, such as preparing meals, cleaning, transportation, and the like. However, social engagement was not found to moderate role overload in general, but this is likely due to limitations on participation in social activities due to caregiving. A review by Bastawrous et al. (2014) looked at a range of studies focusing primarily on adult child caregivers to better understand factors that contribute to their well-being. The results of this study indicate that the overall wellbeing of caregivers is linked to social relationships including better overall health, less anxiety, and reduced health strain when compared to caregivers without relationships outside of caregiving. Colvin et al. (2004) sought to understand the benefits and disadvantages of internet-based support for older adult caregivers; their findings report positive association between social ties and depressive symptoms in that caregivers who have a greater quantity of social ties tend to show fewer depressive symptoms. Furthermore, frequency of social engagement in caregivers shows a linear relationship in conjunction with life satisfaction and depression. Waikui et al., (2012) focused on ways different activities and the level of participation in them related to the psychological health of caregivers. They found both

weekly and monthly social activities improve life satisfaction in caregivers, and a significant relationship between weekly social engagement and reduced depression rates. Finally, Sibalija et al. (2020) examined the relationship between caregiver depression and social support and social participation. They discovered caregivers who perceive greater affectionate support and have experiences of positive social interaction paired with frequent participation in socialization show trends of lower depression scores. The themes of these studies indicate that social interaction for caregivers is a valuable aspect of maintaining overall wellbeing which would then help the individual provide better care to the care recipient because of improved mental and physical health.

There are numerous sources of social support for caregivers including relationships with family, friends, and coworkers. Many caregivers want supportive outlets to help ease the psychological effects of caregiving (Ramsay et al., 2010). Secure attachment relationships with a romantic partner, friends, or relatives offer a sense of safety to the caregiver and may reduce feelings of burden related to caregiving (Stensletten et al., 2016). Attachment relationships give caregivers a place to express negative feelings about the caregiving experience. They can share experiences of sadness, frustration, fear, and failure with someone who loves them and can respond without judgement. Furthermore, the caregiver receives caring and honest feedback which helps them feel supported regardless of their struggles. Secure relationships create a safety net to help get through difficult days.

Beyond those with whom one feels emotionally close, caregivers seek support from professionals and those with similar experiences of caregiving. This includes medical professionals, religious leaders, and former caregivers. For caregivers seeking support from professionals, a comprehensive program is desirable. Caregivers seek programs which include

psychoeducation and cognitive behavioral approaches to their own mental health and that of the care recipient. They desire support groups as well as training regarding the practical aspects of caregiving. Finally, caregivers are interested in assistance with respite care which would enable them to participate in such programs (Ramsay et al., 2010). However, it is unclear how the age of the caregiver might affect their ability to participate in such programs. Limitations caused by aging might be a concern for caregivers. For example, older caregivers may struggle with leaving home due to physical limitations preventing engagement with professionals and support programs. They might want to join online support groups but struggle with the use of technology. Older individuals begin to struggle with driving, especially in the evening preventing them from joining activities without transportation. These constraints may block an older caregiver from receiving adequate support.

Engagement in community activities is important as it helps caregivers with changes in role and identity. Life outside of caregiving gives individuals feedback beyond the caregiving role and helps one gain a more well-rounded view of oneself (Sibalija et al., 2020). Caregivers often find themselves lost in their role, but social engagement allows them to step into a different role and be someone besides the caregiver. This benefits the caregiver as it allows them to develop a well-rounded sense of self.

Although engagement outside of the home is helpful to caregivers, it is not always possible due to obstacles such as lack of respite care, financial strain, travel distance from the social opportunity, and the like (Ramsay et al., 2010). Taking these into consideration, a practical option for caregivers might be to find social engagement online. Social support from the internet may provide many advantages to caregivers beyond the convenience of availability at home. The caregiver does not need to find help to leave the care-recipient at home or feel concerned about

the timing of caregiving activities getting in the way of social interaction. Furthermore, the internet provides an anonymous outlet which allows individuals to relate to others more easily, share thoughts more freely, and feel less concerned about judgement from others. Online socialization is asynchronous, and therefore more convenient. The caregiver can get online during breaks in their schedule and can find information more immediately rather than waiting for the next support group meeting, meet-up with a friend, and the like. Internet support can be individualized to meet one's needs. A person can search for the exact information in which they are interested and skip that which is not pertinent to their situation. Finally, the connectivity of the internet expands the caregiver's network of support beyond their social circle encompassing a greater range of ideas, people in similar situations, and understanding and acceptance of the situation (Colvin et al., 2004).

Technology provides the opportunity to build relationships with others around the globe and can be a major benefit to caregivers who use it to fulfill their needs for socialization. The internet allows for connections with others who share similar experiences and experts who understand the unique needs of the individual. Relationships formed online may be important moderators for burden and depression in caregivers who are unable to leave their home often. However, while online interaction can have benefits, it is important that caregivers also build support systems with individuals in their own community.

Social support relationships can take on many forms for caregivers. Family and friends can be particularly important in providing a sense of security and capability in the role of caregiving. Religious leaders, medical providers, and others offer a sense of competency to the role through the various levels of support they offer. Finally, caregivers can find support in their own homes through internet groups. The internet helps manage their needs for interaction while

overcoming limitations related to caregiving. Social support relationships improve the physical and mental wellbeing of the caregiver which enhances the quality of care for the care recipient and enhances outcomes for the caregiver. Social support in general is important but support from other caregivers is invaluable as well.

### *Peer Support Relationships*

When considering social engagement for caregivers, it is also important to look at the individual's relationships with their peers. For caregivers, this would be other caregivers sharing similar aspects of caregiving such as the illness of the care recipient, the duties of the caregiver, the relationship between the caregiver and the care recipient, and the like. These commonalities allow for a reciprocal support relationship and improve the connection beyond that of a simple friendship relationship (Wasilewski et al., 2017). These types of associations can lead to greater life satisfaction for caregivers (Waikui et al., 2012). They fulfill both the social and educational needs for caregivers (Stoltz et al., 2004). The caregiver can express concerns and form a friendship with their peer while discussing problems of caregiving and learn about techniques that did or did not work in a situation like their own. Peer relationships are beneficial because engagement with those in similar caregiving situations creates a stronger relationship between the individuals. This allows more candid, honest sharing about the difficulties of caregiving and feelings of burden. This optimal level of support helps reduce feelings of isolation and can improve outcomes for both the caregiver and the care recipient (Wasilewski et al., 2017).

