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Spousal Caregivers' Challenges When Caring for Their Loved Ones Battling Alzheimer's Disease

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M.A., Walden University, Minnesota, 2008

B.A., Christopher Newport University, Virginia, 2004

Dissertation Submitted in Partial Fulfillment
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Abstract

In the United States, the occurrence of Alzheimer's dementia is growing. This chronic illness is highly prevalent in the elderly population. Studies have advised that the elderly population is primarily affected by this chronic illness as age progresses. Aging may lead to mental or physical deterioration. This chronic illness can be extremely challenging for the spousal caregivers involved and the challenging decisions that must be made. There remains a crucial gap in the literature concerning the challenges experienced by spousal caregivers and how they cope with these factors daily. Specifically, there are no studies exploring the perceptions of spousal caregivers and the emotions involved with long-term placement. Therefore, the purpose of this qualitative study was to use the grounded theory method and to explore the perceptions of 7 spousal caregivers and the emotions attached to decision making. The method involved open-ended interview questions to attain answers to the research questions involving experiences and observations of the caregiving role. Interview data were open-coded and analyzed for themes. The outcomes of this research will help aid in overcoming the challenges spouses face with the new role of spousal caregiving. This will add existing literature associated with elderly spousal caregivers and challenges faced when caring for an Alzheimer's individual. These outcomes can lead to social change and development through the implementation of positive coping strategies when dealing with the caregiving challenges and emotions attached to this role.

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Dedication

This study is dedicated to my husband and my children. Thank you all for the support and unconditional love you have always shown me and pushing me to conquer my dreams. I love you all so very much. (Derick, Hannah, Emma, Bryson & all our fur babies!)

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Chapter 1: Introduction to the Study

Introduction

Alzheimer's disease is becoming a very common disease among the elderly population in the United States and can come about quickly or be a slow process. This disease affects over 24 million individuals (Naveb, Negarandeh, & Peyrovi, 2012). Alzheimer's disease has been estimated to affect 5.3 million people within America (U. S. Census Bureau, 2014). There are 78.2 million children born between 1946 and 1964 and are referred to as baby boomers. By the year 2039, approximately 20% of the population will be over age 65. The oldest of the baby boomer population began reaching age 65 in 2011 (U. S. Census Bureau, 2014). In 2015, this older population rose by 55 million (He, Goodkind, & Kowal, 2016). Between 2012 and 2050, the United States will encounter significant growth in its older population (Ortman, Velkoff, & Hogan, 2014). Nearly every established nation is now being subjected to a growing number of older adults and with this growth comes an inevitable occurrence of health associated difficulties (Gupta & Sankar, 2003). Amongst various cognitive disorders, dementia has been acknowledged as one of the most severe and incurable cognitive disorders among the elderly population (Alzheimer's Association, 2016).

This leads to the expectation that the number of cases of Alzheimer's disease/dementia will continue to double (Hunt, 2015; Wheeler, 2010). As the rates of dementia among the elderly population rise at a rapid rate, a greater sector of society will be impacted by this illness (Peacock, Hammond-Collins, & Forbes, 2014). The caregiving demands of the elderly diagnosed with Alzheimer's dementia will continue to increase (Bumagin & Hirn, 2001). Dementia is a subject that many individuals are not familiar with (Naveb et al., 2012). Rudd, Viney, and Presetion (1999) suggested that the thought of losing someone close to them such as a friend, spouse, or even themselves is difficult to process. Alzheimer's disease cascades under the canopy phrase dementia, which is the given term identifying a grouping of indicators that come about from deteriorating brain function (Wassman, 2012; Rudd et al., 1999; Bumagin & Hirn, 2011). This disease is continuously on the rise. It is estimated that in the United States, 8% of caregiving is given to impaired elderly individuals by family caregivers (Bumagin & Hirn, 2011). Many of these family caregivers are spouses and adult children (Bumagin & Hirn, 2011). Caregiving of individuals with Alzheimer's dementia has been suggested to be extremely challenging. Due to this significant percentage, the demands on caregivers will also increase causing potential continued stress and time-consuming commitment. Schulz, Boerner, Shear, Zhang, and Gitlin (2006) indicated caregiving stress relates to poor outcomes for caregivers including depression, sickness, and decreased the quality of life. Spousal caregivers of loved ones with dementia experience a greater risk of emotional distress and depression as well as other health-related conditions (Sarkar, 2015). Prominence placed on this illness could help caregivers understand, recognize, and identify ways to cope with the demands of the disease. The more awareness brought about regarding this challenging disease, the more opportunities that could potentially be found for education and coping strategies for caregivers (Bjorn, Samuelsson, Annerstedt, Samuellson, & Grafstrom, 2001; Samuellson, Annerstedt, Elmstahl, Samuelsson, & Grafstrom, 2001).

Research also identifies the emotional distress, depression, grief, and burden an individual can have in caring for an elderly dementia individual (Alzheimer's Association, 2016; Noyes et al., 2009).

The Alzheimer's Association (2013) said that 33% of caregivers describe symptoms related to depression and grief as the outcome of their caregiving duties. However, limited research is found in relation to how individuals cope with guilt and emotions when contemplating the long-term placement of their loved ones battling dementia. Caregiver burnout and strain are major predictors for decisions being made regarding long-term placement (Lewis, 2014; Monahan, 1995).

Noyes et al. (2009) investigated the dynamics involved with caregiving for an elderly dementia individual and said there is a lack of exploration regarding ways to fully cope with this caregiving role, the impact stress has on the caregivers, and the difficult emotions involved that can potentially lead to the onset of grief and depression. Further research may help caregivers identify situations that may bring about these challenging emotions and gain an understanding of how to cope with these emotions such as grief.

This study based on grounded theory looked at the feelings of guilt experienced by spousal dementia caregivers and the relationship this shared with long-term placement. This study looked at the elderly population, specifically spousal couples where one spouse is the caregiver and the other had a diagnosis of Alzheimer's dementia. The data was collected through surveys and interviews emphasizing challenges and emotions involving spousal caregiving for elderly spouses battling this illness.

Participants were in a retirement community setting and at least 65 or and older. This study helped with the recognition of the emotions experienced with this challenging spousal caregiving role and identified strategies that can help spousal caregivers cope with the decisions that have to be made and the impact of Alzheimer's disease. It is vital to have a distinct understanding of the specific occurrences and events that preface a final decision for long-term placement.

Background of the Problem

The topic of Alzheimer's disease is not new in the literature and has remained a topic of study for many years. Alzheimer's disease is the most familiar form of dementia, and 5.2 million individuals have been diagnosed with this illness (Alzheimer's Association, 2013). Current research has focused on the characteristics of the disease, caregiving, and treatments, although there is no cure, as well as ways to promote awareness for this illness (Alzheimer's Association, 2015; National Institutes of Health, 2015). However, limited research exists regarding the impact this illness can have on spousal caregivers and subjective experiences and decisions regarding long-term placement. As the number of new diagnoses of Alzheimer's disease continues to rise, so does stress for caregivers, including spouses, and life-changing decisions should be made regarding potential long-term placement.

Alzheimer's disease is sometimes misconstrued as another illness that can be managed with proper care and medication. However, dementia is much more than just an illness. This disease is a life-changing illness potentially leading to death. This illness is not only a factor for the individuals diagnosed but also for the family or caregivers. Dementia is considered to be a canopy term specifically used to describe a variety of cognitive ailments which include cognitive impairment with memory, language, and motor action (Chapman, Williams, Strine, Anda, & Moore, 2006). One factor relating to this illness is that the families and caregivers face a diversity of challenges when a loved one is diagnosed. There are huge concerns about the increasing rate of this disease throughout the world. The World Health Organization (WHO, 2012) suggested that the total of individuals with dementia is anticipated to double significantly every 20 years. Thus, these caregivers could benefit from education and learning effective coping strategies that can be used within the caregiving role. Due to this growth of individuals being diagnosed with dementia, more families will become caregivers and provide this care within their homes. Currently, more than 15 million Americans are caring for a loved one with dementia (Lewis, 2014). The need to gain more understanding and supportive measures is prevalent. Providing available education for understanding and supportive measures will help caregivers reduce distress experienced with the care process and learn how to adequately care for their loved ones battling this illness (WHO, 2012).

Many challenges can be overwhelming, especially if the caregiver is engaged in the caregiver role due to feelings of obligation that he or she should care for their demented loved one or possibly because there is no one else able to provide this care for the elderly demented individual (Adams, 2006). Chronic stress has been suggested to also increase the risk of dementia for caregivers (Universitet, 2013).

Statement of the Problem

This study addresses the challenges spousal caregivers experienced when caring for their loved ones. Dementia indicates a significant decline in one's mental ability that tends to interrupt the daily lives of an individual (Alzheimers Association, 2011). Fong, Davis, Growden, Albuquerque, and Inouye (2015) said that dementia is one of the most common causes of cognitive impairment and within the elderly population, it is a progressively frequent problem. Currently, there are 33.5 million individuals affected by dementia throughout the world with limited resources available for treatment (Brodaty & Donkin, 2009; Lewis, 2014) This is likely to double every 20 years (Brodaty & Donkin, 2009; Lewis, 2014). The likelihood of having Alzheimer's advances as individuals increase in age for various populations. While the disease can be treated some and possibly maintained, the cure is still yet to be found. When the disease starts to progress rapidly, the challenges faced for family or spouses and the decision-making aspects relating to long-term placement, start to come about and can be challenging to cope with amongst limited resources and support needs (Howard, 2015). There is limited research on the difficulties encountered by caregivers of elderly spouses with dementia (Miller & Guo, 2000).

The impact of dementia can be devastating not only to the individual battling the disorder, but also the surrounding world. The marital life of the caregiver, as well as the demented individual, can be significantly impacted by this disease. This is because these caregivers provide a variety of caregiver duties for the individual who is battling this disease. Some of these demanding caregiver duties involve getting through each day with their loved ones and helping in whatever way they can, as well as assisting with daily tasks the individual can no longer do independently (de Vugt & Verhey, 2013). This qualitative case study will explore 7-10 caregivers of the elderly population in a

Williamsburg, Virginia retirement community to examine themes regarding caregiving responsibilities that might contribute to challenges spouses face with their new role of spousal caregiving. This study will use the grounded theory method and data from this study will be collected through interviews and audio surveys of the participants chosen. The outcomes from this study could potentially offer a unique aid to the existing literature associated with elderly spousal caregivers and challenges faced when caring for an Alzheimer's individual.

Research Questions

RQ1: What are the emotional impressions of spousal caregivers when making long-term care decisions for their demented loved ones?

RQ2: How can understanding the emotions experienced with the placement process help identify effective coping mechanisms?

RQ3: What role does positive support play in the caregivers' perceptions and beliefs?

Conceptual Framework

This study looked at the emotions involved with spousal caregivers and the impact these emotions had on decision-making processes for long-term placement. The guiding theoretical frameworks include Lazarus and Folkman's stress and coping theory and Boss and Greenberg's concept of boundary ambiguity. One of the big factors relevant to the stress and coping theory is the impact of stress on one's health. In this study, spousal caregiving for a spouse battling Alzheimer's disease could potentially be one stress factor and the impact of this psychological stress on the caregiver's health would be of great concern. Lazarus and Folkman (1984) defined psychological stress as the intense demand for environmental factors wearing on an individual's capabilities, leaving them susceptible to psychological distress -promoting potential risks for physical or mental illness as well as emotional distress (Lazarus and Folkman, 1984; Cohen, Kessler, & Gordon, 1997).

Lazarus and Folkman's stress and coping theory have four main concepts, which are psychological stress, cognitive appraisal, coping efforts, and health-related outcomes, with psychological factors being of the utmost importance. This theory helped identify how coping become ineffective, and circumstances can change quickly and become uncontrollable. These changes can then lead to significant stress, illness, and a decline in social functioning. This can then lead to the inability of spousal caregivers to maintain their important roles effectively. This then leads to the caregiver looking for long-term placement for their loved ones. Therefore, these caregivers having effective coping strategies and adaptation helps them manage this stress as well as prevent it from making a negative impact (Contrada, 2011; Lazarus & Folkman, 1984).

In the present study, the stress that has impacted one's health is related to the role of the spousal caregiver. The spousal caregiver had quite a bit on their plate regarding caring for their loved ones battling dementia. Sometimes their resources were exhausted, or their coping strategies became ineffective, causing great distress and emotional change.

The second conceptual framework that was used in this study is known as boundary ambiguity. Boundary ambiguity has developed into a reliable tool for understanding why families wrestle with life obstacles. Boundary ambiguity involves non-normative or normative stressor events where family members are not certain about who is a family member or not, or what member may be performing certain positions and responsibilities within the family system (Boss, 2002).

In many stressful conditions, the individual may not be able to understand the facts neighboring the troubling situation thus concluding with how to solve the problem or even react to it (Boss, 1993; 2002). The concept of boundary ambiguity was first introduced in 1975 through observations of military families who suffered the loss of a loved one in war. Observations were based on how the living family members dealt with the loss of a loved one and the emotions involved (Boss, 1977, 1983, 1993). Boundary ambiguity is commonly seen in situations relating to a sick loved one. An example of this is a spousal caregiver caring for their loved one who has dementia. While the demented loved one may have normal physical capabilities, their psychological capabilities have changed, thus leaving the spousal caregiver in turmoil because the normal situations or boundaries have now changed. The spousal caregiver may question if his or her loved ones are still able to be a part of the daily processes of the family organization (Boss et al., 1990). Chronic illnesses such as dementia are uncertain as the progression is unknown.

