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ELDERLY CARE AND THE MULTIPLE-ROLE WOMAN:
HOW SOCIAL SUPPORT MAY EASE CAREGIVER BURDEN

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ABSTRACT

Informal family caregivers experience a wide range of demands and difficulties that impact their physical, mental, emotional, and relational well-being. Middle-aged women who provide care for an elderly dependent adult are forced to balance caregiving alongside the duties they fulfill in a host of other relationships and roles in their life. Much research has been done on the impacts of caregiving on informal family caregivers, and this study looks specifically at how caregiving affects a woman's relationships and communication within those relationships. The purpose of this study is to better understand the lived experience of female caregivers around midlife who are providing care for an elderly dependent adult while balancing a wide variety of responsibilities in other role spheres of their life. Analyses reveal both the relational benefits that may arise through the caregiving experience and the detrimental impacts it can have on one's health and relational well-being. This study highlights the importance of social support in providing a multidimensional support system for individuals struggling with the hardships of caregiving.

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LITERATURE REVIEW

As global life expectancy continues to grow due to medicinal and technological advances, the number of elderly adults worldwide is rising rapidly. While there are over 900 million individuals aged 60 and over living in the world today, this number is expected to more than double in the next 30 years (“Ageing,” 2018). Although disparities exist among various low-income countries, life expectancy has been steadily increasing throughout the world for decades due to advancements in public health for the elderly population. Furthermore, while the number of elderly adults worldwide is increasing steadily each year, the proportion of elderly adults in today’s society is likewise growing at a rapid rate. The world population aged 60 and over is increasing at a rate of three percent each year, which is faster than any younger age group (“Ageing,” 2018). Due to both declining fertility rates and increased longevity, elderly adults are quickly becoming the fastest growing age group on the planet.

As societies continue to age globally, a greater proportion of the population is likewise becoming susceptible to chronic elderly diseases, and cognitive disorders such as dementia have become particularly prevalent. Dementia is a general term used to describe symptoms common to several specific diseases associated with decline in memory and other cognitive skills that interfere with one’s daily life (“What is dementia,” 2018). While Alzheimer’s disease accounts for roughly three quarters of cases, a variety of mental disabilities may lead to dementia symptoms that reduce one’s ability to perform everyday tasks. Roughly 50 million people worldwide are currently living with dementia, and with an elderly population that is growing faster than ever before, this number is expected to nearly double every 20 years (“Dementia

statistics,” 2015). By the year 2050, it is projected that there will be over 130 million people across the planet living with dementia.

As life expectancies rise globally and the proportion of elderly adults continues to climb, an increasingly greater burden has fallen upon the next generation to provide care for such elderly adults. With cases of dementia and other disabling conditions rising among a growing elderly population, more adults are becoming dependent upon caregivers to perform daily tasks and maintain a healthy lifestyle. Many of these elderly adults are no longer capable of living alone and require daily assistance. In response, there are roughly 15.7 million informal caregivers, more now than ever before, who have stepped into this role to meet the growing demands of the older generation (“Caregiver statistics: demographics,” 2016). In the United States alone, informal caregivers save the healthcare system about 350 billion dollars each year, fulfilling a multitude of care needs (Bastawrous, 2013). Rather than being admitted to hospitals or care homes upon the onset of such a disease, elderly adults often become dependent upon caregivers who provide assistance with a wide range of tasks for daily living.

The vast majority of this type of caregiving falls on the family of the elderly adult, and these families are usually not paid or supported in any way by local, state, or federal programs. About 65 percent of elderly dependent adults rely on support from the informal caregiving of family members and friends, while another 30 percent rely on some combination of family support alongside the assistance of paid caregivers (“Women and caregiving,” 2016). When family members and friends provide this type of support, they are usually not compensated financially for their services, but they assume the role of caregiver out of necessity. Informal caregivers take responsibility by helping elderly adults achieve basic tasks of daily living, including a wide range of services. Typical caregiving duties can include meal preparation,

transportation, management of financial affairs, and countless other tasks. In most situations, there is usually one primary caregiver who fully embraces this role, while several secondary caregivers may play their part to aid the primary caregiver.

Among informal caregivers, the majority of primary caregivers consists of women around midlife. Roughly 66 percent of caregivers are female, and the Family Caregiver Alliance describes the average caregiver as a 49-year-old woman who provides unpaid care for her mother while also working outside the home (“Women and caregiving,” 2016). While there is certainly a wide range of differences between caregivers, the majority of elderly caregivers in today’s world fits the general description of a middle-aged woman who is caring for one of her parents. Beyond providing care services, many of these women juggle multiple other roles in life, and a great number of responsibilities fill the daily life of this prototype woman. Often characterized as “women in the middle”, these women are usually divided among several spheres of life, where they fulfill responsibilities as a wife, mother, employee, friend, or volunteer. Already committed to a wide range of duties, the responsibility of caregiving becomes just one more component that a woman must weave into the fabric of her daily life.

After adding caregiving for an elderly adult to an already enormous load of different responsibilities, most caregivers quickly become susceptible to the stressful and widespread dilemma known broadly as caregiver burden (Adelman et al., 2014). Since caregiver burden takes on many specific forms, it is difficult to pin a strict definition to the term, but Adelman et al. provided a well-rounded definition after conducting a study on caregiving among husbands and wives. They define caregiver burden as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning” (2014, p. 1053). This multidimensional definition provides a thorough framework

for understanding how pervasive caregiver burden can be across all aspects of an individual's life, taking its toll on every component of one's holistic health. Caregiver burden is remarkably prevalent in the world today. While its broadly defined nature makes it difficult to analyze, it is clear that caregiver burden has been a common struggle among caregivers for decades.

While caregiver burden is composed of a number of different aspects, some theories attempt to summarize these modes into a distinct framework of understanding. Following a cross-sectional study of dementia caregivers, Springate (2014) identified three main factors of caregiver burden: direct impact of caregiving on caregivers' lives, guilt, and frustration/embarrassment. Through interviews and a series of surveys, the study found that these three categories provided a fairly comprehensive framework that encompassed most of burdensome factors of caregiving. This serves as evidence that while the daily tasks of caregiving can be physically demanding on an individual, the mental and emotional toll can also have a powerful influence. Indeed, the caregiving experience can induce a wide variety of emotions, fears, and insecurities that burden the individual.

More specifically, behavioral problems and overall health decline in the elderly adult being cared for seem to be two of the largest determinants of caregiver burden. A systematic review by Lee (2014) analyzed 32 studies of caregiver burden models and found that behavioral problems repeatedly surfaced as the largest factor in determining perceived caregiver burden. Consistent with these results, a retrospective study conducted by Stewart (2014) on dementia caregivers also found that behavioral problems among the adults being cared for was associated with increased burden. Stewart also discovered that overall health decline of the elderly adult also contributed greatly to perceived burden, measuring up as another strong determinant.

With its numerous causes and various modes, caregiver burden may lead to a great variety of health complications among caregivers, including depression and anxiety. In a study comparing dementia caregivers with non-caregivers, Stalder (2014) found elevated levels of chronic stress and depression among caregivers. Indeed, the vast majority of the current literature on caregiver burden identifies depression and anxiety as two of the most common symptoms associated with this condition. Often pointing to causes like the ones mentioned above, factors of caregiver burden such as behavioral problems and health decline among the elderly adult are highly associated with depression and anxiety for the caregiver. One literature review conducted gathered evidence from 228 correlational studies on caregiving and found that depression was very frequently accompanied by caregiver burden and the caregiving experience as a whole (Cheng, 2017). The physical and emotional demands of caring for any elderly adult with dementia, let alone one's own parent, take an overwhelming toll on one's mental state.