Caregivers create peer support networks in a variety of ways, but most are formed through continuation of daily activities. Relationships with family, friends, and coworkers help promote social engagement amongst caregivers which then increases opportunities for finding

supportive peer relationships (Wasilewski et al., 2017). One study found that eighty percent of caregivers get peer support from the day-to-day relationships with individuals who are already in their circle of interaction. Caregivers look for practical sources of support which are easier to obtain through daily activities such as going to work or engaging with others who share a hobby (Wasilewski et al., 2016). As mentioned above, online forums are another source of support for caregivers, particularly those who are unable to maintain former activities outside of the home such as work and social groups. They allow caregivers to find peers with issues more like their own which can improve the quality of support (Colvin et al., 2004). Seeking peer support on the internet might be easier for caregivers to find matching peers than within their personal networks, particularly for those who have unique caregiving situations such as in the case of a rare disease or a younger caregiver.

Building a peer support network is mutually beneficial to the caregivers and the recipients of care. Caregivers look to peers to improve their competency in caregiving tasks and increase the quality of care given (Stoltz et al., 2004). Furthermore, peer relationships fulfill social needs and create superior relationships due to similarity of experience. The emotional support caregivers receive from peers helps them feel less isolated and more connected to others who can empathically relate to their experiences. There is a joint understanding that the quality of the relationship is more helpful than the quantity of time spent together (Bastawrous Wasilewski et al., 2016). Having the support of peers helps caregivers feel less alone with the burden of care and can fortify them when tasks feel overwhelming.

## *Work and Retirement*

It is unclear whether working or being retired creates more positive mental health outcomes for caregivers. It is possible that working allows the caregiver a break from the role and offers relief; on the other hand, balancing work and caregiving may increase burden as the caregiver is overwhelmed by their duties. One study found that employment shows little effect on depression (Cannuscio et al., 2004). Another found that depression and role strain were not significantly different in working versus nonworking caregivers, but that certain problems at work could increase role strain (Edwards et al., 2002). A third found that depression rates are twenty percent lower in non-caregivers than in caregivers who work full or part time (Colvin et al., 2004).

Nonetheless retirement from work may increase the likelihood of depression in caregivers. With retirement, there is a major loss of social roles which can cause lower life satisfaction, particularly for those who do not replace the lost role with a new one. This is especially true for those who retire earlier than expected due to health concerns, job loss, or to become a full-time caregiver. Furthermore, retirement may reduce moderators for depression. Work environments can provide social support networks which aid in coping with life stressors. Many employers offer comprehensive health insurance plans, but upon retirement, individuals no longer qualify for these benefits (Dang et al., 2022). Loss of health care can result in negative physical and mental health outcomes which take a toll on the overall wellbeing of the caregiver as it becomes more difficult to obtain and pay for healthcare without insurance. However, the loss of the role outside of caregiving may be a more significant loss to the caregiver as one may lose feelings of competency obtained through work and regular interaction with coworkers.

Although retirement can be problematic for caregivers, work may also have negative effects on caregivers. This is particularly true if the environment at work is negative. It causes the caregiver to suffer from role overload and increased worry and strain. Depressive symptoms are positively associated with work conflict, role overload, and worry and strain; thus, the more difficult the environment, the worse the mental health outcomes for the caregiver. While negative work environments can be detrimental, a positive environment is shown to be a moderator for depression and role overload in caregivers (Edwards, et al., 2002). This is especially true for younger caregivers. Having duties outside of caregiving, such as work, children, and social relationships, may play a beneficial role in the individual's mental health outcomes (Pinquart & Sörensen, 2011).

In determining whether age plays a role in depression rates of caregivers, it is important to consider the advantages and disadvantages of working and retirement. While working may increase the burden of caregiving due to overwhelming the caregiver with more things to do than time to do them, it may also moderate feelings of depression through increased competency and social relationships. Retirement may be beneficial to caregivers as they have fewer tasks to cause overwhelm, but it also has disadvantages. Retirement may lead to loss of financial security, access to healthcare, and decreased social interaction. Further research is necessary to understand how work and retirement affect depression in caregivers, especially among those who are older and more likely to be retired.

### *Leisure*

Leisure time is an important aspect of caregiver wellbeing. One problem for caregivers is that often, the leisure activities which they enjoyed before caregiving are reduced or even



eliminated by the time constraints of the caregiving role. Caregivers frequently lose interest in seeking leisure activities because they feel that they do not have time. They are commonly with the care recipient most of the day and night leading to loss of freedom to make decisions about how to spend their time. They also feel that it takes too much effort to get help so they can get out of the home. Caregivers feel guilty about leaving their loved ones, and they feel it is their duty based on a sense of filial obligation. Lack of trustworthy respite care and financial resources may limit the caregiver's ability to take time for leisure outside of the home. This leads to more time spent at home, often in front of a television or a computer screen. All of this puts caregivers at a higher risk for depression, burden, and stress (Xu et al., 2022).

One way to reduce the risks is for the caregiver to get out of their home to engage in entertainment and activities such as attending religious services and buying groceries. In home caregivers are hopeful for resources which allow opportunities to leave their home, particularly in the form of respite care (Stoltz et al., 2004). One major factor in whether an individual can participate in activities outside of caregiving may be related to the type of caregiving required. Sibalija et al. (2020) found that instrumental help, like assistance with household duties, transportation, and meal preparation allows more time for leisure. Caregivers engaged in more intimate tasks such as bathing, bathroom assistance, and personal grooming, tend to have less time for leisure. However, spending time in leisure activities helps caregivers feel separation from the task of caregiving and makes them feel as though they have a life outside of their role as caregiver (Xu et al., 2022). Leisure can improve overall health by reducing stress, but it is important to note that the quality of the experience is more important than the quantity of leisure time. Participation in leisure moderates stress due to overall satisfaction with the time spent and the activity in which the individual is engaged (Bedini et al., 2018). Finally, participation in

leisure activities at home or outside of the home is associated with better overall mental health. It decreases burden and depression and increases life satisfaction and satisfaction with the role of caregiving (Waikui et al., 2012).

While there is a range of research which discusses the benefits of social engagement for caregivers, there is more to be discovered about the ways social support, peer support, work and retirement, and leisure time affect depression in caregivers. There are gaps in research regarding understanding how distinct types of social engagement affect younger and older caregivers, and whether loss of social engagement is more detrimental to the mental health of one age group over another. Understanding these variables can help organizations create precise programs to improve social outcomes for caregivers leading to improved physical and mental health.