Dahl (2003) advised that the notion of boundary ambiguity can be applied to spousal caregivers regarding how they perceive their demented spouses being involved within or outside of the family division. If the spousal caregiver experiences significant amounts of boundary ambiguity, then he or she will have difficulty reshuffling their life as they will continue to focus on the loved one and the emotions surrounding the situation (Hunt, 2015).

Nature of the Study

This study will explore the emotional impressions that spousal caregivers have when providing care for loved ones with dementia. This study was a qualitative grounded theory study. The grounded theory emphasizes the behavior, actions, and words of individuals being studied. This explanatory approach allowed the environment, interpretations, and interactions that individuals experienced to be observed. This was beneficial to use when gathering information from the elderly caregiver participants and observing their behaviors and interactions through the interview process. The qualitative data collected and analyzed did enrich our understanding of a psychological occurrence.

Creswell (2009) identified the grounded theory approach as “a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study” (p. 13 & 229). The phenomenological technique will be used to discover the paradox from the perspectives of individuals who lived through it. This approach helped identify the participants’ key concerns and how they continuously try to undertake it.

Data was collected through a survey immediately following an interview with a set of specific questions, and a review of this survey was included to warrant reliability and validity within the study. Spousal contributors were asked open-ended questions about their insights, challenges, and decision-making processes when dealing with caregiving and determining proper long-term placement. close-ended interviews were given to obtain demographic information. The entire process took about an hour (60 minutes) and was recorded for validity purposes and accuracy.

Purpose of the Study

Dementia can have significant effects on an individual’s life whether one is battling the disorder or the spousal caregiver. The main purpose of this study was to explore levels of grief and emotional distress and gain a better understanding of how spousal caregivers handle difficult decisions when it comes to caring for their loved ones who are battling dementia. One of the most challenging factors for a dementia caregiver is how to deal with various emotions and decision-making processes involved in helping loved ones battling Alzheimer’s dementia. Caregivers are not expected to be experts at understanding this disease or how to care for the demented individual as the illness progresses (Lewis, 2014). Through proper education regarding the illness, understanding the emotions involved with this caregiving role, and using positive coping mechanisms, these caregivers will be able to find appropriate strategies to deal with challenges and potentially overcome them. This study placed emphasis on understanding the caregivers’ role and the challenges faced when caring for their loved ones with dementia. Premises of both caregiver burden and caregiver resiliency were evaluated through in-depth interviews and proper assessments.

The literature review in Chapter 2 clarifies the involvement of spousal caregivers who face complex decisions when it comes to their loved ones battling dementia and offers background regarding the need for support during these demanding times. A phenomenological exploration was able to assist with identifying whether experiences affianced with spousal caregivers correspond with those experiences of other caregivers and the decision-making process for their loved ones or family members who may also be battling a significant illness. The phenomenological approach has been proposed for use when a researcher is involved in observing a specific paradox and the common capabilities of people with the phenomenon (Creswell, 2007).

Operational Definitions

Alzheimer's Disease/Dementia: A chronic neurodegenerative disease that can start at a slow pace and progresses over time.

Boundary Ambiguity: The state where a family member is unsure about who may be in or out of the family. This condition can be brought about by normal events such as death or abnormal events such as a traumatic car wreck (Boss, 1983).

Emotional-Based Coping: A coping approach in which individual focuses on changing their emotional distress by changing their thought processes about how the source of stress may be affecting them.

Grief: Deep sadness especially due to a significant change such as loved ones death.

Guilt: A bad feeling relating to thinking or knowing that one has personally done something wrong.

Long Term Placement: Settlement within a place that has proper resources and additional support that may be needed.

Marriage: a commitment between two individuals or a partnership.

Problem-focused coping: A coping technique in which some individual tries to eliminate the cause of the stress.

Spousal Caregivers: Individuals whose primary role is to provide their spouses with assistance with the completion of daily tasks and care.

Stress: Change in one normal state involving mental tension and worry, usually relating to problems in one's life.

Stress and Coping Theory: the theory of stress and coping, also known as the appraisal theory, one of the big factors relevant to this theory is the impact of stress on the one's health.

Significance of the Study

This study is unique because it addresses the emotions that a caregiver experiences when providing care for a loved one with dementia. There is little that is understood about decision-making processes when placing a loved one with dementia in long-term care. The results of this grounded study will provide awareness involving the feelings and emotions experienced by spousal caregivers when dealing with an elderly demented individual. Insights from this study can help aide these caregivers regarding the steps, be able to recognize and understand these emotions and use coping mechanisms before severe distress becomes a factor.

Taking care of elderly individuals at home with dementia often has a significant impact on the stress level of caregivers. These stressful situations can negatively obstruct the psychological well-being of caregivers (Dura, Stukenburg, & Keicolt-Glaser, 1990).

In particular, spousal caregivers may be vulnerable to caregiving demands of spouses and become more susceptible to problems that come about (Ott, Sanders, & Kelber, 2007; Susseman & Regehr, 2009).

Dementia is becoming a dominant illness in the world. There are many caregivers without proper assistance and tools needed to help care for their demented loved ones. This study will help change this and help caregivers succeed in caring for their demented loved ones by gaining insight into their feelings of guilt and distress as well as coping mechanisms to control these factors. This study will promote an understanding of the emotional impressions of spouses who care for their demented loved ones. Overall, through this recognition, the grieving process associated with the caregiver role can be positively controlled.

Summary

Chapter 2 will review the literature involved with Alzheimer's dementia and the impact it can have on elderly spousal caregivers. This chapter will also address the challenges faced by spousal caregivers and what leads up to the caregiver contemplating placement. This chapter introduces the feelings expressed by caregivers when caring for demented loved ones and the challenging decisions that can be made. Chapter 3 features the methodology of this study. This chapter will focus on the interviews and observations of the participants when being questioned about this significant illness. This chapter will also identify the challenges faced when caring for a demented spouse along with difficult placement decisions.

Chapter 2: Literature Review

Introduction

Alzheimer's disease is the most familiar type of dementia and can advance swiftly over time. The risk of acquiring this illness advances during the aging process. The number of individuals aged 65 years or older will more than double between 2010 and 2050 to an estimated 88.5 million. One to four family members perform as caregivers for each individual battling Alzheimer's disease (ALZFDN, 2013; Navah et al., 2011). Alzheimer's disease is an unalterable illness that involves memory deficit and degeneration of capabilities such as reading, effective communication, and physical proficiencies (Niedermeyer & Ghigo, 2011; Weiten, 2005).

According to Light (2010), this disease is triggered by a buildup of protein. This buildup of protein in the human mind can cause immense harm to regular motion and functioning capabilities. Though the aging process can trigger debility over time in individuals, so can the influence of this damaging disease. This disease can cause troubles with the standard activity of normal daily life at a quicker speed than the elderly who are simply aging with time (Niedermeyer & Ghigo, 2011; Siedlecki, Honig, & Stern, 2008). This disease can have a premature start which can lead to being seen in younger adults under 65 years of age. As advancement proceeds with this illness, the mind begins to deteriorate and wither. The image used as a metaphor for this disease is a puzzle with numerous pieces. For ages, investigators have been attempting to define what portion of this puzzle is the foundation of this illness. The investigation has established that this disease has an enormous impact on the main chemical in the brain, which is acetylcholine. The biggest outcome that is felt in the brain involves dangerous insufficiencies in the memory zones (Niedermeyer & Ghigo, 2011; Santrock, 2007).

Organization of the Review

As the literature analysis commences, the examination approach will be represented to allow the articles reviewed in this chapter to be used for future reference. Alzheimer’s and dementia will be examined so that the impact of a spousal caregivers’ role can be seen and understood. The dynamics involving this caregiving role will be reviewed so that the stress surrounding caregiving for a demented spouse and attendant challenges can be addressed. The extreme difficulties caregivers face in making complex decisions potentially regarding long-term care will also be looked at in depth.

The developmental need for support may also offer numerous strategies to cope and help caregivers gain a sense of strength and an awareness of support from the community, in addition to helping mitigate any insecurities as a spousal caregiver when taking care of their loved ones battling Alzheimer’s dementia. In addition, this chapter will discuss the mixed emotions involved with this caregiving process and the complex decisions caregivers make when they may no longer be able to care for their loved ones, in addition to how these caregivers can be supported when dealing with many difficult decisions.

Research Approach

Literature for this research was gathered from various search engines including Academic Search Premier, PsycINFO, and EBSCOHost which were retrieved through the Walden University Library. Additional literature resources included books on famous theorists regarding stress

Lazarus and Folkman's Stress and Coping Theory

There has been a great amount of research done on the notion of stress over many centuries. More specifically, a significant amount of attention was focused on the connections between one's emotions and stress especially when involving a caregiving role (Lazarus, 1999). Lazarus and Folkman's coping stress theory also suggests the significance of stress and how it can impact an individual within a caregiving role. Coping is described as persistently altering intellectual and developmental attempts to handle precise outer and inner strains that are assessed as problematic (Lazarus & Folkman, 1984, p. 141).

When a risk of fight is involved, a stressor marks a connection between an individual and the challenge and/or environment that individually recognizes as surpassing their capabilities and can be unsafe to the individual's well-being (Ryan-

Wenger, 2001; Scott, 2012). To apply this theory, one must always take into consideration the individual deviations that may transpire for individuals. Lazarus and Folkman (1984; 1993) emphasized that there are three different appraisal levels that these spousal caregivers could be experiencing. The first appraisal level is the primary level where the determination of the event/situation takes place. This appraisal involves the identification of a stressful situation where the events are identified as being harmful, a threat, or pose a great challenge (Scott, 2012). The secondary appraisal level is the evaluation of the spousal caregiver's ability to control or cope with the situation, whether it be harmful, threatening, or challenging. Generally, during this second appraisal stage, three questions are asked regarding what options are available, what is the likelihood that strategies can be introduced to reduce the stress, and whether this process will work and improve stress. The third appraisal level is known as cognitive reappraisal where the events of concern are constantly being reevaluated. This is commonly seen with spousal caregivers when caring for their loved ones who battle dementia. The situations and events consistently remain the same. However, as the disease progresses, these situations and events can become unmanageable, causing feelings of things being out of control, thus physically and mentally harming the spousal caregivers' well-being (Scott, 2012). This is the stage where evidence starts to point towards emotional based-coping being the method used by the spousal caregivers. Instead of finding strategies to deal with the situation, the spousal caregiver gains strategies for controlling emotional distress through avoidance, distancing, acceptance that this is the way it must be, selective attention, and isolation. While emotionally based coping can be beneficial in potentially reducing the emotional state, it does not address the actual situation/event taking place thus distorting all positive options that address this situation in a positive manner. However, if emotional distress with proper coping mechanisms then spousal caregivers may be able to focus on positive resources that may be available for the assistance needed by reaching for outside support (Scott, 2012).

Boundary Ambiguity

Boundary ambiguity is a concept that suggests how family members adjust to new roles, rules, and rituals upon a loss occurring (Boss et al., 1990). When these changes take place the family members tend to have elevated levels of ambiguity as they are not sure who is within the family setting or who may be out. Overall, boundary ambiguity is a feeling of uncertainty for the family unit where the family is not able to accept a loss that might be experienced. Since the family is in denial of this loss, the structure or reorganization of the family unit is not able to take place continuing chaos (Singh, 1993).

The type of events includes inside events and outside events. Inside events are suggested to be where the family members may understand the event that took place but refused to accept it, thus living in denial. An outside event is when the family continues to live in denial of the loss. The facts are not all present thus allowing the family member to ignore them.

Demographic Trends and the Elderly

The elderly population is continuing to grow at a consistent rate and has been estimated to double between now and the year 2050 to around 80 million. In 2010 the elderly population, 65 years of age and older estimated at a total of 40.4 million. This population represented 13.1 percent of the U.S population (Administration on Aging, 2011; Callahan et al., 2012). The baby boom generation will contribute greatly to this growth and will increase the annual rate by 2.8 percent. Statistics show evidence that elderly women have continuously outlived elderly men. However, this may change in the next 50 years as elderly men continue to live longer. Evidence also suggests that although elderly women tend to live longer they live alone and widowed or single. This suggests that elderly women tend to have less assistance as elderly men who have their spouse as the caregiver (U.S Bureau of the Census, 2011; Callahan, Arling, Rosenman, Counsell, Stump, & Hendrie, 2012).

Due to the elderly population staying alive longer, the door opens wider to chronic illnesses and conditions such as arthritis, osteoporosis, and dementia. Many of these health concerns result in the elderly individual becoming dependent upon others such as family members or their spouse to help with daily living activities (Waldmann &

Liu, 2000). Over the past decade, medical costs and long-term care needs have climbed quite high for the elderly population due to the growing need for help and chronic diseases diagnosed.

These chronic diseases such as Alzheimer's disease or heart disease, unfortunately, open the door to many various limitations of the elderly individual which can ultimately become terminal (Parker & Thorslund, 2007). These disabilities usually result in the elderly individual needing more supervision in a long-term setting whether this is in a nursing home, at home with home health services and personal care assistance (Wiener & Tilly, 2002; Schulz & Martire, 2004). At present, the number of caregivers who provide care is around thirty million (Polivka, 2005).

A large number of dementia caregivers seem to consist of spouses. Spousal caregivers play a momentous role in caring for their loved one's long-term needs. These spousal caregivers will battle difficult decision making to assure quality care and support for their elderly loved one (Quayhagen & Quayhagen, 1996). This spousal caregiver need will continue to grow as the elderly population continues to become older and battle significant chronic illnesses. There is a great need to gain the understanding of the elderly caregiver experiences and identify the challenges and emotions involved when making complex decisions (Quayhagen & Quayhagen, 1996). Research suggests that spousal caregivers have an elevated level of stress which does impact the caregiver's health significantly. Anxiety and depression are most commonly associated with the caregiving role (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005; Gaugler, Pearlin, Leitsch, & Davey, 2001).

