

2015

# The Emotional Impact on Elderly Spouses Who Placed Their Loved Ones in Long-Term

Barbara Hunt  
*Walden University*

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# Walden University

College of Social and Behavioral Sciences

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Barbara Hunt

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2015

Abstract

The Emotional Impact on Elderly Spouses Who Placed Their Loved Ones in Long-Term

Nursing Care

by

Barbara Parkison Hunt

MA, University of Akron, 1993

BS, Kent State University, 1991

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Psychology

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## Abstract

Aging may bring mental and/or physical decline. There may come a point when a loved one needs long-term care in a nursing home. The purpose of this phenomenological study was to examine the community dwelling spouses' emotional state. A study was conducted with 10 individuals (5 men and 5 women) who had a spouse in long-term nursing care. Inclusion criteria was to be at least 65-years old, have been married at least 30 years, and reside alone in his or her own home. The social emotional selectivity theory and the construct of boundary ambiguity were applied to view the epoch. Data were collected with audio recorded interviews and coded as to major idea in each response. Five themes evolved from the responses: reduction of friends, ease or difficulty with change, companionship, vows are forever, and why. The community-dwelling spouse tended to be sad, anxious, and angry. Loss of companionship, increased isolation due to reduction of friends prior to placement, concern about the well-being of his or her spouse, and feelings of "why did this happen to me?" were common themes by the community-dwelling spouse. Wives who did all household chores prior to their husband's institutionalization were more able to accept the placement of their spouse than were husbands who had depended on their wives. There is a need for treatment for the community-dwelling spouse by nursing home staff, friends, and family. Nursing homes can encourage support through community-dwelling support groups and mealtime with their institutionalized spouses. Children of community-dwelling spouse can provide support through contacting their parents frequently, clergy, and friends of the church through visiting the community-dwelling spouse after placement of their spouse.

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## Dedication

I wish to thank and dedicate this study to my family for being so supportive through all the time taken away from them to capture a dream of earning this degree.

Thank you, Alexis, Brandon, Jon, and my Mom for all your support. I love each of you dearly.

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## Chapter 1: Introduction to the Study

### **Introduction**

Aging is inevitable and it brings the possibility of mental and/or physical decline. After exhausting all formal and informal care within the home, a nursing home may be the only option left to meet the 24-hour care needed. The purpose of this phenomenological study was to determine how long-term separation affected the community dwelling spouse who had been married 3 decades or more and first time may now be separated from his or her spouse for the rest of his or her life. Insight into the emotions that a community-dwelling spouse may be experiencing may help family, friends, and professionals understand what type of support or service to offer the spouse who is not receiving the 24-hour care.

The chapter starts with the background, then the problem statement, the purpose of the study, the theory and conceptual framework, the nature of the study, definitions of key concepts, scope and delimitations, assumptions, limitations, significance, and then ends with the summary.

### **Background**

With age, the likelihood of residing in a nursing home increases. The projected number of people needing nursing home care will be 27 million by 2050 (U.S. Census Bureau, 2012). The reason for this increase is due to the growth of the aging population combined with the risk of elderly needing nursing home care (Vincent & Velkoff, 2010). In the United States, those 65-years-old and older are "expected to double from 40.2 million in 2010 to 88.5 million in 2050" (Vincent & Velkoff, 2010, p. 5). It is estimated

that the number of the oldest (aged 85 and over) will triple from 6.3 million in 2015 to 17.9 million in 2050 (U.S. Census Bureau, 2012). The projection of doubling and tripling in our aging population estimates that nursing home care will expand to cover this increase.

There has been expansion in those that are 65-years and older, especially for men. The aging population, in particular those 65 years and older, has increased at a faster rate (15.1%) than the total population (9.7%) from 2000 until 2010 (U.S. Census Bureau, 2010). The United States Census Bureau (2010) did not collect data for those 65 years and older until 1870, and since that year, the 2010 U.S. Census found that the population of those 65-years-old and older was the largest compared to all previous censuses. Additionally, the number of aged males 65 years and older increased compared to previous years during that 10-year span (U.S. Census Bureau, 2010author, year). Women have always been a larger percentage of that age bracket, but in this decade, men are living longer and are starting to narrow the gap between the sexes for those 65 years and older (U.S. Census Bureau, 2010). Since men are starting to live longer, this may result in their residing in a nursing home or being the caregiver to their wife.

Because those 65 years and older are living longer, there is a higher probability that they may have to reside in a nursing home. According to the United States Census (2012), 1.51 million (3.1%) of those 65 years and older were residing in a skilled-nursing home in 2011. Of those 1.51 million, 275,472 (18%) were married (U.S. Census Bureau, 2012). The highest number was those who were widowed at 740,627 (49%), while the never married were the third highest at 263,481 (17.5%; U.S. Census Bureau, 2012). The

largest percentage of people residing in nursing homes is widowed or single; but over a quarter of million married couples are having to use nursing homes.

In this qualitative study, I assessed how the elderly spouse is emotionally impacted after he or she has placed his or her loved one in a nursing home. I explored the feelings and emotions of those who are 65-years-old and older who had their spouse in long-term care facility. Previous scholars have only studied either the male spouse (Eriksson & Sandberg, 2008) or the female spouse (Bartlett, 1994; Kaplan & Ade-Ridder, 1991), all family caregivers' feelings (Kaplan & Boss, 1999; Rudd et al., 1999), the marital happiness perceived by both spouses (Sidell, 2000), patients who were placed due to dementia (Kaplan & Boss, 1999; Rudd et al., 1999), and skilled-nursing care facilities (SNF; Sidell, 2000). Skilled nursing care is short-term rehabilitative and does not mandate long-term placement.

In this study, I focused only on the elderly spouse who was, 65 years and older; I included both sexes, the reason for placement due to any medical complication, and the emotional well-being of the spouse who remained at home. The spouse who was institutionalized had to be in long-term placement. Knowing what an elderly community-dwelling spouse may be feeling from this separation will help family, friends, and professionals in supporting or implementing interventions that could help this life changing transition.

### **Statement of the Problem**

Because the population is aging, the probability of physical decline and the need for additional care for these aging individuals is foreseeable. Additional care usually

starts with care within the home. This additional care may be provided by informal support (e.g., assistance from family, friends, and neighbors), formal support (e.g., visiting nurses, meal support, housekeeping services, etc.), or some combination of the two (Gaugler, Pearlin, Leitsch, & Davey, 2001). Even with informal and/ or formal support, continued caregiving within the home may become too difficult to maintain the spouse's physical and/or emotional wellbeing. The patient may have physically and/or cognitively declined to the point of requiring assistance around the clock to maintain the patient's safety. Long-term nursing care may be the only resource left. This transition can be difficult for both patient and spouse as the patient may have difficulty in adjusting to his or her new environment, staff (Burkhalter et al., 2009). The spouse who remains home may perceive him or herself as still being married even though his or her physically separated from his or her spouse ( Burkhalter et al., 2009; Holt-Lunstad et al., 2008; Lorenz et al., 2008).

Roles may change upon admission to a nursing home. When the wife is institutionalized, the traditional male and female role can reverse. The husband may now take the role of doing laundry, buying groceries, doing household chores, and making decisions that the wife used to make in the home (Rosenkoetter, 1996). The wife may take over all responsibilities, which she may not fully have engaged in when her husband was at home (i.e., upkeep of the house, car maintenance, outdoor duties, and paying bills; Rosenkoetter, 1996). Because the husband and wife's role were defined, the wife may not know whom her husband called for repairs on cars or house appliances. The husband may have never made his own lunch or dinner. He previously did not worry about his



doctor's appointments as his wife would write it immediately on the calendar and remind him. Now, spouses must make decisions on their own or attempt duties that they are not familiar in doing.

Previous researchers have examined the marital happiness the spouse feels about his or her marriage (Sidell, 2000), the perception of marriage for the spouse who has a spouse institutionalized with Alzheimer's (Kaplan, 2001), and the role changes that wives experienced when placing their spouse in a nursing home (Brathwaite, 2002; Kaplan & Ade-Ridder, 1991, Rosenkoetter, 1996). Scholars have also explored the challenges and experiences the spouse has after placement of his or her loved one who has the diagnosis of dementia (Eloniemi-Sulkava et al., 2002; Kaplan & Boss, 1999; Mullin, Simpson, & Froggat, 2013; Rudd et al., 1999), the burden and depression by family caregivers (Majerovitz, 2007), and men's caring identity from being the primary caregiver at home to a nursing home being the caregiver (Eriksson & Sandberg, 2008). However, researchers have not examined the full range of emotions felt by the spouse (both male and female) who continues to remain at home, have their spouse in long-term nursing care, and have no family support. In addition, previous research has only focused on dementia and not any type of medical problem that led to placement in a nursing home (Eloniemi-Sulkava et al., 2002; Kaplan & Boss, 1999; Mullin et al., 2013; Rudd et al., 1999). In each of the previous studies, a number of the community-dwelling spouses indicated that they are coping; however, there was some who indicated that they are lonely and depressed. In this study, I addressed the gap in the literature in understanding

the underlying reasons why one group remains lonely and depressed while others are able to forge ahead and appear to accept the changes in their lives.

### **Purpose of the Study**

A deeper emotional understanding of the spouse who resides at home has not been researched. Scholars have attempted to explore the effects of depression by narrowing their research themes to loneliness (Kaplan & Ade-Ridder, 1991); loss of companionship (Gladstone, 1995; Kaplan & Ade-Ridder, 1991); measuring depression through variables that tap into this perception, which includes boundary ambiguity (the spouse's perception of if their spouse in care was in or out of the marriage); and mastery (whether the spouse feels in control of his or her life or views it as fatalistic; Kaplan & Boss, 1999). However, researchers have not examined if the spouse is feeling depressed, anxious, angry, or happy and what makes him or her feel that emotion with having his or her loved one living in a nursing home. In this study, I asked specific questions as to how daily interaction between the spouses had changed (i.e., sleeping arrangements, eating meals) and how sexual intimacy had changed (i.e., hugs and kisses and sexual intimacy) and how it affected that spouse.

The purpose of this study was to qualitatively examine the full range of emotions that an elderly spouse may be experiencing when his or her loved one resides in a long-term nursing home. The theories, social-emotional selectivity theory and ambiguous boundary, were applied to the study to determine if and how each theory applies to the emotional impact that an elderly spouse may experience when his or she has a loved one in long-term nursing care.

Previous researchers have examined various variables such as depression (Gladstone, 1995; Kaplan & Ade-Ridder, 1991; Kaplan & Boss, 1999), but the elderly minimize depressive symptoms or do not report the symptoms at all, as they do not realize that not sleeping, not eating, and irritability are symptoms of depression (Kaplan & Boss, 1999). In this study, I delved deeper into any or all emotions. I also examined the psychosomatic symptoms that make up depression and anxiety, happiness, frustration, or anger that a spouse may be experiencing with nursing home placement of his or her loved one. In addition, I expounded on how the placement had affected the physical companionship and intimacy that marriage provides.

### **Research Question**

In this study, I addressed the following qualitative research question: What is the emotional impact on elderly spouses who have their loved one in a long-term nursing home?

### **Conceptual Framework**

As the focus of this study was on assessing emotions, particularly the elderly, the guiding conceptual framework included the theories of socio emotional selectivity (Carstensen, 1991, 1995; Fredrickson & Carstensen, 1990) and boundary ambiguity (Boss et al., 1990). According to the theory of socioemotional selectivity theory, over time, the aging adult will be more selective in whom he or she interacts with as a social partner. The aging adult will be more selective to those who are perceived as more emotionally rewarding than emotionally meaningless (Carstensen, 1995; Fredrickson & Carstensen, 1990). This process of selectivity helps with conserving the older adult's

physical energy, as the interaction is usually within small circles such as family, and it helps with regulating positive affect and reducing any negative affect (Fredrickson & Carstensen, 1990). The older adults will maximize their time with their closest relationships and minimize their interaction with less familiar social partners (Carstensen, 1995; Fredrickson & Carstensen, 1990). For example, an 80-year-old may not want to develop a new social relationship, as he or she will prefer to interact with the familiarity of family members and close friends (Fredrickson & Carstensen, 1990). In the present study, the cordial relationship that a spouse develops with his or her spouse's roommate will remain at an acquaintance level. A staff person or the roommate will be someone he or she will communicate socially daily, but once the spouse who resides in a nursing home passes, the relationship will cease.

The second conceptual framework was boundary ambiguity (Boss et al., 1990). This construct was developed in 1975 by a clinical observation of military families who had lost a loved one in war and how they experienced this extreme loss (Boss, 1977, 1983, 1993). Boundary ambiguity is defined as a family knowing who is in or out of the family system (Boss et al., 1990). The family can perceive a family member who is physically present as psychologically absent (Alzheimer's patient) as "out" and not a part of the daily operation of the family system, and the family can perceive a family member who is physically absent as psychologically present (missing-in-action war veteran) as "in" (Boss et al., 1990). The family will continue their daily lives as if the person still exists and will not grieve his or her absence as that person is not gone.

Chronic illnesses are ambiguous as the progression of the illness is unknown and can lead to high boundary ambiguity as the family member does not know when or if their loved one will die (Boss et al., 1990). When a loved one is placed in a nursing home, it is usually because his or her health has declined to the point that 24-hour care is needed. Even though the loved one is in need of 24-hour nursing care, the knowledge of further physical decline or even improvement is not known in advance. A resident could meet criteria for hospice one month and then within six months be removed from hospice care. No one knows how fast or slow a disease will progress. This up and down cycle can confuse the family to think there may be hope or it can give them no hope.

The concept boundary ambiguity was applied to the current study in terms of how the spouse perceived his or her loved one as being within the family unit or out. If the spouse is experiencing high boundary ambiguity of their loved one being within the family unit, he or she may have difficulty in restructuring his or her life as he or she remained preoccupied with the loss of that person who is residing in a nursing home. If the boundary ambiguity is low, then the spouse will think of his or her loved one, but does not have preoccupation with the physical loss of that person as the family system has restructured itself.

### **Nature of Study**

In this study, I explored the emotional impact that a spouse may experience when he or she has placed a loved one in long-term care. I focused on obtaining an in-depth understanding of the emotions of the spouse who remained at home. The study sample was purposeful as flyers were distributed to four nursing homes within Northeastern

Ohio. The flyer was used to solicit volunteers who had their spouse in long-term nursing care and would like to participate in a qualitative study to discuss how they are adjusting to having their loved ones in care. The number of participants was 11 with an equal number of males and females and an equal number of the young-old (65-years-old to 79-years-old) old-old (80-years-old and older) represented (Menec & Chipperfield, 1997). Further, neither gender represented those who had no children. In-depth interviews were offered at the nursing home, a neutral location (such as a library), or their home. Interview questions were derived from the research question in regards to the emotional impact of having their loved one in long-term nursing care (Appendix A). The emotions, depression and anxiety, were addressed by asking about some of the symptoms presented for depression and anxiety in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed., American Psychiatric Association, 2013). These emotions are the underlying constructs in exploring what emotions have been experienced since caregiving has ended, what feelings they are experiencing from being physically separated, how it has affected their emotional and intimate part of marriage, and how they are coping with any or all of the emotions.

### **Definition of Terms**

*Boundary ambiguity*: A state of being in which a family member(s) remains uncertain about who is in the family or is out of the family. This state of being may result from a normal event (e.g., death) or a non-normative event (e.g., kidnapping of a child; Boss 1977, 1983, 2007, 2010).

*Long-term care (LTC) nursing home:* "A facility, which provides long-term comprehensive services, which includes 24-hour nursing care and supervision of those who are chronically ill or unable to take care of daily living needs" (U.S. Department of Health and Human Services, 2013, p. 53 ).

*Skilled-nursing home (SNF):* A facility that provides skilled care through licensed nursing professions to help with medications, wound care, and occupational, speech, respiratory, and physical therapy (U.S. Department of Health and Human Services, 2013). It is offered the first 120-days upon admission and does not mean that patient will become long-term. If the 120-days are exceeded, and the patient does not meet minimal independence, the patient will become a long-term resident.

*Socio-emotional selectivity theory:* Claims that the selection of social interaction is based upon time and emotion. When a person perceives that there is a lot of time left in life, the person is willing to spend time with people or do things that may not give them happiness, but may give them an opportunity to attend a party, a sports activity, or other activities. However, if a person's time of life is seen as limited, a person will seek to regulate his or her emotion and desire to be around people who love and care for him or her. The person, who perceives that his or her life is short, will change his or her social preferences and social behaviors in order to regulate his or her surrounding emotional climate (Carstensen et al., 1996; Fredrickson & Carstensen, 1990). That person will want to be around people who make them happy and not around those who cause them stress. The social circle will become smaller to those who bring him or her the most joy.

### **Scope and Delimitations**

This research study included both genders; those who were at least 65-years-old had been married at least 30 years, and had spouses who were residing in long-term nursing care. The reasoning for excluding those who had been married less than 30 years was the probability of it being considered a long-term marriage. Those who have been widowed or divorced than remarried will have experienced a termination of a relationship and may have a different viewpoint. I focused on individuals who most likely married soon after school or military service and had been together until one was admitted to a long-term nursing home.

The exclusion of skilled nursing care will reduce any hope in the institutionalized spouse returning home. Skilled nursing is short-term rehabilitation, and there is a higher probability that the spouse can return home. If a spouse is considered long-term nursing care, then all hope of returning home is eliminated.

I excluded those younger than 65-years-old to focus on just the elderly who had most likely retired, raised their children, and may have reduced their social circles. Socioemotional selectivity theory states that as people get older, their social circles are more defined around the nuclear family (Carstensen et al., 1996, Fredrickson & Carstensen, 1990). If this is the case, then the community-dwelling spouse may have reduced emotional family support or no family support, especially if he or she had no children.

Other theories have been applied to loved ones admitted into nursing homes. The family systems theory was conceptualized for a case study on wives who institutionalized



their spouses, which means that a change within the system affected the family (Kaplan & Ade-Ridder, 1991). Eriksson and Sandberg (2006) used the gender identity perspective for older men who cared for their wives before they were institutionalized. Kaplan (1994) used couplehood, boundary ambiguity, mastery, social support, and caregiver health as variables as possible predictors of depression in community-dwelling spouses. In Kaplan's study (1994), boundary ambiguity had less ambiguity if the couples were married a long time.

The theory of boundary ambiguity (Boss, 1990) was selected for this research to determine if the community-dwelling spouse adapted to his or her spouse residing in a nursing home due to any ailment. Kaplan's (1994) research was only with spouses who had Alzheimer's.

### **Assumptions and Limitations of the Study**

It assumed that the participants in the study had answered questions truthfully and to the best of their abilities. It also assumed that spouses who participated in the study had awareness of their feelings, insight, and cognitive capabilities to participate in the study.

Limitations to the study were that findings may not be generalizable to the entire population, as the study was limited to four nursing homes that were located within Northeast Ohio. Each of the participants was an individual who had his or her own unique and diverse life experience that limits replicating the same results.

### **Significance of the Study**

Understanding the emotional impact of a spouse who has placed a loved one in long-term care will provide family and professionals an awareness of the emotional hardships that may be occurring for a spouse. Even though a spouse may present him or herself as having no outward difficulty to staff, family, and professionals, an understanding of the emotions and feelings underlying the placement of his or her loved one will help spouses in possible interventions. As the population ages, the possibility increases that a spouse will remain at home while his or her loved one is in a long-term facility until his her death. This research will fill a gap in the literature by showing how the spouse who remains home is emotionally impacted. Little is known regarding how both husbands and wives are emotionally impacted by this life-changing event and how it affects their lives. The potential benefits of this result can be profound for spouses, professional staff, and families. The awareness of the emotions that are affecting a spouse could lead to social change, such as making health care professionals and families aware of what spouses really feel in the separation of their long-time friend and lover and subsequently providing interventions to help through the process.

### **Summary**

The probability of a married spouse having to reside in a long-term nursing home increases with age. Many patients first start out with in-home care, but eventually require 24-hour nursing care. The community-dwelling spouse will go through many changes, and previous researchers have shown that female spouses experience loneliness (Kaplan & Ade Ridder, 1991). The male spouse also has been shown to change his or her identity

of being a caregiver to just a friend (Eriksson & Sandberg, 2008). However, further research needs to be done to explore all of the emotions felt by both male and female spouses, like how their daily living has changed, how their intimacy has changed, and how they are coping with that change.

Two theories, boundary ambiguity and socio selectivity theory were defined and were the conceptual framework to this research. Boundary ambiguity is the perception of if a loved one still partakes within the family (Boss et al., 1990). This theory was developed from family research to describe and predict how families alter its system to fit their perceived uncertainty to a loss. A member of the family system can be physically lost (i.e., missing in action) or mentally lost (i.e., dementia), which creates an ambiguous boundary within the system (Kaplin, 1994). Ambiguous boundaries are the family system's difficulty in deciphering who is in or out of the family, especially regarding roles, rules, and rituals of the family (Boss, 1977, 1980, 1983, 1986, 1991, 1993, 2007, 2010, 2013; Kaplan, 1994).

The second theory is socio selectivity theory, which states that if a person believes he or she will not expire for many years, he or she will be more driven to meet people who can give him or her knowledge or will remain in a relationship that gives him or her stress. Those who perceive their lives to be shorter will want to reduce their friendships to those who give them positive emotion (Carstensen et al., 1999; English & Carstensen, 2014; Notthoff & Carstensen, 2014; Reed & Carstensen, 2013).

Four nursing homes located in Stark County, Ohio were the sites to find volunteers for this research. It was assumed that those who participated had an awareness of their feelings, insights, and cognitive capabilities to participate in the study.

This research will fill a gap in the literature in knowing how the spouse who remains home is emotionally impacted. Little is known regarding how both husbands and wives are emotionally impacted by this life-changing event and how it affects their lives. The potential benefits of this result can be profound for spouses, professional staff, and families

This paper is set up as follows: in Chapter 2, previous literature on the topic will be explored; in Chapter 3, the research methodology and design of the study are covered. In Chapter 4, the findings of the study were analyzed and discussed. Chapter 5 will conclude with a summary, conclusion, and recommendations for further research.