### **Age**

Understanding how age is associated with caregiving and depression is valuable for building support systems for caregivers. One way to consider the differences between younger caregivers and older caregivers is to look at the stages of development theorized by Erik Erikson. For younger caregivers, the sixth and seventh stages of development would be applicable. In the sixth stage, individuals seek intimacy with others and battle against isolation. Typically, people think of this as a stage where one seeks a romantic partner, but intimate relationships can be formed with friends and loved ones as well. The goal of this stage is to “invest in others” (Watts et al., 2015, p. 302). The act of caregiving provides individuals with the opportunity to form a close relationship with the care recipient helping to build resilience against isolation. However, younger caregivers may struggle with caregiving overall because they experience competing

roles. They may have a romantic partner or children in the home; the stress of caregiving lessens the altruistic rewards because they already have a source of intimacy (Hui et al., 2010).

According to Erikson's theory, the seventh stage of development occurs in middle age; individuals seek generativity versus stagnation. This is the stage when one builds contributions to society through raising children and expressing creativity through a variety of activities including work. These individuals fulfill their identity crisis through being needed by others and equipped to provide care for their loved ones (Watts et al., 2015, pp. 305-306). Caregiving helps an individual at this stage win the battle between generativity versus stagnation as they assist the care recipient by improving their quality of life. For a caregiver without a spouse or children, caregiving might be the best or only opportunity to feel one is making a positive contribution to society.

One final benefit to being a younger caregiver is that it is seasonal in nature. Younger caregivers may find some resilience in the hope that the caregiving situation is temporary, and they may eventually have a normal life after caregiving (Bianchi et al., 2016). Although knowing that caregiving will eventually end with the death of care recipients may lead to feelings of guilt and loss for younger caregivers, understanding that they can get back to some resemblance of their life before caregiving may build resilience against the burden of caregiving.

Although being younger caregivers has moderating factors, older caregivers also have several age benefits that may help them in the role. Erikson's stages of development are applicable to older caregivers as they seek to resolve the conflict of his eighth stage, integrity versus despair. After age 65, individuals tend to be past the stage of generativity; they are not expanding their families, raising children, or actively earning income. These individuals may feel

that they are no longer contributing to society, but rather that they are a burden as they use resources rather than create them. In this stage of development, older people have the need to demonstrate dignity and acceptance of their life as it has been. They look to develop a sense of “wholeness” seeing themselves as a useful member of society while looking back to the mark they left for the good of civilization. Those who look back on their life as fulfilling achieve integrity, whereas those who do not experience despair (Gillead, 2020; Watts et al., 2015). Caregiving gives older individuals an opportunity to prove their value to society as they provide services to others. It gives them a sense of accomplishment and allows for the self-perception of value and worth to individuals. In general, being over age 65 is associated with fewer depressive symptoms, less mental distress, and greater satisfaction with life (Anderson et al., 2013; Sibalija et al., 2020). This may be due to the wisdom of aging and the ability to look back on one’s life with a sentiment of value based on recollection of positive events and contributions of the past.

Another reason older caregivers may have more psychological resilience to depression and burden may be related to greater participation in existential activities, which gives them more access to adaptive coping resources. However, the term for caregiving when one is older often ends due to inability to care because of exhaustion, disease, loss of functionality, or death; ultimately when the caregivers need care for themselves. (Bianchi et al., 2016). This may lead to increased feelings of despair and depression as caregivers realize that their lives might not improve, and they may never have the freedom and quality of their former life. They may also experience guilt because of wanting to enjoy their final years without the burden of caring for their aging loved ones.

Hui et al., (2010) sought to determine the caregivers’ understanding of care recipients’ behaviors related to caregiver distress and satisfaction in their relationship with care recipients.

They discovered that older caregivers tend to see caregiving as an age appropriate, and therefore a more normative task, and that they have more life experience to help interpret confusing behaviors of the care recipient. Furthermore, older age was shown to indicate better caregiver relationship satisfaction, lower depression rates, and fewer perceptions of burden. Although this study indicates that older age may be moderating to negative caregiving outcomes, the mean age of the participants of the study is 51.85, younger than the age defined as older for this review. Of 75 participants 13 are aged 60-69, but it is unclear how many fall within the parameters of being over 65. However, 7 participants are considered older by the standards of this review, aged 70-79. So, this is useful information regarding how aging caregivers might respond to the task of caregiving, however, it does not give a clear picture of how older and younger caregivers differ in social relationships, depression rates, and burden. A more direct study is needed to understand how these variables correlate.

### **Current Study**

The evidence reviewed above yields several important insights about the need to understand differences in the caregiving experience for younger and older caregivers. Increased life expectancy leads to a greater need for care in old age, but this means that family members providing care to their loved ones are aging as well. Excellent provision of care leads to improved physical and mental health for the care recipient and better overall quality of life in the final years. However, a review of studies on caregiving shows connections between poor health outcomes, emotional distress, and loss of relationships. These problems for caregivers lead to difficulties in providing excellent care to their loved ones as well as poor outcomes for the caregiver. To improve the quality of life for both parties, it is imperative to understand how to support caregivers in their role. But not all caregivers have the same needs, and there is little

research regarding the differences between younger and older caregivers related to the moderators and causes of burden and depression.

Burden is problematic due to negative effects on caregivers including reduced mental and physical functioning, decreased quality of life, and the greater likelihood of mood and other psychiatric problems. There is little research explaining the differences in how age is related to burden and its sources. Research indicates that social relationships improve mental and physiological health in caregivers. Peer support is an important aspect of socialization as it has many benefits including friendship and mutual understanding of one's situation. Furthermore, work engagement shows both benefits and disadvantages for caregivers, but further clarification of its effects can improve support for caregivers. Leisure gives caregivers a break from the role of caregiving and reduces stress, but there is less clarity regarding the relationship of age and the time spent and sources of leisure for caregivers. Finally, there are many advantages and disadvantages for individuals based on age. Caregiving can help individuals fulfill developmental tasks of intimacy, generativity, and integrity. Gaining knowledge related to the task of caregiving will improve supports which can be tailored to target specific needs rather than generalizing caregivers regardless of their age.

The present study seeks to increase our understanding of how the caregiving experience is affected by the age of the caregiver. Burden and depression are common experiences of caregivers regardless of age. However, it is unclear how age plays a role in moderating the negative outcomes of caregiving. Social interaction can have positive effects for caregivers of any age, but the impact of the changes in socialization caused by aging and retirement are unclear. Thus, it is hypothesized that social engagement is associated with less depression because it allows caregivers to step outside of their role and receive validating feedback based on

other roles. Engagement with others prevents isolation and rumination on the difficulty of caregiving and related feelings of inadequacy. Second, types of social engagement are different for younger and older caregivers. It is predicted that younger caregivers have more natural sources of socialization through work, parenting activities, and so forth, but older caregivers must actively seek sources of socialization at places of worship, volunteer groups, and the like. Third, younger caregivers will have more social time outside of the home and greater access to resources for socialization. Consistent with previous studies, it is predicted that higher burden is associated with more depression because burden limits time for other activities. Extending prior research, this study examines the difference in burden between younger and older caregivers. It is hypothesized that younger caregivers feel more burdened because they often have more duties such as work and dependent children consuming time and energy. For older caregivers, the task of caregiving feels more normative and fewer commitments allow for more time engaging in self-care; furthermore, caregiving fulfills their developmental needs and helps them see themselves as contributors rather than burdens on society.