Understanding Alzheimer's Disease/Dementia

Alzheimer's disease is the greatest collective form of dementia and is the origin for 70% of incidents in connection with cognitive shortfalls. This psychological condition is a disease categorized by memory deficiency, weakening in cognitive competencies including understanding, communication, and can produce deterioration of a person's ordinary degree of function. There is an assortment of disorders that can perhaps indicate signs of cognitive deficits. However, the most typical disease with significant cognitive deficits is Alzheimer's disease (Warner & Butler, 2002; Wheeler, 2010; Niedermeyer & Ghigo, 2011). Alzheimer's disease also known as dementia, has been recognized more recurrently in the elderly population, but still is prevalent in other age groups and termed as early onset of the disease. Alzheimer disease is the form of dementia that disturbs the cerebral cortex. The cerebral cortex is vital for psychological growth involving recollection and communication (Wheeler, 2010; Warner & Butler, 2002; Niedermeyer & Ghigo, 2011).

Phases of Alzheimer's Dementia

A person who becomes diagnosed with Alzheimer's disease will experience several phases throughout the progression of the disease. The primary phase is known as Mild Alzheimer. The start of this phase is usually faint and is a period where the family unit is uncertain about what is happening with the individual or if there is anything wrong. The first phase is quite often the phase that evidence is provided and assessments with a doctor begin to take place (Santrock, 2007. A few practical and psychological variations that the individual might experience involve forgetfulness of familiar names, important numbers or dates, inappropriate dressing for the current weather due to judgment becoming compromised. During this phase, the individual battling the illness learn to develop skills utilized for disguising these abnormalities around other individuals and tends to express irritation and confusion (Santrock, 2007; Wheeler, 2010; Niedermeyer & Ghigo, 2011). The second phase is where this illness is beginning to turn out to be more evident. This phase is known as the initial stages of moderate Alzheimer. A few aspects that tend to be visible during this stage is absent- mindedness and short-term memory loss. Some of the changes that take place during this phase involve a greater deficit with memory, challenges with recalling new information, and trouble with making decisions. Throughout this phase, the individual tends to become more forgetful which is often noticeable. Several behaviors that are also witnessed in this phase includes self-absorbance and socially becoming withdrawn. The third phase is when the challenges become even more advanced and the individual battling this illness is no longer able to eat independently, they may become incontinent, experience weight loss, and may begin to have delusions. This phase is the most severe phase of Alzheimer's disease. During this stage of the illness, the individual tends to live within an illusion and not true reality. These individuals also begin to lose the ability to recognize family members. Behaviors that are visible during this phase include possible hostility and unfriendliness with violent outbursts. In this phase, the development of the illness is inclined to become more advanced, rapidly, which brings about an increase also in the level of deterioration (Santrock, 2007; Wheeler, 2010; Niedermeyer & Ghigo, 2011).

A study by Kovach & Meyer-Arnold (1996) examined 33 clients with cognitive deficiency. These clients' behaviors were witnessed during their time frames of bathing. The investigation confirmed that almost all the participants showed some behaviors with agitation during their private hygiene care. During this study, the participants experienced a great deal of conflict with the goals set. The coping mechanisms that were utilized included a mixture of nonverbal and verbal approaches. The tools used by the individuals with cognitive deficits involved the control factor. Outcomes from this study established that individuals who suffer from cognitive deficits tend to utilize their own coping mechanisms that are utilized during the periods of time where their environment tests the person's deteriorating operative capabilities (Kovach & Meyer-Arnold, 1996; Wheeler, 2010; Light, 2008, 2010). The last phase of Alzheimer's disease is sudden and quick. The individual battling this illness will start to lose the abilities to swallow and eat nutrition. Unfortunately, the complete human system begins to cease and starts shutting down. This stage is the end of life phase and is when the individual can let go of a very long struggle. While Alzheimer's disease is a progressive disease, the individual battling this illness usually passes away due to other causes correlated such as pneumonia, malnourishment, dehydration, and immobilization (Weiten, 2005; Wheeler, 2010; Niedermeyer & Ghigo, 2011).

This chronic and advanced disease causes various challenges for the family or spouse who has potentially been placed in the caregiver role. As the disease advances the individual loses the ability to effectively communicate, increased cognitive decline, and a decline in physical abilities relating to ambulation, feeding, and continence (Warner & Butler, 2002; Wheeler, 2010; Niedermeyer & Ghigo, 2011).

Haley (1967) identified the impact a loved one battling dementia can have on a caregiver regardless if the caregiver is a spouse, adult child, or a family member. The impact of this disease on a caregiver is overwhelming and very challenging for one to deal with. Researchers have suggested that there are many factors relating to the mixture of emotions experienced including depression, grief, guilt, as well as a significant amount of burden (Haley, 1967; Martin et al., 2006).

In summary, Alzheimer’s disease is a chronic and advanced illness that will escalate in frequency and occurrence stemming from demographic trends of the elderly population. As this chronic disease progresses increased challenges for caregivers become present and extremely difficult to manage especially on their own. These challenges can be related to physical or mental health which may trigger the need for more care and assistance in a long-term care setting.

Marriage

The bond of marriage is a secret relationship between two beings that share meaning and experiences. This relationship promotes monogamy, trust, and dedication with two individuals. Each partner works together to express love, appreciation, refuge, and various gifts are equally traded (Stutzer & Frey, 2006).

There are several types of marriages including a delicate relationship or a close relationship. A delicate relationship involves the marriage to be based more on love and concern as the driving forces. In a close relationship the marriage is based more on sensible reasoning and services are able to be maintained (Hunt, 2015; Kelley, 1981).

Comparisons of good health for individuals married versus single have been widely explored. Suggestions have portrayed that individuals who are married are in better health, mentally and physically. Married individuals also tend to live a longer life (Karney, 2010; Waite & Gallagher, 2000). Individuals who are married also have expressed a greater well-being versus individuals who have been divorced, estranged, or widowed. The emotional support provided during a bonding marriage decreases depression and mental poor health. This emotional support also helps ease stress (Sarkar, 2015; Kiecolt-Glaser & Newton, 2001).

Marriage and Aging

As a marital relationship ages between two individuals, emotional ties tend to make changes. Many studies have suggested a U shape metaphor of a marital relationship of an older couple. This U-shape metaphor suggests high satisfaction in the beginning and end of the relationship and low during the middle stage. However, other studies contradict this feedback and suggest that there is consistent stability throughout the marital relationship (Silverstein & Giarrusso, 2010; VanLaningham, Johnson, & Amato, 2001).

A marriage relationship between an older couple is a unique bond as this married couple has aged together, formed a closeness, and their lives are focused around one another. Through the long-time relationship, these older married couples gain an understanding of conflicts management, have set and obtained goals, formed a positive emotional bond within the relationship Hoppman & Gerstorf, 2009; Silverstein & traGiarrusso, 2010).

Hoppman & Gerstorf (2009) findings on spousal interrelations in old age suggest that key influences our health, well-being, and cognition. Evidence has also suggested that while these interrelationships may provide developmental opportunities these factors may also cause vulnerability to the occurrence of loss.

Marital Closeness

Tower, Kasl, & Darefsky (2002) investigated the impact of the marital closeness of 305 older couples who have survived over 6 years in interrelationships. Closeness is defined as one of the partners being dependent on the other for emotional support and being identified as support within various dimensions. Results concluded that a greater chance of mortality was present with older couples who recognized their spouse for emotional support. Evidence also suggested that these older couples who identify their spouse for support are also more prone for depression and that within this close relationship the husband will suffer more if the wife begins to face cognitive deficits (Tower et al., 2002).

Spousal Caregivers and Demands

The research suggests that spousal caregivers have one of the most difficult and challenging jobs and are the least probable to request for support or help (LoboPrabhu et al., 2005; Wassman, 2012). These spousal caregivers deal with various difficult tasks when caring for loved ones battling chronic illnesses. The demented individual's ability to do things on his or her own becomes divergent. They become dependent upon the spousal caregiver for assistance with bathing, dressing, and sometimes decision making. This is especially seen when the ill individual is suffering from Alzheimer's dementia. The individual does not only battle physical disabilities, but also cognitive disabilities which deplete the ability or possibilities of doing anything alone (Schulz & Martire, 2004; Day & Anderson 2011).

Many spousal caregivers refuse extra help from other resources, question housing care, and are the last to surrender caregiving duty to certified caregivers (Isenhart, 1992; Mittelman, Ferris, & Shulman, 1996; Schulz & Martire, 2004). Spousal caregiving requires an extraordinary amount of energy, patience, time, financial means, and involves a task that is not necessarily pleasant. These factors can cause an overwhelming amount of stress and burden for the caregiver, physically and emotionally (Schulz & Martire, 2004). Another factor that has become overwhelming for spousal caregivers is the increase in life expectancy and the aging of this elderly population. The chronic diseases become more challenging to deal with causing more complex tasks to be performed. This is not only stressful for the caregiver but also the spouse being cared for (Day & Anderson, 2011).

The health of spousal caregivers becomes impacted greatly while caring for their loved ones in need. The caregiving may take a huge toll on the caregivers' well- being. Many spousal caregivers begin to feel worn out, isolated, frustrated, burdened, depressed, anxiety-filled, and overall stressed (Wheeler, 2010). This mixture of emotions and feelings impair the spousal caregivers' health causing health problems to occur and the immune system to become suppressed (Schulz & Martire, 2004).

Spousal caregivers are the critical key holders to understanding the changes that their demented loved one may be going through. They are the individuals providing round the clock care and are monitoring closely behaviors, challenges, and changes within the loved ones functioning abilities. They serve as a critical communicator for clinical assessments with doctors, nurses, and even nursing home placement transitions (Wheeler, 2010; Feinberg, Reinhardt, Houser, & Choula, 2011). The American Medical Association (2002) values the challenging job these spousal caregivers do every day and recommends that understanding these caregivers needs and encounters are crucial aspects of caring for loved ones with dementia (AMA, 2002; Schulz & Martire, 2004).

The caregiving role for a demented loved one can be extremely challenging as well as difficult when experiencing scolding and accusations of numerous factors regarding care and decision making (Day & Anderson, 2011; Feinburg et al., 2011).

When these factors take place on top of the stress of 24-hour care for their loved one, feelings of great strain in physical, psychological, emotional, and social factors are experienced. The impact of the emotional strain can impact the spousal caregiver tremendously (Day & Anderson, 2011). The feelings of guilt, anger, worry, anxiety, and frustration can cause the caregiver's body to enter the mode of "flight or fight" where they continue to honor their caregiving duties while using a defense mechanism to suppress these feelings (Samuelsson et al., 2001; Fienburg, Reinhard, Houser, & Choula, 2011).

These various emotions also include overwhelming feelings of being alone and isolation from other relationships. Isolation makes the spousal caregiver feel as though they have no one to talk to about their emotional state and that no one will connect to them. These caregivers feel as though they are experiencing this burden alone and experience feelings of hopelessness, helplessness, and the possibility of depression (Day & Anderson, 2011; Fienburg et al., 2011). The negative factor related to caregiver burden is that it impacts both individuals involved, the caregiver and the loved one battling dementia. This caregiver burden is prominently seen within the elderly population due to the advancement of age and at the highest level of the burden when caring for an elderly spouse (Kim, Chang, Rose, & Kim, 2011).

In today's world family members are the most vital foundation of support for the elderly population. However, many of these individuals do not even refer to themselves as actual caregivers but instead, they describe the relationship between them and the ill individual as a normal relationship with normal family stressors, whether be with a spouse, daughter, or grandchild (Monahan, 1995). When this caregiving role takes place, strain, distress, demands, and potential health concerns become concerning factors, as well as the financial hardship (Polivka, 2005). This is witnessed when the spousal caregiver may have to retire earlier than expected, pull from retirement assets, or pay for additional resources earlier than expected to care for their demented loved one (Feinburg et al., 2011; Day & Anderson, 2011).

A few of the tasks that a spousal caregiver undertakes to include providing and administrating medications; identifying needs and providing services; transportation; be the advocate and communicate with doctors, provide daily care routines, and be the key holder in handling transitions that may be needed for proper placement (Fienburg et al., 2011).

Caregivers need to provide various levels of care to the person with Alzheimer's dementia or chronic illness (Wheeler, 2010). It is vital that the emotions involved with caregiving are identified and addressed. Identifying these emotions and recognizing signs of distress may help with timing of the transition from when the spousal caregiver may have contemplated other resources needed such as long-term care placement (Burns et al., 2003; Kennard, 2006). Because of their obligation and challenging duties of care, spousal caregivers tend to ignore the signs of needing rest and avoid utilizing medical services as suggested (Wheeler, 2010; O'Donnell, 2000).

A recent study investigated the enhancement in caregiver well-being to a deferment in the long-term placement of an individual with Alzheimer's disease. The research suggested that the caregivers of demented individuals who received counseling and intervention support experienced a decrease in distress with the placement of a long-term setting versus caregivers that do not receive any support or intervention (Mittelman, Haley, Clay, & Roth 2006).