While the depression and anxiety associated with caregiver burden often make up the common experience among caregivers globally, women are even more likely than men to experience these symptoms. In another study demonstrating the effects of caregiver burden, the Caregiver Burden Inventory was used to analyze levels of burden among 86 dementia caregivers, and women showed significantly higher scores than men (Iavarone, 2014). The study found consistently higher levels of stress and anxiety among females compared to males, and it also demonstrated a correlation between the severity of dementia and increased caregiver burden. Another study analyzing levels of burden among 873 male and female caregivers also found that women experienced greater levels of caregiver burden than men (Chappell, 2014). These studies, as well as many others within the field, indicate that while caregiver burden and the depressive

symptoms that go along with it are quite ubiquitous throughout the caregiving population, the experience is particularly common among women.

While it is clear that caregiving often leads to many immediate negative health effects, fewer studies have been conducted to test the persistence of such health effects over time, but evidence still suggests that long term effects can be common. In another study, Caputo (2016) interviewed caregivers from a life course perspective and found that the caregiving experience does in fact lead to significant long term health effects. Examining how a caregiver's experiences were shaped and changed dynamically over time, Caputo found that depression stood out as a persistent symptom of caregiver burden that accompanied caregivers over time, often even long after caregiving had ended. Furthermore, Caputo found that depressive symptoms were even more prevalent among caregivers who had cared for an elderly adult within their own home, over those who had performed services outside their home. However, caregivers who lived both with and without their elderly adult demonstrated negative long term health effects.

While dementia caregiving on its own can already be such a stressful, tiresome, and anxiety-inducing experience, many of these female caregivers fulfill a multitude of additional life roles, which often lead to an even greater stress load. While providing care for her parent, a woman may also be carrying out the typical duties of being a wife, a mother, an employee, and likely a member of some other friend group or social organization. The time, energy, and emotional commitments required for each of these obligations can become increasingly taxing on an individual who is being divided across so many role spheres. One helpful theory for describing the nature of this experience is the competing demands hypothesis, which argues that responsibilities across multiple roles create demands on female caregivers that compete for limited time and energy (Shifren, 2009). The competing demands hypothesis offers a theoretical

framework for better understanding the potential negative impacts of fulfilling so many roles. While this theory examines role quantity rather than quality, it may certainly prove useful for understanding the experience of the middle-aged female caregiver.

In her book *How Caregiving Affects Development*, Shifren (2009) explores evidence for the competing demands hypothesis among female caregivers at midlife. Reviewing the existing literature on the topic, Shifren found that these women often experience a wide range of stressors across the various roles they fulfill, and these have significant impacts on psychological well-being. Many of these stressors come from the person receiving care, who may criticize the caregiver and complain frequently; this places greater demands on the caregiver's emotional state. These demands are often matched with stress from a woman's role as both a mother and a wife, as she must spend a great deal of time and energy carrying out the same duties and tasks she was responsible for before caregiving. In their book *Ageing Families and Caregiving*, Qualls and Zarit (2009) also explain how stress among these other roles may also begin to erode the female caregiver's sense of mastery and self-efficacy. When mother-child arguments, marital strains, and complications among other friend groups develop, a woman's physical resources may quickly become depleted, and her reserves of emotional bandwidth may dwindle as well.

When considering a female caregiver's experience from such a wide scope, it quickly becomes evident that these women must balance their desires and motivations to support an elderly adult with the demands and obligations within the rest of their relationships. Most of the time these women are caring for people who are very dear to them, such as a parent, so motivations to offer care in this sphere easily conflict with desires to fulfill duties as a wife, mother, or friend. After interviewing women in this position, Quinn (2013) describes this balance as an ongoing tension that women must wrestle with as they divide their time among several

spheres and encounter several relational dilemmas along the way. Entering dilemmas that force these women to make sacrifices is a common experience even outside of other family relationships. One study also found that female caregivers are less likely to be in the workforce than females who are not caregivers (Lee & Tang, 2013). Indeed, many women must either meet the intense demands of working a job while caregiving or sacrifice employment opportunities; this further demonstrates the continuous balance these women must maintain, which often forces them to make decisions that sacrifice good things.

As the competing demands hypothesis would suggest, several studies show that the impact of caregiving on the other role spheres a woman fulfills can lead to poorer health and a greater level of caregiver burden. After reviewing research done on the impact of informal caregiving on an individual's health across other role spheres, Bauer and Sousa-Posa (2015) found that caregiving is often detrimental to one's psychological health. In turn, Bauer and Sousa-Posa found that these negative impacts on psychological health also led to further complications and harmful influences on physical health. The time a woman spends caregiving is often very demanding, but the effects this stress can have on other role spheres outside of caregiving are profound.

Stress theory and role theory take a similar angle to the competing demands hypothesis to demonstrate the adverse effects of juggling all these roles (Bastawrous, 2013). These theories attempt to offer a better understanding of caregiver burden by clarifying the multidimensional nature of the term in regards to a woman's many role spheres. Stress theory identifies caregiver burden as a primary stressor that may influence other secondary stressors in an individual's life; these differing layers of stress interact with one another and compile to cause depression and anxiety (Bastawrous, 2013). Role theory places this framework within the context of an

individual's entire social community, examining the different needs and expectations across roles. In regard to caregiver burden specifically, role theory reveals how scarcity of an individual's time, energy, and resources may give rise to conflict, highlighting the role overload that is often experienced by an individual who is trying to meet a vast multitude of obligations while providing care for an elderly adult.

While the competing demands hypothesis and the stress theory both demonstrate the adverse effects of carrying a multitude of different life roles, the expansion hypothesis is a competing theory which challenges this concept by revealing potential benefits for women who are divided in this manner across several roles. Contrary to the competing demands hypothesis, the expansion hypothesis argues that women who fulfill responsibilities across many roles may actually experience energy gains, rather than energy depletion (Shifren, 2009). This hypothesis predicts that as women carry out the wide range of duties across different spheres, they grow in confidence and self-esteem while gaining greater satisfaction through mastery of their tasks. As they fulfill obligations and provide support across so many roles, they find identity in their work, grow in life satisfaction, and experience several other benefits of overall health.

While a great deal of research suggests the validity of the competing demands hypothesis among caregivers, evidence has also been offered in favor of the expansion hypothesis. Sumra and Schillaci (2015) studied a sample of 308 multiple-role women and looked for relationships between role engagement, stress, and life satisfaction; the study actually found little correlation between having several roles and experiencing stress, and a small positive correlation was even found between fulfilling these roles and greater life satisfaction. The results also suggested that women may experience higher satisfaction as they find increased competence and efficacy in themselves to carry out all their demanding tasks. The ability to balance so many different roles

and still remain faithful to all their responsibilities may boost a woman's self-esteem and give her greater confidence or life satisfaction.