## METHODS

### Sampling and Procedures

Data was collected to explore the experience of familial caregivers who provide care to adult loved ones. A convenience sample was employed utilizing caregivers from the Nourish for Caregivers program and individuals from caregiver groups on social media. One hundred forty individuals responded to the request for participation. Incomplete responses were not included in the analysis. This excluded the caregivers who did not complete the GDS-15 and the modified ZBI-short questionnaires. Furthermore, individuals who did not provide their age, were not caregivers of family members, and who did not provide care for at least 20 hours or more per week were removed from the sample. The final number of caregivers was 63 participants.

The mean age of the caregivers was 58.18 ( $SD=11.16$ ). Seventy-three percent were aged 33-64, and 27% were 65 and older. Fourteen (22.2%) provided 20-30 hours of care, 5 (7.9%) provided 30-40 hours of care, and 44 (69.8%) provided 40 or more hours of care per week. Of the participants 88.9% were female, 3.2% were male, and 7.9% did not respond. Racial divisions included 1.6% American Indian or Native Alaskan, 1.6% Black or African American, 6.3% Hispanic, 82% percent white, and 7.9 % did not respond. Caregivers living in the same home as the care recipient totaled 77.8%, while 14.3% live separately, and 7.9% did not respond. Thirty-six-point five percent of caregivers indicated that they work outside of the home with 82.6% of these working 30 hours or more. The care recipient ages ranged from 21-102 with a median age of 80 ( $IQR = 70.5, 88.5$ ). Only 93.8% of caregivers responded to reasons the recipient needed care. The reasons were sorted into categories based on the primary concern; these included: age (19.6%), cancer (3.2%), dementia (42.6%), developmental delays (6.5%), intellectual disability



(4.9%), Parkinson's disease (3.2%), physical disability (16.3%), and stroke (3.2%). Demographic information is simplified in Table A.

Prior to data collection, this study was approved by the Institutional Review Board at Fort Hays State University of Hays, Kansas.

## **Measurements**

### *Depression*

To measure depression, the 15-item Geriatric Depression Scale (GDS-15) was used (Scogin et al., 2000). The GDS-15 contains fifteen yes or no questions targeted at older adults to assess for depression. Questions such as "Do you often get bored? Do you feel happy most of the time? Do you feel full of energy?" appear on the measure. Scores range from 0-15. Some items were reverse scored before summing a total score as indicated by the scoring key. Scores ranging from 0-5 indicate little or no depression, 5-9 signals some depression may be present, and 10 -15 suggests depression is present.

In a meta-analysis review of the GDS-15, Mitchell et al. (2010) found the GDS-15 was rated "good" as a measure for depression in the aging population. The pooled sensitivity was 81.3% ( $p < .05$ ) and the pooled specificity was 78.4% ( $p < .05$ ). Although the GDS-15 is targeted to older adults, a study on the validation for individuals ages 18-54 demonstrated that compared to older adults, the GDS-15 showed 72% sensitivity and 97% specificity in younger adults compared to 86% sensitivity and 91% specificity in older adults (Guerin et al, 2015). Reliability for this study was found to be acceptable ( $\alpha = .717$ ). A copy of the GDS-15 can be found in Appendix A.

### *Burden*

To measure burden, the 12-item short form of the Zarit Caregiver Burden Interview (ZBI-short) was given (Zarit, 1985). The measure was created to assess stress levels in caregivers of the elderly and disabled. This is a twelve-question measure utilizing a five-point Likert scale with answers ranging from never to nearly always. The measure was modified by the researcher to be consistent with the format of the GDS; participants simply answered “yes” or “no” to the items. The correlations between the short and full version of the ZBI ranged from .92-.97 demonstrating comparable results when utilizing the short measure (Bédard et al., 2001). Results of this study demonstrated adequate reliability ( $\alpha = .730$ ). Questions include items such as, “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work? Do you feel that your social life has suffered because you are caring for your relative? Do you feel you could do a better job in caring for your relative?” The modified ZBI-short 12 can be found in Appendix B.

### *Social Engagement*

Measurement of social engagement utilized the Quality of Life and Satisfaction Questionnaire (Q-LES-Q; Endicott et al., 1993). This measure was created to quantify the degree of enjoyment and functioning in several aspects of life. The test has nine subsets, but for purposes of this study only those pertinent to the hypotheses were given. The Work subscale consisted of 13 questions ( $\alpha = .727$ ), the Leisure Time Activities scale had 6 questions ( $\alpha = .906$ ), and the Social Relationships scale had 11 questions ( $\alpha = .791$ ). The measure utilizes a five-point Likert scale asking questions such as, “In the last week, how much of the time have you made social plans with friends or relatives for future activities? In the last week, how often

have you enjoyed your work? When you had time, how often did you use that time for leisure activity?” Subscales utilized from the Q-LES-Q can be found in Appendix C.

### *Demographics and Open-Ended Questions*

Participants were asked demographic information including age of the caregiver, age of the care recipient, relationship with care recipient, sex, race, number of hours spent in caregiving, employment engagement, number of hours worked per week, hours spent caregiving, reasons care is necessary, and whether the care recipient has dementia.

Participants were invited to answer two open-ended questions. “What aspects of caregiving do you find have positive effects on your life? What kinds of things do you need help with to improve your well-being and the quality of care you provide (ex. Rides to appointments, financial assistance, respite care, spiritual help, etc.)?” The demographic and open-ended questionnaires are found in appendix D.

### **Analytic Procedures**

To assess the predicted relationship between social engagement and depression a Pearson correlation was calculated based on scores from the Q-LES-Q scales and the GDS-15. The correlative relationship between burden and depression was assessed utilizing a Pearson correlation based on scores from the ZBI-12 and the GDS-15. To determine the difference in feelings of burden a t-test comparing younger and older caregivers’ scores on the ZBI-12 was used. Multiple t-tests were used to examine the relationship between depression and the dependent variables of social engagement, age, and burden for older and younger caregivers. Finally, multiple t-tests compared older and younger caregivers on the social engagement scales,

work, leisure, and social relationships. All analyses were conducted using SPSS version 29 for windows.