Emotions Experienced with Challenging Decisions and the Caregiving Role

Spousal caregivers experience massive amounts of guilt on a consistent basis when caring for their spouse battling dementia (Martin, Gilbert, Mcewan, Irons, 2004; Garity, 2006). Many spousal caregivers feel that asking for help, seeking medical assistance, or even finding proper placement is a sign of abandonment. The spousal caregiver feels overwhelming amounts of guilt for even contemplating long-term placement and feels as though they failed they're demented loved one. These mixed emotions leave the spousal caregiver full of stress and are a potential threat to the caregiver's health (Martin, Gilbert, Mcewan, Irons, 2004; Garity, 2006.) Brodaty and

Luscombe (1998) established a correlation between emotional troubles in caregivers and the advancement of dementia within their loved ones (Wassman, 2012).

Martin, Gilbert, Mcewan, & Irons (2006) suggest guilt is experienced because of the great concern the caregiver has for the demented spouse and feeling responsible for the position he or she is in. Grief can sometimes be mistaken for depression. Although there is sometimes a simultaneous connection, the two emotions are different in nature. Sanders, Ott, Kelber, & Noonan (2008) study suggests that elevated levels of grief are exhibited in caregivers when actively in the caring role. These feelings of grief are a mixture of longing for the past, remorse, guilt, separation, limited autonomy, additional life stressors, and difficulties at times with previous caregiving programs. Findings also suggested that caregivers with elevated levels of grief may be at significant risk for physical and psychological challenges through the continuous of the caring role (Sanders et al., 2008).

Psychological Outcomes

Stress is one psychological effect that can have a significant impact on caregiving and can increase health risk factors for caregivers. Bertrand, Fredman, and Saczynski (2006) investigated 349 caregivers who were either caregiving for a human being with or without dementia. Results concluded from this study suggested that stress levels were increasingly higher for caregivers that cared for individuals who were diagnosed with dementia as opposed to individuals without dementia (Wassman, 2012).

Rudd et al. (1999) established a wave outcome in that women caregiver who are known for higher stress levels also tend to have high intensities of anxiety as a caregiver. The higher intensity of anxiety in women caregivers was identified through the increase in the caregiving role and taking over some of the significant responsibilities formerly handled by their spouses. As this literature indicates, stress saturates the lives of caregivers and more assistance is needed (Wassman, 2012).

Another psychological effect that tends to take a toll on caregivers involves depression. Balhara, Verma, Sharma, and Mathur (2012) interviewed 75 consecutive patient-caregivers and were assessed using a depression scale to confirm depression was present and at elevated levels. Results confirmed that the more burden the caregiver feels the more depression is experienced. Spousal caregivers' caregiving for their loved one, who once could do things independently, have been suggested to struggle the most and show the greatest signs of depression.

Covinsky et al. (2003) also emphasized, in their study that depression is very rampant in the literature on caregivers. These researchers investigated 5,627 patients who had a diagnosis of moderate to advanced dementia and their caregivers across eight populations and were enrolled in a special program known as the Medicare Alzheimer's

Disease Demonstration. Interviews were provided to each caregiver to gain essential information about the individuals battling dementia and their day to day activities. Questions were asked regarding how difficult it was to care for the loved one, some of the challenges being faced, and then the 15-item Geriatric Depression Scale (GDS) to assess caregiver depression was administered. The GDS scale is frequently utilized as a tool to measure depression. Results concluded that thirty-two percent of the caregivers showed at least six or more signs of depression and were classified as being depressed. Evidence from this study demonstrates how prevalent caregiver depression is and how important treatment is for these depressed caregivers.

Grief seems to be an overpowering emotion that caregivers experience during the Alzheimer's disease process of their loved one. Factors that relate to these difficult emotions are due to reminiscence of fond memories, of their spouse or family member who is starting to become unrecognizable (Noyes et al., 2009; Martin, Gilbert, Mcewan, & Irons, 2006). The spousal caregiver may similarly be experiencing feelings of being worn out or experiencing guilt that is associated with potential long-term care placement of the demented individual (Noyes et al., 2009; Martin, Gilbert, Mcewan, & Irons, 2006). With the increase in the caregiving demands and other age-related occurrences such as falls and injuries, it is not uncommon for these prime caregivers to seek long-term placement. These instances usually take place when the caregiver feels they are no longer able to care for their loved one and need assistance from professionals. This may relate to numerous factors including psychological changes, physical health declines, and possible behavioral disturbances (Hope, 1998).

Rudd et al. (1999) suggested that dementia caregivers do experience the stages of grief which include denial and isolation, anger, bargaining, depression, and acceptance. The first step known as denial is what these family members experience, quick to anger, and then guilt because of getting angry with their loved ones they are providing care for. After these stages take place, the caregiver then may experience intense loneliness and sadness. The results confirmed from their qualitative study on the 60 spousal caregivers assessed is that sadness was the most common emotion experienced. Grief and loss were highly prevalent for the spousal caregivers of loved ones with dementia.

Doka (1997) expressed the impact guilt and regret can have on an individual caring for someone who is dealing with someone with a prolonged illness. Some of the emotions experienced are related to resentment, grief, frustration, and distress involving the connection between the caregiver and the individual being cared for (Adams, 2006). Doka (1997) also suggests the importance of recognizing one's feelings and seeking guidance before uncontrollable distress possibly takes over.

Loos and Bowd (1997) identified abandoned inferences of the occurrence of personal loss and anguish with caregivers of individuals battling Alzheimer's dementia.

The article emphasized the distress experienced by caregivers and how support from other family members was well received when in distress. Evidence from this study suggested that many caregivers expressed feelings of helplessness, frustration, guilt, unresolved anger due to the loss of control over life events. Results concluded numerous caregivers experience significantly deepened guilt and emotional well-being is at substantial risk. While this caregiver role is a necessity for the demented individual, this role has been connected to negative factors such as social isolation, signs of depression, emotional distress, physical decline, and a decrease in the capability to work (Bass et al., 2012).

Bjorn et al. (2001) provided information on the complex decisions that should be made when dealing with caring for an elderly demented individual. These articles also expressed the emotions a caregiver may deal with in making these decisions and the impact this unfortunate disease can have on life decisions, finances, and potential placement (Bjorn et al., 2001; Samuelsson et al., 2001).

Loos and Bowd (1997) clarified that many spousal caregivers expressly convey the desire to live freely and take care of their own self, however, only a few surrender these caregiving tasks. The few spousal caregivers that have been able to surrender these caregiving duties still show the difficulty of gaining full control of their own life and happiness. The majority of these spousal caregivers feel enormous amounts of guilt for placing their demented spouse and frustration for not being able to let go effectively (Goynea, Paris, & Saxe Zerden, 2008; Loos & Bowd, 1997).

Sanders et al. (2008) emphasized that there are significantly elevated levels of grief experienced by caregivers of individuals who are battling Alzheimer's disease and related dementia. Evidence from this article suggested that seven significant themes occurred that correlated with elevated levels of grief for caregivers. These themes included longing for the past, guilt and sorrow, loneliness, limited free will, life strains, general concerns, and coping tactics. The important coping strategies identified in these caregivers' life included social support, spiritual faith, and pets. However, the main emphasis is placed on understanding the actual experiences and ways to ameliorate the feelings involved with these processes (Sanders et al., 2008).

Sanders et al. (2008) specified that grief tends to increase for spousal caregivers of loved ones battling dementia, as the disease progresses. These researchers even suggested a term known as dual dying where not only the spousal caregiver experiences grief before the passing of their loved one battling dementia but also when the loved one has physically passed. Pre-grief is suggested to be grief that is predicted due to the upcoming loss of the loved one who is battling dementia (Rando, 1986).

Meuser and Marwit (2001) also agreed with this pre-grief philosophy concluding that pre-grief of a loved one's death is significantly comparable to grief from an actual death. These researchers confirmed that grief is a significant part of the caregiver experience.

Physical Outcomes

Evidence has suggested that caregivers who caregiver for their loved ones usually tend to abandon their own personal wellbeing and physical welfare. Connell and Gallant (1998) established that these caregivers' health is poor due to the demands of their caregiving role and the lack of healthy activities such as exercise, proper sleep and proper nutrition (Wassman,2012). These researchers also concluded that high stages of depression were significantly associated with an increase of changes in the health of the caregivers (Connell & Gallant, 1998).

Financial Outcomes

Financial outcomes are also a contributing factor to stress and burden involving the caregiving role of a loved one battling dementia. Many resources available to caregivers to help with the caregiving role can be cost-effective.

Lai (2012) investigated the outcomes of perceived financial costs on the caregiving burden undergone by caregivers. Telephone interviews were administered to 340 caregivers regarding financial situations as well as many other factors relating to the caregiving role such as the participant's well-being, social life, and affiliation with the loved one. Another tool that was utilized in this study to evaluate the effects of caregiving on monetary costs of caring for a spousal loved one was known as the Cost of Care Index (Kosberg & Cairl, 1998; Lai, 2012).

Results concluded from this study indicated a high correlation between the monetary costs associated with caregiving and caregiving distress. Suggestions from this study concluded the positive benefit of policies and programs that could assist in alleviating financial distress and provide more social and monetary support for the caregivers (Lai, 2012).

Long-Term Placement

Making the choice to place a loved one is one of the most challenging decisions to make. Quite often caregivers of Alzheimer's disease see long-term placement in terms of failure. The decision to place a loved one battling this chronic disease does not always bring relief from negative emotions or stress. The placement process is one of the most challenging and difficult processes to deal with for caregivers (Austrom & Hendrie, 1992). Long-term care placement starts to be looked at more frequently when the chronic illness begins to progress and when care at home begins to become unmanageable.

Day and Anderson (2011) suggested that the reasons for delayed placement reflect upon the feelings of satisfaction and gratification caregivers gain from caring for a family member or spouse with dementia. However, the literature suggests that the difficulty experienced with the additional care and support needed by spousal caregivers is a significant predictor of needing long-term care placement (O'Donnell, 2000). The areas of extra assistance can be related to daily living activities such as bathing, incontinence, or behavioral concerns related to wandering and safety. Once these factors become overbearing, a spouse's perception changes and they come to the realization, with the deterioration witnessed, that long-term placement is most appropriate (Gold, Cohen, Shulman, Zucchero, Andres, & Etezadi, 1995; Day & Anderson, 2011; Kennard, 2006).

Kennard (2006) suggested that even when the decision is made for long-term placement this does not bring relief in terms of worry or emotional havoc. The feelings of guilt and depression begin to progress which identifies the need for help to continue throughout the time the loved one is placed (Day & Anderson, 2006; Schulz & Martire, 2004). Literature suggests that the age of the caregiver plays a vast role in the potential placement of the demented loved one. Older caregivers are less likely to make use of long-term placement than younger caregivers (Mittelman, 1993).

The process of placement has been referred to as a traumatic situation. This is extremely difficult for spousal caregivers. The planning and processes faced with the transition become stressful for the spousal caregivers who are already battling emotions of guilt (Schulz, Steven, Czaja, McGinnis, Stevens, & Zhang, 2004). The turmoil experienced with this placement process results from unanswered questions, worries about the unknown, time management of the move, along with the diverse emotions surrounding placement. Other factors that can bring turmoil include choosing the right long-term care placement, finances, and paperwork completion (Schulz et al., 2004; Penrod, 1998; Rodgers, 1997).

Tilse (1998) suggested that the turning over of care is the most difficult for a spousal caregiver. The thoughts connected to this worry of turning care over stem from the caregivers' perception of quality of care. Caregivers tend to view the quality of care being different at home than when in long-term placement. The homecare gives the caregiver a sense of protection and upholds the self- worth and independence of the caregiver (Schulz et al., 2004; Feinburg, Reinhard, Houser, & Choula, 2011).

The caregivers' perception about care and support given by nursing staff within an institution is usually the deciding factor for placement. Spousal caregivers' reluctance is usually quite high and causes great challenges with making the transition to long-term placement (Mittelman, 1993 & Schulz et al., 2004). When transitions take place within a long-term placement, it is not uncommon for spouses to continue the caregiver role in the long-term setting. Spouses of the Alzheimer's individual tend to visit daily and continue to maintain physical care during the visits (Schulz et al., 2004; Tew, 2012).

Relinquishing all spousal caregiver obligations to a long-term care setting changes the spouse's caregiving role making them overwhelmed with various emotions such as guilt and depression, loss of control, and merely seen as a visitor than a caregiving partner (Kong, Deatrick, & Evans, 2009; Schulz et al., 2004; Samuelsson et al., 2001). Understanding the details related to the experiences, faced by spousal caregivers that are associated with long-term placement, would perhaps be an eye-opener and potentially open the door to the reinforcement of positive coping mechanisms and guidance with the placement process. (Deliasega & Matrian, 1995; Ducharme, Couture, & Lamontagne, 2012).

Long-term care placement is one of the most difficult challenges a spousal caregiver can face. However, when extreme challenges begin to take place at home with physical care and demands for the Alzheimer’s spouse, the pressure begins to overwhelm the caregiver leaving them with no choice but to seek long-term placement (Infurna et al., 2012; Penrod et al., 1998; Schulz et al., 2004).

It is imperative to understand the emotions and experiences associated with long-term care placement of a spouse with Alzheimer’s disease. With awareness of these factors, positive coping mechanisms, guidance, and support can be offered to the spousal caregivers during this challenging time of transition to long-term care placement (Infurna, Gerstorf, & Zarit, 2013; Penrod, 1998; Schulz et al., 2004).

Long-term placement can be offered in a variety of settings which can include assisted living facilities, continuing care retirement facilities, and long-term nursing facilities. It can be very challenging when the spousal caregiver is deciding to make this long-term placement decision to also decide which setting is most appropriate for their loved one. Long-term care encompasses a variety of services for the placed individual. These settings can provide care with meals, laundry, household support, activities, medication, nursing support, and help with dressing, bathing, toileting, as well as a safe and secure environment (Hill, Thorn, Bowling, & Morrison, 2002).