After highlighting evidence for the competing demands hypothesis in their books, Shifren and Qualls also explore ways in which a woman's caregiving experience could be explained through the expansion hypothesis. Shifren (2009) identifies several rewarding and satisfying aspects of caregiving, many of which come from fulfilling a felt obligation to family members and friends. As they see their parent receive the care they need, watch their children grow and develop the right way, and gain the support of their husband, these women may experience energy gains across their various role spheres. Furthermore, Shifren found that even in light of increased stress or workload, the energy gains, emotional support, and self-fulfillment experienced through these roles may actually improve psychological well-being. Qualls and Zarit (2009) also identify how a woman may experience positive spillover, where mastery or achievement in one role may give her a greater confidence and sense of mastery in her other roles. In this way, doing well in one role sphere may encourage a woman to persevere in another, and this in turn may create a feedback loop where positive experiences across various roles continually drive the caregiver forward. Hence, while the competing demands hypothesis suggests all these roles would overwhelm a woman, evidence for the expansion hypothesis may indicate a positive change in one's mental state.

Indeed, even beyond the context of role theory and caregiving among a multitude of other tasks, a large body of research has demonstrated that there may be many positive aspects of caregiving itself. In a qualitative literature review of 14 studies, caregivers described multiple positive dimensions of their caregiving experience and identified several important factors that contributed to these benefits (Lloyd, 2014). Caregivers described many different types of

rewards that they accrued throughout their experience, such as role satisfaction, personal growth, emotional rewards, competence and mastery of tasks, relational gains, a sense of accomplishment, and reciprocity in their work. Indeed, these types of positive gains resulting from the caregiving experience are exactly the kinds of rewards one would expect to see within the framework of the expansion hypothesis.

While both the stressors and the benefits of caregiving may be explored through these theories, the cumulative effect of caregiving on an individual must be understood within the relational context of social life. Whether among the caregiver's immediate family, friend groups, or coworkers, the caregiving experience may influence nearly all dimensions of one's relational life. While its influence may be positive or negative, those who spend a great deal of time providing care for an elderly adult may quickly begin to see how caregiving impacts their availability for other relationships, their energy levels, their emotional bandwidth, and even how they communicate with others.

The current body of research suggests that caregiving often has a wide variety of negative effects on family relations. As primary caregivers are able to spend less time with other family members and perhaps feel that other family members are not doing their fair share to help, it is very common to see increased family conflict (Qualls & Zarit, 2009). As primary caregivers sacrifice their time and energy, they often have limited remaining resources when it comes to loving the rest of their family members and showing them adequate care, just as the competing demands hypothesis would suggest. Likewise, tension and bitterness may develop between a primary caregiver and her siblings, spouse, or children when she feels that these individuals are not contributing as much as they should. For these types of family strains, it is also important to recognize that caregiving impacts more than one immediate family for a primary caregiver. On

one hand, caregiving impacts the immediate family of the one receiving care, including the primary caregiver and all of her siblings; on the other hand, caregiving also has effects on the immediate family of the primary caregiver, including her husband and children. Thus, caregiving places stress on multiple family groups in a variety of ways.

Several studies have examined how family conflict influences the relationship between caregiving and health, and both have revealed correlations (Kang & Marks, 2016). Looking within the context of marriage specifically, one study interviewed caregivers and non-caregivers to determine if marital strain influenced the relationship between caregiving and health in any way; the results showed that caregivers experiencing high strain in their marriages reported poorer health than their non-caregiver peers (Kang & Marks, 2016). Conducting a national sample of employed caregivers for disabled adults, another study revealed that family strain often leads to large correlations between family-to-work conflict and caregiving demands (Li, 2015). This survey also found that high levels of family-to-work conflict were also associated with lower life satisfaction and increased depression among caregivers, but only when perceived social support was low. While this reveals that caregiving may often be associated with family conflict, it also suggests an indirect relationship between caregiving demands and psychological well-being.

While caregiving may lead to family conflict, there are also plenty of instances where caregiving has led to positive influences on individuals' family life. For example, a caregiving experience that introduces family conflict may then also lead to unification within family relationships as members work together to care for the adult and support the primary caregiver. When the primary caregiver feels that her family members adequately support her in her duties, this may unite the family under a shared goal while relieving some of the primary caregiver's

burden (Qualls & Zarit, 2009). Furthermore, while conflicts often arise when caregiving decisions must be made for an elderly adult, this also gives families an opportunity to work through the issue together and engage in effective problem solving. In these ways, family relationships that endure conflict through the process of caregiving may still find benefits from the experience.

While all of these relationships are likely to be impacted throughout the caregiving experience, whether for better or for worse, these relationships may also offer the vital social support that an individual caregiver needs to carry out her tasks and cope with caregiver burden. In his book *Bowling Alone*, Putnam (2000) defines social capital as the “features of social organization such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit” (p. 67). While Putnam offers a wide variety of benefits experienced within a community as social capital increases, the relationships forged among friends and family members may serve as a tremendous encouragement for those who are experiencing hardship. Whether within an individual’s family, close friendships, local church, or some other organization, social capital offers caregivers the opportunity to communicate their struggles with others who may be able to comfort and support them.

While Putnam’s model of social capital suggests that an increase in such communal contact and participation would decrease caregiver burden, there is a growing body of research to support that this is the case. In a cross-sectional correlational study of caregivers and non-caregivers, Papastavrou (2015) found a negative correlation between social capital and caregiver burden within a community, suggesting that increases in social capital may help relieve caregiver burden. While non-caregivers showed higher scores of social capital, caregivers experienced higher levels of burden and depression. Interestingly, the study also found that as non-caregiver

community participation increased, caregiver burden decreased within the community, indicating that the non-caregivers may have a responsibility to step up and provide loving support and aid to those who are struggling through the hardships of caregiver burden.

Supporting this notion, another study of dementia caregivers showed how social support may help alleviate the pains of caregiver burden and help promote positive benefits of caregiving. The study found that a positive caregiving experience was associated with several factors, one of which was perceived social support (Grover, 2017). Those who had a greater perceived social support reported lower scores of caregiver burden, and these individuals also demonstrated stronger motivations for caregiving. As one would assume, those with lower caregiver burden reported having a more positive caregiving experience overall. The study also found that caregiver satisfaction, which was associated with a better and more supportive environment, was also associated with a higher quality of life among caregivers.

While several studies have shown ways in which social capital may be related to reduced caregiver burden, another study conducted by Brand et al. (2014) found evidence for why specifically this may be the case. This study found a correlation between receiving greater social support and more benefit finding, which in turn was correlated with a higher quality of life (Brand et al., 2014). After sending questionnaires to 84 caregivers, the results revealed that quality of life was predicted by benefit finding, optimism and social support. Moreover, the association between benefit finding and quality of life was explained by social support, but not optimism; caregivers who reported greater benefit finding perceived their social support to be higher which, in turn, had a positive effect on their overall quality of life. These results demonstrate one way that social support may relieve caregiver burden, and they underscore the importance of harnessing benefit finding to enhance caregiver quality of life.

While several studies have found a greater quality of life for caregivers who are also receiving social support, research likewise suggests that caregiver burden is more prevalent where family support is lacking. In a cross-sectional correlational study interviewing informal family dementia caregivers, results showed that both self-esteem and lack of family support were correlated with caregiver burden and psychological well-being (Alvira, 2014). Where caregivers did not perceive much family support, greater scores for caregiver burden were recorded, and these individuals also demonstrated lower psychological well-being. Associations were also found between caregiver burden and quality of life, and these factors also went hand-in-hand with a variety of health problems and complications among caregivers.