Following the format of other research in the field, descriptive data was analyzed using frequency and percentages. Open-ended questions were compiled, and themes were noted. These themes do not necessarily address the value of the respondents' needs, but they do provide an overview of the subjects' mindfulness to themes.

## RESULTS

### **Social Engagement**

#### *Social Engagement and Depression*

It was hypothesized that more social engagement is associated with less depression. For the purposes of this study, social engagement was measured from three perspectives, leisure time, work, and social relationships. Table B shows correlations between depression and work, leisure, and social relationships, utilizing Pearson Correlations. As shown in the table, all three measures of social engagement were significantly  $p < 0.05$  correlated with depression. Higher levels of depression are associated with lower levels of social engagement at work, quality of leisure, and enjoyment of social relationships in support of the hypothesis that social engagement and depression are negatively associated.

#### *Types of Social Engagement and Age*

It was projected that types of social engagement are different for younger (age 64 and younger) versus older (aged 65 and older) caregivers. The rationale for dividing groups at age 65 is related to the retirement age in the United States. By age 65 many individuals are either retired or planning to soon; furthermore, many will have no more children left in the home. These factors might change levels of engagement for the two age groups. Multiple t-tests were performed based on the age groupings and the Q-LES-Q scales for Work, Leisure, and Social Relationships. There was not a significant difference found between the older and younger caregivers on any of the three measures of social engagement when assuming equal variances and one tailed significance. When younger and older caregivers were compared on the variables

work  $t(22) = .634, p = .533$ , leisure  $t(56) = -.520, p = .602$ , and social relationships  $t(55) = .010, p = .992$  little diversity in type of social engagement was present.

#### *Time for Social Engagement and Age*

A t-test was used to assess the hypothesis that younger caregivers have more social time outside of their home and greater access to resources for socialization. A t-test was conducted comparing younger and older caregivers and the amount of leisure time in which they engaged. No significant differences were found between younger and older caregivers in relation to the amount of leisure time they had weekly ( $t(53) = .567, p = .303$ ); although older caregivers reported more leisure, the difference was not significant.

### **Burden**

#### *Burden and Depression*

It was hypothesized that more depressive symptoms are associated with greater burden. The relationship was assessed using a Pearson correlation between the burden interview and the depression scale. The results generated a significant correlation  $r(61) = 0.414, p = 0.001$ . As hypothesized, more burden was associated with higher levels of depression.

#### *Burden and Age*

It was also predicted that younger caregivers would experience greater burden than older caregivers. Utilizing an independent samples t-test, younger and older caregivers were compared. Younger caregivers experienced significantly more burden ( $M = 8.24, SD = 3.01$ ) than

older caregivers ( $M = 6.39, SD = 2.56$ )  $t(62) = 2.47, p = 0.01$  supporting the hypothesis that younger caregivers experience greater burden.

### **Caregiver Report of Needs**

Qualitative data was collected to gain a greater understanding of the specific needs of caregivers. An open-ended format was utilized to allow caregivers to make suggestions beyond the scope of this study. Caregivers indicated needs for respite care, financial help, instrumental help, social and family time away from the care recipient, spiritual aid, and extended time away from caregiving. Table C summarizes these themes.

## DISCUSSION

The human lifespan has increased with innovations in medicine and technology. This means that there are more older people in need of instrumental support provided by caregivers. This role is often filled by members of the family. Because the population care recipients are aging, it is likely that those caring for them age alongside of them. Taking this into consideration, this study sought to understand how caregiving relates to aging. The objective was to determine if younger caregivers and older caregivers have different needs and experiences related to burden, depression, and social engagement. The results of this study can provide insight to providers about the kinds of support that caregivers have and those that they may still need. This knowledge can help the providers to create better systems of support for caregivers and improve the overall quality of care delivered.

It was predicted that younger caregivers experience more burden than those who are older. As predicted, younger caregivers reported significantly higher levels of burden than older caregivers. There are several reasons this could be true. Younger people tend to be more involved in other activities that require great amounts of time and energy. These individuals may be working full time, caring for children, and maintaining a household. These activities are challenging for anyone, but adding caregiving into the mix is an additional challenge to an already difficult season in life. Young people may not feel as ready to provide care to loved ones particularly if their peers are not providing care. They may feel caregiving creates limitations on their ability to engage in activities such as travel, romantic relationships, and child rearing. This supports Hui et al.'s (2010) statement that older caregivers see caregiving as a normative task. Younger people hope to spend time doing many things, but caregiving does not fit into their expectations and therefore may increase their feelings of burden. Perhaps one solution is to



connect younger caregivers with one another in supportive peer relationships. If young caregivers only connect with other caregivers who are older than them, it might make them feel isolated and fuel their feelings that caregiving is burdensome. Improving connections between young caregivers may reduce burden for them thus helping them feel better about their role.

Another reason it is important to reduce feelings of burden in younger caregivers is related to the hypothesis that burden is correlated to depression. The results of this study indicate that individuals who experience more burden have greater depressive symptoms. Roth et al. (2009) discovered that burden is related to quality of life in caregivers. This could be because those with poor quality of life feel as though things are hopeless and will not become better regardless of their efforts. This may be truer for caregivers who care for individuals with permanent disabilities or those who are near death. In either situation, caregiving ultimately ends with the death of their loved one. This may create a sense of dissonance as the individual wants the burden to go away, but they do not want to lose the person they care for deeply. The internal struggle could lead to depression due to guilt related to the desire to be free from caregiving. As described in the results to the second open-ended question and summarized in Table C, caregivers listed respite care as important to helping with improving outcomes in their social engagement. Other needs mentioned in subject's responses may help reduce feelings of burden. They mentioned needs such as financial support, engagement in care from other families, help with transportation, and assistance with household activities such as cooking, cleaning, and home maintenance. Many caregivers also mentioned the need for spiritual help. Availability of resources to support caregivers would likely cause a decrease in burden which could also decrease depression. Ultimately, this may improve the quality of care provided because the caregiver might feel more capable and less overwhelmed.

It was predicted that social engagement would have a negative correlation with depression which is supported by this study. The relationship between social engagement and depression is valuable because it demonstrates that caregivers need involvement outside of this role. It was also predicted that older and younger caregivers would participate in different types of social activities and that older caregivers would have more time to be social than those who are younger. Older and younger caregivers did not differ in types of social activities, but consistent with the study by Bedini et al. (2018), quality of engagement makes the most impact. This is further supported by responses of caregivers to the second open-ended question at the end of the study “What kinds of things do you need help with to improve your well-being and the quality of care you provide?” Of the 58 caregivers who responded to this query, 37 stated respite care. One responder indicated how helpful getting away from caregiving would be stating, “Respite, respite, respite!” Other caregivers indicated their need for respite care to have some social interaction with responses such as, “Respite for some time off to be with my family.” “Respite, the ability to return to my work and self-care.” “Respite. If I took better care of myself, I would feel so much better about everything, but I am so sad and lonely.” Xu et al. (2022) found similar results in their study which suggested lack of trustworthy respite care as a reason for limited leisure time outside of the home for caregivers.