Transitions

Transitions are a changeover of one position to another such as placement of a loved one into a long-term setting (Infurna et al., 2012; Tew, 2012). Decisions to place a loved one in a long-term setting are generally loaded with feelings of guilt and distress (Winslow & Flaskerud, 2009). The various changes that arise in transitions involve changes in the daily lives of individuals and families including roles, spousal relationships, and behaviors experienced (Brown & Chen, 2008; Seltzer & Li, 2000; Schumacher & Meleis, 1994).

These factors alone produce overwhelming feelings of anxiety and resistance towards accepting placement. Research suggests that transitions tend to happen in various phases. Seltzer and Li (2000) suggested that there are three main phases that a caregiver goes through when providing care for a spouse with Alzheimer's disease. These stages include submission of the caregiving role, decisions for long-term care placement, and grief or sorrow (Seltzer & Li, 2000; Wassman, 2012).

The caregiver role can be looked at as a career with wins and losses throughout the disease process and transition periods. The impact of the various phases on a caregiver depends on the kindled relationship with the Alzheimer individual (Seltzer & Li, 2000). When the relationship is between spousal partners research suggests that there is a decline in the caregivers' well-being when entering the role as a caregiver and recovers quite often upon exiting this role (Seltzer & Li, 2000).

Seltzer and Li (2000) suggested that life transitions can be referred to as life turning points. This is the case for spousal caregivers and is witnessed throughout the caregiving process and involves the decisions making for long-term placement. These transitions begin for the spousal caregiver when entering the caregiving role with the loss of family and friend relationships, less socialization with others, and compromised psychological well- being (Brown & Chen, 2008; Schumacher & Meleis, 1994). As soon as the transition meets the level of moving their loved one to a long-term setting, gains are witnessed with socialization and personal growth as the caregiving role has been handed over. There are many gains and losses associated with the caregiving role. These factors are experienced at various intensities (McClendon, Smyth, & Neundorfer, 2006).

When these various intensities transpire the demands placed on the caregiver become overpowering. These demands bring a shadow over the caregivers' identity. The loss of one's identity or "self" is suggested to be experienced due to the engulfment of the caregiving role (McClendon, Smyth, & Neundorfer, 2006). This caregiving entanglement may affect the caregivers' ability to recognize the need for additional resources such as long-term placement (Skaff & Pearlin, 1992).

Caregiving transitions are one of the most challenging transitions to deal with emotionally, physically, and mentally. They are complex processes and may occur simultaneously with other life obstacles that may come into play whether these are developmental, situational, organizational, health-illness situations (Chick & Meleis, 1986; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Schumacher & Meleis, 1994).

Schulz et al. (2004) investigated the impact of placing a loved one with dementia in a long-term care facility on the caregivers' well-being and health. The results confirmed that the depression symptoms and anxiety levels were still as high as they were when caring for their loved one at home versus in long-term placement. Suggestion from this study indicates how challenging long-term placement can be for a spousal caregiver. Many of these spousal caregivers continue to visit daily and continue to aid with care during their visits, while their loved ones are in the long-term setting (Schulz et al., 2004;

Wassman, 2012). This clearly suggests the increased need for support and educational preparation regarding these long-term transitions.

Significance of Counseling

According to Light (2010) counseling an individual with Alzheimer's disease and their family is a very important factor in understanding the illness they are dealing with and to gain the support system needed to get through it all. This counseling promotes education for these individuals regarding the condition being dealt with, to help identify aspects that impact the current and long-term fundamentals of the illness, and to support in developing a treatment strategy. The treatment strategies are detailed to the individual with the illness and the caregivers. Many of these strategies are established from data collected from the psychosocial assessment completed at the start of the analysis process. The counseling meeting is a place where all anxieties, difficulties, and strategies can be tackled. It is imperative that this family counseling is continued during the entire process of the disease. Continued counseling will allow the family or caregiver to continue to be given reassurance of the support system available and continue to gain insight on how vital it is for the caregivers to be supportive for their loved one battling the illness even if the individual is not aware of the support provided.

According to Light (2010), special apprehensions are upraised when taking care of individuals who have mild to severe cognitive impairments. Throughout each day, providing care for an individual with these cognitive deficits stimulates new encounters for a family member or caregiver as they continue to cope with the constant changing abilities and conducts of the cognitively impaired loved one. Facts have suggested that even the caregiver is theoretically more vulnerable to emotional distress and sickness. This is especially visible if the proper support system is not put into place (Redinbaugh, MaCallum, & Kiecolt-Glaser, 1995).

Numerous specialists believe that the family unit can be a worthy support system for the person battling Alzheimer’s disease, however, this support can also be costly on the family and promote strain if not balanced properly. These individuals can become physically and emotionally drained from physically caring for their loved ones with daily tasks such as bathing, nourishing, dressing them as well as dealing with restless and hostile behaviors (Redinbaugh et al., 1995).

It is imperative that the caregivers and family members receive proper education in regard to the constant changing means and encounters that will be challenged when caring for their loved one battling this illness. Continued promotion of positive approaches and practices may be supportive in conveying normality and be a counteractive to agitated behaviors. Communication is also a crucial factor when dealing with individuals battling Alzheimer’s disease. It is important to understand the behaviors that are being experienced and communicate effectively so that these behavioral disturbances are not provoked. Allowing these individuals battling this disease to have praise and gratitude for the good things that they can still do can also help with managing behaviors (Fitzgerald, 2000).

When the disease starts to advance, behaviors such as aggression, grief, and agitation might be observed. It is essential that the caregivers and family unit are aware of these various behaviors and have effective strategies on how to minimize the behaviors. Through counseling, each obstacle that is being faced by the person battling this disease can be conveyed to the caregivers and the family which will allow for proficient and applicable strategies to be utilized. Counseling is a crucial part of managing processes for this disease ((Fitzgerald, 2000).

Due to the elderly population staying alive longer, the door opens wider to chronic illnesses and conditions such as arthritis, osteoporosis, and dementia. Many of these health concerns result in the elderly individual becoming dependent upon others such as family members or their spouse to help with daily living activities (Waldmann & Liu, 2000). Over the past decade, medical costs and long-term care needs have climbed quite high for the elderly population due to the growing need for help and chronic diseases being battled. These chronic diseases such as Alzheimer’s disease or heart disease, unfortunately, open the door to many various limitations of the elderly individual which can ultimately become terminal. (Parker & Thorslund, 2007). These disabilities usually result in the elderly individual needing more supervision in a long-term setting whether this is in a nursing home, at home with home health services and personal care assistance (Wiener & Tilly, 2002). Many of the caregivers involve the spouses of the loved one battling dementia. Spouses are and will continue to play a momentous role in caring for their loved one and ensuring the long-term care needs of their elderly loved one are met. They will battle difficult decision making to assure quality care and support for their elderly loved one (Quayhagen & Quayhagen, 1996). This spousal caregiver need will continue to grow as the elderly population continues to become older and battle significant chronic illnesses. There is an excessive need to gain an understanding of the elderly caregiver involvement and identify the challenges and emotions involved when making difficult decisions.

Summary

There is significant research supporting various challenges and processes related to long-term care placement. However, there is a lack of supporting research that investigates the emotions and challenges expressed with spousal caregivers when seeking long-term placement for their demented loved one (Chick & Meleis, 1986; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Schumacher & Meleis, 1994). A qualitative study would explore the emotions and challenges associated with the spousal caregiving decision role as well as identify positive coping mechanisms to utilize when dealing with transitional caregiving decisions with long-term placement.

Alzheimer disease is a chronic illness that impairs each diagnosed individual differently, which leads to the challenges faced by spousal caregivers to be diverse and sometimes complex. Insight into these differences involving emotions and decision-making processes would aid in the development of supports and interventions for spousal caregivers caring for an individual battling this chronic illness (Brown & Chen, 2008).

In this study, a qualitative approach and methodology were utilized to investigate elderly caregivers coping with the guilt of placing their spouse with dementia in nursing care. Qualitative methods have provided supporting information about caregivers.

Chapter 3: Research Method

Introduction

As explained in Chapters 1 and 2, Alzheimer's disease is a chronic illness that is extremely challenging to cope with. Alzheimer's disease is a progressive and chronic illness that affects the elderly population significantly. The literature identifies numerous factors that identify the elderly population at an increased risk of developing and suffering the ramifications of Alzheimer's disease compared to other age groups. One of the most significant and challenging factors with this chronic illness is the caregiving role (Brown & Chen, 2008).

Caregivers have various decisions to make involving the care of the Alzheimer individual such as meeting physical, mental, and emotional needs and making decisions relating to proper placement (Bjorn et al., 2001; Noyes et al., 2009; Samuelsson et al., 2001). The purpose of this study was to discover the perceptions and decision factors made by spousal caregivers' role for Alzheimer individuals. This qualitative study was focused on spousal caregivers' guilt and the challenging decisions associated with long-term care placement of the Alzheimer individual. The main focus of the study was to gain an understanding of caregiving experiences and ways to comprehend the feelings involved.

In this chapter, qualitative research methodology is defined for exploring caregiver perceptions, emotions, and meanings of changes associated with long-term placement of elderly spouses with Alzheimer's disease. Areas of discussion include subject selection, ethical guidelines for the protection of subjects' rights, and the role of the researcher. Other areas that will be addressed include data collection procedures, analyses, and explanation of verification.

Research Methodology

This study used a qualitative methodology. Creswell (2003) said the crucial factor associated with using this approach is that the subject is incapable of being measured. The study was merely explored by the perceptions, beliefs, and reality of the subject within this defined population and impacted by experiences. The proposed study benefited from grounded theory because it used comparative analysis and allowed for similarities of concepts to be identified and gave an understanding of factors already accumulated (Creswell, 2003).

With the use of grounded theory, the information collected from the study was able to be placed into various categories which allowed help with identifying any periodic themes, notions, and perceptions of the subjects. Themes were evident throughout the interview and observation process with the subjects.

Measures

The focus of this grounded theory study was to understand the perceptions and beliefs of spousal caregivers regarding placement of their loved ones battling dementia in Virginia. In this study, the subjects were selected from a convenience sample of spousal caregivers of individuals with Alzheimer's dementia who were experiencing long-term placement decisions within Williamsburg, Virginia. The spousal caregivers and demented loved ones were recruited from a retirement community within the Williamsburg, Virginia area and were 65 years or older. These subjects were in a caregiving role with a loved one battling dementia and were considering on long-term care.

Beliefs and observations were discovered by using open-ended questions which permitted subjects to express freely their interpretations of the spousal caregiver role and emotions experienced during the long-term care placement process. With the subjects openly expressing their feelings and thoughts, the researcher had the opportunity to gather detailed and vital information which helped identify recurrent themes within the sample pool. The questions that will be used are in appendix B.

Research Questions

RQ1: What are the emotional impressions of spousal caregivers when making long-term care decisions for their demented loved ones?

RQ2: How can understanding the emotions experienced with the placement process help identify effective coping mechanisms?

RQ3: What role does positive support play in the caregivers' perceptions and beliefs?

Human Subject Considerations

Permission was gained to conduct this study with the Institutional Review Board of the University Office of Research Administration. Participants were given a consent form to sign authorizing that face-to-face interview can be audiotaped, and data collected can be used for research purposes (see Appendix A). This consent form was explained in detail with each participant, and any questions or concerns were addressed. The participants were offered a copy of the consent form for their personal recordings and information. The original copy of the consent forms was secured and locked within a drawer.

It is vital that qualitative researchers definitively identify the research method for human subject protection. The data that was collected from these spousal caregivers and personal experiences that were expressed regarding placement remained confidential at all times and involved complete discretion. The recorded face-to-face interviews were free of references to names, characteristics, and locations.

It was important that the protection of these participants was maintained. These individuals had the right to be informed about the research in which they participated. The informed consent form helped clarify to the participants the benefits and potential risks associated with the research. The participants also had the right to withdraw from this study without discrimination if they felt it was necessary.

Role of the Researcher

The researcher clarified the phenomenological perspective through the process, was responsible for informed consents, delivered the survey, and conducted face- to- face interviews. The researcher answered all questions and concerns related to this process and handle the validation process. The researcher gained insight through the participants' feedback and ongoing interactions and behaviors (Creswell, 2003). The researcher was also the writer of this study and was fluent in English.

The researcher's professional life has offered great experiences with the elderly population and with the chronic illness, Alzheimer's disease, being explored. Working within a counselor role, the researcher has recognized various beliefs and perceptions of caregivers when caring for an individual battling Alzheimer's dementia. Additionally, the researcher has experienced the challenges faced by the placement of the loved one and the emotions experienced during this placement process.

The researcher accessed participants within the elderly retirement communities gained feedback and offered reassurance regarding confidentiality, comfort, honesty, and trust during the interview process. Being a counselor and working with individuals facing these obstacles, challenges, and understanding of the disease helps with identifying factors related to these caregivers' concerns and needs within the caregiving and with the long-term placement process. The researcher was also obligated and attentive to potential biases that were brought about due to the experiences already expressed within the unique population. The researcher made no assumptions and all major conceptions were made clear. By review of recordings and proper note taking, the information was clear and without biases.

Context

The data collections for this study took place in a meeting or confidential area of the building or location chosen by the participant. The data was collected by the researcher who was aware of confidentiality laws and the Health Insurance Portability and Accountability Act (1996) which provides safety for the privacy of certain individually distinguishable health data, denoted to as protected health information (PHI). Approval by proper parties to use meeting places, if within a retirement community or private setting, was obtained in order to conduct this study. This study was conducted in a confidential room where participants were free from distractions and privacy, comfort, and appropriate audio taping was ensured. Face to face interviews was conducted in this private setting using a semi-structured interview guide and was audio recorded. Qualitative research is a phenomenal way to build significant knowledge from an individual's personal experience. The researcher was responsible for sharing the research findings in a suitable and clear manner.