## Chapter 2: Literature Review

### **Introduction**

As the population ages, many couples must make the decision to place their loved one in a nursing home. How this emotionally affects each spouse is unique. Scholars have focused on only wives (Kaplan & Ade-Ridder, 1991) or only husbands (Eriksson & Sandberg, 2008) who placed their loved one in a nursing home or spouses who placed their loved one in a nursing home who are diagnosed with Alzheimer's (Kaplan & Boss, 1999). While some spouses felt that they were married, others felt that were not married as the physical separation affected the intimacy shared between the spouses. Hugs and kisses were the primary source of intimacy between couples (Kaplan & Ade-Ridder, 1991), and some male spouses reported that their role changed from a loving spouse to just a friend (Eriksson & Sandberg, 2008). The role of caregiver changes from the noninstitutionalized spouse to nursing staff being the caregiver (Kaplan & Ade-Ridder, 1991; Kaplan & Boss, 1999). The caregiver experiences a mixture of relief, guilt, and sadness for the loss of being the primary caregiver to his or her loved one (Rosenkoetter, 1996). When a spouse declines physically or mentally, it affects each spouse differently. Husbands report being more depressed when their wives decline mentally than when they declined physically (Tower et al., 2012). Tower et al. explains this finding is because husbands talk to their wives more about important decisions, as well as, day-to-day life excursions while women talked to their friends, children, and family about day-to-day life excursions and important decisions.

This literature review will begin with a review of the older adult in the United States and how nursing homes are being used as a placement for the older adult. Two theories are presented, socio emotional selectivity and boundary ambiguity, which will provide the basis for how older spouses evolve emotionally in their later years with the placement of a loved one in a nursing home. I focused on marriages of older couples and selectivity theory, which illustrates how an elderly person narrows his or her social group to immediate family for emotional support. The second theory is boundary ambiguity, which defines how an elderly spouse perceives his or her reality and his or her reactions to the situation being experienced.

### **Literature Search Strategy**

Searches were conducted using the online databases PubMed, Sociological Abstracts, PsycINFO, PsycARTICLES, ERIC, and Google Scholar, using combinations of the keywords: *spouse, marriage, community-dwelling spouse, older adult, nursing home, long-term care, institutionalized, geriatric, elderly, gender roles, marital roles, depression, loneliness, anxiety, caregiving, and emotional impact*. Articles and chapters were primarily obtained electronically in PDF format, while some chapter books were obtained physically. There were limited articles on just long-term nursing homes and spouses published within the last 5 years; owever, I did use an expansive selection of articles, books, and pertinent pamphlets or lectures.

### **Socio Emotional Selectivity**

Researchers have found that older adults are able to hide their feelings better than younger adults (Charles, Mather, & Carstensen, 2003). Even though aging brings a

decline in cognition and physical well-being, emotional stability improves over time. Contrary to the “grumpy old man” stereotype, the older person tends to be more positive, has less emotional intensity, and is less self-centered when compared to younger adults (Lachman & Bertrand, 2001; Mroczek & Spiro, 2003; Phillips & Allen, 2004). A majority of the elderly do not let things bother them, they see the good in others, and will put others before themselves.

This emotional stability with age appears to evolve from life experiences and the awareness of what is important in life. The older adult is selective in choosing more meaningful, qualitative events than the need to please others (English & Carstensen, 2014; Notthoff & Carstensen, 2014; Reed & Carstensen, 2013). It is through his or her lifespan of emotional experiences that the older adult learns to select what information or experience will provide positive outcomes instead of distressful outcomes. The older adult uses more coping strategies to help regulate his or her emotions than younger adults (Blanchard-Fields et al., 1997; Heckhausen & Krueger, 1993). In addition, the older adult will focus on the positives and avoid negative emotions (Carstensen et al., 1996). The older adult prefers to be happy. They see life positively and that things will work out for the better.

Coping has been divided into three strategies (Billing & Moos, 1981; Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984; Moos, 1986) which are cognitive coping, behavioral coping, and emotional coping. In cognitive coping, a person attempts to find meaning in the event, so it has less effect on the person. In behavioral coping, a person will confront the event and then deal with the consequences. Lastly, in

emotional coping, the person will stabilize his or her emotions from the event effects. The older adult will use emotional coping more than then younger adults do; the older adults may wish to distance themselves from the problem and re-establish their emotions (Folkman et al., 1987). The older adult will view an obstacle in a way to calm their emotions. They will try to distance themselves from the person or the event, and will rationalize it in a positive outlook.

The older adult does start to narrow their social circle to only those that are positive and family.. Carstensen (1991, 1993) developed the socio emotional selectivity theory. Socioemotional theorist defines the emotional selectivity that the older population develops to process positive and negative experiences. The older individual develops social networks that will enhance his or her emotional well-being while reducing those that are distressing. As the adult population ages, they interact more with significant others and less with socially casual relationships (Carstensen, 1992). For older individuals, their goals are more emotionally regulated, which can reduce undue stress, and they will actively select social partners that they are familiar with such as a spouse, children, and extended family (Carstenson, 1995). A younger adult is more information seeking, and they have a higher need to explore different cultures and understand diversity (Carstensen, 1995). The selectivity process helps the older adult in two ways: it conserves physical energy and helps with regulating emotions (Fredrickson & Carstensen, 1990). The aging adult realizes that the number of years left for him or her is shorter, but he or she does not necessarily fear it, but savors it. They will want to live



their remaining years in an emotional balance by perceiving life events more positive than negative (Carstensen et al., 2003).

Socio-emotional selectivity theory evolved over time by combining two theories. Carstensen (1995) developed the socioemotional selectivity theory from two predominant theories that address the aging population. The first theory is activity theory, and it views the slowing down of social interaction as a societally induced problem or barrier (Carstensen, 1995; Fredrickson & Carstensen, 1990). An example of this societally induced problem is a mandatory retirement, and an example of a barrier is death of a friend or loved one (Fredrickson & Carstensen, 1990). The other theory used by Carstensen (1995) is disengagement theory, and it proposes that subconsciously the elderly are withdrawing from society due to a preconscious awareness of death. Both of these theories have dominated the gerontology fields, but they still could not answer why the elderly forego social opportunities even if their health is good (Carstensen, 1995).

Disengagement theory states that older adults will actively avoid emotional experiences due to an awareness of death (Carstensen, 1995; Cumming & Henry, 1961), but researchers have found that this is not necessarily true as the elderly experience and regulates incoming emotions similarly to younger adults (Lawton et al., 1992). Carstensen and Turk-Charles (1994) found that the older adult was able to recall information that had more emotional material than the younger adult did. Carstensen and Turk-Charles used a memory test by using two Agatha Christie novels that had emotionally laden events and nonemotional events; four different-aged groups participated: young adult, middle-aged adult, older adult, and elderly adult. Those who were in the older-adult and elderly adult

groups could recall more of the emotional-laden events. This finding supports social-emotional selectivity theory (SST), which indicates as an individual ages, more attention is centered on emotion regulation. I stopped reviewing here due to time constraints. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at Chapter 3.

#### Socio-emotional Selectivity Theory (Carstensen, 1991, 1993, 1995, 2006)

hypothesized three testable statements. (1) The reduction of social contact does not just happen suddenly in old age, but over time. (2) Other variables such as geographical location, perception of time will influence the selection of social partners. (3) Emotions become more salient over time (Carstensen, 1995, 2006).

A longitudinal study by McFarlane (1938) was reanalyzed utilizing the socio-emotional selectivity theory. McFarlane completed the initial Child Guidance Study (GS) for Berkley in 1930 to assess normal child development and parenting over a span of 60 years (Carstensen, 1992). The participants had been recruited from the Child Guidance Study and were interviewed at the ages of 18, 30, 40, and 50 over a 34-year period. The research examined the frequency of interaction, emotional closeness, and satisfaction with different types of relationships. Over time, there was a reduction in acquaintance relationships and more focus on the interaction and emotional closeness with the nuclear family (Carstensen, 1992).

Fredrickson and Carstensen's (1990) study used 18 cards that were labeled with a particular descriptive an (e.g., close friend, spouse, neighbor), and each card was to be placed in one of three piles. This card sorting study was tested on young and old adults

(16 years old to 92 years old) who tested the socio-emotional selectivity theory. The subjects were to sort 18 cards based on descriptions of the social partner (e.g., a close friend, spouse, neighbor), and how they feel about interacting with that social partner. Each participant was to sort these cards into the least amount of piles based as to how they would feel in interacting with that particular person. The three paradigms which participants classified their cards were the potential for meaningful contact, the potential for future contact, and lastly, the potential to gain information (Cartensen, 1995; Fredrickson & Cartensen, 1990). The older adults sorted their cards based on emotional meaningfulness while the younger adult included social partners that they did not know in their stack as they would like to get to know them better (Fredrickson & Carstensen, 1990). Either the older adults did not include a novel person in their stack or if they did, it was ranked lower than a social partner who had emotional ties to them (Fredrickson & Carstensen, 1990).

Socio-emotional Selectivity Theory predicts that the elderly spouse who has placed their loved one in a long-term nursing home may have limited their social partners to just the nuclear family. If this is the case, then the elderly spouse should identify only a few social partners that could help regulate their emotions. If the elderly spouse does not have any children or extended family members nearby, then he or she would have very limited social partners to help with his or her emotions.

Using predetermined criteria, this study examined socio-emotional selectivity theory by having an equal representation of males to females, have one spouse still residing at home, and have some representation within the sample of being childless.

Based upon the theory, it is expected that by the time their spouse is admitted to a nursing home, the remaining spouse would have reduced their social support system to a just a few people. Having a very limited social support system, limited family within the area and/or no children or family within the area, an elderly spouse is expected to feel very isolated. This in turn could affect how they emotionally adjust to having their spouse living in a nursing home, and having a very limited support system.

### **Boundary Ambiguity**

Boundary Ambiguity, which developed out of family research, is a concept that describes and predicts how a family adjusts to its roles, rules, and rituals once a loss have occurred (Aldous, 1978; Berger & Luckmann, 1966; Boss et al., 1990; Boszormeni-Nagy & Spark, 1973; Buckley, 1976; Goffman, 1974; Hage, 1972; Hill, 1949, 1971; Homans, 1950; Kantor & Lehr, 1975; Lewin, 1951; Minuchin, 1974; Moos and Moos, 1961; Reise, 1971, 1981; Rice, 1969; Wtaker & Keith, 1981). The ambiguity arises within the family if they do not know who is in the family or out of the family (Boss et al., 1990). The construct, boundary ambiguity, is both an uncertainty of loss or there is a physical loss, but the family is unable to accept the loss. Due to the inability to clarify a loss, the family system has difficulty re-organizing itself. This ambiguity creates a blocked system, which leads to the difficulty in the family system to adapt or change to the loss (Boss et al., 1991; Kaplan, 1994).

Events may be characterized as happening outside the family or inside the family. For an outside event, it is difficult for the family to accept the loss as the facts are not present for them, or the facts are present, but the family denies or ignores these facts. An

example of an outside event is when a person is reported missing, or family member is chronically ill and the loss is uncertain (Boss et al., 1990). The family is not sure if the person is alive or dead so they may continue to include that person as if they are still alive and will return or if chronically ill that they will get better.

For an inside event, the family can understand the facts for death or loss, but they appear to ignore or deny these facts. An example is a family member that has dementia, is present physically, and is excluded psychologically, or an adolescent runaway is not present, but the family continues to center itself on that adolescent (Boss et al., 1990). The family may make plans that include the demented individual, but not include them in the decision.

Boundary ambiguity has six theoretical propositions (Boss et al., 1990, pp. 5-6).

1. More stress and dysfunction will occur within the family if there is higher boundary ambiguity.
2. Boundary ambiguity can occur right after a loss, but it does not mean dysfunction. Over time, the family can adapt itself. This restructuring reestablishes its boundaries and system.
3. If the boundary ambiguity remains high over time, the family system will remain stressed and dysfunctional.
4. Families having differing belief system of feeling that they are in control or that they have no control at all will also view their family boundaries.
5. Families will endure the boundary ambiguity based on their belief system of feeling mastery or fatalism.

6. How a family defines the event will determine how they will cope.

Kaplan and Boss (1999) found that boundary ambiguity and mastery were the main reasons for depressive symptoms of spouses who had loved ones that were diagnosed with Senile Dementia, Alzheimer's type (SDAT) and were residing in a nursing home. The mean average for the sample was 75-to-78-year-old with 34 male spouses and 50 female spouses. Kaplan and Boss (1999) hypothesized that there are three variables that makeup the marital relationship; if these three were affected, then it would lead to more depressive symptoms. The three were boundary ambiguity (the perception that the spouse is in or out of the marriage, mastery (the caregiver's belief that they have control over their life), and couple hood (the perception that they are still a marital unit; Kaplan & Boss, 1999). This research was only tested with those that had a loved one in a nursing home that is diagnosed with SDAT experienced boundary ambiguity which lead to depressive symptoms. The lack of congruence between people being alive, but not psychologically present affected those in this study. There was a negative relationship between boundary ambiguity and number of years married. Those that were married longer always felt that their loved one was "in" the marriage so they would have less boundary ambiguity (Kaplan & Boss, 1999). If an individual felt that they had less mastery, which is control, then they reported more depression. The finding in the study of community-dwelling spouses, who placed their mates with Alzheimer's in an institution, found that depression was linked more to boundary ambiguity than to mastery (Kaplan & Boss, 1999). The explanation the authors gave was those that felt less in control of their spouse's lives were more depressed. Since they gave control to the nursing home, they

lost that sense of mastery (Kaplan & Boss, 1999). The authors then speculated that spouses that were married the longest never lost their sense of control or mastery. These two explanations given by the authors' conflict with each other; one-explanation states that the longer a couple is married they feel more control (mastery), but if that one spouse goes into a nursing home, then they lose that control (mastery) even if they have been married for a very long time.

A research study reported by Boss et al. (1990) and completed by Friday (1985) found that women who had been widowed at least 6 months showed a positive correlation between high-boundary ambiguity and quality of marriage ( $r = .309$ ,  $p = .015$ ) and religion ( $r = .321$ ,  $p = .012$ ). Those that reported a good marriage and being highly religious had more difficulty with the process of grieving and restructuring their lives; but, as time continued boundary ambiguity lowered, and the widow was able to accept the closure (Friday, 1985)

The theory of Boundary Ambiguity can determine where, emotionally speaking, the elderly spouse is in regards to perception of their marriage. If the elderly spouse has high-boundary ambiguity, he or she will experience more depression. Kaplan (1994) found that the highest correlation between spouses having high-boundary ambiguity and depression was when their spouse was in a nursing home, due to Alzheimer's disease. The explanation for this high ambiguity for those that had their loved one institutionalized due to Alzheimer's is that the spouse who was institutionalized is physically present but psychologically absent (Kaplan, 1994) This incongruence of being physically present, but psychologically absent, creates ambiguity for the community-

dwelling spouse which leads to depression (Kaplan, 1994). The community-dwelling spouse visits their spouse, but the other spouse does not remember daily living skills, milestones in their marriage, and possibly their spouse at all. Further research was recommended to explore the institutionalized spouse that is psychologically present, but physically absent, to determine the level of boundary ambiguity (Kaplan, 1994). This incongruence can allow the community-dwelling spouse to discuss life and reminiscence, but the ability to walk with their spouse, or vacation with their spouse is not feasible. The community-dwelling spouse will have difficulty adjusting to their lives as their roles and relationships appear to them as being ambiguous.

If the spouse has low-boundary ambiguity, he or she can accept that their spouse is in a nursing home, and they can make changes to their daily lives. Kaplan (1994) found that those who were married longer had lower boundary ambiguity than those that were married for a few years.

This study looked at how the elderly spouse, who has been married for at least 30 years, perceived their institutionalized spouse as being in or out of the marriage. The study examined whether the spouse can accept the placement of their loved one and continue with their life or if he or she negates the ability to accept this change, possibly creating feelings of hopelessness and helplessness. Additionally, all types of medical illnesses of institutionalized spouses, which have an illness other than Alzheimer's, allowed for a full representation as suggested by Kaplan (1994).



### **Emotional impact**

A study by Sandburg et al. (2001) of 14 spouses (11 wives and 3 husbands) found that there were common themes when the participants' spouses are placed in a nursing home. The decision of placement had been made by either a professional or family, which in turn had taken the power and lack of recognition of loss and grief from the spouse. With this lack of recognition from professionals, family, and the nursing home staff, they felt very lonely and isolated. Placement created separation, and the most difficult experience for the spouse was to be unprepared for the loss of their life-long partner.

A number of themes emerged and were reported from the initial placement by Sandberg et al. (2001) which were pretending, dawning, putting on a brave face, and seeking solace. Some families never discussed the issues of placement to either a spouse who was to be placed or the spouse that was to remain at home. When full disclosure had not been presented to the spouse who was going to be placed, a method of pretending was presented. The family would state that it would be short-term, but knowing it was going to be long-term. The term dawning is when the spouse who resides still at home becomes aware that their spouse is going to be institutionalized long term.

Another theme a family may portray is the brave face. The brave face theme was the lack of recognition of the emotions that the community-dwelling spouse is experiencing. Professionals, family, and nursing home staff now paid attention primarily to the institutionalized spouse. Some spouses were able to seek solace with family, professionals, and staff, but the majority did not (Sandburg et al., 2001) others sought

solace through their faith in religion and God instead of discussing it with others (Sandburg, et.al. 2001).

Feelings of anger directed to staff by the community-dwelling spouse were assumed by Schmidt (1987) to be feelings of guilt due to placing their loved one in a nursing home. Gladstone (1995) researched 160 spouses who were either residing in a nursing home or had a loved one residing in a nursing home. The primary reason for the study was to determine positive and negative feelings that residents and their spouses may feel after they have been placed in long-term care (Gladstone, 1995). Kelley (1981) defined a marriage on two types of relationships. One type is close, and the other is personal. A close relationship is when a couple has interdependence upon each other, but consideration for the other person is not felt. A personal relationship also relies on interdependency, but they also have shared feelings of love and concern for each other. For example, the institutionalized spouse will also consider how the placement has relieved their spouse of caregiving. Gladstone (1995) found that spouses who had placed their loved one in a nursing home had more positive feelings if their marriage was based on a personal level

Positive feelings in Gladstone's (1995) research was identified as a spouse was receiving good care, there was reduction of caregiving tasks, feeling less guilt about placement and understanding the operations of nursing homes. If the marital relationship were more in discord, then spouses would report more negative feelings about placement (Gladstone, 1995). Negative feelings were identified as feeling that their spouse was not

receiving quality care, stress when visiting spouse, loss of purpose, and loneliness (Gladstone, 1995).

### **Marriage**

The institution of marriage creates a shared meaning and experience, both positive and negative (Walker & Luszcz, 2009). It is considered the most influential institution in affecting a person's life and well-being. It encourages monogamy and commitment between spouses (Stutzer & Frey, 2006). Each spouse interacts with an expectation that expressed love, gratitude, recognition, security, and material rewards are mutually exchanged (Stutzer & Frey, 2006).

As previously mentioned, there are two types of marital relationships: close and personal (Kelley, 1981). In a close marital relationship, the interdependency is based upon a factual level. A spouse will interact and provide services in a sensible way, but in a personal level, the relationship is based on an abstract level. Love and concern are the driving force for its relationship (Kelley, 1981).

The health benefits of being married instead of being single has been widely researched in the fields of social science. Married people are in better physical health, and psychological health (e.g., less substance abuse and depression), and live longer compared to single people (Burman & Margolin, 1992; Ross et al., 1990; Waite & Gallagher, 2000).

Horwitz et al. (1996) found a significant benefit for married men by a reduction in alcohol abuse and for married women there was a reduction in depression. Researchers have proposed the reason for this health benefit is due to "marriage protection effect" and

“marriage selection effect” (Burman & Margolin, 1992; Goldman, 1993). The marriage protection effect means that a marriage helps increase social support, income and reduces risky behavior and stress; which in turn, leads to better health (Ross et al., 1990; Waldron et al., 1996; Wyke & Ford, 1992). Marriage selection means that more healthy individuals will marry (Goldman, 1993).

Just being married has shown a marriage protection effect, demonstrated as an increased survival rate for male and female patients with cancer and heart disease (Burman & Margolin, 1992). However, in other studies the female spouse did not show a significant difference compared to the male spouse and unmarried females in regards to mortality rate (Burman & Margolin, 1992; Ross et al., 1990; House et al., 1982; Shumaker & Hill, 1991; Waldron, 1996). A possible reason that marriage provides the male spouse with more protection may be because wives are the main primary confident and emotional support, whereas women can have a diverse support system outside of the marriage (Shumaker & Hill, 1991). Women express their emotions and feelings outside of the marriage more than men do (Monin & Clark, 2011). Women are more involved in formal and informal events (i.e. attendance of meetings and religious services, talking on the phone with neighbors and friends) compared to their husbands (Monin & Clark, 2011). Women also have more supportive relationships with their adult child (ren) compared to the men (Monin & Clark, 2011).

Marriage is viewed as the smallest, intimate unit of a social network (Wilson & Oswald, 2005), but other variables can increase or decrease the chance of early mortality. The Tecumseh Community Health Study of 1967-1969 randomly selected married

couples within the age of 35-to-69 years old, and followed them to assess mortality in 1978-1979 (Berkman & Syme, 1979). The highest indicator for men was if they smoked, were retired, and socially isolated themselves (Berkman & Syme, 1979). The type of social network variables such as hobbies and activities (passive or active) helped reduced mortality. Those that were more actively involved in church ( $p < 0.025$ ; Waite & Lehrer, 2003), spectator sports, volunteer associations reduced mortality for men ( $p < 0.05$ ; (Berkman & Syme, 1979). While this study showed significant benefits for males, it did not for females.

In regards to the marriage protection effect and gender, women who were not a part of the labor force showed a stronger marriage protection than those that were a part of the labor force (Waldron et al., 1996, Waldron & Jacobs, 1989). For the race, white women showed more significant protection than black women (Schoenbach et al., 1986; Waldron et al., 1996; Waldron & Jacobs, 1989).

In addition to health benefits, being married helps with being happier compared to single people (Diener et al., 2000; Stack & Eshlem, 1998; Coombs, 1991; Myers, 1999). Both married men and women reported greater subjective well-being compared to those that have never been married, divorced, separated, and widowed (Stutzer & Frey, 2006). This emotional support reduces depression and mental illness for married couples (Ross et al., 1990) which in turn, can help with reducing stress (Berkman, 1988; Kessler & Essex, 1982).

In the younger couples, women are more expressive emotionally and confronting; while men are more defensive and disengage emotionally (Carstensen, et. al., 1995). In a

study completed by Carstensen et al. (1995), the authors found that older couples were more affectionate and did not interact negatively with each other in comparison to younger couples.

### **Marriage Roles in Aging**

Marriage for older couples provides social, emotional, financial, and physical support and stability (Walder & Luszcz, 2009). Late in life, couples have lower rates of divorce, but they have challenges due to a decline in physical activity and increased depression (Henry et al., 2005).

Lauer, Lauer, and Kerr (1990) completed a survey with 100 couples that resided in retirement communities in eight states. The authors reported that being married to someone you liked, having common ideas, and enjoying their companionship made for marital happiness.