Among various intervention methods, social or family support methods have been tested and affirmed as successful methods for alleviating caregiver burden. Several studies have demonstrated the value in using social support as a means for helping those suffering from caregiver burden. One literature review examined over 50 studies on individuals caregiving for ageing adults and those with disabilities, and family-support interventions generally benefited participants' overall well-being (Heller, 2015). The results also revealed that family support often led to greater caregiver satisfaction and improved caregivers' access to other forms of social service. Another systematic review of 39 studies examined the effectiveness of social support interventions in improving the well-being of dementia caregivers. Although the evidence was not entirely clear and consistent, the review did find that multiple-component social support interventions were the most effective (Dam, 2016). Interventions that included a mix of friendship, family aid, support groups, and other forms of contact tended to show the best effects on caregiver well-being, which emphasizes the fact that supporting someone struggling with caregiver burden may require more than one solution.

Through this lens, it is vital to understand that caregivers experience a variety of different needs, and receiving help from friends and family may be one of the best methods for providing such multidimensional support. Another literature review examining the diverse needs of family dementia caregivers identified three major categories in which these individuals require support (Thompson, 2014). First, caregivers have a mix of physical, emotional, and psychological needs that must be met. Second, caregivers require assistance and information when making decisions about how to best care for the elderly adult. Third, caregivers also need instrumental support for the daily tasks of caregiving. With such a wide range of needs, many of which last for an extended duration of time, only a multidimensional approach can adequately meet each area of concern. The relationships available throughout a community that is composed of family, friends, social workers, and others may provide valuable social support that best fits the diverse needs of a caregiver.

The purpose of this study is to better understand the experience of middle-aged females that fulfill a variety of roles while providing care to a dependent elder adult. This study will also compare the experiences of female caregivers with the larger body of research. In particular, this research aims to better understand how communication within each of a woman's role spheres influences well-being and caregiver burden. Research questions include: How does caregiving impact relationships within the different spheres of the caregiver's life? Within each role, do people offer the caregiver proper social support that helps ease caregiver burden or improve well-being? If so, what forms of communication are helpful, and how can they improve? If not, where does communication in these relationships fail, and how does it need to change? It is expected that the results of this study will be largely consistent with the current body of literature. It is predicted that the complications of caregiver burden will have adverse effects on

the health and relational well-being of multiple-role women, but the social support offered through these various role spheres will offer several redeeming qualities of the caregiving experience.

METHOD

Study design

A series of qualitative, semi-structured interviews was conducted to explore and better understand the lived experience of informal female caregivers around midlife who have cared for elderly dependent adults.

Participants

The participants were 10 female caregivers around midlife from the northeast region of the United States. There were several eligibility requirements for the participants in this study. First, only females were selected to participate in the study. Second, each individual was required to have experience providing informal care for an elderly dependent adult. Third, each participant had to fall within the age range of 45-69 during the time of their caregiving experience. Regarding the upper limit of the age requirement, participants experiencing early signs of dementia or loss of any cognitive faculty were not recruited for this study.

The snowball sampling method was used to gather participants for this study; this method was implemented for convenience and accessibility of data collection. The participants were volunteers who responded to phone calls, emails, and face-to-face conversation. When recruiting

participants, it was stated that the study was being conducted for an honors thesis in the Communication Arts and Sciences Department at the Pennsylvania State University. Individuals were told that interviews would be conducted over the phone and that the process would take about 30 minutes. While women were told that they could freely choose to drop out of the study at any point or skip any interview questions they felt uncomfortable with, none of the participants that agreed to the study dropped out or skipped any questions. Both the use of a convenience sample and the fact that most participants came from a single geographical region significantly restrict the generalizability of the results, and generalizations to the population should be made with great caution.

The mean age of the participants was 59 years, with participants ranging anywhere from 54 years old to 69 years old. Six of these participants were in their 50s while four of them were in their 60s. All of the women in the study were Caucasian. All of the women reported having some sort of spiritual life, to various extents. Eight of the ten participants described a recent past caregiving experience, while two described a current experience. In every case, the individual receiving care was the parent of either the caregiver or the caregiver's husband. For every participant, the older adult receiving care was dependent in some way, and in most cases these adults demonstrated some form of dementia. While most of the women in this study lived in a separate home from their care recipient, a few individuals lived in the same home, and several caregivers spent a great deal of time at the home of their care recipient. While all of the participants were informal family caregivers, the sample consisted mostly of eight primary caregivers and two secondary caregivers.

Data collection and procedure

Data was collected through in-depth, semi-structured phone interviews conducted by the author. Each phone interview lasted about 30 minutes in duration, and interviews were conducted in the summer of 2018, ranging from May through September. The same written guide of questions was used for each interview, and the questions were mostly asked in order. The participants were also given categories or options for how to answer many of the questions. For example, when asked how many hours a week one spent caregiving, one could answer whether it was in the 1-5 hour range, 6-10 hour range, or 10 hours and above. While this format was implemented for many of the questions, several questions, particularly the ones regarding communication and relational support, were much more open-ended. Interviews occasionally took turns in different directions and became less structured as participants shared life experiences, but nearly all the questions were still answered in each interview.

The written guide of interview questions was divided into three main segments. The first section was very brief and consisted of a few demographics questions. The second section included questions about the participant's caregiving experience, including how much time they spend caregiving, what tasks they perform, and how various difficulties have impacted their overall well-being. Lastly, the third section consisted of questions regarding the participant's role spheres outside of caregiving, including what other roles these women fulfill, what communication is like in these roles, and whether these women felt supported within these relationships. A complete list of the interview questions may be found in Appendix A.

Data analysis

Responses to interview questions were recorded on paper by the interviewer during the course of the interview. The interviews were not tape recorded. Since many of the questions were designed to have short responses or answers that could fit into specific categories, it did not take long to record most responses. For questions that gave way to open ended responses, the interviewer took more time to record comments and made sure to include all that was being shared. Immediately following each interview, the interviewer read over and reviewed the responses that had been recorded, making any additional notes, revisions, or clarifications that were necessary.

When analyzing the results, the interviewer looked for overarching themes and connections among the entire pool of participants. The responses were studied and read repeatedly in hopes of finding recurring themes and trends among the life experiences of these ten caregivers. Specifically, the responses were also analyzed in light of the extensive body of literature on the topic, and the researcher looked for ways that the shared experiences of these women related to common phenomena in the caregiving world. Additionally, the researcher also sought ways in which the experiences of these caregivers differed both among one another and in relation to the larger body of literature. Similarities and differences were explored in an attempt to best understand how the experiences of these female caregivers compare to the common caregiving experience as portrayed by the complete body of research.

Ethical considerations

The participants of this study were free to choose not to answer any questions they did not feel comfortable with, and they were free to withdraw from the study at any time. The participants were also guaranteed that their answers would remain confidential.

RESULTS

Sample characteristics

The mean age of the participants was 59 years, with participants ranging anywhere from 54 years old to 69 years old. Six of these participants were in their 50s while four of them were in their 60s. All of the women in the study were Caucasian. All of the women reported having some sort of spiritual life, to various extents. On a 10-point scale, women reported their spiritual life anywhere from 5 to 10, with the mean score being 8. Eight of the ten participants described a recent past caregiving experience, while two described a current experience. In every case, the individual receiving care was the parent of either the caregiver or the caregiver's husband. For every participant, the elderly adult receiving care was dependent in some way, and in most cases these adults demonstrated some form of dementia. While most of the women in this study lived in a separate home from their care recipient, a few individuals lived in the same home, and several caregivers spent a great deal of time at the home of their care recipient. While all of the participants were informal family caregivers, the sample consisted of eight primary caregivers and two secondary caregivers.