Participant Selection

A research study at the exploratory level is usually completed with a small sample size due to the importance of completing an in-depth study (Sandelowski, 1995). The participants must be able to meet the criteria that will be used for the selection process (Creswell, 2003). Participants for this study were chosen from a convenience sample of elderly spousal caregivers of individuals with Alzheimer's disease who recently were experiencing the caregiving role and processes of long-term placement. The participants were 65 years of age or older and lived within a retirement community of the Williamsburg, Virginia area. The participant was the primary caregiver and had been caring for a spouse with Alzheimer Disease for at least one year. There were no restrictions relating to the length of caregiving, years of marriage, or the use of long-term care services within the home setting. The sample size consisted of seven individuals who stated they were contemplating placement for their spouse with Alzheimer's disease and were recruited from Retirement communities in Williamsburg Virginia.

With consultation with supporting staff of these various retirement communities, the researcher was not provided to explain the purpose of this study and to request participation but was asked to provide informational flyers that served this purpose of sharing information and gaining the volunteers needed without bias taking place. Participants were accessed through interest shown and follow up phone calls concluding interest. These phone calls were made to each person interested in participating in the study and to follow up with any additional questions they may have. Arrangements were also made for the participant interviews.

Ethical Protection for Participants

Detailed steps were outlined to confirm the ethical protection of all the contributors. The Institutional Review Board (IRB) from Walden University did sanction the request to conduct this study. The participants were volunteers and did choose to participate freely and without pressure. The informed consent forms were discussed thoroughly placing emphasis on confidentiality, risks, and benefits involved and gaining authorization required for the audio taping of the interview.

This feedback was related to personal opinions, views, and beliefs of the participants that may create some distress. The participants were able to stop the participation of the interview at any time they saw fit without any consequences.

All records gained by the participants were stored in a secure and confidential setting. The data and information collected has only been visible to the researcher and has been analyzed without distinguishing information relating back to any of the participants.

Procedures

The following was the itemized method to recruit the participants, obtain informed consents, face-to-face interview, collect and analyze the data and validation of data.

1. The researcher did contact the local Retirement communities within the Williamsburg, Virginia area. A brief summary letter of the study was offered to these communities as a resource to give participating residents within that community the opportunity to take part. A copy of this summary letter will be provided in Appendix C.
2. With consultation with supporting staff, of these various retirement communities, the researcher was asked to provide a flyer for information purposes and to prevent bias or pressure from being placed on participation. Participants were accessed through interest shown and follow up phone calls. These phone calls were made to each person interested in participating in the study and to follow up with any additional questions they may have had.

3. Once receiving the IRB Notification of Approval to Conduct Research, the researcher got in contact with the Retirement Communities letting these parties know the study was given approval. The researcher gained a contact list of potential volunteers who were interested in participating in this study.
4. The researcher selected a total of seven participants from the convenience sample of volunteers that voiced interest with participation.
5. Upon contact lists being received of potential participants being interested in participating, an initial phone call was placed to provide these individuals with an introduction of the researcher, the study, as well as conclude full approval for participation. Clarification was given at this time to each potential participant if needed.
6. Individual appointments were made at a time that is convenient for each potential participant and the researcher. A contact number was provided for communication purposes in case appointment needed to be rescheduled for the potential participants.
7. At the introduction of each face-to-face interview, the researcher provided a clear picture of the study and what it involved, the informed consent form, the voluntary agreement on deciding to participate, and the awareness to know that participants could stop at any time. Confidentiality, risks, and benefits

were also discussed and clarified with each potential participant. After all, was communicated and an agreement was given, the researcher and the participant signed a copy of the Informed Consent and a copy was offered to the participant.

8. Upon the conclusion of approval for participation in the study, the researcher explained the necessity for audio taping the face-to-face interview and the participant then signed the Consent to Audiotape Form. A copy of the Consent to Audiotape Form was offered to the participant.
9. Upon all signatures and forms being obtained, a demographic data collection was carried out with each participant.
10. In conclusion to the demographic data collection, the face-to-face interview and audio taping took place. The face-to-face interview started with the introduction of the study, the purpose, and the researcher giving thanks for these participants taking part in the furthering research of emotions and challenges faced by spousal caregivers with the long-term placement of an individual with Alzheimer's disease.
11. Upon rapport and security being created, the actual interview started with open-ended questions being asked. Additional questions were asked to specify

explanations, add more in-depth details, or to carry out the interview. Notes were taken throughout each face-to-face interview.

12. Upon conclusion of each interview, the researcher did suggest to each participant to elaborate on the major concepts that had surfaced during the interview as well as give a clarification that was needed in addition. This follow-up allowed the researcher to form summaries of each interview and effectively endorse the major perceptions and themes introduced during the interview (Creswell, 2003).
13. With the conclusion of the validation process, the researcher gave appreciation for each participant’s willingness to participate in the study. The full participation time consisted of 45-60 minutes per participant.
14. Additional researcher notes, thoughts, events, and impressions were noted before leaving the congregation area (Creswell, 2003).
15. Each session was transcribed and given back to the participant to validate. This validation concluded the participant confirming that it is what they said. Once they approved it was analyzed.
16. Each audiotape was reviewed and compared with notes from the interviews. The names of the participants remained anonymous and the results were included in the data analysis session.

17. A letter of gratitude and thanks was mailed out in two weeks of partaking in the interview. A copy of this letter can be found in Appendix D.

Data Collection and Analysis

The research questions identified involved a qualitative approach to fully apprehend the participants' delicate practices in a more universal, conceptual means (Wassman, 2012; Monette, 2011). The data was composed in this study by using demographic surveys and face to face interviews with open-ended questions. Rapport and empathy were developed in order to have each participant comfortable, secure, and trustworthy of the researcher. Rapport was initiated at the arrival of the participant by introducing them to the assessment environment and offering a beverage if desired. The researcher did identify if any complications took place while traveling to the location to allow the participant to gain feelings of comfort and empathy through general conversation.

The participants were shown gratitude for taking the time to partake in this study. At this same time, the informed consent form was clarified, and a few minutes were used with each participant to gather proper signatures for participation. The demographic survey was administered. The main purpose of this assessment was to collect the data relating to socioeconomic status, the level of education, demographic information which will assure clarification of proper protocol being met for participation. This allowed the opportunity to clarify any questions the participant may have regarding the survey or participation. The face to face interview took place upon the conclusion of the demographic survey.

There was a total of six open-ended questions used in this study. The main purpose of these open-ended questions was to have the participants express freely his or her views on the spousal caregiving role and emotions experienced with decision making. These open-ended questions allowed for opinions, beliefs, and perceptions of the spousal caregivers to be identified. The main objective was to recover any reoccurring beliefs or perceptions regarding the spousal caregiving role of an individual battling Alzheimer dementia. The first interview question was to identify what they hear about caregiving for a loved one battling Alzheimer dementia. This allowed communication to take place about other individuals in the same situation and the beliefs related to them as well. This allowed the researcher to gain insight into the basic beliefs and thoughts processes of the participants.

The second interview question focused on the understanding of the caregiving experience and emotions expressed because of this caregiving role. This allowed observation to take place regarding the various emotions and factors involved with the spousal caregiving role. The third interview question focused on the impact of providing care to an individual who has dementia can have on the caregiving in relation to stress and depression. Emphasis was placed on these specific outcomes and how stress and depression can impact the caregivers' decision-making and overall caregiving role. The fourth interview question focused on social support. The question asked each caregiver to elaborate on how they were able to cope with the stressors of caregiving. The fifth question focused on asking the caregiver to identify whether they felt the caregiving role was becoming too much and that they may not be able to do it any longer. Finally, the sixth interview question focused on the topic of when the caregiver may realize when it may be the right time for their loved one to be placed in a long-term placement as well the factors involved with making that decision.

All interview questions were analyzed for reliability to confirm that these questions are dependable and will produce similar types of answer. These interview questions were also examined for validity to make sure the questions are asking what is proposed by the researcher. Each interview was audio recorded by a handheld audio recording device and took place in a confidential and secure setting.

Upon the conclusion of the interviews, all data obtained was recorded precisely by the researcher. A categorizing scheme was utilized to sort the data into specific classifications themes during analyzation of the data. Berg's (2007) analysis method of thematic clustering was applied. A thematic analysis was used to classify themes. This tool allowed the researcher to look at the data and clarify a patterned theme. This theme helped the researcher organize the observations and potentially helped interpret the aspects of the phenomenon. In summary, this type of analysis helped the researcher make sense of material, analyze information and a way to observe a person or situation in a systematic way (Boyatzis, 1998).

Chapter 4: Verification of Findings

This chapter is a detailed summary of the characteristics of participants and the findings of this study. The protection of all participants and confidentiality was maintained by providing the participants with an assigned letter from A through G. Each topic and major theme is discussed in detail in this chapter as well.

Demographic Information and Interview Results

This chapter discusses the substance of the data collected from the investigator one-on-one interviews with the participants. This study consisted of seven spousal caregivers who spoke of their experiences and emotions involved in the long-term placement of their loved ones who have a diagnosis of dementia. The participants were nominated from a convenience sample of elderly spousal caregivers of individuals with Alzheimer's disease. The participants were 65 years of age or older and live within a retirement community in Williamsburg, Virginia. The participants in this study were primary caregivers who had been caring for their spouse with Alzheimer's Disease for at least 1 year. There were no restrictions regarding the length of caregiving, years of marriage, or the use of long-term care services within the home setting. Everyone was interviewed in a private and secure location where participants felt comfortable. Some of the care recipients were in the initial stages of the disease while others were in the more advanced stages, which required more care and support. The participants testified regarding their associations with their loved ones, life changes, caregiving needs, and any stress that may have resulted from caregiving roles.

The participant caregivers in this study consisted of three men and four women who were all married, 65 years of age or older, and were Caucasian-American. The participants' anonymity and confidentiality were maintained by keeping all identifiable information anonymous and assigning letters to participants.

Changes in the Relationships between Spouses

Participants all suggested that changes in their spousal relationship were taking place such as communication, personal needs along with relationships with friends and family members. Many participants described feelings of being alone and isolated at times. The theme of role exchange between the partners became evident. Participants confirmed that they felt help was not accessible when they needed it or that the help that was offered by outside resources was not something that they were willing to accept. Accepting help from others made many spousal caregivers feel as though they may be inadequate in terms of caring for their loved ones.

Role Exchange and Support from Family

This theme seemed to be a significant commonality in terms of relationships between participants and their spouses. Participant B expressed a great deal of stress and feelings of being overwhelmed. Her spouse used to take care of all financials and support for the couple, and now she was faced with figuring these processes out with limited support from family. Given the mental deficits her spouse was experiencing, she had to become the financial planner. Participant D felt that the role placed upon her was changing from week to week. She expressed a great deal of frustration in trying to identify with the caregiving role for a spouse who could no longer care for himself. Many of the other participants were consistent with the feelings of change in roles; however, Participant F felt confident with the switch in duties and suggested she could adjust quickly knowing she was doing the duties in her spouse's place that he loved so much to do. Participant G expressed feeling overwhelmed with all the new duties including cleaning, cooking, laundry, and financials. Many of these participants were alive during the Great Depression and tried not to shatter upon their family or children for the additional support given their new caregiving roles.

Life Changes Experienced in Caregiving Duties

Commonalities between the participants regarding life changes being experienced included copious amounts of stress, feelings of isolation, and depression due to the dependency experienced with the caregiving role for their loved ones.

Stress Levels

Many of the participants expressed they felt a great deal of stress with the new roles involved in caregiving. Participant G reported feeling trapped within the role of caregiving and not having an outlet for himself when needing to step away. Stress levels made the participant express feelings of heartache and frustration. He stated that he asked this question often: “why did this happen to us?” However, he believes he is still blessed to have her with him even if it is not the way he may want her to be. Participant F said her stress levels were elevated when her spouse would behave angrily and agitated toward herself and others. Finding ways to cope with this anger was challenging. She could find strategies that worked over time, and most of these strategies worked effectively for her and the staff supporting him within the facility. Participant E felt stress for not only having to take care of her spouse mentally but also physically, which was starting to take a great toll on her mental and physical abilities as well. Participant B said that stress levels increased due to running out of patience with all that must be done for her spouse. She stated that her stress levels would get so high that she became overwhelmed with fear of inability to handle things she has never had to do before. These duties included providing medication and assisting with daily living activities such as bathing, toileting, as well as other tasks such as financial responsibilities and support. She suggested that the increased number of duties was overwhelming and led to a great deal of stress.

Isolation

All participants expressed feelings of being alone and isolated. Whether the loved one was living with the participant or within a facility, free time available was spent caring for their spouse or spending time with them. Many participants felt that friendships were depleted because of their increased caregiving role. Many activities were limited, and day and night revolved around their spouse battling this disease. Participants started to deny many activities that they enjoyed doing before such as traveling, playing games with friends, and even simple activities such as going out to dinner due to the duties of caregiving as well as feelings of guilt that their loved one cannot participate in these activities with them any longer.

Caregiving Positives

While there are many challenges faced with the caregiving role there are still positives that come from it. The positives consist of still being able to spend time with their spouse even if they are not mentally fully aware of their presence and being able to be a part of special moments where their loved ones may remember them or their life experiences together and be able to reminisce with one another during these times.