The University of Southern California developed a Longitudinal Study of Generations (LSOG) in 1971, with 2,044 participants representing three generations. This study captured many of the challenges faced in marriages (Henry et al., 2005). Data was collected in 1971, 1985, 1988, 1991, 1997, and 2000. The sample for this study was drawn from the second generation of the original sample (Henry et al., 2005). For wives, their primary complaints of their spouses were personal behaviors and health; while husbands were concerned about financial issues. The personal behaviors consisted of three themes: grooming, driving habits, and substance use. The health problems consisted of general health problems, memory problems, hearing loss, doctor

appointments, and caregiving issues. The financial issues consisted of spending and investing (Henry et al., 2005).

Leisure activities, intimacy, and financial matters are the three main concerns that spouses have during their long-term marriages (Henry et.al, 2005). Late-life couples have more leisure time, and each spouse wants to spend it on their own activities which may lead to the other feeling left out or jilted (i.e. one enjoys traveling while the other wants to stay home). Intimacy was reflected in both physical and emotional aspects. One spouse not communicating with the other spouse reflected the emotional aspect (Henry et al., 2005). Financial matters of late-life couples were usually on a limited income and needed to budget for their means, as well as, for future generations that may need money lent to them (Henry et al., 2005).

An aging, married couple's social life begins to dissolve due to death of friends, decreased mobility, illness, and disability (Ade-Ridder & Kaplan, 1993; Braithwaite, 2002). Each partner becomes more dependent upon the other for companionship and physical assistance, and due to this, the bond of marriage is strengthened (Braithwaite, 2002). The older couple becomes more reliant upon each other for companionship and physical assistance, which, in turn, creates more of a bond (Braithwaite, 2002). Older couples have a stronger commitment, higher interdependency, and satisfaction; but yet are more formal in communication compared to younger couples (Sillars & Wilmot, 1989).

Marriage in long-term older couples is unique as the spouses are usually very close, and their lives are centered on each other (Hoppman & Gerstorf, 2009). Being

together for at least three decades of their life, they have mutually experienced and managed conflicts, setting the same goals, creating a positive emotional interaction and obtaining a deeper emotional meaning within their relationship (Carstenson et al., 1996; Hoppman & Gerstorf, 2009). Many of these studies revealed a positive outcome of elderly couples that have been married for more than 30 years, successfully handled the ups-and-downs of life with positive thinking, and were physically and psychologically healthy (Baltes & Smith, 2003; Cowan & Cowan, 1992; Gertorf et al., 2008; Gottman & Notarius, 2000; Hoppmann & Gerstorf, 2009).

Hoppman and Gerstorf (2009) reported in their 14-year Seattle Longitudinal Study, that over time, spouses' intellectual ability become very similar; which in turn, as reported by an Australian Longitudinal Study, as one spouse's cognition ability declines, the other spouse's cognitive ability declines in response. Perceptual speed tasks were tested on both spouses in an 11-year expanse, and the husband's perceptual speed predicted a decline in the wife's perceptual speed (Hoppman & Gerstorf, 2009). A limitation to these longitudinal studies is focusing only on the individual cognitive functioning and not the possibility of collaboration between the spouses (Hoppman & Gertoff, 2009). Hoppman and Gerloff (2009) suggested a resolution to this issue by considering how the spouses work as a team to resolve cognitive tasks. Findings have shown that the more collaboration on cognitive tasks the better outcome than completing the task individually or if paired with a stranger (Hoppman & Gertoff, 2009).

Dixon and Gould (1998) found that both young and older couples have high collaborative communication in completing story recall tasks. The assumption, to this



high performance for the older couples, is the reliance of each other to work out the task (Dixon & Gould, 1998). When one spouse shows a decline in recall, the other spouse will compensate for that weakness (Dixon & Gould, 1998).

The emotional experience of marriage cycles from high to low (Sandberg & Harper, 2000). Hoppman and Gerstorf (2009) reported in the Cardiovascular Health Study that those over the age of 65 had similar emotional and cognitive aspects of their life. Negative emotions from one spouse were integrated and accepted by the other spouse more than positive emotions. Older couples compared to younger couples try to maintain a positive relationship and are able to regulate their emotions better by filtering negative out and maintaining positive information (Carstensen et al., 1996). Older couples would have fewer disagreements and would use less negative emotions compared to middle-aged couples. The wives were more expressive of their negative and positive emotions while the husbands would be more defensive and withdrawn (Carstensen et al., 1996). Couples start to help each other in dividing household tasks when one of the mates starts physically to decline (Melton, Hersen, Van Sickle, and Van Hasselt, 1995). Racher (2002) reported that frail, elderly couples would support each other through role reciprocity and interdependence in order to allow them to live independently within their homes. For example, one spouse may prepare dinner, but both would help in cleaning the dishes (Melton et al., 1995; Racher, 2002).

Lee and Shehan (1989) found in long-term marriages that the longer the husbands are married, the more they viewed the marriage as equitable. For wives, how they perceived their gender roles directly correlated to how they viewed their equity within the

marriage. When both spouses utilized the traditional gender roles, the marriage was perceived to be more equitable (Melton et al., 1995). Keith, Schafer, and Wacker (1992) found with 82 couples (males, M=71 yrs.; women, M=69 yrs.), there was no perception of equity in roles such as housekeeping, food preparation, the breadwinner role and companionship between genders. A study by Kulik (2002) found that the husband of Israeli couples (n=116) with an age range of 58-85 years old did have feelings of inequality with chores, financial and social roles; in turn, felt trapped and depressed.

Carr (2004) argues that for the older married man, if the marriage is more of a traditional marriage, in which the female assumes most of the household tasks, his self-esteem was higher. If the male relied more on his wife for home maintenance and financial tasks, his self-esteem would be lower. Thus, it is how the gender roles are assigned within the marriage, which determines self-esteem for men. Research has shown that just being married helps improve the self-esteem for men, but not for women (Bernard, 1972, Gove, 1972).

Numerous research studies have shown that gender differences affect the marital equity on each spouse's well-being (Goodman & Shippy, 2002; Meyler et al., 2007; Pruchno et al., 1989) When the wife in a close marriage has cognitive impairment, the husband is at a higher risk for depression. A close marriage is defined when the husband is perceived to be confident, emotionally supportive, and there is high marital satisfaction. (Tower et al., 2002)

### **Marital Closeness**

Higher mortality risk was directly correlated in older couples who identified their spouse as their emotional support (Tower, Kasi, & Darefsky, 2002). Tower et al.'s (2002) research found that spouses that viewed their spouse in this manner were more likely to have similar levels of depression. If they have been married a long time, there is an increase in this association. If the marriage is defined as close, the husband will suffer more if his wife is cognitively impaired. Women will be more depressed if the spouse does not name her or she does not name her spouse as a close confidante, while men who name and are named as confidante are the least depressed. (Tower et al., 2002).

After many years of marriage, couples often assimilate each other's mannerisms, moods, and attitudes (Ruthing, Trisko, & Stewart, 2012). Many of the reasons for this occurrence is that if one spouse experiences a stressor the other spouse will most likely be impacted by their loved one's moods, emotions and well-being (Goodman & Shippey, 2002). Goodman and Shippey (2002) called this phenomenon "emotional contagion." Emotional contagion means that the relationship in marriage is interdependent, and what one spouse experiences the other will too (Goodman & Shippey, 2002).

Researchers have found that this emotional contagion impacted spouses with depression (Siegal, Bradley, Gallo, & Kasl, 2004), well-being (Bookwala & Schulz, 1996), and anxiety (Tambs, 1991). In addition, there are gender differences as well. Hagedoorn et al. (2002) indicated that women reported more distress when their spouse was ill than men. This distress was seen more in women who felt their caregiving was not being helpful to their spouse. Hagedoorn et al. (2002) suggests that women who practiced

a traditional sexual identity role linked their emotions to their caregiving. Women would experience more depression and low esteem when their spouse was ill (Nijboer et al., 2000) while men were not affected at all (Ayotte, et al., 2010). Ruthig et al.'s (2012) study of 71 married couples who reside within the community, with a mean age of 70 years, reported a difference to prior studies with emotional contagion. Their finding concluded that men's well-being was dependent upon their wives' well-being, while the wives' well-being was dependent upon the wives own health (Ruthig et al., 2012)

### **Marriage roles and Illness**

In a marriage, when illness affects one of the spouses, the other spouse will provide the most help in nursing their loved one back to health (Johnson, 1985; Johnson, 1983; Palmore, 1976; Shanas, 1960). This transition in life is referred to as “role acquisition” or “role enactment” (Kramer & Lambert, 1999; Pearlin & Aneshensel, 1994). The role acquisition is when one spouse changes their role into being a caregiver.

Older wives reported more traditional gender roles such as doing more indoor activities or chores like cooking, cleaning dishes, washing clothes, writing letters and cleaning and vacuuming of the home (Brubaker & Kinsel, 1985; Szinovacz, 1986); while the husbands reported more outdoor activities such as yard work, car maintenance, and home repairs (Brubaker & Kinsel, 1985; Szinovacz, 1986). When one spouse becomes a caregiver, he or she shifts to doing all the indoor and outdoor tasks (Wright, 1981).

When a spouse becomes chronically ill, there will be a decrease in social activities with events or other couples (Barber & Pasley, 1995). One area that did not decline for the elderly was church attendance (George & Gwyther, 1986). Religious involvement is a

very important social connection and support for older adults (Kramer & Lambert, 1999). Some research has reported that church attendance remained stable for the elder (Markides & Mindel, 1988), while others reported a decline (Blazer & Palmore, 1976).

Marital happiness is also affected when a spouse becomes chronically ill (Kramer & Lambert, 1999). Studies on spouses who had dementia reported a significant decline in marital intimacy and quality when this role transition occurs (Blieszner & Shiflett, 1990; Morris, et al., 1988; Wright, 1981). Kramer and Lambert (1999) reported that older husbands felt a decline in their marital happiness compared to younger husbands.

Being a caregiver does not help one's psychological well-being. Studies have shown that male caregivers were more depressed than non-caregiving husbands (Fuller-Jonap & Haley, 1995; Kramer & Lambert, 1999; Marks, 1998). A study by Wallsten (1993) reported that the husbands were less depressed and reported less psychosomatic complaints compared to the wives who were caregivers. Pruchno and Resch (1989) found that husbands were more invested in caring for their wives. There was a sense of duty by the males; but the wives showed more depression and resentment being a caregiver as they were hoping their golden years would be full of opportunities for personal growth (Wallsten, 1993; Wallsten & Snyder, 1990; Zarit et al., 1986).

The view of being a caregiver between wives and husbands showed no difference in feelings of being burdened (Zarit et al., 1980), however, in other studies, husbands reported more difficulties (Pruchno & Resch, 1989). In a study completed by Zarit et al. (1986), the authors found that wives reported being a caregiver as a burden; but then, on the second interview the wives reported no difference. The belief is that wives felt more

of a burden in taking over the finances, but once they were able to overcome this task they felt relief and pride (Zarit et al., 1986). If the marriage was perceived as happy, then caregiving wives felt greater satisfaction in being the caregiver; but if the marriage was not perceived as happy, wives reported feelings of obligation and lower satisfaction in being a caregiver (Motenko, 1989).

Gladstone (1995) found that spouses that report more negative feelings in the placement of their loved one if their relationship had a higher degree of “role engulfment.” Role engulfment means that the role of caregiver is the main source of identity for that spouse so that when it ends there is loss of purpose (Skaff & Pearlin, 1992). The spouse that had been a caregiver will visit their loved one daily and is unable to reestablish a life for themselves (Gladstone, 1995).

Having a spouse with a chronic illness does place a hardship on the marriage, but for the ill spouse, marriage provides feelings of being valued by another and gives a higher probability for survival for the ill spouse (Burman & Margolin, 1992). The marital relationship in and of itself provides social support, intimacy, and role identity for each spouse (Cannon & Cavanaugh, 1998).

### **Marriage roles related to nursing homes**

When the decision for the placement of their loved one happens, the caregiver may experience insurmountable feelings of guilt and relief (Carson, et al., 2006; McAuley, et al., 1997; Sandberg et al., 2000). For the spouse there is a constant changing from the one in control to being the “outsider.” Usually prior to a loved one being admitted into a nursing home, they have been residing home being taken care of by their

spouse. A study by Braithwaite (2002) of 21 wives that placed their spouse in long-term care found, the wives reported a loss from being a caregiver and giving that caregiving role to the nursing home staff. Even though the shift of care went to the nursing home staff, the wives had to cope with their loved one's needs not being in the way that the wives would have liked their care to be. In Braithwaite's study, not only was it a physical toll, but also an emotional toll if the spouse had some form of dementia. These women reported that their own physical health had declined due to the constant care of their loved one, but also they become socially isolated from others due to the constant care. Sandberg et al. (2000) found that there was no preparation or structure for the placement of the loved one. The emotions felt by the spouse were not recognized by the nursing home staff, since there was no inclusion of the spouse's expertise in caregiving, thus the staff enhanced the loneliness and isolation that the spouse felt for losing their lifetime partner (Sandberg, et al., 2000).

Placement of a loved one is usually not planned; rather professionals and family are the ones that drive the need for placement (Sandburg et al., 2001). Due to placement being "expert driven," the professionals, family, and staff at the nursing home may not recognize the feelings of guilt and remorse by the spouse. The nursing home becomes the "expert" and the spouse feels powerless and the "outsider" (Sandburg et al., 2001). Sandburg et al.'s (2001) study found that the 14 spouses (11 wives and 3 husbands) had expressed the desire to be involved with their spouses' care, but rarely was it encouraged by the nursing home staff or was even prohibited.

While the placement relieves some stress to the spouse, different stressors now affect them. These stressors still pertain to the loved one, but now the stress is how and when to travel to the nursing home for visits, overseeing the resident's care, managing financial, mechanical or housing repairs that may not have had to concern themselves prior to their spouse's decline and placement (Majerovitz, 2007).

If the marriage is of a traditional type, the roles are reversed. The husband will become more of the nurturer. He will do all the grocery shopping, laundry, maintaining the household, and make decisions that his wife used to make. The wife may start taking responsibility in paying bills, house repairs and upkeep and make decisions that her husband used to make (Rosenkotter, 1996).

Spouses have expressed a change in their roles when their loved ones are institutionalized. Kaplan and Ade-Ridder (1991) found that their married sample noted a role change from spouse to a parental role in which they would give permission to the nursing home to care for their loved one. By the time their loved one was in the nursing home the spouse felt their role had changed from a loving spouse to just a friend or visitor (Eriksson and Sandberg , 2008; Rosenkoetter, 1996)

With these roles are expectations that are set by the institution as to how they can act, what they can do, and when they can be together (Rosenkoetter, 1996). Once that spouse becomes a resident, there are a number of people in the decision making process. The couple now has less autonomy in determining their life and future (Rosenkoetter, 1996). The spouse, who is the resident, feels a loss of control in his or her life due to not being involved in former social groups and the loss of intimacy and affection that was



once provided by his or her spouse, who resides at home. The resident spouse now feels rejected by the residing spouse because their present intimacy and affection are not as they experienced it when they resided at home. The spouse who had been the caretaker may feel guilt and anger because they are not physically present when there are decisions to be made (Rosenkoetter, 1996).

Both institutionalized and non-institutionalized spouses reported that their marriage could withstand a separation as long as they were able to continue the physical and emotional contact (Gladstone, 1995). If both spouses were able to visit, talk, and participate together in various activities while at the nursing home, they felt their marriage could endure the separation.

### **Impact on Marriage When a Spouse Is Institutionalized**

There has been limited research on the impact of marriage when a spouse is placed in a nursing home (Walker & Luszcz, 2009). In Gladstone's (2005) qualitative study, the non-institutionalized spouse and institutionalized spouse were interviewed to obtain information as to how it affected the marriage for him or her. Four themes evolved from the non-institutionalized spouse in their perception of the marriage: Marriage as a memory, illusionary marriage, the changed marriage, and the continuing marriage (Gladstone, 1995, p.55). The theme "marriage as a memory" was associated with a marriage that was over, with the loss of companionship or verbal communication between the spouses due to cognitive decline. For the theme "illusionary marriage," the marriage was associated with the spouse being in a state of ambiguity about their marriage. They did not feel their marriage was over, but were not sure if they still were

married. The theme “the changed marriage,” was associated with a role change in their marriage. They felt more like a parent and their spouse was the child. For the theme “the continuing marriage,” their marriage had not changed at all (Gladstone, 1995).

For the institutionalized spouse, there were three themes, which were: happy marriage, detached marriage, and altered marriage (Gladstone, 1995, p. 56). The theme “happy marriage” was associated with their marriage continuing to be a happy, rewarding marriage. The theme “detached marriage” was associated with tension within the marriage. The theme “altered marriage” was associated with the marriage having changed from being lovers to strangers (Gladstone, 1995).

In contrast, Kaplan et al. (1995) interviewed three women who placed their spouses in a nursing home. Six themes were identified for these women: changes to the marriage, the decision to institutionalize their spouse, support systems, physical aspects of their relationship, communication patterns, and adjusting to living alone (Kaplan et al., 1995, p. 93). The women felt that just being married did not make them feel married. Feelings of still being married depended upon how healthy their spouses were and if they could still communicate with their spouse (Kaplan et al., 1995). Each woman felt she had no other choice but to institutionalize her spouse. Family support was their biggest asset, while support from friends was not as available. Physical intimacy declined to kisses and hugs even though the nursing homes provided privacy. The biggest adjustments the participants reported were living alone and lack of companionship (Kaplan et al., 1995). The authors suggested that future research should examine whether the community dwelling spouse experiences more stress with a spouse that is institutionalized due to

physical decline but remains cognitively intact, or one that is physically intact but cognitively impaired (Kaplan et al., 1995).

Two studies in Sweden (Lundh et al., 2000; Sandberg et al., 2001) studied the impact of the non-institutionalized spouse in regards to the transition phase and how it impacted their perception of being married. Sandberg et al. (2001) found that spouses did try to maintain a relationship with their loved one placed in a nursing home by keeping in touch, keeping it special, and keeping an eye on things. The spouse would visit quite often, and would try to keep their relationship special by providing items and hobbies that identified their special time together, and lastly, they would make sure the staff was taking good care of their loved one by noticing the care (Sandburg, et al., 2001).

Kaplan and Ade-Ridder's (1991) qualitative study on three female spouses, who had institutionalized their spouses, explored issues as to how it impacted their marriage. The common themes, which evolved from the interviews, were: how it had changed their marriage, how the decision of institutionalizing their mate was made, what their support systems are, and how they have adjusted to living alone. Each of the women felt there was a change in their marriage, as if they were in a marriage in name only (Kaplan & Ade-Ridder, 1991). One of the women felt lost in not having to cook and care for her spouse anymore.

The theoretical framework for Kaplan and Ade-Ridder's (1991) study was Family Systems Theory, in which the system is impacted if one member of the system has declining health it will affect the other spouse's life. The study found the quality of the marriage had changed by the institution (Kaplan & Ade-Ridder, 1991). All three of the

women felt that the communication with their spouses had declined upon institutionalization. The assumption to this is that one spouse was cognitively impaired, but another explanation was that they did not want to share their feelings to the institutionalized spouse for fear of upsetting him or her (Kaplan & Ade-Ridder, 1991). This explanation, of not sharing information to a cognitively impaired loved one (Kaplan and Ade-Ridder, 1991) will be examined in the present study to see if spouses feel they can freely share their feelings. In Kaplan and Ade-Ridder's (1991) study, two women had spouses that were physically debilitated, but not cognitively debilitated. One of the women had a spouse that was more cognitively debilitated. Kaplan and Ade-Ridder (1991) stated that future research is needed to examine whether the community living spouse's emotional impact was dependent upon the institutionalized spouse's disability. This study included all medical conditions that required placement, and inquired how their spouse's medical condition had impacted the relationship.

Each of the three women in Kaplan and Ade-Ridder's (1991) study had children, but future research was suggested to explore non-institutionalized spouses who did not have children. Support was received by their children, but in regards to support from friends, this support had declined. A reason for this decline is that the non-institutionalized spouse spent most of their time with their spouse in the nursing home (Kaplan & Ade-Ridder, 1991). The present study inquired about support systems prior to their spouse's placement and then after placement.

The expression of affection had changed for each of the women. Hugs and kisses were now the only type of intimacy expressed (Kaplan & Ade-Ridder, 1991). Any sexual

desires was ignored or forgotten. Each woman stated that a private room helped with privacy, but they did not attempt any sexual intimacy. Suggested reasons were that they felt that were under the scrutiny of the nursing home staff, visitors, decline in sexual attraction towards mate, or unconsciously they feel it is not allowed in a nursing home. Future research has been suggested to see if there is a decline in intimacy and affection with couples in a nursing home (Kaplan & Ade-Ridder, 1991). The present study did explore the intimacy between the spouses prior to admission and the level of intimacy after placement. Some example questions include: Did the spouses share a bed prior to admission, or did they have separate rooms before? What effect does it have on the community spouse who can no longer share their bed with his or her mate?

Only one qualitative study addressed how, and if, intimacy continued once a spouse was placed in an institution (Kaplan & Ade-Ridder, 1991). The authors (Kaplan & Ade-Ridder, 1991) speculated that sexual desire was not expressed by community dwelling spouse due to lack of interest. A clinical implication study evolved from the Kaplan and Ade-Ridder (1991) study, which further explored the issues of intimacy. Four issues were discussed: sexual intimacy for the resident, sexual intimacy for the community spouse, sexually aggressive behaviors, and the role of the nursing home in promoting sexual intimacy between spouses (Kaplan, 1996). The elderly, even with cognitive impairment, have sexual desires, but due to advancing age and declining health, sexual intimacy may cease, especially upon admission to a nursing home. Nursing homes do not promote sexual intimacy based on having two residents to a room, and staff may not knock upon entering which discourages privacy (Kaplan, 1996). Each marital unit

needs to be taken individually, as some marriages want continued sexual intimacy and some do not (Kaplan, 1996). It is best for the nursing home to interview each marital unit and cater to their needs and not to generalize that everyone is the same (Kaplan, 1996). The present study asked each participant, both male and female, about their sexual intimacy before their loved one was institutionalized. It is expected that if spouses did not have sexual intimacy prior to admission then they would not be interested in continuing that part of their life. Of interest will be, if sexual intimacy has changed, what changed it, how does it make them feel, and how do they cope with it?