Caregiving experience

While the unique caregiving responsibilities differed from woman to woman, there was a great deal of overlap among the participants in terms of the overall caregiving experience. While many women reported that the time they spent caregiving changed a lot from week to week, about half of them considered caregiving to essentially be their full time job. Five of the women reported spending over ten hours each week caregiving, while three women spent 6-10 hours, and 2 women spent 1-5 hours. Many of these women reported spending more time each week with their care recipient as the caregiving experience progressed. While three women described an experience lasting 1-3 years, seven women described a caregiving experience that lasted 4-7 years. Most of the women in the study provided care for about 4-5 years, with 7 years being the longest time span of caregiving.

The caregiving tasks that women performed, whether sporadically or regularly, included preparing and serving meals, feeding, housekeeping, shopping, dressing, helping use the restroom, bathing and grooming, walking, transportation, giving medication, performing medical tasks, planning appointments, and managing financial affairs. While many women were not required to complete many of these tasks, most of these duties were carried out by the majority of participants. The majority of women (seven of the ten) reported that their care recipient mostly had a thankful attitude when receiving care; the other three women expressed that their care recipient would often get frustrated or be upset with them. While many women said that the attitude of their care recipient would at times pose a struggle, these individuals were usually thankful for the work that was done for them.

When asked about which responsibilities were the most difficult, women pointed to a variety of different tasks. While there were several mentions of responsibilities like making

decisions, scheduling appointments, and living with the care recipient, there were two particularly prevalent themes that women discussed. The first was more of a physical duty, that of mobility and transportation. Many women found that moving their care recipient from point A to point B, whether within the home or across town, was one of their most difficult tasks. The second recurring theme, which was equally prevalent among these women, was the difficulty of being honest with their care recipient and “telling them how it is” when they need to hear something. This was particularly hard for women emotionally, as they struggled to tell their care recipient the things they needed to hear that would ultimately be for their own good, but were nonetheless quite difficult to deliver in an honest and straightforward manner.

When asked about how caregiving impacted these women’s physical and emotional well-being, the results pointed mostly to changes in emotional wellness. There was a mix of results for women regarding what physical changes they noticed in themselves throughout the time they spent caregiving. On a scale of 1-10, with 10 being large changes, four of the women reported a score of 1-3, indicating little to no change in well-being. Three of the women reported a score of 4-6, while three women reported 7-9. These mixed results show that while some women experienced dramatic physical changes in their health, many women felt very little impact. As for emotional change, the results were much more uniform, with three women reporting a score of 4-6 and seven women reporting a score of 7-9. This trend clearly demonstrates the strong emotional influence of caregiving on the women in this study. Several women said specifically that caregiving led to a lot of pain, stress, family complications, and a loss of freedom. One individual said the experience was so influential on her that she didn’t even feel like the same person afterward. Clearly the caregiving experience had at least some emotional impact on all who participated in the study, as these powerful changes in emotional well-being reveal.

Influence on other role spheres

Most of the women in this study described at least two to three other roles outside of caregiving in which they were required to meet some form of responsibility. Nine of them were married or described being involved in a romantic relationship, nine were mothers, and eight were employed. Many women also mentioned a variety of other social connections such as extended family, community groups, volunteer networks, and other various friendships. While there were one or two individuals that said these other roles took up more of their time than caregiving, most of these women said that caregiving took up just as much time as their other roles or more. Some women noted how time spent caregiving often became intertwined with time spent in other roles, especially when the care recipient lived in the same home as the rest of the woman's family. Several other women also said that time spent between caregiving and their other various roles was often about the same, although it could certainly vary dramatically from week to week. As a general trend, the caregiving role was certainly one of the biggest, if not the biggest role in many of these women's lives in terms of time consumption.

When asked about how the amount of time women spent in these various roles changed when they started caregiving, there was a mix of results. While six of the women reported at least some significant changes in time spent in other roles, four women said there was little to no change, depending on the week. For three women that experienced change, nearly all of the roles changed, and women found less time to be with others in almost every role after they started caregiving. For the other three women, changes were less dramatic and often occurred among friendships. Most women described how the time spent in other roles had an ebb and flow to it, and it certainly depended on the week. For the many women who did experience change in other

roles spheres, one common exception was that women often spent more time with their siblings as they were forced to communicate more about caregiving logistics.

While there were mixed results regarding how caregiving impacted the amount of time spent in other spheres, all of the women in the study reported feeling stressed and overwhelmed at some point while balancing all these responsibilities. While some women felt like they did have enough time for all their roles, they still found it rather overwhelming at times. Again, responses seemed to indicate that there was an ebb and flow to the stress levels experienced, especially depending on what types of events or circumstances were at play in each role sphere and how their care recipient was doing. A few individuals also noted how things got particularly difficult and stressful as the process went on, especially closer to the end of their experience.

While all women described how stressful caregiving could be in light of other relationships, caregiving seemed to have varying levels of impact on the relationships themselves. Seven of the women reported at least some improvement in relationships coming from the caregiving experience, especially within their spheres as a mother and wife. Although it may have been difficult, many relationships were strengthened as people rallied together as a team to face the challenges of caregiving; this especially happened in a few marriages where husbands were very supportive. While stressful situations often arose, many women ultimately reported growing a stronger bond with family and friends in these other role spheres.

While several women described improvement and growth in other relationships, some women described neglect or damage among friendships and family relations. While three women said there was little to no change in other relationships, many others expressed varying levels of negative influence. Many relationships were suspended temporarily or 'put on hold' for caregiving; while these relationships did not necessarily suffer greatly in permanent ways, it is

still a form of neglect directly resulting from the demands of caregiving. For a few women, relationships weakened or deteriorated as the process became more stressful, especially near the end. Where relationships were damaged, this was often among a caregiver's siblings, and it was usually in a situation where the siblings lived far away and offered little help in caring for their parent. However, of the three women who reported damage to relationships with siblings, two of these women reported growth and strengthening among other family relationships within their wife or mother role. Overall, caregiving seemed to have a mix of positive and negative impacts on other relationships.

Focusing specifically on communication within these relationships, while a couple women said there was no real change, most women expressed some form of change, whether for better or worse. Many women reported having reduced communication with others, mainly as a result of not seeing other people as much and being forced to neglect other relationships. Others described how communication became more difficult under stress, especially as dialogue took a greater caregiving focus. While a couple women described positive communication within these relationships that led to growth as they were forced to talk about caregiving, this was not the normal response for this study. For many women who experienced change, caregiving strained communication in other relationships by either decreasing its volume or increasing the stress within it. However, when it came to levels of honesty and transparency, half of the women reported that although communication was hard, women did see an increase in honesty for talking to others about the burdens of caregiving.

Looking within the family specifically, seven of the women reported that caregiving led to some form of family conflict, but much of it was resolved or even helped improve relationships. Most conflicts women described arose over decisions regarding the care recipient's

living situation or the daily caregiving tasks, but most of these were adequately resolved. In terms of family unity, five women found that caregiving united the family while five did not. For those who found that caregiving united the family, several found many encouraging benefits in how it brought their family together as a team. Women described how it led to an increased ability to compromise and work through conflict together, and it ultimately led to family growth. For those who did not find that caregiving united the family, only a couple women framed this in a negative way; women said that it did not further unite the family only because the family was already so close to begin with. However, it should certainly still be noted that there were individuals who reported conflicts that did not unite the family and did not lead to positive results. All in all though, while most women reported family conflicts, most of these were resolved, and families often either maintained a pre-existing unity or unified even further.