Participants express being able to be in the presence of one another is very rewarding no matter what deficits are being faced in this walk of caregiving. Participant D expresses “taking one day at a time together is all I can do and as long as I have him then I am complete, even if it is not in the way I hoped for, but our presence is still known. Participant F stated:

> My spouse stays within the facility, but I visit daily to spend time together and even though he has memory deficits he still knows mostly who I am and when I come to visit it is that very special to him that we talk about memories together from our past. These daily visits make my day a little brighter. The decision to place him was one of the most difficult and somewhat forced by the doctor, but definitely, the best outcome gave where we stand at this moment.

Caregiving Difficulties

Caregiving is a very challenging role especially when it is connected to loved ones who are not the same as they once were before. One of the most challenging things to watch with the caregiving role was the decline of their spouse. Some of these declines were advanced and some were slow, regardless all was one of the most difficult things to deal with. Another challenge that took place was when the spouse had behavioral changes and agitation, frustration, and anger came about. This expressed a great deal of difficulty to deal with for the caregivers as well as the facilities that the loved one may have been being cared for within.

Diminishing Abilities of The Loved One

Participants concluded that diminishing abilities began to be noticeable as the disease progressed and when their loved one started to change with their capabilities. Participant A stated that there are good days and bad days with his spouse. Some days she can perform regular tasks such as bathing and get dressed. However, there are some days that she simply is not and needs guidance. Often, if left alone to get dressed his spouse will continue to place the same pair of clothes on every day not recognizing they are dirty. Participant B stressed her worry with the continued decline of her husband. She suggests this worry with the ability to continue caring for her spouse within the home of the community, as he is a larger man and she is quite frail herself and limited on what she may be able to do for him. She has suggested the decline she has witnesses with her spouse was the denial of not wanting to bathe or change clothes. She expressed the anger and frustration experienced by her husband when these tasks were suggested to him to do with help at all. Participant F suggested that she noticed her spouse's decline when he had a significant fall and could not care for himself without becoming combative with others trying to assist. She knew with the guidance of the Doctor at the rehab facility that her spouse needed the special placement to protect him and give him the support with daily activities such as bathing, dressing, and eating that he needed. The participant expressed she felt this was the best decision she could make and was still able to be a part of his daily life with visits and spending time with her spouse enjoying activities such as listening to music or watching the news together. These were still certain tasks that her husband loved to do with her and still remembered a little bit of versus the frustration experienced in other areas with his decline. Participant G confirmed that she noticed her spouse declining when he would wake up early hours in the morning or late evening and began to wander aimlessly. Sometimes this wandering took place outside and he was not aware of where he was or what he was attempting to do. This wandering is a common behavior of a loved one with Alzheimer's disease but can be dramatic and take place quickly. This participant also expressed she noticed her husband's abilities diminishing when he was not able to care for the finances of the household any longer or utilize the microwave in a proper manner.

Decisions Surrounding When to Seek Placement in a Facility

With the witnessing of the diminishing abilities taking place for their loved ones, participants also became aware that these declines were a sign that placement within the nursing or memory unit within the retirement community was most likely needed. Participant F and G both concluded within their interviews that placement had already taken place for their loved ones as diminishing abilities with physical and mental capabilities happened quickly. Participant F made this decision with placement when her spouse had an acute health issue that had a dramatic effect on his memory. This dramatic effect resulted in extreme memory deficits along with behavioral issues that were not manageable at home even within the retirement community. Participant G confirmed that placement took place due to the concerns of her spouse not being aware of his surroundings and wandering. She worried for his safety and felt at their house within the community was still not enough security. Recommendations were made that a secure memory unit was most appropriate for her spouse. Participants C and D are a little overwhelmed at the thoughts of placing their loved ones. These participants realize that placements will eventually need to take place, but they seem to be wanting guidance as to when is the right time and want to hold onto their loved ones at the home front as long as they can. Participant D has such conflicting thoughts regarding placement that a comment was event made during the interview regarding who would take care of her spouse if anything happened to her such as a sickness or injury. This clearly showed that the participant was hesitant and not in the right mindset for placement at that moment.

Emotional Distress and Stressors

All participants were in significant agreement that emotional distress was evident within their caregiving roles. Per the participants, the emotional stress began to take place from the beginning with the diagnosis, to how they learn to deal/live with this life-changing disease to seeing their loved one decline with forgetfulness and witnessing deficits continuously taking place. Other feelings of emotional distress that was evident for these caregivers was frustration and feelings of depression. Of the seven participants, 6 expressed an emotional toll taking place because of all the change that was being experienced. The 7th participant expressed more of an emotional toll placed given the disruptive behaviors her spouse was having an often directed towards her. Overall many concluded a great deal of emotional stress connected to the fact that their spouse was slowly losing who they were and what they had together for so many years.

Other stressors that took place were physical concerns for participants. Many participants confirmed feelings of being worn or lack of energy. Participants expressed a great deal of concern with how they could care for their loved ones when they were in physical decline themselves. Participant G and F expressed that they had started to recognize this physical distress, and this was just one more reason as to why they agreed to secure placement for their loved ones. Other participants expressed the physical demand caring for their significant others was having on their own health. There were a few participants who had been through instances where a traumatic sickness such as the flu came over them and the difficult challenges experienced with caring for their spouse were faced abruptly. Many had to coordinate extra support in the home, a respite stays for both them and their spouse in the rehabilitation center of the community or having family fly in and stay for support. With all of this came the financial stress as expenses to care for their loved became a little heavier. Many participants did suggest that since the caregiving role has taken place their health has taken a toll as not only are they doing more for themselves and their spouse, but also not able to participate as often in the fitness activities that they use to before.

Stressors-Financial, Emotional, Physical

All spousal caregivers that were interviewed classified emotional stress as having the highest impact on the caregiving role. The participants concluded that emotional stress was the most stressful. The spousal caregivers confirmed that the financial stressors were the least of their worries as their spouse they were caring for provided and prepared well for their future financially. The spousal caregivers loved ones, all participants, even went to the extent to provide Power of Attorneys and Advance Directives to assist in the guidance of finances and medical authorities within the future. The spousal caregivers did express some concern over their own health and well-being. All participants suggested at one point in time of the caregiving role they have neglected their own health. Examples of this neglect included sleep deprivation, not eating adequately, not following up on medical appointments as needed, and battling more illnesses than usual due to a lack of care for oneself. The emotional stress that had the most impact on these spousal caregivers consisted of depression, sadness, anxiety, isolation, frustration, guilt, and grief. Four of the participants concluded that depression and anxiety were significant within their daily life and a doctor was seen to discuss treatment such as antidepressants.

Looking after Oneself

When asking the participants if they were still taking care of themselves many agreed with the importance of continuing activities that they enjoyed. However, many expressed that these activities were limited and did not happen as often as they may like them to. Several of these activities included going to exercise classes, having dinner with friends, playing card games or going to community events. Quite a few of the participants suggested that these became limited to maybe one activity a week and this could vary depending on the day their spouse was having, if they could gain extra support in the home to attend, or if it was an event that their spouse could come along to comfortably. All participants did stress that they all did attend the support groups that were weekly as care was provided for their spouses while they attended their Alzheimer's support group session.

Participant G and F spoke about the many activities they could go participate in with their spouse within the special care unit the resided at. The activities they could participate in consisted of news hour, music hour, social events, and even lunch. They expressed the rewarding feelings to still enjoy these activities with their loved ones in a setting that makes their spouse feel comfortable and have support as needed. Having this support allows the participants to take better care of themselves and be available to their spouse emotional and physically. Participant C spoke about the activities he truly enjoyed with his spouse such as travel that he can no longer do now given her decline. He expresses that he does not do much of it himself now given the feelings of guilt expressed of leaving her, even if proper care is in place and she would not necessarily know given her mental decline.

Strategies Used for Coping

All participants agreed, living within the same retirement community, that the support groups provided for the caregiving spouses was of the biggest coping mechanisms utilized. In addition to this support group, the participants spoke about the support of the Community Doctor as well as all the staff surrounding them. Family and children were also high on the list as great support and help with coping and caring for their loved one. Participant C suggested that one of her personal coping strategies was to take one day at a time and hope that the day they were dealing with was a good one where more memories could be made. Participants F and G suggested that the way they coped with their loved one battling this disease and being apart within them in place, was to keep busy and make sure there is common ground between individual activities they like to do as well as joint activities throughout each day when going to spend time with their loved ones. Participant G suggested some of the joint events are quite special that it almost feels sometimes that they are on a date like once before.

All participants confirmed that the support of others going through the same thing and battling the same battles daily are the biggest support of all. The participants expressed that they all lean on one another within the support group as well as outside. They not only have become a listening ear to one another but also an advocate for others who may just be starting this journey of caregiving or are not sure how to walk through it.

The Timing of Placement for Loved Ones

All participants reside in a retirement community that offers various levels of care. There is Independent Living, Assisted Living/Nursing, and Special Care/Memory Unit. Depending on the levels of need and support in the home is dependent on where a resident may reside. The residents that reside in this community are 65 years of age or older and know that during the next years of life changes and limitations will come about. This community provides support as needed for these life changes along the way. All seven of the participants interviewed decided to become a part of this community given the diagnosis provided to their significant other. Two of the seven participants have made the decisions to place their loved ones in the special unit. This was done due to various behavioral issues and wandering concerns. While there were reasons for this placement this was still a very hard decision for the participants to make. Other participants have not made it to this point yet or have used their avoidance skills to prevent it if possible. Participant C suggested when asked the question about long-term placement, that she was waiting for the Doctor’s final direction when all else has been exhausted. He also suggested that she was hoping that day would not come as he hoped to keep his spouse home with him for the duration. Participant D spoke about bringing in home care services within their independent living home setting. She suggested that this was the most beneficial for her and her loved ones’ situation feared the thoughts of separation. Overall the theme followed through with all participants was that the decision or thoughts involving placement were a scary process. Many had extreme feelings of guilt and separation. The participants suggested that the feeling of guilt demonstrated related to letting their spouse down or stating with the decision to place that they were not able to provide care services for their spouse any longer. While these participants had a great deal of support within the Retirement Community then others do outside of the community, they still battled the same emotions and difficult decision-making processes.

Support in All Communities

Many participants confirmed upon conclusion of their interviews that there is consistent help needed for individuals who are in the same situation as they may be with their spouses. Whether it is a diagnosis of Alzheimer’s Disease or cancer, Participant B stated, “no one can ever prepare you.” While there is education and support out there for caregivers and support of Alzheimer’s disease there is limited support and information shared about the challenges faced and the decisions having to be made by a spousal caregiver for their partner. Support groups, resources, and guidance need to continue to be provided for all individuals dealing with something like this. Especially for individuals who may not have the financial means to provide the type of support this Retirement Community has for their residents.

Progression of the Disease

All participants expressed the surprise of how quickly this disease was identified and diagnosed for their loved ones. Many concluded that research had been investigated and the various types of behaviors and traits that can be brought about by Alzheimer's Disease were shocking. Two of the participants expressed the rapid progression of the disease upon injuries that took place. These injuries consisted of significant falls and recovery time which made the progression of the disease advance rapidly given the trauma related to the injury. These participants stated that unfortunately these injuries and the progression of disease made them make the decision for long-term placement. One participant concluded that long-term placement had to take place due to concerns about safety. Her spouse had continuously started wandering and several times this wandering took place outside of the home which caused chaos and emotional stress when searching for the spouse's whereabouts. The long-term placement had to take place within a secure setting to ensure that her loved one would not leave the secure area without constant supervision. All participants reported that their loved ones seem to have good days and bad days. Sometimes the bad days lead to more memory loss, agitation, and limitations with physical abilities such as bathing and dressing.

Chapter 5: Discussion

Introduction

The current study's purpose was to identify and describe the experiences and perceptions of spousal caregivers caring for their loved ones battling Alzheimer's disease and the impact this role has on the spousal caregiver. The main emphasis of this study was to enhance our society's knowledge of the physical and mental implications related to spousal caregiving and bring awareness to available resources and services that assist with the spousal caregiving role.

Synopsis of Results

There is limited research that explores spousal caregiving roles and the unique needs that are expressed with this role. As an outcome, this population of spousal caregivers under review were experiencing challenges including emotional and physical hardships, some difficulty with proper resources and services needed for their spouse battling Alzheimer's disease, and a lack of clear understanding regarding the difficulties of providing spousal care for their loved ones. The data from this study suggested that spousal caregiving has a profound effect on the caregivers mental and physical well-being. The spousal caregivers had their own age-related needs, as many of these caregivers were as old as their spouses they were providing for. It is vital to the spousal caregiver’s well-being to preserve mental and physical health (Pinquart & Sorensen, 2004).

The elderly population of spousal caregivers was an important population to explore. These spousal caregivers endure a great deal of burden and stress relating to this caregiver role and are faced with difficult decisions to make. Etters, Goodall, and Harrison (2008) said that dementia caregiving has been linked with negative effects on the health of caregivers. This research also confirmed that this burden and stress can lead to expedited long-term placement for loved ones battling dementia. Researchers concluded that interventions and a diverse group of services need to be accessible for caregivers to minimize this burden and stress, enhance the quality of life, and provide the home care needed for their loved ones if they are able to do so (Etters et al., 2008).

A phenomenological qualitative method was used to discover spousal caregiver observations and experiences regarding this caregiving role. The sample size for this study consisted of seven spousal caregivers. The method involved open-ended interview questions to attain answers to the interview questions involving experiences and observations of the caregiving role. This study concluded that caregiving for loved ones battling Alzheimer’s disease was not an easy job. These spousal caregivers felt obligated to perform this duty of caregiving without enough guidance or resources which left them with emotional distress and sadness. There were seven themes that originated from spousal caregivers' interview and feedback responses.