### **Effects on Non-Institutionalized Spouse**

The spouse who places their loved one in long-term care has an initial adjustment similar to the process of bereavement except their loved one is still alive. Braithwaite (2002) investigated the role changes when a loved one had gone into a nursing home. The community-dwelling spouse will grieve the loss of a relationship with their spouse, the loss of their identity as a couple, and loss of the person whom they had known as a healthy functioning being (Ade-Ridder & Kaplan, 1993; Braithwaite, 2002). Losing their identity as a couple may also cause the loss of friendships that were made when they had their identity as a couple (Braithwaite, 2002). Prior social events that were attended as a couple must now be attended alone, and questions about the other spouse will be explaining how the spouse is doing in the “nursing home” (Rosenkoetter, 1996).

Most of their married life revolved around his or her spouse, and during the later years, their meaning and purpose may have centered in caring for their spouse (Rosenkoetter, 1996). The spouse that remains at home begins to feel lonely and

experiences a lack of companionship (Kaplan and Ade-Ridder, 1991). The non-institutionalized spouse's whole way of life will change once placement of their loved one in a long-term nursing home. Grief and mourning may occur due to the loss of a relationship with a spouse (Smyer & Frysinger, 1985). This grief is different from bereavement as the loss is open-ended and does not end until death (Sommers & Shields, 1987).

Relocating a loved one into a nursing home not only affects the location of residency but also the symbolic loss of their spouse (Gladstone, 1995). The home represents a personal identification of family, and when there has been a physical departure of a spouse, it will disrupt the community-dwelling spouse's psychological sense of familiarity and foundation (Sixsmith, 1990; Willcocks et al., 1987). Visiting a spouse becomes a way of life, and can bring feelings of insecurity as the physical and/or mental decline of their loved one is more noticeable to the visiting spouse than when they were at home (Gladstone, 1995). Their loved one may continue asking to go home which causes the community-dwelling spouse guilt and unsettledness (Gladstone, 1995). Gladstone (1995) found in the research of 161 elderly couples that the physical separation did not affect spouses when both went into an institution and had separate rooms. The assumption is that one spouse is cognitively impaired, and institutionalization gives the other spouse peace (Kosberg et al., 1990), or they chose to live separately due to continued tension in their marriage or they were already sleeping in separate rooms (Gladstone, 1995).

Studies (Braithwaite, 2002; Dye, 1982; Kaplan & Ade-Ridder, 1991; Sidell, 2000) have shown that community-dwelling spouses have a weaker social support by the time their loved one enters the nursing home. Reasons for the weaker social support are that more time and energy was devoted to caring for the spouse and less to social support and activities out of the home (Horowitz, 1985). Community-dwelling wives may not feel supported by their children. A study by Bartlett (1994), a number of the sons could not understand their mother's daily visits to the nursing homes while the daughters were more understanding of their mother's daily need to visit the spouse (Bartlett, 1994). In Kaplan and Ade-Ridder's (1991) study, the community-dwelling spouse never reported a lack of support from their family, but they did feel their circle of friends decreased. The reasoning for this decrease was due to the spouse wanting to spend their time with their loved one at the nursing home, instead of making time to visit with friends and family (Bartlett, 1994; Kaplan & Ade-Ridder, 1991). The wives of the spouse who was institutionalized did cultivate friends; however, the wives who visited daily were not able to develop friendships (Bartlett, 1994).

The spouse who places their loved one in a nursing home experiences loneliness (Kaplan & Ade-Ridder, 1991); this loneliness may take place prior to placement for caregivers whose loved ones suffer cognitive impairment (Beeson, 2003; Siriopoulos et al., 1999). Before the placement, each spouse could quickly strike up a conversation and exchange ideas with each other, but when there is a physical separation or cognitive decline the community-dwelling spouse has been reported to experience loneliness and depression (Beeson, 2003). Living separately from the other spouse causes a delay in



discussing issues. Once at the nursing home, some issues may appear trivial and not discussed between them, while those that have a spouse that is cognitively impaired, no issue may be discussed. When separation happens, the extent of social interaction with friends helps protect loneliness from this separation (Kaplan & Ade-Ridder, 1991) Anxiety, depression, and social isolation increases for those spouses that are unable to adopt new social roles and activities (Martin, Miranada, & Bean, 2008).

Kaplan and Ade-Ridder (1991) found that the women they had studied expressed loneliness and lack of companionship as their biggest hardship. The stress had changed from being the main caregiver to giving the caregiving role to the institution. The women had shifted a stress, but in turn, received a different stress. Morgan and Zimmerman (1990) reported that the non-institutionalized spouse wanted to be more involved in the care of their loved one, but were not allowed to be a part of the ongoing care once placed in a nursing home.

Community dwelling spouses go through a period of trying to redefine their role. They often try to preserve the rituals or routines of their loved one by instruction (Bowers, 1988) or an active role of caring which can infringe upon staff's rules and daily care (Darbyshire, 1987; Robinson & Thomas, 1984). Spouses frequently wish to be involved in the ongoing care of their loved one. They felt more knowledgeable in their spouses' needs and wanted to share their knowledge with staff (Morgan & Zimmerman, 1990). The study by Morgan and Zimmerman (1990) found that the 10 spouses who were able to have continued influence in their loved ones care reduced their level of stress.

Community dwelling spouses stated that they felt their marriage changed once their loved one had been placed into the nursing home. They felt loss of companionship due to the physical separation or due to the cognitive decline of their spouse (Gladstone, 1995). There were four groups that resulted from the study. Forty-eight percent of the Community-dwelling spouses felt that their marriage was just a memory and that there was no longer a marriage, especially when their spouse suffered from cognitive decline (Gladstone, 1995). Twenty-five percent felt that the marriage was unchanged; they felt that it was just the phase of their marriage. Fifteen percent felt that their marriage had changed in which they felt they were a parent and their loved one was a child. Twelve percent felt their marriage was illusionary, in which they are married, but their spouse does not remember being married (Gladstone, 1995).

A study completed by Bartlett (1994), involving 24 wives who had placed their spouses in a nursing home, explored the wives' experiences with being a caregiver prior to placement and the differences after placement. The wives reported a change in their roles of not being the caregiver; but, they felt they experienced a more meaningful role by providing the emotional and tactile stimulation through touching their husband that nursing staff would not do (i.e. holding spouses hand, rubbing his back or shoulders; Bartlett, 1994). While placement decreased their level of care given, it also decreased the actual time for tasks that gave personal identity (i.e., meal preparation and the intimacy of sleeping together). The most expressed feelings of loss that were experienced before and after placement were affection, communication and intimacy. The decline in marital relations was mostly due to the cognitive and physical decline of their spouses (Bartlett,

1994). These wives were deeply committed to their spouses in that most of them visited daily while the least frequent was three-to-four-times a week. Those that visited daily started to have physical exhaustion, a decrease in energy, and appetite (Bartlett, 1994; Sidell, 2000).

A qualitative study by Eriksson and Sandberg (2008) explored the older men's perspective of gender identity after they had placed their wives in a nursing home. Seven men, between the ages of 67 to 93 years old, were caregivers to their wives before placement. Even after 12 months, since their wives had been institutionalized, the men continued to struggle with the realization of not being the caregiver of their spouse (Eriksson & Sandberg, 2008). Most of the men felt a great sense of loss, and little control over caring for their wives after placement (Eriksson & Sandberg, 2008). The men in the study described doing limited care with their wives after placement. Their relationship went from a caring husband to one in which they have only a friendship. The intimate caring that these men had bestowed upon their wives has now passed onto professional hands in the nursing home (Eriksson & Sandberg, 2008).

A quantitative study completed by Sidell (2000) on marital happiness when a loved one is placed in a nursing home found that the number of years married, having social support, having the resources helped with coping, and spiritual support explained 35% of the variance contributed to happiness in marriage. The 65% was unexplained, but speculated, due to individual personality traits, the relationship between that non-institutionalized spouse and staff, or the quality of interaction between the spouses (Sidell, 2000). The sample size was 65 with 43 females and 22 males. Sidell's (2000)

quantitative study sought to find out how happy in the marriage the community dwelling spouse felt if their spouse was institutionalized. The study could only speculate why the 65% of variance was unexplained. The present qualitative study delved into the relationship between the spouses and staff. Only community dwelling spouses who have been married 30 years or more, be 65 year and older, and have a spouse in long term care.

### **Separation**

Dye (1982) generalized that placing a spouse within a nursing home for long-term care, is a proclamation that death is now eminent, but yet, not the finality of death. Attachments are broken and felt among most family members; the life of the non-institutionalized spouse is greatly affected and changed (Dye, 1982). Mourning and grief may occur due to the loss of their spouse and their relationship, their identity as a unit, and the loss of the once healthy spouse (Smyer & Frysinger, 1985). Dye (1982) stated that this grief is different from bereavement as the loss is open-ended, and the non-institutionalized spouse cannot resume their life.

A study of 1222 caregivers and care recipients who had placed their loved one in a nursing home due to dementia found that the level of depression and anxiety before placement for the caregiver and care recipients did not reduce after placement (Tornatore & Grant, 2002). In addition, there was an increased use of anti-anxiety medications after placement for the community dwelling caregiver. Those that reported higher depression on the Center for Epidemiological Studies-Depression (CES-D) scale (Radloff, 1977) were those who were married to the patient, visited the most frequently, and felt a dissatisfaction in the care given by the nursing home staff (Tornatore & Grant, 2002).

More visiting and dissatisfaction with support from others was also linked to higher anxiety scores. These data suggest that the transition to institutional care is particularly difficult for spouses, almost half of whom visited the patient daily and continued to provide help with physical care during their visits.

### **Depression**

Prior to a spouse being admitted into a nursing home, he or she usually had been taken care of at home, typically by the other spouse. Studies have shown that spouses who had been caregivers to dementia patients experience depression once their caregiving ended (Kaplan & Boss, 1999; Rudd et al., 1999). There have been contradictory reports in caregiver feelings after placement as some studies state that once a caregiver becomes free of this burden, they have positive life changes (Aneshensel et al., 1993; Emstahl et al., 1998; Graftstrom & Winblad, 1995; Zarit & Whitlatch, 1992). While other studies have found that the caregiver will experience more guilt (Baumgarten et al., 1994; Harper & Lund, 1990; Mullan, 1992; Zarit & Whitlatch, 1992); difficulties with coping (Gold et al., 1995; Zarit & Whitlatch, 1992); loneliness, depressive feelings and sorrow (Eloniemi-Sulkava et al., 2002); and health problems (Baumgarten et al., 1994; Eloniemi-Sulkava et al., 2002; Kecolt-Glaser et al., 1991).

A study by Eloniemi-Sulkava et al. (2002) of 64 caregivers whose caregiving of their demented loved one ceased, found that the average duration of cessation in feelings of being a caregiver was 3 years from the time their loved one was placed in an institution. The feelings of loneliness, feelings of depression, and sorrow was still present for the spousal caregivers. Spouses reported a higher incidence of loneliness (36%), and

increased health problems (32%) compared to non-spousal caregivers who reported feelings of relief (91%; Eloniemi i-Sulkava et al., 2002).

These continued feelings of loneliness, depression and increased health problems that the spousal caregiver continued to experience, in spite of no caregiving, were investigated in more depth. Harper and Lund (1990) found that it was due to the increase in dementia of their loved one, level of support from friends and family, the level of care given to the loved one in the nursing home, and the overall satisfaction with their own life. Ritchie and Ledesert (1992) found an increase in depression for the community dwelling spouse, as placement of their loved one created additional stress and worry over cost of care, having poor family relationships, and poor relationships with the nursing home staff, and loss of being in control. Schultz (2004) found that caregivers who visited their loved one in the nursing home most often and felt the level of care from the nursing home was below par had more depression (Mullin et al., 2013). Tornatore and Grant (2002) found that depression was seen more often in the oldest of their sample, those that had been a caregiver for only a short time, and the caregiver who gave the greatest assistance in care.

Bartlett (1994) found that 14 of the 24 wives, who had placed their loved ones in a nursing home, scored as depressed on the CES-D Depression scale(Radloff, 1977). One participant was so distraught that she could not complete the interview or the CES-D Depression scales (Bartlett, 1994). The wives in this study were caregivers for 8 years before placement. This study also found abusive relations toward the wives by the spouse. Twelve of the 24 wives reported a form of abuse received by their spouse, and six

of the 24 reported both verbal and physical abuse from the spouse (Bartlett, 1994). These wives who received such treatment considered it a part of the disease; even though 5 of the 12 husbands, identified as abusive, had different diseases than Alzheimer's, which does produce verbal and physical abuse (Bartlett, 1994). Those five had suffered from stroke, alcoholism, depression, or polio. Each of the wives had felt that the expressed violence was due to the illness except for the two identified as alcoholics (Bartlett, 1994).

A contradiction as to feelings of depression and burden as a caregiver was seen in a study by Pruchno and Resch (1989) who reported that caregiving wives, who were less emotionally invested to their spouses, felt less depression and burden. Since women have more social contacts outside the marriage than men do, caregiving for men engulfs their life and they stand to lose more as men are deemed to have limited friendships (Horowitz, 1985). The present study addressed both male and females. Questions to be addressed include: what their supports were before they placed their spouse in a nursing home, their hobbies and interests outside of their marriage, and had they cared for their spouse prior to placement and for how long?

### **Diagnosis of Depression**

According to the most current issue of the Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> ed., DSM 5); American Psychiatric Association, 2000), the diagnosis of Major Depression is given when a person presents with one or more core elements: Depressed Mood and/or Lack of Interest. In addition, four or more of the following symptoms must be present for at least two weeks: feelings of worthlessness or inappropriate guilt; diminished ability to concentrate or make decisions; fatigue;

psychomotor agitation or retardation; insomnia or hypersomnia; significant decrease or increase in weight or appetite; and recurrent thoughts of death or suicidal ideation.

There are two types of depression: Early Onset and Late Onset. Early Onset means that the first episode of depression occurs before the age of 60. Late Onset is the first depressive episode occurs after the age of 60.

The diagnosis of Early Onset is more common if there are personality abnormalities, a family history of psychiatric illness, and dysfunctional past marital relationships; but there are no difference between early and late onset in the elderly in the severity, phenomenology, history of previous episode, and neuropsychological performance (Blazer, 2003). The diagnosis for late-life depression is harder to diagnosis due to comorbidity with prodromal symptoms from physical diseases such as cancer, or side effects from medical treatments (Munk, 2007). In the oldest old (85-years and older), depression is more frequent as there is more likelihood of physical disability, cognitive impairment, and lower socioeconomic status; but if those variables are controlled, then there is no relationship to depression and age (Blazer, 2003).

Major depression is less frequent in the elderly (Hasin et al. 2005), but when it does occur, it increases morbidity, suicide, physical decline, cognitive decline, and self-neglect (Blazer 2003). Numerous studies have found that the prevalence for Major Depression declines with the advancement in age (Jorm, 2000; Korten et al., 1997; Mojtabai and Olfson, 2004 ; Palsson and Skoog, 1997; ). Symptoms of depression may persist if there is physical illness and low social economic status (Mojtabai & Olfson, 2004) or if depression symptoms are more of a mild form compared to the diagnosis of



Major Depression (Luppa et al., 2012). There has been criticism of the symptom criteria of Major Depression in the DSM-IV-TR that it is not suitable for diagnosing the elderly, as depression in the elderly tends to be more somatic (Luppa et al., 2012). The elderly present more with sleep disturbance, loss of appetite, fatigue, hopelessness for the future, subjective memory complaints, and cognitive deficits as prevailing symptoms versus the younger adult (Luppa et al., 2012). Comparisons between younger and older adults with the diagnosis of Major Depression tend to show the same the pattern in which there are more females diagnosed, they have less formal education, are unemployed, have lower social economic status, and are divorced separated, or widowed (Mojtabai and Olfson, 2004). Why these variables are more associated with Major Depression is not fully understood.

Depression is more likely to be diagnosed in females, but the reasoning is debatable. Biological factors have been proposed as reasons due to endocrinology and genetic influence; but then, social factors such as gender roles have been also been suggested as the reason for gender differences (Mojtabai & Olfson, 2004). The argument against these reasons is that the time during which gender roles are more prevalent (e.g. child-bearing, raising young children) is at the young to middle years, but Major Depression is common for females across all ages. The second explanation is that it cannot be due to an endocrinology factor because when women reach their mid-to-late sixties there tends to be a decline in depression (Mojtabai & Olfson, 2004).

A national survey (N=3,614) completed in 1986 on widowhood, life strains and depression, was analyzed by Umberson, Wortman, and Kessler (1992) to determine what

different types of life strains were present and how widowhood affects men and women differently. The results indicate that men are more apt to stay depressed longer after the loss of their spouse in comparison to females (Umberson et al. 1992). Reasoning for this difference is based on the defined marital roles within the marriage. For women, their biggest stressor is financial, while for the men the biggest stressor is maintaining the household. Both of these stressors come from being accountable to tasks that were primarily the other spouse's role (Umberson et al. 1992).

Steinman et al. (2007) reported a 1999 U.S. Surgeon General Report that between 8-20% of elderly community dwellers suffers from symptoms of depression while 37% of the elderly that are institutionalized suffer from symptoms of depression. Many of those are unreported and receive no treatment (Steinman et al., 2007). In the general population, 1-to-5 percent of the elderly are diagnosed with Major Depression (Fiske et al., 2009). Women are twice as likely as men to be affected; but the symptoms of depression in the elderly increase considerably for both sexes at 20 percent (Glaesmer et al., 2011). Increase for depression for both sexes as they age is suggestive due to financial strain (van de Velde et al., 2010). Contributing to lower socioeconomic status and depression was psychosocial factors and poor physical health (Koster et al., 2006, Lorant et al., 2003). Studies have pointed out limitations in identifying depression in the elderly as most research is with community dwellers and not institutionalized ones, the instruments selected do not capture somatic complaints (Luppa, et al., 2012), and those that are able to complete the self-questionnaires are the only ones included in their studies (Glaesmer et al., 2011). The present study delved into the health of the community

dwelling spouse, by asking how are they sleeping, eating, and medically doing since they placed their loved in long-term nursing care.

### **Anxiety**

The prevalence of an anxiety disorder within the elderly population is common, but less common when compared to younger adults (Wolitzky-Taylor et. al., 2010). Reasoning could be that older adults with anxiety are underdiagnosed, as their symptoms may be perceived as medical comorbidity, cognitive decline, and changes in life circumstances (Wolitzky-Taylor et. al., 2010). Older adults have a tendency to minimize their symptoms, will use the word “concern” instead of “worry,” when describing their symptoms, attribute their anxiety to their physical illness, and may have difficulty in remembering their symptoms when asked by their physician (Lenze et al., 2011).

When a concise instrument, The Kessler Psychological Distress Scale (K10) was given, those over 75-years old responded with a higher percentage of anxiety than those 55-64 years old on two questions that tested for anxiety (Knauper & Wittchen, 1994). Research on the elderly and anxiety has been limited, but suggestions for continued research has been suggested (Wolitzky-Taylor et al., 2010). A suggestion was that a shorter more direct assessment be developed for the elderly (Wolitzky-Taylor et al., 2010).

A suggestion for the barrier discussed by Lenze et al. (2010) that the elderly minimize or use the word “concerns” instead of “worry,” was for clinicians to use the word “concern” in place of what the DSM-IV-TR symptom of “uncontrollable worry” (Wolitzky-Taylor et al., 2010). Anxiety described by an older adult was more somatic

and experienced as dizziness and shakiness (Flint, 2005). Due to this difference in terminology, an elderly adult may not be diagnosed with an anxiety disorder (Wolitzky-Taylor et al., 2010).

Older adults worry more about their physical health compared to younger adults who worry more about family, finances, and work.(Wolitzky-Taylor et al., 2010) In general, the diagnosing of anxiety is very difficult due to the comorbidity between anxiety and medical illness (Wolitzky-Taylor et al., 2010). Gurian and Miner (1991) reported that the older adults felt their muscle tension, hyper vigilance, and sleep difficulties were due to a medical condition instead of anxiety. There are some medical conditions such as cardiovascular disease, respiratory disease, hyperthyroidism, pulmonary, and vestibular difficulties that present as symptoms of anxiety but are not the underlying cause (Alwahbabi, 2003; Kogan et al., 2000). Future research has been suggested to decipher which medical conditions can produce anxiety disorders, which anxiety disorders can produce a medical condition, and which medications have anxiety as a side effect (Wolitzky-Taylor et al., 2010).

The most prevalent form of anxiety within the elderly is Specific Phobia (SP) and Generalized Anxiety Disorder (GAD; Wolitzky-Taylor et al., 2010). Anxiety correlates with depression for older adults as it does for younger adults (Wolitzky-Taylor et al., 2010). Comorbidity between depression and GAD is more chronic within the ages 64-84 than just diagnosed GAD or depression alone (Schoevers, et al., 2005). Parmelee et al. (1993) found that 60% of the nursing home residents that meet the criteria for Generalized Anxiety Disorder (GAD) also meet the criteria for Major Depression.

This study asked the community dwelling spouse if they worry about their spouse, or anything in their lives that they did not worry about previously, but worry about now? Somatic complaints such as headaches, difficulty in sleeping, and stomach complaints were asked about; in particular, have the symptoms occurred since placement of their loved one.

### **Gender Differences with Bereavement**

It has been described that the separation of a loved one when they enter a nursing home for long-term is the proclamation that death is coming, but without the finality (Dye, 1982). Placement in a nursing home causes physical separation; but cognitive decline from dementia causes emotional separation between spouses (Mullin, et al., 2013). Research has shown that spouses who have placed their loved ones in a nursing home do grieve, but the analysis of the similarity in grief of bereavement and placement has not been researched.

The term “married widowhood” (Rollins et al., 1985) and “married widow (ers)” (Brandwein et al., 1979) was given to community dwellers that had placed their loved ones into institutions and were experiencing role ambiguity. That person has many of the physiological, physical, and sociological reactions as a spouse who lost their loved by death (Rollins et al., 1985). The problems these individuals experience were related to financial pressure, the need to learn new skills, and trying to adapt to being married, but not having the person around to help ease the problems (Mackenzie & MacLean, 1992).

In 2000, the mean age for losing a spouse was 69 years for men and 66 years for women (Federal Interagency Forum on Aging Related Statistics, 2000). More women

than men had lost their spouses at 65 years and older, 45% to 15% respectively (Federal Interagency Forum on Aging Related Statistics, 2000). How it psychologically impacts a spouse depends upon their relationship prior to death.

Researchers have supported the finding that widowers are more depressed at the loss of their spouse than widows (Glick et al., 1974, Radloff, 1975; Umberson et al., 1992). Widowers' depression may last two to four years after the loss of their loved one (Glick et al., 1974). This gender difference presents itself even when a death is a close member of the family that is not the spouse. Men reported more depressive symptoms than females six months after the loss of a close family member (Siegel & Kuykendall, 1990). This gender difference for higher likelihood of depression has been found in other studies outside the United States. Great Britain has reported the same gender differences (Cramer, 1993) as did the Netherlands (Van Grootheest et al., 1999).