Furthermore, caregivers understand the importance of social engagement for their wellbeing. Several stated that they need help so they can socialize. One caregiver said that they “just [want] someone who is understanding, allowing me to vent without cause.” Another indicated that they would like to go back to work, “[I] had to take a leave from work to be able to do this because the demand of everything 24/7 was impossible.” And several others simply stated, “social life.” Caregiving time may overtake social time for many which may be a reason

that Cannuscio et al. (2004) found that depression rates are six and a half times greater in caregivers that spend more time caregiving. One commonly prescribed behavior to reduce depression is socialization; if there is not time to be with others, it makes sense that caregivers struggle with depression.

It is evident from prior research and supported by this study that caregivers need engagement socially. They may achieve this through relationships, working, and leisure activities. Where support comes from and how much time they can spend in social engagement is less important than the quality of the engagement the caregiver receives. One-way caregivers hope to achieve more social opportunities is through respite care which allows them to leave their loved one with the peace of mind they will be cared for and safe. The ability to engage with others and the correlation of reduction of depressive symptoms is unsurprising as social engagement is a frequent recommendation to individuals with depression. Therefore a conclusion may be made that one way to improve mental health outcomes for caregivers and ultimately improve the quality of care, is to encourage social engagement.

It was postulated that younger caregivers would have more time to engage in social engagement than older caregivers. The results of this study showed that older caregivers had slightly more social time than those who are younger. This is likely due to working, child rearing, and other similar activities; nonetheless, the difference was not significant. This indicates that time for socialization may be problematic for all caregivers regardless of their age.

When discussing the challenges of caregiving, it is important to remember that individuals become caregivers for several reasons, but likely due to love for their family member. This love helps them to find the task rewarding. When asked, caregivers said

mentioned reciprocal love, “My girls are the happiest people on the planet. They love you no matter what.” Other caregivers mentioned that they appreciate the quality time with their loved one and the ability to receive stories and family histories they might have otherwise missed. They describe feeling fulfilled due to knowledge that they are providing a necessary service to their loved one and improving their quality of life. One said, “I have a kind and generous nature. I am where I want to be, doing what I want to be doing. My husband expresses appreciation frequently.”

### **Limitations**

While this study showed significant results in some areas, the small sample size may be a limiting factor. A larger sample population may show greater significance in age related differences producing important information regarding creating supportive programming. Increasing the sample of older caregivers may yield more information about age related differences, particularly related to social engagement. This study is also limited due to utilization of convenience sample methods. The caregivers who responded were members of either in-person or online support groups created for caregivers. This means that they are actively seeking support, but samples from caregivers not engaged in a support group may change results on scales of social engagement and depression.

### **Future Study**

Future studies related to caregiving and age could improve the understanding of age differences by looking at differences in depression rates based on age. The results of this study approached significance when comparing differences in social engagement on age, but a larger sample size of older caregivers might produce stronger results. Furthermore, this study does not

focus on multicultural aspects of caregiving and age. In a study of caregiver demographics by Anderson et al. (2013), the majority of caregivers identified their race as non-Hispanic black. The sample from this study does not reflect that. Obtaining a racially diverse sample of caregivers and examination of both age and racial variables in relation to social engagement, burden, and depression would give a greater scope of understanding of the nature of support caregivers require. Finally, creation of a measure rather than utilizing the Q-LES-Q may provide more precise measurement of social engagement activities and time spent connecting with others.

### **Conclusion**

To help caregivers improve their experience of caregiving and encourage them to focus on the positive aspects of caregiving, it is necessary to reduce their negative experiences. Ultimately, this means focusing on two areas of support. As this study suggests, social engagement is positively associated with depression in caregivers while burden is negatively associated with it. Providers should focus on creating and improving outlets of social engagement for caregivers. They should encourage caregivers to take advantage of any opportunity to spend time with other people and do things they enjoy regularly. Furthermore, providers should explore resources that help reduce burden in caregiving. According to the themes provided to this study (see Table C), this includes respite care, social and familial interaction, financial assistance, help with instrumental tasks at home and in caregiving, spiritual help, and extended time away from caregiving. Provision of better care for caregivers will likely cause better care for care recipients and improve the quality of life for both.

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TABLE A  
Demographic Results

	<i>N</i>	<i>%</i>
Age		
33-64	45	71.4
65 and Older	18	28.6
	<i>(M = 58.4, SD = 11.18)</i>	
Hours of Care/Week		
20-30 hours	14	22.2
30-40 hours	5	7.9
40 or more hours	44	69.8
Sex		
Female	56	88.9
Male	2	3.2
Race		
Native American or Native Alaskan	1	1.6
Black or African American	1	1.6
Hispanic	4	6.3
White	52	82
Cohabitate with Care Recipient		
Yes	49	77.8
No	9	14.3
Work Outside of Home		
Yes	23	36.5
No	34	54
Hours of Work/Week		
<10 hours	1	1.6
10 - 20 hours	1	1.6
20-30 hours	2	3.1
30-40 hours	8	12.5
40 or more hours	11	17.2
Care Recipient Ages		
20-39	6	8.6
40-59	3	4.2
60-69	10	14.2

	70-79	18	25.7
	80-89	22	31.4
	90 or greater	11	15.7
		<i>m</i> = 80 ( <i>IQR</i> = 70.5, 88.5)	
Reason for Care			
	Age	12	19.6
	Cancer	2	3.2
	Dementia	26	42.6
	Developmental Delays	4	6.5
	Intellectual Disability	3	4.9
	Parkinson's Disease	2	3.2
	Physical Disability	10	16.3
	Stroke	2	3.2

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TABLE B

**Correlations of Depression and Social Engagement**

	<i>r</i>	<i>Significance (1-tailed)</i>	<i>N</i>
Work	-0.434*	0.017	24
Leisure	-0.266*	0.022	58
Social Relationships	-0.429**	<0.001	57

\*\*Correlation is significant at the 0.01 level (1 tailed)

\*Correlation is significant at the 0.05 level (1 tailed)

TABLE C

**Themes of Caregiver Needs**

	<i>n</i>	%
Respite Care	37	63.8
Financial Help	13	22.4
Instrumental Help (cooking, cleaning, driving, etc.)	13	22.4
More Social Time & Time with Family	8	13.8
Spiritual Help/ Prayers	6	10.3
Extended Time Away (Vacation)	5	08.6

Table C

*n* = 58

APPENDIX A

**15-Item Geriatric Depression Scale**

Instructions: Circle the answer that best describes how you felt over the past week.