Theme 1: Caregivers' Well-being

Spousal caregivers reported significant impacts relating to their mental and physical health resulting from the caregiver role. Spousal caregivers' mental and physical well-being was a result of stress from providing challenging care for their loved ones. This caregiving role is emotionally draining because of the caregivers' obligations and challenging duties of care, and spousal caregivers tend to ignore the signs of requiring rest and avoid using medical services as advised (O'Donnell, 2000; Wheeler, 2010). This emotional distress has elements of depression, isolation, sadness, fatigue, guilt, and grief. These were forerunners to an array of other illnesses. As the loved ones' decline took place, the more stress was placed upon the spousal caregivers and the more they began to neglect their own well-being (Schulz & Martire, 2004).

Theme 2: Role Exchange

Spousal caregivers reported that role exchange with their loved one was one of the most difficult aspects to deal with. They expressed concerns with how rapid changes happened. This frustration expressed due to role change led to sadness given the decline their loved one battling Alzheimer's Disease was going through. Spousal caregivers expressed how closeness with their spouse was changing and how they realized they were undergoing the loss of their life partner. Most of the caregivers said that the caregiving role had become more like a parent-child relationship. Caregivers expressed emotions involving isolation and depression given these changes.

Theme 3: Caregiving Difficulties

Spousal caregivers undergo numerous changes in their life. These changes involve their social life as well as the quality of life They also experienced loss of friendships, lack of self-care or independence, and emotional distress since they had become a spousal caregiver. Roland, Jenkins, and Johnson (2010) said that caregivers reported sadness growing deeper as the disease progressed.

Theme 4: Emotional Distress

Spousal caregivers reported having significant amounts of stress when caring for their loved ones. Almost all spousal caregivers reported feeling frustrated, depressed, anxiety-filled, guilt, and isolation. Some of the spousal caregivers expressed seeking mental support groups to interact with others who were dealing with the same issues. Other spousal caregivers suggested that there was no time for this as they would feel guilty for leaving their spouse who was battling Alzheimer’s disease and did not want to make them deal with any more than they had to. The spousal caregivers reported that this mental stress was wearing on their own health at times and without any type of support, they would be lost regarding what to do. Many of these spousal caregivers were leaning on the support of the retirement community during their time of need.

Theme 5: Caregiving Positives

The spousal caregivers reported that while it was difficult to care for their loved one battling dementia there was still some rewarding factors that remained positive. The first positive factor related to spending time with their loved ones. While their loved ones were declining due to the illness, they were still able to share with their spouse, time side by side and being in the presence of one another. The spousal caregivers did report that they realize that their spouse may not always know whom they are due to memory deficits, but just being with one another in the same home was a great feeling and all that was needed.

Theme 6-Decisions of Long-Term Placement

Spousal caregivers reported that one of the most challenging decisions to contemplate was placing their loved one in a long-term facility. They reported that there was understanding with how the decline could be for their loved one, but quite a few of them did not want to fathom the idea of them placing their loved one elsewhere than home with them. Two of the seven spousal caregivers had gone through this process of placing their loved ones battling Alzheimer’s disease. However, these placements were due to incidents that took place which included a significant injury that would take some time to recover from and for security and wandering issues. Many feelings coming about when dealing with this difficult decision of long-term placement. Many spousal caregivers feel a great deal of guilt for not being able to care for their spouse at home often due to continued physical and mental health of the loved one battling Alzheimer's Disease. Other emotion expressed is sadness and grief. Mittelman, Haley, Clay, & Roth (2006) reported through research that evidence has leaned towards the positive effects of counseling and support intervention for caregivers which can help with the delay of long-term placement.

Theme 7- Support

Spousal caregivers reported feeling grateful for the support that is available and provided by the Retirement community they live within. Caregivers expressed that while they may not have been utilizing all support that was available to them, knowing that it was there was helpful. The report that was available consisted of memory support groups, home care assistance, and 24-hour care within a long-term placement setting such as the memory or nursing unit. The spousal caregivers stressed how challenging it was to watch their spouse's mental and functional abilities decline, however, it was a peace of mind knowing that when the time came or more support needed there will be guidance and help along the way. These spousal caregivers emphasized that they were grateful for the financial means provided by their spouse over time so that this community was an option for a place of living. Without this financial support, these spousal caregivers would be limited to the resources available and have a lack of understanding of the illness they were dealing with and that their spouse was battling. The caregivers of this study articulated the importance of providing resources and guidance to all caregivers who are caring for their loved ones battling an illness. They suggested that without this report the job is not possible and continuous challenges arise including the safety of themselves and their loved one battling the illness. The more support and resources that can be provided to caregivers the better care they can provide to their loved ones battling this illness. These available resources and support also allow the caregivers to take better care of their own health which allows for positive outcomes to take place during this very difficult time (Elliott, Burgio, & Decoster, 2010).

Findings and Theory

This qualitative phenomenological method was based on the theoretical framework of the grounded theory. This grounded theory allowed for the data collected from the participant interviews to be placed into various categories which allowed for themes and perceptions to be identified. Two other theories that were utilized in this study was the Lazarus' and Folkman's Stress & Coping Theory (Lazarus, 1999) and Boundary Ambiguity (Boss et al., 1990). Lazarus' and Folkman's Stress & Coping Theory (Lazarus, 1999) focused attention to the stress involved with the caregiving role and how this stress impacts the relationship between the spousal caregiver and their loved one as well as the emotional toll experienced. This stress has been reported to be a difference between strains and resources. Through this theory, spousal caregivers had a very difficult time handling this stressor of caregiving for their loved one. These spousal caregivers reported that caregiving was a higher stressor that they could not come to terms with. The overwhelming challenges faced with their spouse becoming ill, role exchange taking place within the relationship, the feelings of isolation, grief, guilt sadness was reported at times just too much for them to handle (Krohnc, 2002).

Boundary Ambiguity theory was used to analyze how these spousal caregivers adjusted to the new roles, guidelines, and life changes due to their loved ones who were diagnosed with Alzheimer's disease. Through this study, it was witnessed that boundary ambiguity was present due to the spousal caregivers having a hard time expecting the loss presented with their spouse's diagnosis of Alzheimer's disease and what support within the family was present during this life-changing process. Boundary ambiguity identified the depression symptoms and signs within the spousal caregivers. Kaplan and Boss (2004) concluded that boundary ambiguity is quite evident within the spousal caregivers' roles and is experienced with depressive symptoms upon difficult decisions being made regarding their loved one battling Alzheimer's disease. Results concluded that interventions and education provided to spousal caregivers on how to live with boundary ambiguity and overcome it regardless of the life-changing situation one was dealing with would be a positive step towards bettering the health of the spousal caregivers and support the caregiving role (Kaplan & Boss, 2004).

This current study concluded that spousal caregivers were of a predominantly special population of caregivers due to being of the elderly population, need support, resources, and a great understanding of the caregiving roles they are embarking on. Evidence has conveyed that the determined and dedicated efforts of spousal caregivers to provide the utmost care for their loved ones battling Alzheimer’s disease no matter what it may entail. There are many significant needs of spousal caregivers that have been identified and needs attention to support this caregiving role in a positive and supportive measure.

Discussion

The findings from this current study exposed that spousal caregivers felt an obligation for their loved ones battling Alzheimer’s Disease and providing as much support as needed even if this meant at the outlay of their own health. Haley, LaMonde, Han, Narramore, and Schonwetter (2017) confirmed the importance of the support and resources needed for spousal caregivers. Their research also expressed evidence that without the proper resources and support provided the more caregiver stress progresses. This then leads to great possibilities of depression and poor health of spousal caregivers.

Stress-related illnesses and lack of social support were widespread among the population of spousal caregivers. Past findings have suggested a significant level of stress suffered by spousal caregivers indicated a great possibility for adverse effects including isolation, lack of social support, feelings of burden and guilt, depression, and a decline in one's own physical and mental health (Salleh, 2008).

However, even with these adverse effects visible, spousal caregivers continued to provide as much support as they could for their loved ones. Of all seven spousal caregivers' information was shared by all that the caregiving role was difficult but with the support from their retirement community, these duties became a little more understood and handled. Two of the seven spousal caregivers had to make the decision for long-term placement given the perplexity of the caregiving needs at home for their loved ones. However, with the support of the retirement community, it was confirmed that this was the best decision made for their safety, caregiving needs, and security.

Spousal caregivers freely recognized that stress related to the caregiving role was extremely challenging and was frustrating for caregivers to ask for help when needed due to the lack of the ability of this help within communities. The spousal caregivers within this study confirmed the gratefulness for the support they received within the retirement community but did express this support was provided given the available financial means. These spousal caregivers emphasized the importance of support and resources for all caregivers and that these services should be available and not be weighed upon financial means (Werner, Mittleman, Goldstein, & Heinik, 2012).

Limitations of the Study

One noticeable limitation of this was the sampling. Qualitative phenomenological studies do focus necessarily on the count of participants, but more on the richness and quality of the data being collected. The downfall of small sample size is that results are not a full representation of the entire caregiving populace. Another limitation is that this study focused specifically on the spousal caregivers of a retirement community and so the results cannot be entirely duplicated in other populations as the caregiving involvement is exclusive to everyone that participated.

Finally, another limitation of this research is that this population of exploration was specific to a time frame of caring for a loved one specifically battling Alzheimer's Disease, of a certain age bracket, and living within a certain location and retirement community. These results may have been different if this research were to take place in a different location, different age, and caring for the loved ones for a longer period. A difference in responses referencing coping techniques, resources, and management of emotions could be a potential possibility if a study used a more diverse participant pool relating to demographics.

Implications for Future Research

Upcoming research of spousal caregiving needs to be directed in the areas of learning more about Alzheimer’s Disease, resources needed for caregivers, and the support needed for all involved. There needs to be focus placed on the understanding of the needs of spousal caregivers and what resources are available to them within the areas needed. Future research also needs to focus on more psycho-education specifically on the areas of emotions, coping techniques, and family dynamics. Further research needs to be placed on gaining a better understanding of family dynamics to prepare these caregivers for the demands of the caregiving role. With this understanding could come more education on caregiving issues that may be faced along the way of the illness. Also, more sharing of these caregiving experiences with others in the family and through support groups can enrich the encounter for all involved.

Other potential future areas of research would include diverse groups within society and the resources available to these groups, awareness of the benefits of proper interventions, and values and expectancies regarding caregiving. Overall, future research embedded in programs and services to address the needs of the caregivers’ population in all diverse areas is of utmost importance.

Conclusion

Caregiving is one of the most difficult and challenging roles a person can have. Caregiving for a loved one battling a chronic illness continues to pose many challenges for caregivers, family members, and healthcare providers as caregivers play a crucial part in the care of their loved ones and resources and programs are quite limited now that allow the help needed to improve and sustain the quality of life of the caregiver. Education and support programs are needed, and research needs to continue to grow within these areas so that caregivers can provide the most positive support for their loved one as well as take care of their own health and well-being. For these caregivers to be 100 percent for their loved ones in this caregiving role the more support, positive coping strategies, and resources they need. A better prepared and health caregiver, a more taken care of a loved one fighting a chronic illness will be.

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Appendix C: Interview Questions for the Study

1. What are some of the things you as an individual hear about caregiving for a loved one battling Alzheimer dementia?

2. What are some of the caregiving experiences and emotions expressed because of this caregiving role?

3. What impact has providing care to your spouse who has dementia have on you in relation to stress and depression? Have the factors promoted any challenges with making decisions?

4. Can you, as the caregiver, elaborate on how you are able to cope with the stressors of caregiving?

5. Could you identify whether you feel the caregiving role is becoming too much and that you may not be able to do it any longer and need to look at other options for care?

6. When do you think, as the caregiver, that it may be the right time for your loved one to be placed in a long-term placement and what are some of the factors you feel are involved with making that decision?

Appendix D: Demographic Survey

1. What is your gender?

☐ Male

☐ Female

2. What is your age?

☐ 18-29 years old
☐ 30-49 years old
☐ 50-64 years old
☐ 65 years and over

3. What is the highest level of education you have completed?

☐ some high school
☐ high school graduate
☐ some college
☐ trade/technical/vocational training
☐ college graduate
☐ some postgraduate work
☐ postgraduate degree

4. What is your religious preference?

☐ Christian Scientist
☐ Roman Catholic
☐ Protestant
☐ Mormon
☐ Jewish
☐ Muslim
☐ an Orthodox church such as the Greek or Russian Orthodox Church
☐ Seventh-Day Adventist
☐ Something else (please specify)

5. Ethnicity: I want to be sure that a broad mix of people is spoken to in your area. Are you, yourself, of Hispanic origin or descent, such as Mexican, Puerto Rican, Cuban, or another Spanish background?

☐ Yes

☐ No

6. Race: What is your race? Are you white, African-American, or some other race?

☐ white

☐ African-American

☐ Other (please specify)

7. Are you now employed full-time, part-time, not employed, or retired?

☐ full time

☐ part-time

☐ not employed

☐ retired

8. Including yourself, how many people live within your household?

9. Are there any children under the age of eighteen years currently living in your household?

☐ Yes

☐ No

10. What is your marital status?

☐ single/never been married

☐ married

☐ separated

☐ divorced

☐ widowed

11. Are you a caregiver to a spouse loved one?

☐ Yes

☐ No

12. Does your spouse have a diagnose of Alzheimer’s Disease and/or a type of dementia?

☐ Yes

☐ No

13. Do you live within a retirement community in the Williamsburg VA area?

☐ Yes

☐ No

End of survey