Psychological stress for women during widowhood was due to financial strain (Morgan, 1986; Umberson et al., 1992). For men, their psychological stress was due to the hardship in maintaining the household, limited close friendships (Carr, 2004; Antonucci, 1990; Peters & Liefbroer, 1997), and the reliance upon the wife's practice of healthy behaviors (Carr, 2004; Zisook, Shuchter, Zisook & Mulvihill, 1990). It appears that men are more dependent upon their wives as reflected in emotional support, housekeeping, and promoting healthy habits (Carr, 2004). Parkes & Weiss (1983) concluded in their study of non-elderly widows, that those that were more dependent in their relationship with their deceased spouse experienced more pathological grief reaction.

This study explored the issue of how the community spouse was experiencing the loss of their loved one by definitive separation before death, by inquiring how they foresee the future. Exploring how the community dwelling spouse had thought out their future suggested if they accepted the separation of their spouse or if they are living day-to-day with no future..

### **Loneliness**

Older adults are more apt to feel lonely due to changes in their social networks than younger adults. Upon retirement, their social relationships connected to work will reduce, children grow and may leave the area, a disability or an illness may prevent continued participation in activities, a change in living arrangements (De Jong-Gierveld, 1987), death of a significant other (McWhirter, 1990), or a change in income (Creecy et al., 1985). Each of these continues to reduce or change the social relationships which in turn, can increase loneliness (Alpass & Neville, 2003).

Older adults who were not in a relationship felt lonelier than those that had a partner (Peters & Liefbrower, 1997). Men felt lonelier than females when they did not have a partner. Antonucci and Akiyama (1987) argued that men rely more on their wives for social support than friends and family.

Alpass and Neville (2003) found that loneliness was related to depression, but not to social supports. The older adult has some social support, but it is very limited. A study limitation was that the different types of social support were not identified.

Martin et al. (2008) interpreted the words "eating alone" and "being alone at home" as "loneliness" when wives described how their relationship changed when a

spouse was in long-term nursing home. This social isolation was difficult to generalize, but it did show how spouses would change their socialization from outside activities to the nursing home being their social outlet (Martin et al. (2008).

This study asked the community dwelling spouse if they felt lonely. When did they feel lonely and if they experienced this feeling since their loved one has been in placement?

### **Coping**

Coping is how a person reacts and thinks in response to a stressor (Sidell, 2000). Successfully coping with a stressful situation will improve mood and give a person a better sense of well-being (Lachman et al., 2006). The coping strategy utilized by an individual can be both effective and ineffective. The same event will affect each person differently, so, in turn, their coping strategy will be different. How a spouse may cope with the placement of their loved one depends upon several factors.

Lazarus and Folkman (1984) identified two types of coping strategies: problem-focused coping and emotion-focused coping. Problem-focused coping is using a strategy to do something to alter the problem while emotion-focused coping is using a strategy to reduce the emotional distress that is being endured with the stress (Lazarus & Folkman, 1984).

Numerous studies have shown that women utilize both maladaptive and adaptive strategies to cope with stress more than men (Nolen-Hoeksema & Aldao, 2011; Tamres et al., 2002; Thoits, 1991, 1994). Adaptive strategies include seeking social support, positive self-talk (aka reappraisal), active coping and turning to religion (Carver et al.,



1989). Maladaptive strategies rumination and suppression (Tamres et al., 2002, Nolen-Hoeksema & Aldao, 2011), Women were more likely than men to use all those coping strategies; in addition, the women appraised the stressor higher than men. ).Older men (65 years-old to 75 years-old) did not utilize self-talk (reappraisal), active coping, and acceptance in comparison to younger women and men (Nolen-Hoeksema & Aldao, 2011). Older men experience more difficulty in coping with loss or illness (Schulz & Heckhausen, 1997).

The oldest age group across each gender uses suppression to cope with stressors (Blanchard-Fields et al., 1997, 2004). As the older adult ages, they try to avoid that stressor so as to not experience the negative emotional arousal it brings (Consedine et al., 2002). Nolen-Hoeksema and Aldao (2011) argue that older adult women had an increase in using suppression and that they did not decrease in the use of acceptance to cope. They report that older females have difficulty with accepting and will in turn, try to avoid the stressor.

A number of studies show that men cope better with stressors because they use problem-focus coping compared to women who use emotion-focus coping strategies (Billings & Moos, 1981; de Ridder, 2000; Endler & Parker, 1990; Folkman & Lazarus, 1980; Pearlin & Schooler, 1978; Ptacek et al., 1992; Stone & Neale, 1984; Stroebe et al., 2001; Vingerhoets & van Heck, 1990). Thoits (1991) argued that there was no gender difference between coping styles. There were no gender or age differences when coping strategies were maladaptive and having higher depressive symptoms (Nolen-Hoeksema & Aldao, 2011); ages for the study were from 25-years old to 75-year-old. The use of

emotional regulation for coping declined with age except with women who increased suppression and decreased using acceptance (Nolen-Hoeksema & Aldao, 2011). In the study's older group (65-75), the use of emotional regulation strategies declined. Nolen-Hoeksema and Aldao (2011) applied Carstensen's socio-emotional selectivity theory of becoming more selective with social supports with age.

Problem-focus coping strategies are argued to be better coping strategies, which would mean that men would do a better job in coping compared to women (Billings & Moos, 1984; Hobfoll et al., 1994; Hovanitz & Kozora, 1989). However, other studies have argued that problem solving strategies are not the best type of strategy to cope with uncontrollable situations (de Ridder, 2000; Folkman, 1992; Stroebe et al., 2004).

A spouse's biggest strain in coping is when they visit their loved one who may have memory deficits and behavior problems (Whitlatch, et. al., 2001). If the spouse experiences a negative visit due to these impairments, depression is highly associated after placement (Majerovitz, 2007; Whitlatch, et. al, 2001).

This study explored how the community-dwelling spouse copes with the placement of their loved one by asking them about their day-to-day activities. How it changed from before to after the placement of their loved one? How they are handling that change and what coping strategies are used?

### **Role changes**

Spouses have expressed a change in their roles when their loved ones are institutionalized. Kaplan and Ade-Ridder (1991) found that their married sample noted a role change from spouse to a parental role in which they would give permission to the

nursing home to care for their loved one. Eriksson and Sandberg (2008) reported that the spouse felt their role had changed from a loving spouse to just a friend even before their spouse was placed in a nursing home.

A typology of “couple-hood” had been developed by Kaplan et al. (1995) as a way to categorize the perceptions of how female spouses perceived their marriage after their mate was institutionalized due to Alzheimer’s disease. A symbolic interaction of being married or not was using the plural meaning “we” or singular “I.” This typology has been used for further research and found that there tends to be equal numbers in each category (Kaplan et al., 1995; Braithwaite, 2002).

Kaplan et al. (1996) delineated three categories of couple-hood for wives with their spouses in a nursing home. The first category is No Couplehood. No Couplehood means that the wife was married, but felt single (Kaplan, 2001). In No Couplehood, the spouse feels that there is no marriage; even though they are legally married they question why remain married. The second category is Low Couplehood. Low Couplehood means the wife felt married, but that she did not have a husband. These women feel a sense of couple-hood, but do not have a husband that lives with them. The highest feeling of being married is called High Couplehood. High Couplehood means that the wife was married, and felt continued couple hood. They felt no matter how their husbands' health impacted their relationship, they were married until death (Kaplan, 2001).

This study explored how the community-dwelling spouse felt about their relationship since their spouse is in long-term care. How the relationship changed since placement or it remained the same.

## **Intimacy**

Lindau and Gavrilova (2010) reported 40% of men and 11% of women between 75-years old to 85-year old stated that they felt sexual desire. In a national survey reported by Lindau and Gavrilova (2010) men were more sexually active than women in each age group. In the age group 57-64 years old, 80% of men and 60% of women report still being sexually active; for the 64-75 years old, men were 66% and women 40%, and for the 75-85 year olds, men were 40% and women were 17% of being sexually active (Lindau & Gavrilova, 2010).

Kaplan and Ade-Ridder (1991) stated that the physical intimacy experienced by wives who had placed their loved ones in nursing homes was mostly kisses and hugs. Any sexual desire was ignored or forgotten. Even though they could have privacy, they did not use it, due to the feelings of being under the scrutiny of others. One wife had expressed no desire, which she indicated was not due to the physical environment or due to the health reason of their spouse.

Future research was suggested to examine if just placing a loved one in a nursing home decreases the sexual desire between couples (Kaplan & Ade-Ridder, 1991) Bartlett (1994) found that wives, who had placed their spouses in nursing homes, had experienced a decrease in intimacy prior to their spouse being institutionalized. Their spouses had already begun to decline, either physically or cognitively, which lead to a decline in any affection (Bartlett, 1994).

This study explored the intimacy between the spouses prior to placement by exploring how it has changed from before placement. Questions such as if they had been

sleeping in the same bed or if they were intimate before placement gave a glimpse into their level of intimacy and changes.

### **Conclusion**

This literature review examined the issue of the elderly spouse placing their loved one in a nursing home, and the impact of placement affects that spouse. The review found that studies have been researched on only husbands, or just wives (Kaplan & Ade-Ridder, 1991), family members, spouse that reside in a nursing home that are diagnosed only with Alzheimer's (Kaplan & Boss, 1999). Residing in a nursing home becomes more likely with age. The United States Census' (2010) data suggests a higher percentage of the aged reside in nursing homes; for example, "0.9% of those 65 to 75 years old, 3.2 % for those 75-to-84 years old, 10.4% for those 85-to 94 years old, 24.7% of those 95 to 99 years old and of those 100 years and older, 32.3% were in nursing homes." Females were more likely to be in a nursing home as they aged compared to males (U.S. Census, 2010).

A lens to analyze the possibility of how it may impact an elderly spouse is Socio-emotional Selectivity (Carstensen, 1987, 1991, 2006) and Boundary Ambiguity (Boss et al., 1990). Socio-emotional Selectivity theory defines that the elderly are more selective to positive experiences than to negative ones. They will narrow their interaction with family and dear friends then to acquaintances. The elderly person's social support group becomes very small due to limiting their interaction (Carstensen, 1987, 1990, 2006). For Boundary Ambiguity, it is the families' ability to understand the loss that has occurred within the family. The higher the boundary ambiguity the more stress and dysfunction the family will harbor (Boss et al., 1990).

Marriage for the older couple provides social, emotional, financial, and physical support and stability (Walder & Luszcz, 2009). With aging, couples become more dependent upon each other. They experience of friends and family dying, decreased mobility, illness, and disability starts to isolate the couple (Ade-Ridder & Kaplan, 1993; Braithwaite, 2002). With these events happening in the couple's lives, they become more attentive to each other if one of the spouses is the one suffering an illness or decline in health (Racher 2002).

The more emotionally dependent upon his or her spouse, the higher risk of depression if one spouse becomes ill. Women become more depressed if their spouse is the one ill (Nijboer et al., 2000) while men become more depressed if their wives cognition declines (Tower et al., 2002).

A spouse will provide caregiving to his or her spouse to keep them home. It is a hardship emotionally and physically for the caregiving spouse (Braithwaite, 2002). There comes a time in which a professional or family will drive the need for placement (Sandburg et al., 2001). Placement creates a role change for a couple, as now one spouse becomes a resident and the other visitor (Rosenkoetter, 1996).

Previous research has found that the spouse that remains at home feels a loss of control over their loved ones cares; feeling of guilt for placing them in a nursing home, but at the same time, reprieve (Carson et al., 2006; Cotter et al., 1998; McAuley et al., 1997; Sandberg & Harper, 2000). The couple now has a loss of autonomy and decision-making (Rosenkoetter, 1996).

The literature on the community-dwelling spouse has examined the perception of being married in respect to the community-dwelling spouse and residential spouse, and how placement brought loneliness, depression and a lack of control, yet the full range of emotions experienced, and the difference between a male and female spouses, has not been fully explored. The literature has examined how placement of a spouse in an institution explored the role changing for the community-dwelling spouse from caregiver to visitor. The concept of depression was surmised by community-dwelling spouse, as they reported despair in the dispersion of the person they had exchanged vows and their identity as a couple (Ade-Ridder & Kaplan, 1993; Braithwaite, 2002), and how they perceive their marriage (Gladstone, 1995).

Even though the stress from being a caregiver has reduced when a spouse has been institutionalized, an additional stress of being the primary caretaker of financial and daily living responsibilities replace the caregiving stress (Rosenkotter, 1996). The spouse is reported to feel a sense of loss in the marriage in respect to affection and intimacy, prior to placement and after placement and a diminished support system for the community-dwelling spouse, as daily visits with the spouse leaves very little time to cultivate friendships (Bartlett, 1994; Sandberg et al., 2001). Feeling relieved of not being the primary caregiver, but yet feeling guilty for not taking care of their spouse, the non-institutionalized spouse anguishes over their loved one being in a nursing home (Gladstone, 1995).

Research has examined caregivers that were non-spouses and illustrated their feelings about placement (Montgomery & Kosloski, 1994). However, previous research

has not explored both wives and husbands in the same study, that are community dwelling spouses. Previous research has not explored the full range of emotions that a community-dwelling spouse may experience, for example, if they have no children or if they do have children, but they are not geographically close to giving extended support. The spouse that was institutionalized due to Alzheimer's has been explored ( Kaplan, 1994; Kaplan & Boss, 1999), and the affects with community-dwelling spouses, but diverse medical conditions requiring placement have not been fully explored. The present research study explored each of those issues that have not been researched.

This study explored the emotional impact of elderly spouses in a qualitative study. Questions were focused on psychosomatic symptoms of depression and anxiety, how they were presently coping, how had it affected the physical intimacy and interaction, and what they foresaw in the future.

Chapter 3 will discuss the reasoning for the qualitative method for this research. An analysis of the type of research design and the data analysis was outlined.



## Chapter 3: Research Method

### **Introduction**

In this study, I used the theories of socio emotional selectivity (Carstensen 1987, 1991, 2006) and boundary ambiguity (Boss, Greenberg, & Pearce-McCall, 1990) to elicit a detailed description of the experiences of older spouses who had their spouse in long-term nursing care. These theoretical frameworks may contribute to how the older spouse, who remains at home, may be emotionally coping. A flyer to recruit participants was distributed within nursing homes based in Northeast Ohio. The primary criteria for volunteering was to be at least 65 years of age, preferably residing within his or her own home, and had a spouse who is living in a long-term care facility (LTC). In-depth interviewing of the participants captured the emotional impact that the home residing spouse was experiencing.

This chapter will begin with the research design and methodology that was used in this study. A complete, detailed description of the method follows, including a historical foundation. The sections that follow include a summary of the technical and structural steps of the study, ethical considerations, confidentiality, research approach, participant selection, data collection and analysis, the role of the researcher, and the reliability and validity of the study. The social impact of this study will conclude this chapter.

### **Research Design and Rationale**

An emotion, such as depression, has been deduced from previous qualitative research on wives (Bartlett, 1994; Kaplan & Ade-Ridder, 1991) husbands (Eriksson &

Sandberg, 2006), or both spouses if one spouse had a spouse with a certain illness (Mullin et al., 2013), but the full range of emotions that may be experienced by an elderly spouse has never been explored. One quantitative researcher did explore depression using the Center for Epidemiological Studies Depression Scale (CES-D; Kaplan, 1994).

In previous research, only depression has been studied. In these studies, it was hypothesized that when a spouse said “loss” it meant he or she was depressed. Researchers indicated it was “depression” when the men expressed the loss of their caregiving role (Eriksson & Sandberg, 2006) or when wives stated a loss of being a couple and having to do things alone (Braithwaite, 2002; Rosenkoetter, 1996) or when spouses experienced a loss of communication with a spouse who declined with Alzheimer’s disease (Mullin et al., 2013). The word loneliness was also construed as depression by two female spouses who felt a loss of privacy with their spouse in a nursing home (Gladstone, 1995), and three wives expressed loneliness for having to adjust to living by themselves (Kaplan & Ade-Ridder, 1991). Just having one word of loss or loneliness was construed as depression. In According to the American Psychiatric Association (2013), it takes a number of symptoms or words to diagnose depression. In this study, a number of symptoms that are synonymous with depression were asked (i.e., sad, blue).

Previous scholars have not examined the differences between genders (males vs. females), the differences in ages of the same gender (i.e., 65-year-old female vs. 85-year-old female), or between the genders (i.e., 65-year-old female vs. 65-year-old male). These

gaps illustrated in the literature review in Chapter 2 provided the motive for the current research study.

A qualitative methodology obtained a deeper understanding of the emotions experienced by elderly spouses who had a loved one in long-term nursing home care. The lived experience can be best captured by using a qualitative methodology (Creswell, 2012). The experience captured by being within the environment is referred to as a quality (Eisner, 2003). Empirical research is the experience of the phenomena, and for the experience to be felt through all the senses, the researcher needs to be a part of the quality (Eisner, 2003, p. 20). Empirical comes from the Latin word *empiria*, which means the experience (Eisner, 2003, p. 20). Sitting and interviewing the person can provide insight to the researcher of the full sensory experience of that lived phenomena. It provides deep sensory quality that a questionnaire, survey, or testing instrument could never capture.

Qualitative researchers use descriptive language and the meanings to that language to describe the quality (Eisner, 2003); the lived experience is described in richness and depth by the participant. Guba and Lincoln (1988) proposed that qualitative research makes philosophical assumptions or paradigms. Philosophy is important within a study as it shapes what the research question is and how the researcher will go about answering it (Huff, 2009). Understanding the depth and variety of philosophical paradigms strengthens the foundation of qualitative research (Ponterotto, 2005; Rennie et al., 2002).

Researchers select an approach to capture the participant's experience. Creswell (2013) described five approaches that can be used to inquire about this experience –

narrative, ethnography, case study, grounded theory, and phenomenology. Each of these approaches allows the researcher to approach the study methodologically and to develop his or her findings from the approach selected. It provides a thorough descriptive meaning of each approach and a more scholarly presentation of data (Creswell, 2012). These approaches will now be described.

### **Narrative**

Narrative is a specific type of qualitative design that gives chronological order to a lived experience either by the spoken or written word (Czarnaiwska, 2004). The narrative method evolved from literature, history, anthropology, sociology, sociolinguistics, and education and has been adapted into other disciplines (Chase, 2005). There are many different approaches to gather the data, but Crewell (2013) discussed four types that are the most popular: biographical, auto ethnography, life history, and oral history.

The biographical study is written about someone else's life experience, while the auto ethnography is written by the researcher who tells his or her life experience within an event. The life history is the entire life of that individual or community, while the oral history is about a particular event that is reflected from one person or a group that shared that particular event (Creswell, 2013). The narrative methodology was not selected for this study as it is commonly used for researching the lived experience of one individual, and I examined the experience of a number of spouses.

## **Ethnography**

Ethnographic is qualitative research that is concerned with the patterns, beliefs, and language of a culturally shared group of individuals (Creswell, 2013). The researcher is a part of the research by observing the daily interaction and interviewing the participants. Ethnography evolved from anthropologists who studied cultural groups within the field (Creswell, 2013). There are many different forms of ethnography, such as structural functionalism, symbolic interaction, feminism, and Marxism (Atkinson & Hammersley, 1994), but the two most popular are realist ethnography (Van Maanen, 1988) and critical ethnography (Thomas, 1993). Realist ethnographers are objective and narrate within the third person on accounts of what is being observed (Van Maanen, 1988). Critical ethnographers critically observe and report through a political lens as to what is being observed (Thomas, 1993).

The ethnography methodology was not selected for this study as the community-dwelling spouse may share parts of being affiliated with having a loved one in a nursing home; ethnography is made up of what is the cultural behaviors, values, beliefs, and language of belonging to that group.

## **Case Study**

A case study is a qualitative method in which the researcher uses multiply sources of data to explore an in-depth study of one person or a number of persons (Merriam, 1998). The main feature of a case study is to identify certain parameters that guide the research (i.e., a certain place, time, or process; Yin, 2009). Case studies originated from a case study by anthropologist Malinowski about the Trobriand Islands (Hamel et al.,

1993). What the researcher intends to find through the case study determines which type of case study he/she will use. Stake (1995) described three types that can be used: single instrumental, multiple case, and intrinsic case study. The single instrumental case study focuses only on one concern and looks at only one case to study. The multiple case studies focus also on only one concern, but looks at a number of cases. The intrinsic case study is focusing on just the concern and expanding upon that concern (Stake, 1995).

The case study methodology was not selected for this study as the community-dwelling spouse may share the same emotions with having a loved one in a nursing home, but a case study would have the exact emotion driving the parameters of the research (i.e., depression), and I hoped to capture all of the emotions

### **Grounded Theory**

Grounded Theory is a qualitative method in which the researcher develops a theory from the process that is experienced by the participants (Strauss & Corbin, 1990). Grounded Theory originated from sociology in the late 60's as an effort to decipher causal factors (Creswell, 2013).

There are a number of approaches to grounded theory, but the two most popular are systematic procedures (Strauss & Corbin, 1990) and constructivist (Charmaz, 2006). In the systematic procedure, the researcher has a series of steps in analyzing and processing the data (Strauss & Corbin, 1990). In constructivist, have flexible guidelines to gather the data, but it emphasis the views, beliefs, feelings, assumptions and ideologies (Charmaz, 2006).

Grounded Theory was not selected as the qualitative method for this study as a number of theories have been developed regarding the elderly population and emotions, and the concept emotional ambiguity and theory socio emotional selectivity will be the framework to integrate into this study.

### **Phenomenology**

Phenomenological research is a qualitative method that “grasps” the meaning of the lived experience of several individuals (van Manen, 1990). This meaning or phenomenon is collected and then a description of this experience from a number of individuals is unfolded through themes (Moustakas, 1994). Phenomenology originated from philosophy (Creswell, 2013).

There are two approaches to phenomenology: hermeneutic (van Manen, 1990) and psychological phenomenology (Moustakas, 1994). Hermeneutic means life while phenomenology means experience so van Manen (1990) wanted the researcher to interpret the life experience of humans. Moustakas’s (1994) psychological phenomenology has less emphasis on the interpretation, but more on the description of the experience.

The phenomenological approach for this study was to follow Moustakas’s (1994) psychological phenomenology. Moustakas (1994) states that a researcher needs to approach a phenomenological method transcendently. Transcendental phenomenology is an approach to a study in which the researcher has systematic process (known as epoche) that is nonjudgmental to the phenomenon and open and unbiased to all the comments made by the participants (Moustakas, 1994). Epoche is a Greek word meaning

to abstain from being bias and to learn to see what is present without a tainted view (Moustakas, 1994).