- |   |            |           |
|---|------------|-----------|
| 1. Are you basically satisfied with your life?                            | yes        | <b>no</b> |
| 2. Have you dropped many of your activities and interests?                | <b>yes</b> | no        |
| 3. Do you feel that your life is empty?                                   | <b>yes</b> | no        |
| 4. Do you often get bored?  | <b>yes</b> | no        |
| 5. Are you in good spirits most of the time?                              | yes        | <b>no</b> |
| 6. Are you afraid that something bad is going to happen to you?           | <b>yes</b> | no        |
| 7. Do you feel happy most of the time?                                    | yes        | <b>no</b> |
| 8. Do you often feel helpless?  | <b>yes</b> | no        |
| 9. Do you prefer to stay at home, rather than going out and doing things? | <b>yes</b> | no        |
| 10. Do you feel that you have more problems with memory than most?        | <b>yes</b> | no        |
| 11. Do you think it is wonderful to be alive now?                         | yes        | <b>no</b> |
| 12. Do you feel worthless the way you are now?                            | <b>yes</b> | no        |
| 13. Do you feel full of energy?   | yes        | <b>no</b> |
| 14. Do you feel that your situation is hopeless?                          | <b>yes</b> | no        |
| 15. Do you think that most people are better off than you are?            | <b>yes</b> | no        |

Score: \_\_\_\_\_



APPENDIX B

**Zarit Caregiver Burden Interview (Short, 12-items)**

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	No	Yes
Do you feel you don't have enough time for yourself?	0	1
Do you feel stressed between caring and meeting other responsibilities?	0	1
Do you feel angry when you are around your relative?	0	1
Do you feel your relative affects your relationship with others in a negative way?	0	1
Do you feel strained when are around your relative?	0	1
Do you feel your health has suffered because of your involvement with your relative?	0	1
Do you feel you don't have as much privacy as you would like, because of your relative?	0	1
Do you feel your social life has suffered because you are caring for your relative?	0	1
Do you feel you have lost control of your life since your relative's illness?	0	1
Do you feel uncertain about what to do about your relative?	0	1
Do you feel you should be doing more for your relative?	0	1
Do you feel you could do a better job in caring for your relative?	0	1

Scoring Instructions: Add Items 1-12 (maximum score = 12) \_\_\_\_\_

APPENDIX C

**Quality of Life Enjoyment and Satisfaction Questionnaire**

*Work*

Do you:

- have a job?            yes                    no  
 work for yourself?   yes                    no  
 do volunteer work?   yes                    no

If *no to **all three*** questions above, why?

- \_\_\_\_\_ Too physically ill  
 \_\_\_\_\_ Too emotionally upset  
 \_\_\_\_\_ Retired  
 \_\_\_\_\_ Other (please specify) \_\_\_\_\_

If *yes to **any of the three*** questions above, please complete this section (Consider paid work, volunteer work, and self-employment work).

In the past *week*, how often have you...

	<b>Not At All or Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often or Most of the Time</b>	<b>Frequently or All of the Time</b>
Enjoyed your work?	1	2	3	4	5
Solved work problems or dealt with them without undue stress?	1	2	3	4	5
Thought clearly about work?	1	2	3	4	5
Been decisive about work or made decisions when needed?	1	2	3	4	5
Accomplished what you wanted to do?	1	2	3	4	5
Been pleased with your work accomplishments?	1	2	3	4	5
Worked well?	1	2	3	4	5
Been interested in your work?	1	2	3	4	5
Concentrated on your work?	1	2	3	4	5
Worked carefully?	1	2	3	4	5
Kept up with expected work?	1	2	3	4	5
Taken care of work by yourself when it was necessary?	1	2	3	4	5
Communicated and interacted with ease with others while working?	1	2	3	4	5

Score: \_\_\_\_\_

*Leisure Time Activities*

The following questions refer to activities such as watching TV, reading the newspaper or magazines, tending to houseplants or gardening, hobbies, going to museums or the movies, or to sports events, etc.

In the past *week*....

About how many hours did you spend in leisure (round to nearest half hour so one- and one-half hours would be 1.5) \_\_\_\_\_ hours.

	<b>Not At All or Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often or Most of the Time</b>	<b>Frequently or All of the Time</b>
When you had time, how often did you use that time for a leisure activity?	1	2	3	4	5
How often did you enjoy the leisure activities?	1	2	3	4	5
How often did you look forward to the leisure activities before spending time at them?	1	2	3	4	5
How often did you pay attention to the leisure activities and pay attention to them?	1	2	3	4	5
If a problem arose in your leisure activities, how often did you solve it or deal with it without undue stress?	1	2	3	4	5
How often did leisure activities sustain your interest?	1	2	3	4	5

Score: \_\_\_\_\_

*Social Relationships*

During the past week, how much time have you...

	<b>Not At All or Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often or Most of the Time</b>	<b>Frequently or All of the Time</b>
Enjoyed talking or being with friends or relatives?	1	2	3	4	5
Looked forward to getting together with friends or relatives?	1	2	3	4	5
Made social plans with friends or relatives for future activities?	1	2	3	4	5
Enjoyed talking with coworkers or neighbors?	1	2	3	4	5
Been patient with others when others were irritating in their actions or words?	1	2	3	4	5
Been interested in the problems of other people?	1	2	3	4	5
Felt affection toward one or more people?	1	2	3	4	5
Got along well with other people?	1	2	3	4	5
Joked or laughed with other people?	1	2	3	4	5
Felt you met the needs of friends or relatives?	1	2	3	4	5
Felt your relationships with friends or relatives were without major problems or conflicts?	1	2	3	4	5

Score: \_\_\_\_\_

## APPENDIX D

### Demographic Information

1. How old are you?
2. What sex are you?
  - a. Male
  - b. Female
3. What is your race?
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or Other Pacific Islander
  - e. White
  - f. Hispanic or Latino
4. What is your relationship with the person for whom you provide care?
  - a. Child (or Stepchild)
  - b. Spouse
  - c. Child In-Law
  - d. Parent of an Adult Child
  - e. Other (please specify)
5. How old is the person receiving care?
6. Do you live in the same home as the individual receiving care?
7. How many hours per week do you spend caregiving?
  - a. Less than 10
  - b. 10-20
  - c. 20-30
  - d. 30-40
  - e. More than 40
8. What is the reason the individual receiving care needs it?
9. Does the individual receiving care have some form of dementia diagnosis (Alzheimer's, Lewy Body, Vascular, etc.)?
  - a. Yes
  - b. No
10. Are you employed?
  - a. Yes
  - b. No
11. How many hours do you work each week?