Many women referred to positive family experiences like these when asked whether they felt emotionally supported in these relationships, to which a slight majority said yes. While seven of the women reported feeling mostly emotionally supported, only five of them really felt supported as a caregiver. Emotionally, while several women expressed that they did not always feel supported due to various stressors and difficulties, they felt that the support came when they needed it. Many women felt very positive about this and continued to refer to how strong their support team was among their family or friends. On the other hand, three individuals felt that they were not emotionally supported; they expressed a lack of good opportunities to talk to friends or family about their hardship. When asked if they felt supported as a caregiver or if they felt like they were working alone, the split was even both ways. Half of the women again said that while it was not perfect, they received the help they needed from others to carry out caregiving tasks. The other five women either felt only marginally supported or not supported at

all, describing themselves as more of a solo team. Whether emotional support or assistance for caregiving responsibilities, while half or just over half of these women received the help they needed, several women expressed a lack of support from others.

Regarding communication within these role spheres, most women reported talking to other people specifically about caregiving, but there were mixed attitudes regarding how helpful this communication has been. While eight women reported talking somewhat regularly about caregiving, only two women said that they rarely ever do. While most women said that communication about caregiving was helpful, many of them said there was still plenty of room for improvement. Communication was very helpful in offering women new perspectives, giving them a chance to share difficulties, and receiving tips and advice from other caregivers. While many of the women gained valuable tools and comforts from these types of conversations, none of the women reported that communication regarding caregiving was ever particularly harmful in any way; if anything it simply was not helpful.

While only three women reported that communication regarding caregiving could not improve in any substantial way, the other seven women offered a variety of practical ways in which communication could become more beneficial for caregivers. One woman said there should be more clarity in conversations with friends and families, and people should listen better to gain a greater understanding of the precise struggle and conflicts that arise within the caregiving experience. On a similar note, another woman also mentioned that there could be more clarity between doctors, patients, and caregivers within the context of healthcare; there could especially be improvement in how doctors relate to families in communicating about dementia diagnoses. Furthermore, a few women mentioned that communication could improve simply by becoming more frequent. Whether that be within a marriage or a long distance

relationship with a friend or sibling, a few women felt that there could be more conversations, phone calls, and emails exchanged within these different role spheres.

In a similar vein to wanting a greater volume of caregiving-related communication, a few women mentioned that there should be more opportunities for support. Some women felt that there were not many support groups or opportunities for community-based assistance available to them; they would have liked more opportunities to talk openly and honestly with others about caregiving. When each woman was asked if she had sought any type of personal counseling, therapy, or any other kind of formal support, four of the women said they received none. A few of these women in particular felt that such options were not very accessible for them. The rest of the women, who did seek and receive such support, found it in a variety of places, but friendship was a recurring trend. Many women joined caregiving support groups and talked to friends at church where they could learn more about others' experiences and gain helpful tools and strategies for caregiving while also receiving emotional support. One woman even attended a workshop on dementia and read a book about the subject, which she noted was a helpful and informative experience. Overall, while not every woman sought support or even had access to it, those who did often found the friendships and social connections they made to be rewarding and beneficial for themselves personally and as caregivers.

DISCUSSION

The findings of this study are largely consistent with the overarching body of literature on informal family caregivers. Regarding the caregiving experience specifically, many of the trends and recurring themes that arose among the women in this study were compatible with the current

understanding of caregiver burden theory, with some slight deviations. First, while there was little physical impact on the well-being of the participants, caregiving had a significant influence on the emotional well-being of all women to a varying degree. The participants' accounts of stress and emotional hardship were quite consistent with the prevalence of anxiety and depression often cited in caregiver burden literature.

Regarding the determinants of caregiver burden, the experiences described in this study supported current theories of the most common causes of stress and anxiety for caregivers. The care recipient's behavioral problems and declining health were both often mentioned as major stressors for the women in this study, which the current literature cites as two of the most influential factors of caregiver burden. While most of the women noted that their care recipient usually had a thankful disposition, caregiving became very difficult for women when their care recipient would start acting up. Furthermore, several women mentioned that the most difficult aspect of caregiving was having to be honest with their care recipient and tell them difficult truths, which occasionally would lead to conflicts or a lack of cooperation. These types of conversations and the conflicts they often led to took a strong psychological toll on many women. The second most common determinant of caregiver burden defined by the literature is declining health of the care recipient, and this was a prevalent theme in this study as well. Many women noted that the health of their care recipient declined significantly over time, and this often made the caregiving situation more difficult and stressful. Hence, both the behavior and the health of the care recipient stood out as key factors of caregiver burden in this study, both of which are frequently cited in the larger body of literature.

While both behavioral problems and declining health arose as prevalent determinants of caregiver burden in this study, there are also many other factors involved that should be

considered, especially concerning the broader relational context across an individual's many role spheres. Regarding the multiple-role nature of these women, nearly all of them were engaged in at least two to three other roles besides caregiving. However, outside of a couple cases, caregiving was one of the most, if not the most time-demanding role sphere these women fulfilled. While not every woman experienced a significant change in the time spent among other roles, several women described how caregiving led to severe decreases in time spent in nearly every other role, demonstrating the immense influence such an experience can have on the rest of one's life and relationships. Recognizing the entire relational context of the multiple-role woman is critical to gaining a better understanding of the various determinants of caregiver burden.

Within this larger relational context, every woman in the study described feeling stressed and overwhelmed to some extent throughout the caregiving experience. These results are consistent with the competing demands hypothesis, as well as both the stress theory and role theory, revealing how these different roles and duties compete for a woman's time and energy and leave her feeling stressed and overwhelmed. This study further demonstrates that caregiving is an incredibly demanding responsibility, and fulfilling duties in a wide range of other role spheres often causes even higher levels of stress, even if there may be other positive outcomes.

Within these different role spheres, caregiving had a mixed impact on women's relationships. Many women were forced to neglect other relationships due to the demands of caregiving, demonstrating the powerful impact caregiving can have to disrupt every aspect of one's life. Beyond neglect, the relational effects described by women offered support for both the competing demands and expansion hypothesis. While some women felt that the stressors of caregiving made relationships more strained, others saw a wealth of benefits in how caregiving strengthened relationships and united families, both of which outcomes were consistent with the

literature. Regarding the positive gains found in the strengthening of relationships, evidence was found for the expansion hypothesis, revealing the benefits that may arise from fulfilling duties in such a wide variety of role spheres.

Specifically regarding the expansion hypothesis, most of the positive experiences women gained through caregiving happened within the context of these other relationships, especially where families were unified. While many family relationships were challenged through the hardships of caregiving, several women found that the experience only strengthened the family. While there were many family conflicts, most of them were resolved, and about half of women in this study felt that the experience united their family, particularly in the family's ability to compromise and work as a team. This demonstrates that while caregiving can be a very demanding load both as an individual and within the context of other role spheres, the relational rewards for those who persevere can be quite valuable.