This naïve, open view (the epoche) is the beginning of the research, and then comes the transcendental-phenomenological reduction (Moustakas, 1994).

Transcendental means to view the experience as if it is the first time, phenomenological is to transform it into a phenomena (an experience), and reduction means to go back to its existence, its meaning (Schmitt, 1967, p.61). The next step after the researcher has reduced the phenomenological experience is to break down the phenomena into imaginative variation (Moustakas, 1994). The imaginative variation is finding themes, descriptions within the phenomena (Moustakas, 1994). The present study started with the epoche, viewing the experience through transcendental-phenomenological, and finally, narrowing the phenomena into imaginative variation. By completing those steps this study built credibility and a full understanding of the emotions that an elderly spouse feels when having their loved one in a nursing home.

### **Role of the Researcher**

The role of the researcher will be divided into different roles, but each role will be interdependent upon each other. The first role is of recruiter, then interviewer, then data analyst, and finally, reporter. The primary skills required for each role is to be an effective communicator, ability to portray genuineness, trustworthiness, and competence. The success of this research is to build trust, caring, and competence so the participant feels safe to share their deepest feelings to a stranger.



The epoche process is the first essential task that the researcher begins prior to the interview. The researcher needs to let go of any biases or assumed facts (Moustakas, 1994). The epoche may need to continue during the phenomenological interview. The phenomenological interview is the primary method of data collection (Moustakas, 1994). The researcher's primary focus is to provide and maintain the most comfortable climate for the participant to be able to share their experience (Moustakas, 1994).

As I am a geriatric counselor and provide contracted services in a number of nursing homes within Stark County, any participant's spouse that may be referred for counseling in the future will not be accepted by me and will be referred to another counselor. All data regarding the spouse's interview will not be shared with nursing home staff and/or residents. All data was kept in a locked, portable box, which is separate from nursing home records, and kept confidential. My role was identified not as a counselor but as a graduate student.

Professionally as a counselor, I have had a number of patients whose spouses have emotionally struggled with their loved one in a nursing home and then some that have not had any trouble. To address any undue biases, the focus of the interview was on only responses from the participants. Clarification may be warranted in order to further establish reliability of participant's experience. I need to be extremely cognizant of the power imbalance perceived by being a researcher to the participant (Creswell, 2013). I continually built trust and avoided any leading questions. No modification of participants' experience was done except during member checking.

## **Methodology**

### **Procedures for Recruitment, Participation, and Data Collection**

The sampling strategy for this study was a convenience sample with set criteria for recruitment. Recruitment was only at long-term nursing homes in the county of Stark, Ohio. In Stark County, Ohio there are 38 Nursing homes which have a total of 3,093 residents (“Local Nursing Homes,” 2014). The probability of meeting the sample size required based on the criteria was achieved based on the total number of residents that reside in Stark County, Ohio nursing homes. The minimum number of participants required is 14 with an equal representation of male to female. Duke (1984) recommends 3-to-10 subjects in a phenomenological research. Having 10 participants with an equal ratio of male to female was met with the same size and saturation.

If Stark County, Ohio nursing homes did not yield the number of participants required to meet criteria, then Mahoning County, Ohio nursing homes were considered. There are 26 nursing homes in Mahoning County and 2,709 residents (“Local Nursing Home,” 2014).

Nursing homes located in Stark County, Ohio which is the Northeastern part of Ohio are the primary locations for recruitment. Four nursing home administrators were contacted to obtain permission for the researcher to conduct a research within their facilities by recruiting residents' spouses that meets the criteria by using flyers, and if a participant volunteers, the use of a private room if needed.

If an individual wished to participate in the study, a place and time was scheduled, this met the wishes of the participant. The researcher provided a detailed outline of the

study and consent form (see Appendix B), a demographic sheet (see Appendix C), which was all verbally reviewed. The consent form was included to state how confidentiality was protected by the use of pseudo names and locked file boxes.

To determine the competency of participants to be able to consent to study, questions to test declarative memory was asked each participant. The following questions were used: their name; where they live; how many years they have been married; how many children they have, if any; where they were born and raised; and if they have siblings. If a volunteer struggled with these questions, which tests for declarative memory, the researcher would have asked two interview questions and then thank them for participating, but any information gathered was not used in the study. Since the volunteer had taken the time to set up a scheduled appointment and has the desire to share their phenomena, it would be insensitive to not allow them to share their experience.

The first contact was by phone to arrange for time and location of interview. The nursing home that the spouse visits their loved one was an option or their residence. A private-conference room was utilized for the interview at the nursing home. As this study is limited to participants that are of a protected group (older adults), there were additional precautions to promote consideration of this population. There were opportunities for the participant to take breaks, and to have a supportive person with them during the interview process, if they desired. Drinks and snacks were also provided during the interview process.

### **Informed Consent**

Since this study sample is restricted to the protected population, it was necessary to take the time to explain fully and ensure complete understanding of the procedures and potential risks involved in participating. During the initial phone contact, and again at the beginning of the interview, a detailed description was reviewed with the prospective participant with the option to continue with the process. Upon the consent to continue, the consent form was provided to each participant which fully explains that their participation is voluntary, details the steps to the study, permission to record their experience, giving permission to utilize their experience, and that the option to drop out of the study is available at any time.

Being that the participants are elderly, it is very important that the interviews be held in a comfortable and accessible location so as to ensure confidentiality and security. Utilizing a private room at each site allows for convenience and familiar surroundings, but if a participant prefers their own home or an alternative location, the researcher made arrangements for the best time.

### **Instrumentation**

This study used structured in-depth interviews to capture the essence of experience of the participants. The interview began with an overview of consent to participate, structure of the interview, and general housekeeping (i.e. location of restrooms, breaks). The open-ended questions (Appendix A) provided the foundation of the interview, which relate to the emotions the experienced by the participant. No psychometric instruments or tools were utilized in this research. The forms used in this

study included the informed consent and study description (Appendix D), demographic form (Appendix C), and a letter of cooperation from a research partner (Appendix E).

### **For Researcher-Developed Instruments**

This research study implemented a pilot study so as to refine the research questions developed, assess any bias perceived, determine if any research question needs reframed for better clarity, and change any research procedures ( Sampson, 2004).

By using a pilot study, it can reaffirm content validity. If the research questions do not tap the emotions of the community-dwelling spouse, than it is not capturing the construct under study.

### **Procedures for Pilot Study**

A pilot study was conducted with two volunteers to test any procedural difficulties and verify that the designed questions tap into the research study question. The pilot sample was derive from a convenience sample of individuals that researcher is aware of through nursing home work. The individuals were asked if they wish to participate in a pilot study, with the option to say yes, or no. The study followed the steps designed for the full research. It began by giving the participant a flyer for review, and then the steps of initial phone contact, review of the study, consent forms, and demographic questionnaire, and the interview using the interview questions.

The researcher had the opportunity to clarify any questions that seemed irrelevant or ambiguous by instituting a pilot study. It gave the participants an opportunity to describe their experience and discuss any issues, suggestions, and/or opinions that they had with the interview questions.

### **Procedures for Recruitment, Participation, and Data Collection**

As the current study utilized a phenomenological approach, criterion sampling will be used (Creswell, 2013). Criterion sample is a purposeful strategy to seek out individuals that have experienced the phenomenon, which is being researched (Creswell, 2013).

The sample size for phenomenology approach has a number of recommendations from 3 to 10 subjects (Duke, 1984; Riemen, 1986) up to 25 subjects (Creswell, 2013). For the present study 11 participants were recruited, which have equal representation of males to females. Flyers were distributed to nursing homes located within Stark County, Ohio with an index card attached to the back of the flyer (see Appendix B). If they wish to participate, then they were asked to fill out an index card and drop it in a box at the entrance of nursing home or to contact the researcher.

The participants were elderly spouses that have been married at least 30 years, be at least 65 years old, preferably reside alone in the home or apartment, and have a spouse that has to be institutionalized in long-term care due to either cognitive impairment or physical decline. At least four or more childless couples were to be included, with equal representation of both sexes; the sample size being 10 to 16 with half representing each sex

Each participant received an introduction which includes the topic, review of consent form, contact numbers, and the interview process. In addition, any questions or clarification of the interview process were answered in the beginning.

A full one-hour interview was planned for each participant. If the allotted hour interview does not fulfill the completion of the research study, I would have asked the participant for another time and date to schedule additional time.

### **Data Analysis Plan**

Interview questions were developed to promote the research question, which is the phenomenon that participants experienced emotionally with having a loved one in a nursing home (see Appendix A). Each participant was asked to respond to the same open-ended interview questions, which allowed them to expound upon their experience.

To test socio-emotional theory, interview questions asked the participant how often they see their family and friends, two years prior to admission and then after admission (see Appendix A). If a community dwelling spouse is narrowing their support system, this may compound the emotional impact they feel with having a spouse in long-term care.

To test boundary ambiguity, interview questions focused on how the community dwelling spouse managed household tasks, and if it was different when the spouse had been at home (see Appendix A). If a community dwelling spouse is having more difficulty in managing household duties, making decisions, and envisioning their spouse may return home, the community dwelling spouse will have more ambiguity and the system will not have closure.

To test for other emotions, interview questions asked if the community dwelling spouse is sad or blue, worried or concerned or angry (see Appendix A). To tap into the community dwelling spouse's feelings about this change in their life, the direction of the

interview started with how life was before placement and then it ended with how they see their future (see Appendix A). It is through this process that the community dwelling spouse may see a difference in how their life had been and how it has evolved. The types of data collected in this study were digital recordings of verbal interviews, and field notes. All of the recorded interviews were transcribed into written text and analyzed using Atlas.ti, which is a qualitative research software program.

Moustakas (1994, p 120-121) modified van Kaam's (1966) method of analysis into the following steps to analyze data. The first step for analyzing the data is horizontalization. Horizontalization is to list similar data based on shared experience. (Moustakas, 1994). The second step was to determine if the experience is pertinent. These derived experiences are called Invariant Constituents. A two-step requirement to keep that data is to determine if that experience is necessary to understand it and can it be labeled. If that experience cannot pass those two requirements, then it was eliminated.

The third step was to cluster the experiences into Themes. The fourth step was to compare the Invariant Constituents and Themes throughout the interview to determine if they validate what is either explicitly stated or insinuated. If neither, then that theme is eliminated. The fifth step was to develop an Individual Textual Description from the Invariant Constituents, themes, and verbatim descriptors from the interview. The Individual Textual Description is statements that summarize the Invariant Constituents, themes and verbatim descriptors. The sixth step was to develop an Individual Structural Experience based upon the Individual Textual Descriptions. The Individual Structural Experience is the vivid description through themes that evolve from the feelings and



thoughts of that experience (Copen, 1993). The seventh step was constructing Individual Structural Experience for each participant by implementing the first six steps. The last step was to develop a Composite Description by reducing down each participant Individual Structural Experience into grouped phenomena.

Upon completion of organizing and analyzing of data, the findings were integrated into the schema of the research question (Creswell, 2013), which is the emotional impact of the elderly spouse who has a loved one in a nursing home. In addition, the findings were compared with previous research listed in the literature review for consistency to previous research and possible social implications for future research (Moustakas, 1994). To validate each of the participants' individual textual descriptions and structural experience, the researcher had contacted the participant to offer to send a summary of their results and request for feedback.

### **Issues of Trustworthiness**

Guba and Lincoln (1981, 1989) replaced the quantitative terms validity and reliability in qualitative research as the concept of trustworthiness. Trustworthiness is made up of credibility, transferability, dependability, and conformability (Guba & Lincoln, 1981; Lincoln & Guba, 1982; Lincoln & Guba, 1985). Specific strategies have been developed to promote qualitative rigor. Some of these strategies are an audit trail, prolonged engagement, conformability, and negative cases (Guba & Lincoln, 1981; Lincoln & Guba, 1982; Lincoln & Guba, 1985). As a geriatric counselor for eight years, I witness daily the culture, norms, and social interaction of nursing homes which, in and of itself, is the prolonged engagement. But, the issue of conformability is the essence of

remaining neutral by identifying myself as a graduate student, being completely open to participants epoche and not motivated by my own biases or interest ( Lincoln & Guba, 1982). I was hyper-vigilant to negative case analysis in which I try to support a theme that is not within any of the participants' responses (Creswell, 2013).

The goal of rigor for quantitative research is internal validity, external validity, reliability, and objectivity while qualitative research is credibility, transferability, dependability, and conformability (Lincoln & Guba, 1985). In addition to qualitative, the researcher needs to be sensitive, easily adaptable, and able to clarify and summarize, and be responsive (Guba & Lincoln, 1981). Husserl (1970) defined objective reality as what is presented subjectively by another. In phenomenological approach, the use of subjective reflection is using a logical, systematic, and coherent analysis so as to a synthesis and arrive at essential descriptions of experience (Moustakas, 1994, p. 47).

To affirm this objective reality and establish reliability to the data, the criterion-based sampling method was used. For criterion-based sampling the participant is required to have experienced the phenomena that are to be studied (Creswell, 2011). Participants for this study were spouses that are at least 65 years-old, and who have a spouse residing in long-term care.

An initial phone inquiry was affirmed if the participant had met the inclusion criteria of experiencing the phenomena and setting the date and place for an interview. Participants were provided and reviewed an informed consent, a demographic questionnaire, and interview. The interview was open-ended questions as to the emotions experienced by a spouse who has a loved one in long-term care.

To affirm validity, the use of member checking was used in order to verify the creditability of the data analysis (Creswell, 2013). Member checking gives the participants an opportunity to review the data, analysis, interpretations, and conclusions of the study to determine if they are accurate (Creswell, 2013). Each participant was offered the opportunity to review the summary of his or her interview to validate for accuracy.

To continue with the rigor of qualitative research of trustworthiness, a detailed audit trail was maintained for verification of the data collected (Guba & Lincoln, 1981). The collection of data was documented and organized based upon the process of data analysis. The transcribed data was stored and made available upon request to other researchers.

Measures of transferability in qualitative methods are to establish an accurate description of a specific phenomenon by its sample selection (Creswell, 2013). In qualitative, there is no generalizing to the larger population as in quantitative research (Creswell, 2013), but an elaboration of the emotional experience that an elderly spouse may experience when having their loved one in long-term care.

Clarifying researcher bias at the beginning of the study is rudimentary to trustworthiness. The researcher must state any biases, prejudices, and orientations that could have shaped the interpretation of the study (Creswell, 2013). Depression and anxiety cannot be assumed. The participant needs to say it or at least state they are exhibiting symptoms for depression and anxiety, as listed in the DSM 5.

Lincoln and Guba (1985) identified six categories to audit records for confirmability. These categories are maintain and share data with an external auditor to review if the study was objective and could lead to similar results. The categories are as follows: (a) raw data (field notes, video and audio recordings), (b) notes and hypothesis to view how the data is reduced and analyzed, (c) an outline of the categories, (d) how the process of the study was done, (e) A field journal, and (f) any information from the pilot study or any surveys completed (Lincoln & Guba, 1985). This audit is usually not done until the end of the study.

### **Ethical Procedures**

Before any initial steps of contacting nursing home administrators began, Walden University's Institutional Review Board (IRB) gave approval for this study (#01-01-15-0139917). The IRB required an application by each researcher detailing the potential risks, benefits, and protection in detail, the informed consent, and that the participant may withdraw from the study at any time (Creswell, 2013).

Each nursing home administrator in Stark County, Ohio was contacted to obtain permission to recruit, distribute flyers, and utilize a private room. Flyers (please see Appendix B) asked for volunteers to participate in the research study was given to assigned nursing home staff. Nursing home staff was not be informed as to who volunteered for the study.

To maintain confidentiality of the participants, pseudo names were used in place of the real names. All data obtained through field notes, demographic inquiry, and informed consent forms were maintained in locked file boxes. The raw data and

transcribed data will be kept locked in file boxes for seven years, and then all data will be destroyed as mandated by American Psychological Association (APA, 2011).

Consideration of participants' well-being is of the utmost importance. The participant needs to feel emotionally heard and physically safe at all times. The interview allowed for breaks, privacy, comfort, and time for the participant to share their experience. If at any time the participant does not wish to participate in the study, he or she can do so at any time. They were informed of this right at the initial phone contact, and again at the interview.

Due to feelings that may arise as a result, of a being a part of this study, each participant was provided the phone number of the Crisis Center of Stark County (Please see Appendix E). In addition, the phone numbers of my chair and the IRB at Walden University were provided to assure participant of any additional support if needed (Please see Appendix E).

### **Summary**

Transcendental phenomenology (Creswell, 2013) was the research design that explored the phenomena of the elderly spouse and their emotional impact when a loved one is in a nursing home. This qualitative research began with an open view (the epoche), and then transformed the phenomena (experience) into a meaningful existence (Moustakas, 1994).

The participants were 10 elderly spouses that have been married at least 30 years, at least 65 years old, preferably reside alone in the home or apartment, and have a spouse that has to be institutionalized in long-term care due to either cognitive impairment or

physical decline. At least four or more childless couples would be included, equal representation of both sexes. The sample size was 10 with half representing each sex.

Before any arrangements for recruitment, Walden University's Institutional Review Board (IRB) gave approval for this study. Once permitted, a pilot study was instituted to determine if the interview questions tap into the research questions being explored.

After analysis of the data from the pilot study to assure validity of tapping into the construct wanting to explore, flyers were distributed to nursing homes within the surrounding Stark County, Ohio area. Volunteers were contacted first by phone to reassure participation and date and time of interview was set up with the participant. In-depth interviews explored the phenomena of each participant.

Strategies such as an audit trail, prolonged engagement, conformability, and negative cases were employed to achieve validity and reliability.(Guba & Lincoln, 1981; Lincoln & Guba, 1982; Lincoln & Guba, 1985). After capturing the person's phenomena, I analyzed the data into textural descriptions. These textural descriptions developed the meaning and essence of the phenomena, which is called the structural experience (Moustakas, 1994).

Chapter 4 will provide the results and themes of the participants' interviews, which are structured around the research question. Chapter 5 will discuss the results, the limitations of the study, what are implications for social change, and recommendations.

## **Chapter 4: Results**

The purpose of this study was to examine the emotional impact an elderly spouse may experience by having their loved one in long-term nursing care. Staff, family, and friends daily meet the resident spouse's physical and emotion needs, while the community-dwelling spouse watches the care given to their loved one. In this study, I explored what and how community-dwelling spouses feel, as well as how well they take care of themselves.

Seven interview questions were used to capture the essence of the community dwelling spouse's experience. The first two questions were used to determine what life was like for the couple before the spouse entered the nursing home. In the third question, I tried to gain insight into what and how the community spouse feels since his or her spouse is in the nursing home. The fourth and fifth questions were used to ascertain how the community spouse is managing without his or her spouse residing in the home. The sixth question was used to explore the emotional element of what they miss the most about their spouse while the last question explores if there is any hope or thought for their future. In this chapter, I will discuss the pilot study completed, the setting of the study, demographics of the participants, how the data were collected, how the result were analyzed, the evidence of trustworthiness, the results, and then the summary.

### **Pilot Study**

Two participants participated in the pilot study. They were community-dwelling spouses who had a spouse in the nursing home (differentiated henceforth as the

institutionalized spouse), but did not meet the criteria to join. Both participants were younger than 65-years-old and had not been married at least 30 years.

Upon review of the pilot study, it was seen that I needed to be specific as to the period of time regarding before spouse was placed into a nursing home and then the time after spouse was placed. The participants confused time before admission of the spouse to the time of placement. I would reiterate that this is before your spouse was admitted to the nursing home, and then reiterate if it was a question of placement.

### **Setting**

All of the interviews were completed at the respective nursing homes where the resident spouse resided. The participant may not have felt sufficiently relaxed due to being interviewed in a nursing home meeting room and being audio recorded. Having knowledge of being recorded can create anxiety in some individuals, as they may feel they need to be perfect in their speech. Because the flyers were distributed at the nursing home, some may have felt it was more of an obligation instead of a volunteer participation with no strings attached. Many of the nursing homes have a number of meetings for their families, and they may have felt this was another obligation that should be attended. In order to reduce this sense of obligation, I reiterated that it was a volunteer opportunity to each participant on the telephone and at the interview.

### **Demographics**

Ten participants met full criteria for being at least 65-years-old and married at least 30 years. There were two female participants in their second marriage, but each of their second marriages met the criteria of 30 years. There were five Caucasian men and



five Caucasian women. A demographic profile of the 10 participants is illustrated in Table 1.

*Table 1.*

*Demographics of Wives and Husbands*

| Sub #           | Age | Yrs married | Placement of Spouse | Reason for Placement     | Number of Children                      |
|-----------------|-----|-------------|---------------------|--------------------------|---|
| <i>Wives</i>    |     |             |                     |                          |   |
| 1               | 76  | 30          | 2013                | Parkinson's              | 4 (Spouse had 3 from previous marriage) |
| 2               | 67  | 43          | 2014                | Dementia                 | 2                                       |
| 3               | 70  | 49          | 2008                | Huntington's             | 4                                       |
| 4               | 74  | 44          | 2014                | Alzheimer's              | 2 (Spouse had 4 from previous marriage) |
| 5               | 71  | 55          | 2014                | Alzheimer's/ Blind       | 2                                       |
| <i>Husbands</i> |     |             |                     |                          |   |
| 1               | 85  | 83          | 2012                | Alzheimer's              | 2                                       |
| 2               | 74  | 74          | 2005                | Huntington's             | 3*                                      |
| 3               | 69  | 69          | 2008                | Global Stroke            | 1*                                      |
| 4               | 74  | 74          | 2014                | Congestive Heart Failure | 1*                                      |
| 5               | 72  | 72          | 2014                | Alzheimer's              | 2*                                      |

*Note.* \*Children that reside out of state or in distant cities

As shown in Table 1, wives' ages ranged from 65-76 ( $M = 70.5$  yrs.). Husbands' ages ranged from 69-85 ( $M = 74.8$  yrs.). For the greatest number of years married, for wives it was 55 years, while for husbands it was 62 years. All of the husbands were married only once and had one to three children who reside out of the state or not locally.

Three of the wives had stepchildren, as this was their second marriage. Three of the wives had four biological children, and three had two biological children. Four of the spouses were institutionalized due to alzheimer's, two due to huntington's, one due to dementia, one to global stroke, one due to parkinson's, and one due to congestive heart failure. Even though there was a diverse representation of diseases, all of the resident spouses, except one, were cognitively impaired. For wives, three of their husbands were placed in the nursing home in 2014, one in 2013, and one in 2008; for the husbands, one had placed his wife in the nursing home in 2005, one in 2008, and one in 2012 and two in 2014. All of the spouses of the wife participants had cognitive and speech impairments. One was on hospice, and one was blind. Four of the five spouses of the husband participants had cognitive and speech impairment. Only one of the spouses had a husband who was able to speak fluently.