- a. Less than 10
- b. 10-20
- c. 20-30
- d. 30-40
- e. More than 40
- f. I am not employed

#### Open-Ended Questions

1. What aspects of caregiving do you find have positive effects on your life?
2. What kinds of things do you need help with to improve your well-being and the quality of care you provide (ex. Rides to appointments, financial assistance, respite care, spiritual help, etc.)

APPENDIX E

**IRB Letter of Exemption**



**FORT HAYS STATE  
UNIVERSITY**

*Forward thinking. World ready.*

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OFFICE OF SCHOLARSHIP AND SPONSORED PROJECTS

DATE: June 7, 2023

TO: Danielle Forbes

FROM: Fort Hays State University IRB

STUDY TITLE: [2061418-1] The Association of Burden and Social Engagement with Depression in Adult Child Caregivers by Age

IRB REFERENCE #: 23-0115

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: June 7, 2023

REVIEW CATEGORY: Exemption category # 2

Thank you for your submission of New Project materials for this research study. The departmental human subjects research committee and/or the Fort Hays State University IRB/IRB Administrator has determined that this project is EXEMPT FROM IRB REVIEW according to federal regulations.

Please note that any changes to this study may result in a change in exempt status. Any changes must be submitted to the IRB for review prior to implementation. In the event of a change, please follow the Instructions for Revisions at <http://www.fhsu.edu/academic/gradschl/irb/>.

The IRB administrator should be notified of adverse events or circumstances that meet the definition of unanticipated problems involving risks to subjects. See <http://www.hhs.gov/ohrp/policy/AdvEvtGuid.htm>.

We will put a copy of this correspondence on file in our office. Exempt studies are not subject to continuing review.

If you have any questions, please contact Keith Bremer at [IRB@fhsu.edu](mailto:IRB@fhsu.edu). Please include your project title and reference number in all correspondence with this committee.

## APPENDIX F

### **Recruitment Message**

Greetings! My name is Danielle Forbes. I am a student of clinical psychology at Fort Hays State University in Hays, Kansas. In order to fulfill the requirements for my degree, I have chosen to engage in a research project. The goal of this project is to gain a greater understanding of the experience of caregivers who provide care to other adults. The study consists of several surveys related to feeling about caregiving and life in general. It should take about 20-30 minutes of your time. If you are interested in learning more about participation, please click the link below, and you will be taken to a page with additional information.



## APPENDIX G

### Informed Consent

#### INTRODUCTION

The Department of Psychology at Fort Hays State University supports the practice of protection for human subjects participating in research. **You are being asked to participate in a research study. It is your choice whether or not to participate.** The following information is provided for you to decide whether you wish to participate in the present study. You may refuse consent and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or Fort Hays State University.

#### PURPOSE OF THE STUDY

This study focuses on the experiences of individuals providing care to adults. The research can give insight into the challenges and benefits of caregivers, and how the age of the caregiver may differentiate the experience of providing care.

#### PROCEDURES

During this study, you will be asked to answer questions about your mood and activities. There are several short questionnaires. At the end of the questionnaires there will be several questions regarding your demographic information, but no identifying information will be collected. Finally, there are two open-ended questions that may be utilized to share any information or insights not contained in the questionnaire.

**If you decide to participate in this research study, you will be asked to check “yes” in the box below. The length of time of your participation in this study is 20-30 minutes. Approximately 60 participants will be in this study.**

#### RISKS

There are no anticipated risks associated with the survey. However, there are questions related to your mental wellness. If you become upset by the survey, please stop the survey, and call a licensed psychotherapist in your area or the crisis line at 988.

#### BENEFITS

Benefits related to this study include greater understanding of the needs of caregivers. This research may be utilized to create and enhance support systems to improve the experience of caregiving and improve the quality of care given.

#### PAYMENT TO PARTICIPANTS

There is no payment incentive for participation in this study.

#### PARTICIPANT CONFIDENTIALITY (HOW WILL PRIVACY BE PROTECTED)

Identifying information is not to be collected in this study, thus all information shared will remain confidential.

Permission granted on this date to use and disclose your information remains in effect indefinitely. By selecting “yes” below you give permission for the use and disclosure of your information for purposes of this study at any time in the future.”

### **OTHER IMPORTANT ITEMS YOU SHOULD KNOW**

- **Withdrawal from the study:** You may choose to stop your participation in this study at any time. Your decision to stop your participation will have no effect on the quality of care, participation in caregiver support groups, etc.
- **Funding:** There is no outside funding for this research project.

### **REFUSAL TO SIGN CONSENT AND AUTHORIZATION**

You are not required to select “yes” to this Consent and Authorization form, and you may refuse to do so without affecting your right to any services you are receiving or may receive from Fort Hays State University or to participate in any programs or events of Fort Hays State University. However, if you refuse to select “yes,” you cannot participate in this study.

### **CANCELLING THIS CONSENT AND AUTHORIZATION**

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose further information collected about you, in writing, at any time, by sending your written request to:

Danielle Forbes  
c/o Stephanie Weigel, PhD.  
600 Park St.  
Fort Hays State University  
Hays, KS 67601

If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

### **QUESTIONS ABOUT PARTICIPATION**

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

### **PARTICIPANT CERTIFICATION:**

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 628-4349, write the Office of Scholarship and Sponsored Projects (OSSP), Fort Hays State University, 600 Park St., Hays, Kansas 67601, or email [irb@fhsu.edu](mailto:irb@fhsu.edu).

I agree to take part in this study as a research participant. By selecting “yes” I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

**RESEARCHER CONTACT INFORMATION:**

Danielle Forbes	Stephanie Weigel, Ph.D.
Principal Investigator	Faculty Supervisor
Department of Psychology	Department of Psychology
600 Park St.	600 Park St.
Fort Hays State University	Fort Hays State University
Hays, KS 67601	Hays, KS 67601
(785) 628-5555	(785) 628-5555

Do you give consent to participate in this study?

- a. Yes
- b. No

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Non-Exclusive License Author Agreement**

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I agree that authorized readers of the Thesis have the right to use the Thesis for non-commercial, academic purposes, as defined by the "fair use" doctrine of U.S. copyright law, so long as all attributions and copyright statements are retained.

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Thesis: The Association of Burden and Social Engagement with Depression in Caregivers of Adults by Age

Author: Danielle Leigh Forbes

Signature:  \_\_\_\_\_

Date: 17 November 2023