However, as a few women noted, not all relationships are strengthened by this trial, and some may experience permanent damage. Within this study, one area in particular where women seemed to experience family tension was within relationships with their siblings. Women often saw division and conflict in relationships where siblings were geographically distant or did not offer much caregiving support. This may indicate a perceived responsibility among women for their siblings to play their part and help support a dependent parent; a lack of such support often had detrimental effects on relationships.

Looking specifically at communication within these relationships, most women reported that caregiving brought some form of change, whether for better or worse. While the demands caregiving placed on some relationships actually led to improved communication, caregiving often led to a neglect in communication with some people or placed a strain on communication

with others. As for honesty and vulnerability, while about half of the women noted no change or a slight decrease, the other half noted an increase. In fact, eight of the ten women talked about caregiving with others. This indicates that while caregiving can be difficult to talk about, it often forces one to be more vulnerable and honest with others, as the hardship and challenges one faces are almost too hard not to share.

While communication was often strained in these relationships, most women did feel emotionally supported during their caregiving experience. This is consistent with the literature in showing how social capital and relational support have the power to relieve caregiver burden. While stress levels still ran high, women who felt emotionally supported found several benefits from the caregiving experience, such as family unification and other relational rewards, that helped relieve the pains of caregiving. Most of the women sought and found social support, and most of these women reported positive experiences among the friendships they forged through such support networks.

However, in terms of carrying out duties and responsibilities for their care recipient, only half of the women felt supported as a caregiver. This indicates that there could certainly be more support for women from their friends, families, and communities at large to help share the load for women in this position. Furthermore, women who did not feel emotionally supported expressed a lack of opportunity for support, indicating a need for greater availability and accessibility to support groups and other forms of community services. Considering all the different physical, emotional, and relational demands caregivers faces on a daily basis, a community-wide effort must be made by the friends and families of caregivers to provide the multidimensional support they need to function well and maintain a healthy quality of life.

This study has its limitations. First off, the sample was neither random nor substantial in size, so generalizations cannot be made to all caregivers. Furthermore, many of the study's questions and measures lack high precision, as most questions forced participants to make some form of interpretation for how they understood various aspects of their caregiving experience and their relationships. Whether answering how much time one spends caregiving or what communication was like within other relationships, responses often involved vague criteria that was very subjective to the individual being questioned. This led to a substantial amount of interpretation both for the participant and the interview analyst.

While the limitations of this study keep its conclusions from being generalized to all caregivers, its findings are largely consistent with the current literature and lead to more important questions that should be addressed in future research. One area that could be explored more is the relationships between caregivers and their siblings, especially when they live great distances apart. It would also be valuable to conduct further research on how communication within these role spheres changes over time throughout the caregiving experience.

CONCLUSION

By describing the lived experience of middle-aged female caregivers, this study seeks a better understanding of the personal challenges and relational difficulties a woman may experience while providing care for an elderly dependent adult and fulfilling responsibilities in several other role spheres. Consistent with much of the larger body of literature, this study reveals the pervasive impact caregiving can have on every aspect of one's life. While relationships were challenged and communication was often strained, many of the women in this

study described some of the hard-earned rewards that can be experienced through the caregiving process. While many women still experienced much pain and damage to relationships, this study turns its focus to the benefits that can be reaped by caregivers in a community where all individuals play their role to help an individual in need. Through the community-wide efforts of friends, family, and other support groups, the benefits offered through positive social interactions may provide the multidimensional support that every female caregiver needs.

APPENDIX
INTERVIEW QUESTIONS

1. What year were you born?
2. Do you consider yourself a spiritual person? On a scale of 1-10 (10 being very spiritual, 1 being not spiritual)
3. How would you identify yourself culturally?
4. Are you currently caregiving or was this a past experience?
5. Whom are you caregiving for?
6. What is that individual's current health status? On a scale of 1-10 (10 being excellent, 1 being very poor)
7. Are you the primary caregiver? Are there secondary caregivers?
8. How long have you been caregiving? When did it start?
9. How many hours a week, on average, do you spend caregiving? 1-5, 6-10, over 10?
10. What tasks does your caregiving include (of the following)? Examples: preparing/serving meals, feeding, housekeeping, shopping, dressing, transportation, giving medication, bathing/grooming, walking, medical/nursing tasks, planning appointments, managing financial matters, helping use restroom
11. What are the hardest caregiving responsibilities of those tasks listed (or others)?
12. How did the care recipient receive your help? Were they thankful or upset?
13. Have you experienced changes in your physical well-being since you started caregiving? On a scale of 1-10 (10 being large changes, 1 being no change)
14. Do you feel as if caregiving has affected your mental or emotional well-being in any way? On a scale of 1-10 (10 being large changes, 1 being no change)
15. What other roles do you fulfill? Are you a wife, mother, employee, or part of another group?
16. How much time do you spend in each role? Is it more or less time than you do caregiving?
17. Has the amount of time spent in each role changed since you started caregiving?
18. Do you have enough time and energy for each of these roles, or do you feel stressed or overwhelmed?
19. How have your relationships in these roles changed due to caregiving?
20. What is communication like within these relationships? Has it changed?
21. Have levels of vulnerability, openness, and honesty increased or decreased?
22. Has caregiving led to family conflict? Have conflicts been resolved?
23. Has caregiving united the family in any ways?
24. Have any of these family relationships grown stronger or declined?
25. Do you feel emotionally supported in your relationships?
26. Do you feel supported as a caregiver, or more like a solo team, working alone?

27. Do you talk to others about caregiving? How has communication regarding caregiving been helpful or harmful?
28. How can communication in these spheres improve?
29. Have you ever received personal counsel or support for caregiving?

BIBLIOGRAPHY

- Adelman, R.D., Tmanova, L.L., Delgado, D., Dion, S., & Lachs, M.S. (2014). Caregiver burden a clinical review. *Journal of the American Medical Association* 311(10), 1052–1060. doi:10.1001/jama.2014.304
- Ageing. (2018). In United Nations. Retrieved November 12, 2018, from <http://www.un.org/en/sections/issues-depth/ageing/index.html>
- Alvira, M.C., Risco, E., Cabrera, E., Farré, M., Hallberg, I.R., Bleijlevens, M.H.C., Meyer, G., Koskenniemi, J., Soto, M., & Zabalegui, A. (2014). The association between positive–negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study. *Journal of Advanced Nursing*, 71(6), 1417–1434. doi: 10.1111/jan.12528
- Bastawrous, M. (2013, March). Caregiver burden—A critical discussion. *International Journal of Nursing Studies*, 50(3), 431-441. doi:10.1016/j.ijnurstu.2012.10.005
- Bauer, J. M., & Sousa-Posa, A. (2015, September). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family. *Journal of Population Ageing*, 8(3), 113-145. doi:10.1007/s12062-015-9116-0
- Brand, C., Barry, L., & Gallagher, S. (2014, September 9). Social support mediates the association between benefit finding and quality of life in caregivers. *Journal of Health Psychology*, 21(6), 1126-1136. doi:10.1177/1359105314547244