All of the wives and husbands lived alone and had adult children. All of the wives had children in the surrounding area who were a daily support to them. Four of the husbands had children who resided out of state or in distant cities that were of limited support due to location. The wives were more likely to have daily interaction with their children than the husbands.

### **Data Collection**

There were a total of 10 participants who consented to participate in the research study, five men and five women. A flier had been distributed in four nursing homes that are located in Northeast Ohio. The participants were to complete an index card attached

to the flyer with their name and phone number. I contacted each over the phone and arranged a time and location at the nursing home for the interviews. .

I met with each participant in a private room for approximately 1 hour. I have been a counselor for 20 years and have been counseling in nursing homes for 5 years. I am comfortable with working with this population; and being the interviewer, my comfort level and awareness of how to interview this age group would have affected the participant's responses. Many of the participants shared much deeper stories and expressed sadness through crying that may have not occurred if I was not a counselor by trade.

The consent form was reviewed with each participant and signed. To assure confidentiality, any direct quotations were identified by gender and corresponding number as listed in Table 1 (For example, wife [1], husband [2])

The permission to audio tape was reviewed with the participant. Once the consent for audio taping was obtained, I turned the audio tape on to begin the interview. Each of the research questions were asked in the order arranged. There was no deviation from the data collection, as detailed in Chapter 3, except for additional emphasis on before placement of spouse and then upon placement of the spouse as it had confused the pilot study participants. I reminded the participant that the time of interest was 2 years prior to placement or the time is now after placement.

There were no unusual circumstances encountered in the data collection. Each participant attended alone and had no difficulty with remote or long-term memory. Each interview was identified as the audio file number to that interview.

### **Data Analysis**

The interview questions were arranged to ask the same questions, but at different points in time. The interview questions began with asking the participant how his or her life was prior to the spouse being placed in long-term care, and then the same questions were asked in regards to once his or her spouse was placed in care. Similarities emerged between the two periods of time and across all of the participants.

Through structural coding, the data were reduced to five themes. The first theme, reduction in friends, evolved from the amount of time spent on friends and social aspect of their lives. Most wives and husbands had already reduced their socializing with friends and hobbies before their spouse had been placed. The codes for this theme were how often friends were seen: every 2 weeks maybe, at church, no friends, work acquaintances. For example, Wife (3) stated, "I would see them for church and special occasions, but we didn't go back and forth to visit." Wife (5) said, "I don't really have friends. I have acquaintances. Work is where I have friends

The second theme, "Ease or Difficulty in Change," evolved from questions as to whether they reported being sad, anxious, and who was doing what household task before admission of the spouse. All the husbands reported feeling sad while four of the wives reported feeling sad. In contrast, for anxiety, three husbands and three wives reported anxiety. For household duties, the wives were doing it all. They were cooking, cleaning, and paying the bills prior to their spouse getting sick, so it was not that big of a change after placement. The codes that captured this as: who cooked, cleaned, and paid bills prior, eating habits, sleeping arrangements, day to day activities. Some examples of these

types of comments include the following. Wife (4) stated "I use to cook and clean. I didn't have to work until 2002. After he had retired, he stepped in. Up until he got sick, he did the wash." Wife (5): "The only thing he did was getting on the lawn mower and mowed. I did all the maintenance on the house, the trim, and painting. He never helped me do anything."

The third theme, "Companionship," evolved from the narrowing of friends to just activities with their spouse and the word itself. Nine out of 10 of the participants said that companionship is what they miss the most of his or her spouse not being home. Some relevant examples include: prior to admission five of the spouses did not do any activities separately, but together. Wife (3): "We did everything together" Husband (3) stated "I like fishing, and she would go fishing with me. She would take her book and read while I fished. We were homebodies and were always together."

The fourth theme, "Vows are forever," came from two husbands that said they committed to their wives through sickness and health, and showed it by the actions of their daily visits. Husband (2) stated "I feel it is pay back. She helped me all those years. I feel I owe it to her, but it is a different situation." Husband (1) stated "I know it is for better or worse. This is for the better for her, and I have to put up with the worse." Every one of these spouses visits their spouses daily.

The fifth theme, "Why," evolved from the question regarding anger. Six of the 10 asked, "why us," "why did this happen to us." Husband (2): "Why does all the bad stuff happen to good people? She was a better person than I. She was so kind to people and good for the church." Wife (3) stated:

I was angry in the beginning when he was diagnosed because I thought why in the world we would get hit with this? There are so many people who don't care, don't go to church, don't have a family, just running around not making anything with their life, and we are trying to be honest, and work, save and we get thrown into this?

### **Evidence of Trustworthiness**

#### **Credibility**

Credibility is to ensure the internal validity of the research. To affirm credibility, the use of member checking with each of the participants was offered to verify their experience. Seven of the participants met with the researcher to verify their experience while three of the participants did by phone. No changes resulted from these contacts. To promote honesty, the participant was provided the chance to discontinue at any time of the interview. This will insure that the data collected was from participants who genuinely wish to be a part of the study (Guba, 1987). In addition, I reviewed that their information will be kept anonymous and confidential. I emphasized my position was a student researcher and explained general steps to how the research is designed and the process of completing the research.

#### **Transferability**

Transferability deals with external validity. Lincoln and Guba (1985) described transferability as the study's ability to be generalized. A number of steps are advocated by Teague, Teague, & Marchionini (1987) in increasing transferability in qualitative studies. The steps are: what are the criteria to participate, the number of participants, type

of data collection, the number and length of data collection, and how long it took to gather all the information.

To promote transferability, the sample was drawn from criterion based sampling at five different nursing homes located throughout Northeast Ohio. The criteria to participate were a community-dwelling spouse that is at least 65-years old and had been married at least 30 years. The institutionalized spouse must be long-term. The sample was to be at least 10 participants with an equal ratio of female to males.

Since qualitative research is not able to generalize to the larger population (Creswell, 2013), an elaboration of the emotional experience is described by these 10 participants. This is referred to as thick description (Lincoln & Guba, 1985). Each participant was interviewed for one hour, but when a participant wished to share deeper information the time was extended with their permission. Each participant was asked the same interview questions, but given the time to fully express themselves. All interviews were set up and completed in three weeks.

### **Dependability**

Dependability deals with reliability. To promote this study reliability, steps are described in detail so, if repeated in the same context, method and type of participants, then the results should be similar (Teague, Teague, & Marchionini, 1987).

In the present phenomenological study, community-dwelling spouses were recruited that were at least 65-years old and married at least 30 years. Their spouse needed to be in long-term nursing care. Each participant was interviewed for one hour at

a location of their choosing, the consent form was reviewed and signed, and each of the interview questions were asked in the order established.

### **Confirmability**

Confirmability deals with objectivity. To promote that I was objective and without bias, any biases, prejudices, and orientations that could have shaped the interpretation will be reported (Creswell, 2013). The primary use of the audit trail was used to remain without bias. A strategic method of analysis and coding of the data to derive at themes was based upon two tables. Each table had all the research questions and responses. Codes were categorized. Themes and patterns emerged from the responses. A field journal was utilized to document any pertinent information or how the interview appeared to ebb and flow.

### **Results**

The seven research questions are as follows: (1) Tell me about what your life was like for the last two years before your spouse entered the nursing home? (2) Tell me about your relationship with your spouse at this earlier time? (3) Tell me about what your life since your spouse entered the nursing home? (4) Tell me about your relationship with your spouse? (5) How do you travel to the nursing home? How do you feel when you can't go to visit? (6). what do you miss the most about your spouse not being at home? (7) What do you see for your future as a couple? For yourself?

Five themes evolved from the seven research questions. Many of the responses were very similar for both sexes; however there were differences between them. The five



themes are: Reduction of Friends, Ease or Difficulty with Change, Companionship, Vows are forever and Why? Each theme will be explained further.

### **Theme 1: Reduction of Friends**

Eight of the 10 spouses had already reduced their friends prior to their spouse being placed. Once they were placed, the reduction in socializing with friends reduced even more. Husband (2) had been very social with friends, but once his wife declined even more with cognitive ability and speech friends quit visiting her at the nursing home. He stated "Our friends now say that they can't understand her and that they don't want to bother. It sure has changed the relationship with friends." Husband (2) eloquently summed up how the changes in his social life with this statement "a social worker at Ohio State said that your social life involves the nursing facility, and that is true. We go to the nursing home Christmas party and things here. That is my life right now is here."

Friends were reduced to seeing them while doing an activity with a spouse. Wife (1) stated "We didn't have friends outside of the family, and we would see them somewhat." "We didn't socialize much. If we went anywhere, it was shopping or going out to eat."

One wife had to continue to work due to her spouse's placement. Her friendships come only through work. Wife (5) stated "I don't have friends. I have acquaintances. Work is where I have friends."

Many, due to the spouse residing in a nursing home do not have the time for friends and church. Wife (4) remarked on seeing friends now "No, I don't. Mainly

between time here and doing things at home, I don't have the time." Also "We use to attend church. Now, I don't as I come up here on Sundays."

Another wife did not have friends due to her spouse's illness. Her husband became very paranoid and did not want anyone to visit. Wife (2) stated "I didn't see them a lot as he didn't want them around." Husband (5) reported "Friends don't come as often. Some have moved away. I still see people. I see them at the gym. That is my outlet. That is my family."

Four of the spouses have friends at church that they socialize with on Sundays. Husband (4) continues to attend church and prior to his wife's placement he stated "We used to go to Church every week until last fall when she became incontinent."

Five of the spouses increased their interaction with their children since their spouse is in placement. Wife (5) had a bad marriage but stated that her sons are visiting her more often, but for the father "They don't visit. They never got along. He wasn't father material. My youngest refuses to come, and my oldest son have visited one time, but they help me."

Four of the male spouses had children, but they reside either out of town or out of state that provide very little support for them on a day to day basis. One husband had said that the disease had affected the whole family. His daughter was suffering from her health issues. Husband (2) stated "They always remember their Mom as healthy. We are thankful that she was able to take care of them when they were still young."

The children that reside out of town do not visit as frequently. One husband feels it bothers them to see their mother this way. He stated "that the kids were here Christmas

week, and Carol\* was so happy to see Mom, but then she broke down crying in the car.

Paul\* doesn't cry, but still loves his Mom." (\*pseudonyms)

In summary of Theme 1, it appears that couples reduce their friendships even prior to their loved one being in placement. Most of the spouses interviewed enjoyed just spending time together instead of spending time with friends jointly or separately. One wife remained very involved with her church friends, and one husband continued to attend his weekly Sunday services.

The wives were more involved with their children daily and weekly compared to the husbands. The husbands had children, but their children did not reside local as the wives children.

## **Theme 2: Ease or Difficulty in Change**

Nine of the spouses stated they are sad. All five of the husbands reported sadness, but two of the wives did not. The two husbands that have had their wives in placement the longest still have days of sorrow. Husband (3) stated he gets sad and lonely in the evenings after he returns home. He stated that

Sometimes she cries when I am leaving to go home, and it hurts. My daughter will say, "You know, Mom will do that because she has you wrapped around her finger." I said I know that, but it still hurts. My family has tried to stop me from coming every day, but I have to. I can't imagine when something will happen

Husband (2) who has had his wife in placement since 2007 feels that he has already lost her. He stated "I certainly miss pulling in the garage, and she was at home to greet me. That doesn't happen now, or I would be driving and she was sitting next to me."

Husband (2) has had his spouse in placement the longest and stated this in regards to having it being so long "People ask me how I deal with it, and I tell them it is part of my life now. I don't know anything differently. I just do it."

Husband (5) stated:

I feel fine until I have to clean things out. There are times I look around the house and get feelings. Like yesterday, I looked down at her snow boots and "ah" she will never get to wear those again. Those things bother me.

Wife (2) stated: "I don't sleep very well without him there." She feels guilty if she cannot visit daily and says the reason is "because he is here, and I am not (cries). I just don't feel right. I feel I should be here at all times."

Two wives did not report sadness, but Wife (5) cried throughout the interview. Wife (5) had a very difficult marriage and had more worries about surviving herself. She has always had to work and contend with all the bills. She has more anger at him and stated "Look what you are doing to me now. All this money goes here. I am responsible, and I don't think it is fair. I had to spend down so much money. I had to spend down some insurance policies."

All the wives had cooked and cleaned during their marriage. Two of the wives did not pay the bills while the rest of the women did. For the husbands, all their wives had cooked and cleaned. Two of the husbands had been paying the bills while three of them their wives had been taking care of the bills.

Being the wives had always taken care of cooking and cleaning, they did not have a big change when their spouse had gone into long-term care. Some of the wives were

more interactive with their grown children and had dinners with them. Wife (3) stated "I eat very well. My daughter invites me over a lot. I do make meat, potatoes, and vegetables. I just make the quantity smaller." Wife (4) stated "One day last week my daughter sent me some spaghetti. A lot of times my daughter sends me stuff to eat."

Wife (5) makes full dinners but invites her children over to eat. She stated "I eat well. I made beef and noodles today. My son is coming up so I will make a cake too. I don't cook large portions. I will make a sweet potato and chicken sandwich."

The one wife who did cook and cleaned, but did not take care of the bills and outside work struggles the most with taking care of important decisions. Wife (2) stated:

Like today, I made a big mistake of telling him the battery went dead in the car, but I needed him to tell me what to do. He just looked at me and asked me why did you ask me that? I told him that I know you would know what I should do or need to go.

She has learned to go to the previous repair people that her spouse had utilized and ask what type of battery her husband put in their cars. She never had to make important decisions and feels very lost. She recently had to purchase a newer car and stated "it is a 2009 car, and I hated buying this car, because I never had to make those decisions. Pete\* made those decisions."(\*pseudonym)

Even though only two institutionalized spouses could speak, four of the spouses will talk to their spouse about a decision they need to make. Wife (3) stated that when she was thinking about buying furniture she would talk to her husband. It was mostly

informing the husband as Wife (3) said “I would tell him about it. I just talked to him about getting a couch for the basement, and I said I am looking for a couch.”

The seven other spouses did not discuss important decisions as they felt it would get their spouse upset, or they would not understand it. One spouse who had a verbally responsive spouse did not discuss any important decisions with his wife even prior to placement as she would get angry with him.

The husbands did not adjust to this transition as smoothly as the wives did. In regards to eating, Husband (2) stated: “I am doing better than I use to. I get by. I made sloppy joes last night. I know processed isn't good, but I make the Stouffer's frozen dinners.” Two of the Husbands eat at the nursing home with their wives. Husband (3) stated:

I eat lunch here with her. For supper, I use the George Forman. I get hamburgers, pork chops, and chicken. I have it packaged for one meal. Thaw it out and throw it on the George Forman. Have some coffee. Not vegetables.

Husband (1) eats both lunch and dinner at the nursing home. He stated that for breakfast he gets it himself and makes oatmeal. He says he learned how to make from the directions on the box.

Husband (5) does better with his eating. He fixes his breakfast of egg beaters, cheese, and wheat toast. He stated that he usually eats lunch at the nursing home. For dinners, he makes his dinners or buys meals at the nursing home to take home and freeze. His friends invite him over twice a week for dinner. He will get Chinese food or Pizza and have lunch and dinner for the week. He reported cooking more than the other

husbands. He stated, "I make soups and chili in the crockpot. I use Spicy V8 juice instead of water."

Husband (4) has Meals on Wheels that delivery lunch and dinner for him. He stated that he did cook, as he had to start cooking two years prior to his spouse coming into the nursing home.

In summary of Theme 2, sadness was expressed by both wives and husband participants. Time did not appear to reduce this emotion. Husband (2)'s wife has been institutionalized since 2005, and he expressed a great deal of sadness and loneliness.

The wives that did more of the upkeep of the home and the bill paying fared better than wives who did not and the husbands. Wives were used to cooking meals so they just reduced the amount while the husband would eat frozen entrees, meals on wheels, or at the nursing home.

### **Theme 3: Companionship**

Eight of the 10 spouses stated that companionship is what they miss the most. Husband (1) says what he misses the most about his spouse not being at home is "The conversation. She did a lot of puzzles and a lot of reading. I did a lot of reading, and we would have a lot of conversations."

Nine of the spouses stated the word "Companionship". Husband (5) indicated that what he misses most about his spouse not being at home is

Companionship. We have always been together. We have never been apart. We got married before the service, and then I went to dental school. We went to Ohio

State for four years. When I went away to the service for two weeks, she stayed with her mom. We were always together.

Wife (2) stated "The companionship and being side by side. We would drink our morning coffee together in the front of the garage. The last time he came home to visit he didn't want to."

Wife (1) also misses having the spouse around for companionship. She stated, "Having someone there, having someone to watch TV with. Now, I do it by myself."

Wife (3) also enjoyed more low-keyed activities and missed those times together. She indicated that she missed "Companionship. Sitting there and watching TV, playing cards."

Husband (2) reported that what he misses the most is

Being able to talk, share, and the company: both of us discussing decisions jointly. Eating by myself is not as much fun as having a conversation with someone. We would always go into the family room and talk. We would split a bottle of beer and recap the day.

The wife and husband that were in verbally abusive marriages also illustrated missing the companionship of a spouse. Wife (5) did indicate that she missed not having her spouse at home as "we always had a glass of wine at dinner. We didn't talk very much. He and I never had anything in common." The husband who had an emotionally abusive marriage stated he misses "The companionship. Just having her there."



All of the spouses that had participated visit their spouses daily. Most come in the morning and then in the afternoon, but one husband spends the whole day with his wife. Husband (1) eats lunch and dinner with his spouse, leaves shortly after that.

If a spouse is unable to visit their loved one, most felt ok knowing that they can call the nursing home to check on their spouse. Wife (5) felt relief when she cannot make it up to visit due to illness or weather. Wife (2) stated she feels guilty when she is unable to visit. She stated "because he is here, and I am not (cries). I just don't feel right. I feel I should be here at all times." The spouses that have spouses that can verbally interact can call them on the phone.

In summary of Theme 3, all of the spouses expressed the word companionship or they shared things that they did together with their spouse as what they missed the most of not having their spouse at home. Even if a marriage is not a happy one, just having that spouse at home helped alleviate the sadness expressed by the two participants who had abusive relationships.

#### **Theme 4: Vows Are Forever**

Through sickness and health are taken very literally for each of these participants. Two of the spouses even repeated that is what the marriage vows state. "It is my duty for better or for worse. This is for the better for her, and I have to put up with the worse" (Husband (1)).

The wife (5) who had a verbally abusive marriage said why she visits daily was "To make sure he is taken care of. When he was moved back there, he was ignored. I came up, and he was all wet and cold from not being changed, and I don't want this to

happen. I will come in the morning and check on him. I have feelings for him, and I don't want him mistreated. I don't love him like I should....We were married, but it wasn't a good marriage. Everyone thinks he is a good guy here, but they didn't live with him. He wasn't a nice person.

Husband (2) stated "It was a shock when I had to take over. I feel it is a payback. She helped me all those years. I feel I owe her, but it is a different situation." In spite of his wife being cognitively and speech impaired, his love for her remains. He stated "I feel like I lost her, but I still enjoy seeing her. I guess that bond is there. Others would have gotten a divorce and remarried. I have never given that a thought."

In summary of Theme 4, all of these participants visited their loved ones daily, and many of them were active in their spouse's care. Husband (2) would arrive to help feed his wife. Wife (5) visited before work and after work. Each of them are committed to their spouses and had explicitly stated the words "until death do we part."

### **Theme 5: Why?**

When asked if they have days when they felt angry, six of the 10 spouses responded with "Why us?" "Why did it have to happen to us?" Husband (2) felt "Why does all the bad stuff happen to good people? She was a better person than I. She was so kind to people and good for the church." Wife (3) stated

I was angry in the beginning when he was diagnosed because I thought why in the world we would get hit with this? There are so many people who don't care, don't go to church, don't have a family, just running around not making anything with

their life, and we are trying to be honest, and work, save and we get thrown into this?

Two of the husbands felt that faith has helped them through discouragement.

Husband (4) stated "I often wondered why this has happened to her, but on the other hand I think the good Lord has been with us both and has helped us through these situations."

Husband (5) stated "I have never felt angry about why me. I have too much faith. I pray for myself and her. I have lived a charmed life. God won't give me anything I can't handle."

When considering the future, responses ranged from no change to bleak or nonexistent. Wife (3) felt that her spouses will remain at the nursing home until he passes, and she would continue to visit. She states that she would be fine, but she would miss seeing the staff and residents she has seen all these years. She watches her grandchildren twice a week now, and felt she would start a new hobby to pass the time when the time comes.

One husband did not express a future without his wife, but then it evolved into isolation. He stated

Well, I guess, do the best I can to help her. Keep things going for her at home. I am the main person at home. My parents are gone, and her parents are gone. I came back to her hometown so she could be near her parents, and now I am the only one left.

Wife (2) also did not want to consider a future without her spouse. When asked about her future she responded: "This...this. I don't look ahead. No one knows what the

future will be. If that is what it is, then that is what it is." Another wife also stated "I just take it day-by-day. I don't plan anything."

Husband (1) hoped to live until he was 100 years old. He wanted to outlive her.

Husband (2) stated:

I don't care about the future. I just want to live one day longer than \*Cathy lives.

That is my prayer. I hope I am here long enough to take care of her. We had a wonderful marriage. She still the person that I fell in love with (\*pseudonym)

Husband (3) also expressed a bleak future. When asked how saw his future, he stated "Taking care of her until her last day. I will be a complete loss without her. I feel I will probably be here. I can't imagine it without her." Wife (5) also had a very bleak future as she stated:

Not very good. If I sell my house, they will take the money, and that is not fair. I have a lot of stress on myself. I was always good with money, and I wanted to make sure I never had bill collectors come after me.

In summary of Theme 5, the word anger conjured up the word "why." Why did this have to happen to us or to her or him? The participants struggled with why did this have to happen to us, and now that it has, it is too difficult to think of my future. Again, the wives fared better than the men. The husbands were more dependent on their wives for cooking and cleaning. The wife participants continued to live their lives the same after placement except now they reduce the quantity of their food, visit their spouse daily, and have more interaction and support from their children.

## Summary

The research showed five themes that had evolved from the seven research questions. The five themes are as follows: Reduction of Friends, Ease or Difficulty with Change, Companionship, Vows are forever and Why?

The first theme "Reduction in Friends" evolved from the amount of time spent with friends and the social aspect of their lives. Most wives and husbands had already reduced their socializing with friends and hobbies before their spouse had been placed. Three of 10 spouses continued attending church and seeing their friends from the church, but most of them quit attending church so as to visit their spouse at the nursing home.