- Caputo, J., Pavalko, E., & Hardy, M. (2016, July 16). The long-term effects of caregiving on women's health and mortality. *Journal of Marriage and Family*, 78(5), 1382-1398.
doi:10.1111/jomf.12332
- Caregiver Statistics: Demographics. (2016). In Family Caregiver Alliance. Retrieved November 12, 2018, from <https://www.caregiver.org/caregiver-statistics-demographics>
- Chappell, N. L., Dujela, C., & Smith, A. (2014, September 12). Caregiver well-being: intersections of relationship and gender. *Research on Aging*, 37(6), 623-645.
doi:10.1177/0164027514549258
- Cheng, S. (2017, August 10). Dementia caregiver burden: a research update and critical analysis. *Current Psychiatric Reports*, 19(9), 64-71. doi:10.1007/s11920-017-0818-2
- Dam, A., de Vugt, M., & Klinkenberg, I. (2016, March 1). A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*, 85(C), 117-130. doi:10.1016/j.maturitas.2015.12.008
- Dementia statistics. (2015). In The Global Voice on Dementia. Retrieved November 12, 2018, from <https://www.alz.co.uk/research/statistics>
- Grover, Sandeep; Nehra, Ritu; Malhotra, Rama and Kate, Natasha. (2017, June). Positive aspects of caregiving experience among caregivers of patients with dementia. *East Asian Archives of Psychiatry*, 27(2), 71-78.
- Heller, T., Gibbons, H. M., & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and Developmental Disabilities*, 53(5), 329-345,377,379. Retrieved from <http://ezaccess.libraries.psu.edu/login?url=https://search.proquest.com/docview/1724232628?accountid=13158>

- Iavarone, A., Ziello, A. R., Pastore, F., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatric Disease and Treatment, 10*, 1407–1413. doi:10.2147/NDT.S58063
- Kang, S., & Marks, N. (2016). Marital strain exacerbates health risks of filial caregiving: evidence from the 2005 National Survey of Midlife in the United States. *Journal of Family Issues, 37*(8), 1123-1150. doi:10.1177/0192513X14526392
- Lee, J. (2014, May). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Aging Research Reviews, 15*, 76-93. doi:10.1016/j.arr.2014.03.003
- Lee, Y., & Tang, F. (2013, November 5). More caregiving, less working: caregiving roles and gender difference. *Journal of Applied Gerontology, 34*(4), 465-483. doi:10.1177/0733464813508649
- Li, A., Shaffer, J., & Bagger, J. (2015). The psychological well-being of disability caregivers: Examining the roles of family strain, family-to-work conflict, and perceived supervisor support. *Journal of Occupational Health Psychology, 20*(1), 40-49. doi:10.1037/a0037878
- Lloyd, J., Patterson, T., & Muers, J. (2014, December 29). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia, 15*(6), 1534-1561. doi:10.1177/1471301214564792
- Papastavrou E., Andreou P., Middleton N., Tsangari H. & Papacostas S. (2015) Dementia caregiver burden association with community participation aspect of social capital. *Journal of Advanced Nursing, 71*(12), 2898–2910. doi: 10.1111/jan.12762

- Putnam, R. D. (2000). *Bowling Alone: The Collapse and Revival of American Community* (pp. 66-68). New York, NY: Simon & Shuster. Retrieved November 12, 2018, from <http://xroads.virginia.edu/~hyper/DETOC/assoc/bowling.html>
- Qualls, S. H., & Zarit, S. H. (2009). *Aging Families and Caregiving* (pp. 68-72). Hoboken, NJ: John Wiley & Sons, Inc.
- Quinn, C., Clare, L., & Woods, R. (2013, July 19). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia, 14*(2), 220-237. doi:10.1177/1471301213495863
- Shifren, K. (2009). *How Caregiving Affects Development* (pp. 151-159). Washington DC, DC: American Psychological Association.
- Springate, B. A., & Tremont, G. (2014, March). Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *The American Journal of Geriatric Psychiatry, 22*(3), 294-300. doi:10.1016/j.jagp.2012.09.006
- Stalder, T., Tietze, A., & Steudte, S. (2014, September). Elevated hair cortisol levels in chronically stressed dementia caregivers. *Psychoneuroendocrinology, 47*, 26-30. doi:10.1016/j.psyneuen.2014.04.021
- Stewart, N. J. (2014, January 26). Rural caregivers for a family member with dementia: models of burden and distress differ for women and men. *Journal of Applied Gerontology, 35*(2), 150-178. doi:10.1177/0733464813517547
- Sumra, M., & Schillaci, M. (2015, March 27). Stress and the multiple-role woman: taking a closer look at the “Superwoman”. *PLoS ONE, 10*(3). doi:10.1371/journal.pone.0120952

Thompson, G., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliative and Supportive Care*, 12(3), 223-231.

doi:10.1017/S1478951513000461

What Is Dementia?. (2018). In Alzheimer's Association. Retrieved November 12, 2018, from <https://www.alz.org/alzheimers-dementia/what-is-dementia>

Women and Caregiving: Facts and Figures. (2016). In Family Caregiver Alliance. Retrieved November 12, 2018, from <https://www.caregiver.org/women-and-caregiving-facts-and-figures>

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Honors in Communication Arts and Sciences
- Thesis Title: Elderly Care and the Multiple-Role Woman: How Social Support May Ease Caregiver Burden April 2019
- Supervisor: Jon F. Nussbaum, Liberal Arts Professor of Communication Arts and Sciences and Human Development and Family Studies
- Work: Public Speaking Mentor for Undergraduate Speaking Center 2017-2019
- Helping students with speech assignments
 - Building mentor relationships with fellow students
 - Offering in-class presentations for public speaking techniques
- Verdant View Farm Staff Summer 2018
- Worked with animals
 - Performed general farm maintenance jobs
 - Worked as a tour guide
 - Led and taught workshops on making ice cream and cheese
- Watermarke Christian Church Youth Intern Summer 2017
- Planned, organized, and led all Youth Group activities
 - Helped plan and lead youth mission project in New Castle, Pa
 - Led a weekly Bible study
- Computer Technician for Bellefonte Area School District Summer 2014
- Set-up computers and installed software
 - Provided technology support for staff
 - Installed wireless modems across the district
- Awards: Evan Pugh Scholar Senior Award Spring 2018
Adma Hammam Shibley Memorial Scholarship Fall 2017
Richard B. Gregg Memorial Award Spring 2017
President Sparks Award Spring 2017
Michael Hodes Scholarship Fall 2016
- Presentations:
- Penn State Undergraduate Exhibition for Research Spring 2017
- Presented research on improving antibiotic knowledge

Special Coursework:

Organizational Communication	Fall 2018
Small Group Communication	Spring 2018
Civic and Community Engagement	Spring 2018
Speech Writing	Fall 2017
Teaching Assistant for Effective Public Speaking	Spring 2017
Peer Mentoring for Public Speaking	Fall 2016

Community Service Involvement:

Reformed University Fellowship- Penn State Chapter	2015-2019
<ul style="list-style-type: none">• President• Master of ceremonies• Leadership team member• Small group Bible study leader• Served on multiple mission trips within the United States• Planned and organized a weekend conference	
Watermarke Christian Church	2006-2019
<ul style="list-style-type: none">• Involved in local church plant• Served on multiple mission trips within the United States• Served with communion, offering, set-up, and greeting• Served as Youth Intern• Preached two sermons for the congregation	
Saint Paul's Community Soup Kitchen	2018-2019
<ul style="list-style-type: none">• Serving as dishwasher• Serving food to community members	
Penn State Dance Marathon	2015-2019
<ul style="list-style-type: none">• Official dancer in 46-hour dance marathon (2018)• Active volunteer in fundraising efforts for Four Diamonds	

Language Proficiency:

English (native)