The second theme "Ease or Difficulty in Change" evolved from questions if they reported being sad, anxious, and who was doing what household task before admission of the spouse. All the husbands reported feeling sad while four of the wives reported feeling sad. For anxiety, three husbands, and three wives reported anxiety. For household duties, the wives were doing it all. They were cooking, cleaning, and paying the bills prior to their spouse getting sick, so it was not that big of a change after placement.

The third theme "Companionship" evolved from the narrowing of friends to just activities with their spouse and the word itself. Nine out of the 10 participants said that companionship is what they miss the most of their spouse not being home. Prior to admission five of the spouses did not do any activities separately, but together.

The fourth theme "Vows are forever" came from two husbands that said through sickness and health, and by the actions of their daily visits. In spite of two marriages being verbally abusive, the spouse would visit daily to make sure their spouse would be

taken care of by the staff. All of these spouses visit daily, and only one Husband and one Wife had a spouse that could verbally interact with him.

The fifth theme "Why" evolved from the question of feeling anger. Six of the 10 participants answered "why us," "why did this happen to us." Three of the participants have a strong religious faith and do not question their situation.

Chapter 5 will discuss the interpretation of the results. The findings will be compared to previous published research, how the theoretical framework applies to the results, and the limitations of the research, recommendations that could be further studied, and how this research could provide social change to those that have a loved one in long-term nursing care.

## Chapter 5: Discussion

Researchers have linked depression with themes of loneliness (Kaplan & Ade-Ridder, 1991) and loss of companionship (Gladstone, 1995; Hennings, Froggatt, & Payne, 2013; Kaplan & Ade-Ridder, 1991; Sury, Burns, & Brodaty, 2013). Authors have examined depression through variables that tap into the emotions, which includes boundary ambiguity (the spouse's perception of his or her spouse in care was in or out of the marriage) and mastery (does the spouse feel in control of his or her life or views it as fatalistic; Kaplan & Boss, 1999). However, scholars have not examined questions that directly ask if the spouse is feeling depressed, anxious, angry, or happy and if so, what makes them feel that emotion. In this qualitative study, I explored these emotions by asking 10 community-dwelling spouses if they felt sad, anxious, and angry and why they felt that emotion. To determine if the community-dwelling spouse felt boundary ambiguity and mastery, they were asked how they foresee their future. In order to compare the time before placement to after placement, the question if friends and family were interactive with the community-dwelling spouse and their spouse was asked.

Nine of the participants had already reduced interaction with friends prior to placement because they enjoyed spending their time with their spouse. The three participants who reported having friends prior to placement had changes after placement. Husband (2) stated that friends started to withdraw because they could not understand his wife or they did not want to intrude, but Husband (5) stated that his friends remained the same as he continued to attend church weekly. All of the wives reported an increase in interaction with their children and grandchildren after placement, and Wife (2) stated that

she babysat her grandchildren 3 days a week and talked to her daughter on the phone daily. Wife (4) stated that she also spoke daily on the phone with her daughter. In addition, her grandson would mow her lawn weekly or shovel snow during the winter.

I found that all five of the husbands and four of the wives in the study reported being sad. Those who felt sadness contributed it to feeling lonely and the loss of companionship. Simple things such as having coffee together in the morning was missed, knowing that person was waiting at home for their arrival, or having someone watch television with them was missed.

Three of the husbands and three wives reported feeling anxious. The reason for the anxiety was contributed to concern over their loved one in the nursing home. Nine of the participants' spouses had difficulty in verbally expressing their needs; so, the community-dwelling spouse would inquire nursing home staff for particular care or reasons for absence of care. Husband (3) was informed that his wife had a broken arm, but the nursing staff did not know what happened. Wife (5) found her husband cold and wet in his bed due to neglect. Three of the husbands feared the loss of their spouse through death, even though they have not had a conversation with their spouse for at least 2 years.

When participants were asked if they felt angry and what made them feel this way, six of the 10 participants expressed "Why us?" "Why did it happen to us?" Nine of the participants indicated that they have difficulty seeing the future beyond what it is today. Husband (5) did not want to think about his future. He just hoped he would live 1 day longer than his spouse. Husband (1) wanted to live until he was 100-years-old. He is



presently 85-years-old. Many of the participants just saw their life as it is now visiting daily with their spouses. Husband (3) could not imagine life without his spouse.

Spouses reported that they reduced their friendships even prior to their loved-one being placed in long-term care; therefore, when they are placed, the friendships are limited or friends are seen only at church functions. The wives tended to have more social support by their children and/or grandchildren through daily telephone conversations, invitations to dinner, and help around homes. All but one husband had children located in distant cities or states, which provided them with little support on a day-to-day basis.

Most of the wives did the cooking, cleaning, and paying the bills while the husbands managed the bills, but not the cooking and cleaning. The wives continued to cook as they always did, but in smaller portions while the husbands resorted to frozen entrees, the nursing homes, meals on wheels, or restaurant food being bought as a meal for 2 nights.

### **Interpretation of the Findings**

The quality of marriage generally declines when a spouse cognitively declines (Berg et al., 2011) and is institutionalized (Kaplan & Ade-Ridder, 1991; Sury et al., 2013). In the Kaplan and Ade-Ridder (1991) study, participants indicated that since the resident spouse was cognitively impaired, he or she would not be able to understand the conversation; also the resident spouse did not want to upset him or her.

In the current study, nine of the 10 participants' spouses were cognitively and speech impaired. Similar to Kaplan and Ade-Ridder's (1991) finding, I found that seven of the 10 participants did not share important decisions with their spouses as they did not

want to confuse them or upset them. Three wives in this study did talk about important decisions with their spouses. Some examples included the following: Wife (2) needed a solution, but Wife (3) just wanted to let her spouse know that she was going to purchase a couch.

Previous researchers have suggested that the support of friends declined because the community-dwelling spouse was spending more time at the nursing home (Kaplan & Ade-Ridder, 1991; Sury et al., 2013) and the support from children increased. I also found that support from friends declined, but not because the community-dwelling spouse was spending more time at the nursing home. Instead, the current participants reported that the decline in friendship occurred prior to placement: eight of the 10 spouses had already reduced their friends prior to their loved one being placed. A spouse had friends as a couple prior to his wife's placement, but these friends quit visiting and calling the couple. Friends gave excuses as to why they did not visit anymore, such as they cannot understand the resident spouse or they did not want to bother the resident spouse by visiting.

These findings are supported by prior scholars (Braithwaite, 2002; Dye, 1982; Kaplan & Ade Ridder, 1991; Sidell, 2000; Sury et al., 2013) who showed that community-dwelling spouses have weaker social support by the time their loved one enters the nursing home due to the time and energy needed to care for the spouse at home. I found that prior to the placement of the spouse, the married couples enjoyed spending their time primarily together, which is the reported reason there was a reduction in social supports. In addition, prior to placement, only Wife (5) did activities separately

from her spouse while the other five wives only did activities with their spouses. Three out of the five husbands did activities separately from their spouses. The reasoning for both spouses not doing anything separately from their spouse was because they enjoyed doing things together and not separately.

Having someone around and experiencing day-to-day life tasks with them is missed by all spouses who have their loved ones living in a nursing home. Gladstone (1995) found that a loss of companionship was the biggest loss felt by community dwelling spouses who had their loved ones in nursing homes and diagnosed with dementia (Førsund et al., 2015; Sury et al., 2013). I confirmed that companionship was what the community-dwelling spouse reported most missing about having their spouse in long-term nursing care was just having someone there to talk to or with whom to share ideas.

Spouses who visited daily started to have physical exhaustion, a decrease in energy, and appetite (Bartlett, 1994; Lieberman & Fisher, 2001; Novak & Guest, 1992; Sidell, 2000). In the present study, each of the participants felt that they took good care of themselves, had no trouble sleeping, and did eat. One wife who worked expressed feelings of exhaustion in visiting daily and working. All of the wives cooked well-balanced meals while one husband cooked. The other husbands ate frozen entrees, at the nursing home, or had meals on wheels.

Depression is felt by the community dwelling spouse that places their spouse in a nursing home.. Bartlett (1994) found that 14 of the 24 wives who had their spouses in a nursing home had reported depression on the CES-D Depression scale. Bond et al. (2003)

found that after placement, community-dwelling spouses may experience a second wave of grief. The first wave of grief was from the loss of their spouse with dementia and then the second wave was upon placement into a nursing home. In this study, participants also expressed depression, as 90% of the participants stated that they were sad and depressed. The research questions to assess depression were symptoms from the DSM 5. Each symptom was asked to each participant. To fulfill the diagnosis of clinical depression, the symptoms cannot be a response due to a significant loss such as bereavement (American Psychiatric Association, 2013). Bereavement is considered death so the symptoms listed in DSM 5 can be considered as clinical depression. Because for the participants, it has been at least 10 months since their spouse's placement, the diagnosis of adjustment disorder with mixed emotions would not be considered. In adjustment disorder, the symptoms must be present up to 6 months after the identifying precipitator. After 6 months, another diagnosis such as major depression or anxiety disorder needs to be considered (American Psychiatric Association, 2013).

For the diagnosis of major depressive disorder, the individual must have five of the nine symptoms in a 2-week period. The symptoms that were reported by the participants were feelings of depressed mood most of the day, diminished interest or pleasure in all, or almost all activities most of the day, a decrease or increase in appetite, fatigue nearly every day, feelings of worthlessness or excessive or inappropriate guilt, diminished ability to think or concentrate (American Psychiatric Association, 2013). Nine of the 10 participants would fulfill a diagnosis of clinical depression such as major depressive disorder.

All five of the husbands reported sadness, but two of the wives did not. The two husbands that have had their wives in placement the longest still have days of sadness and appear to exhibit all the symptoms for depression. Three of the men appear to meet the criteria for Persistent Depressive Disorder as they meet the criteria of having these symptoms for two years (American Psychiatric Association, 2013). Three wives reported feeling sad and depressed. These three wives appear to meet the criteria for major depressive disorder, but not for persistent depressive disorder due to the criteria of two years. Bartlett (1994) also confirmed that 14 of her 24 participants scored within the range for depression. Bartlett was the only study to use an instrument to capture depression with wives who had recently placed their spouse in a nursing home. Bartlett's study included wives that were also institutionalized. The present study confirmed that wives and husbands both exhibit symptoms of depression 10 months and longer from placement.

Nine of the participants do not have reciprocal interaction with their spouses especially since their spouses have cognitive impairment.

Caregiving wives, who were less emotionally invested to their spouses, felt less depression and burden (Capistran et al., 2014; Pruchno & Resch, 1989) In the current study, a wife and a husband who were in verbally abusive marriages both expressed depression. The wife expressed more burdens due to finances and loss of her house and assets while the husband did not have those financial worries.

Carr (2004) found that men are more dependent upon their wives as reflected in emotional support, housekeeping, and promoting healthy habits. The present study,

showed that men are more dependent upon their wives in cooking, and cleaning; but three of the husbands had been paying the bills. Wives were more independent and had cooked, cleaned, and paid the bills except one wife. This wife was also having more difficulties with adjusting to her spouse's placement as he made all the decisions and paid the bills. This finding was consistent with Parkes and Weiss (1983) that those individual who were more dependent in their relationship with their deceased spouse experienced more pathological grief reaction.

Alpass and Neville (2003) found that loneliness was related to depression, but not to social supports. They felt the older adult had social supports even though it was very limited. In the current study, being lonely and depressed was confirmed due to lack of social support. All the husbands expressed being depressed, feeling lonely, and had few friends and limited family support. Only one husband had a son that resided only two hours away, but he does not see him much due to the distance. The other husbands had children that live farther out of state or cities. Two husbands reported interaction with his fellow church congregation on Sundays. The wives indicated more family involvement, but limited social support from friends.

Whitlatch et al. (2001) stated that the biggest strain in coping for the community dwelling spouse is when they are visiting their loved one who may have a memory deficit and are having behavior problems. If the spouse experiences a negative visit due to the impairments, depression is highly associated after placement (Majerovitz, 2007; Whitlatch et al., 2001). The current study confirms that one of the husbands reported feeling sad when his spouse was not having a good day; but both a wife and a husband

reported feeling more anxious when their loved one was having a bad day. Husband (4) was worried that his spouse had broken her arm while being in care and no one knew why it had happened. Wife (2) reported worrying about her spouse when he was having a bad day. Since he cannot verbalize his needs, he exhibits behavior problems such as hitting, throwing items, and yelling.

Kaplan et al. (1996, 2001) delineated three categories of couplehood for wives in their spouses in a nursing home. The first category is No Couplehood. No Couplehood means that the wife was married, but felt single (Kaplan, 2001). In No Couplehood, the spouse feels that there is no marriage; even though they are legally married they question why they remain married. The second category is Low Couplehood. Low Couplehood means the wife felt married, but that she did not have a husband. These women feel a sense of couplehood, but do not have a husband that lives with them. The highest feeling of being married is called High Couplehood, this means that the wife was married, and felt continued couplehood. They felt no matter how their husbands' health impacted their relationship, they were married until death (Kaplan, 2001). Førsvund et al. (2015) applied Kaplan's couplehood to couples who have a spouse with dementia. They found that the spouse felt a loss of couplehood when they were separated from their spouse and alone.

The present study confirmed that all the participants felt a High Couplehood. Two of the Husbands stated "for better or worse, until death do we part." Wife (5) who had been verbally abused throughout the marriage felt obligated to visit him daily to make sure he was taken care of by staff. Husband (2) who had his wife in a nursing home for eight years remained very committed to his wife. He has not been able to communicate

with her for seven years; but made sure he was at the nursing home at lunch and dinner time so he could feed her. He was afraid she would choke on her food. He said he never even considered divorcing his wife as he stated he still loves her and enjoys seeing her each day.

Eight of the 10 participants stated that they missed the companionship of their spouse the most. The other two stated they missed doing daily activities with their spouse or just having them physically present with them.

Bartlett (1994) and Benbow and Beeston (2012) found that wives, who had placed their spouses in nursing homes, experienced a decrease in intimacy prior to their spouse being institutionalized. Their spouses had already begun to decline, either physically or cognitively, which led to a decline in affection (Bartlett, 1994; Benbow, & Beeston, 2012). The present research also confirmed that the only intimacy that occurred was hugs and kisses with nine of the participants as their spouses suffered from either cognitive or physical decline two years prior to being institutionalized.

### **Socio-Emotional Selectivity**

This theory defines the emotional selectivity that the older population develops to process positive and negative experiences. The older individual develops social networks that enhance their emotional well-being while reducing those that are distressing. As the population ages, they interact more with significant others and less with socially casual relationships (Carstensen, 1992, 2003, 2006).

All of the present study's participants have reduced their friendships to just their spouse even prior to their spouse being institutionalized. Most of them had spouses that



had already declined cognitively up to two years prior to being institutionalized. Those that had friends were starting to withdraw from them, but also the friends were withdrawing from the community dwelling spouse. Two of the participants remained active in their churches, but most of them stopped attending church as they were visiting their spouses at the nursing home.

Carstensen (1991, 1993, 1995, 2003, 2006) speculated, in Socio-emotional Selectivity Theory, three testable statements. (1) The reduction of social contact does not happen suddenly in old age, but over time. (2) Other variables such as geographical location and perception of time will influence the selection of social partners. That is, if the person resides physically closer to the aging individual, the social contact is more likely to continue; and as the person ages, the more positive social interaction they prefer. They will select those social contacts that produce more positive interaction. (3) Emotions become more salient over time.

The present study showed that over time couples reduced their social interactions to just each other. Some may have friends, but most of them do not. If they do, they do not do many activities separate from their spouse. Church friends were very important to three of the participants, but only one saw them more than Sundays.

Women participants' children were more involved on a daily basis with them more than the male participants' children. The wives had children that lived nearby, but the husbands did not. If they did, the child was not involved with their fathers on a daily basis.

Selection of social partners appeared to be based on the environment the community-dwelling spouse interacts with the most. Two of the participants continued to be involved with their church, two wives had to work so their social interaction were with fellow colleagues, one husband attended a gym, but for most their social interaction on a daily basis was the nursing home staff.

Emotionally all the participants expressed sadness, anxiety, and anger. Each of the participants visit daily with their spouses, they sit quietly next to their loved one in the spouse's room or lunch room, they attend nursing home functions with their spouses while deep down they are experiencing a number of emotions that they do not show on the outside. The community-dwelling spouse's physical and mental health is taken care of daily, but the spouses emotions are quietly kept inside.

### **Boundary Ambiguity**

The construct, boundary ambiguity, is defined as both an uncertainty of loss or there is a physical loss, but the family is unable to accept the loss. Due to the inability to clarify a loss, the family system has difficulty re-organizing itself. This ambiguity creates a blocked system, which leads to the difficulty in the family system to adapt or change to the loss (Boss et al., 1991; Kaplan, 1994; Schulz et al., 2014).

Boss et al. (1990) reported that the part of boundary ambiguity that can lead to difficulty or resolution to a loss is how well the family unit feels that they are in control or mastery of their lives. Boundary ambiguity can occur right after a loss, but it does not mean dysfunction. Over time, the family can adapt itself especially if they feel some control over the situation. Five of the participants had their loved ones recently placed in

long-term nursing care in 2014. These five spouses still struggle with why their spouse needs long-term care. Each of the participants' spouses had been admitted to the long-term nursing care directly from the hospital. These spouses had already declined physically and cognitively; but once hospitalized the physician would not allow the community-dwelling spouse to take their loved one home. These spouses felt a loss of control, evidence of boundary ambiguity. One wife was still in denial of her husband's diagnosis. She felt that the doctors had not taken the time to share with her what was wrong with him. He had numerous hospitalizations due to the behaviors resulting from dementia, a prior nursing home stay in a dementia unit; and presently, continued placement in a dementia unit.

It appears that when the community-dwelling spouse has had time and education of the disease they are more aware of the progression of the disease. Wife (2) has had her spouse in long-term nursing care since 2008, and Husband (2) has had his spouse in long-term nursing care since 2005; both of their spouses have Huntington's disease. They both have been on their own the longest compared to the other participants. They have read a great deal about the disease, attended disease-specific support groups, and appear to have a better understanding of the prognosis of the disease compared to the other participants. Both Husband (2) and Wife (2) state that their spouse has lived longer than expected. Wife (2) had stated that her spouse lived through five bouts of pneumonia and a diabetic coma. The nursing staff refers to him as "Bounce back Harry\*." (\*pseudonym) She told them "she understood that, but one day he was not going to bounce back...All the kids know Dad is on borrowed time and we all understand this."

One wife who had her spouse placed in long-term nursing care in 2013 for Parkinson's disease could accept the word Parkinson's, but she did not realize that dementia was the prognosis and continued to consider returning him home. He was unable to walk, talk, feed, or toilet himself. She was unable to accept the loss of her spouse.

### **Limitations of the Study**

Each of the assumptions for trustworthiness was met. Each of the participants expressed their feelings, insights, and cognitive capabilities to participate in the study throughout the study.

To affirm credibility, the use of member checking with each of the participants was offered to verify their experience. Seven of the participants met with the researcher to verify their experience while three of the participants did by phone. No changes resulted from these contacts.

To affirm transferability, each participant was interviewed for one hour, but when a participant wished to share deeper information the time was extended with their permission. Each participant was asked the same interview questions, but given the time to fully express themselves. All interviews were set up and completed in three weeks.

To affirm dependability, recruitment was based on a set criteria for community-dwelling spouse be at least 65-years old and married at least 30 years. Their spouse needed to be in long-term nursing care and not skilled nursing care. Each participant was interviewed for one hour at a location of their choosing, the consent form was reviewed and signed, and each of the interview questions were asked in the order established.

To promote confirmability, an audit trail was used throughout the process so as to remain without bias. Prior to each interview a packet was developed and stapled. This packet provided organization and uniformity. The packet had the demographic sheet, index card and each research questions typed, notes would be taken, and an audiotape was used. A field journal was used to document any nuances or concerns that occurred during the interview process. Each interview was typed up and reviewed for themes. A strategic method of analysis and coding of the data to derive at themes was based upon two tables. Each table had all the research questions and responses. Codes were categorized. Themes and patterns emerged from the responses.

A limitation to this study is that the most recent research on community-dwelling spouses in regards to long-term nursing care is over 10 years old. Recent research on community-dwelling spouses has tended to be based on how that spouse emotionally handles the admission process or short-term nursing care (Davis et al., 2011; Gaugler et al., 2011; Sury et al., 2013). Other research has examined the process when caregiving to a dementia patient stops when placed in nursing home (Hennings et al., 2013), and grief of family members to nursing home residents with advanced dementia (Givens et al., 2011).

A limitation of this study is being unable to generalize the findings for the entire population, as there were 10 participants from four rural nursing homes located in Northeast Ohio. Each participant comes with their own unique and diverse experience.

### **Recommendations**

For future research, having participants that have spouses that do not have cognitive decline could provide insight and possible differences between spouses who have spouses with cognitive limitations. In the present study, nine of the ten spouses who resided in the nursing home evidenced physical and cognitive decline. The present study did have diversity in the diagnosis for placement, which previous research recommended, but having an institutionalized spouse that could fully engage in conversation would have given an overall perspective for depth of sadness. Nine of the participants reported that their spouses were at a state of cognitive deficit, and that they had been unable to have a conversation with their spouses for at least two years prior to their placement, and some of the spouses have not been able to communicate for even longer. There was only one participant in the present study that could converse with their spouses; however, he did not have a good relationship with his wife.

A continued recommendation for future research is to interview community-dwelling spouses that are childless. I had hoped to recruit a community dwelling spouse that was childless, but all the participants in this study did have children. Previous studies had recommended a childless community dwelling spouse as well. The husbands had children that did not reside nearby so they did not have daily interaction with their children. Most of the husbands but not all heard from their child(ren) by phone weekly.

In this research study, the female participants did more of the household chores and paying bills compared to the male participants. Five of the wives cooked, cleaned, and paid the bills prior to the spouse entering the nursing home. All the husbands had

relied on their wives for cooking and cleaning. In this generation, the roles were traditional. For future research, recruiting those that are younger than 65 years old and married less than 30 years might show more non-traditional roles. If there is more balance in the household tasks, would there be less dependency and more ease with a loved one placed in long-term nursing care?

### **Implications**

The present study confirmed that spouses of those that reside in long-term nursing home are sad, lonely, anxious, and angry, prior research has implied these emotions based on research only on wives (Bartlett, 1994; Kaplan & Ade-Ridder, 1991); or just husbands (Eriksson & Sandberg, 2008); or all family caregivers' feelings (Givens et al., 2011; Kaplan & Boss, 1999; Rudd et al., 1999). The present study found that these individuals painstakingly visit daily with their loved ones. On the outside they appear calm and quiet, but inside they are worried and sad about not having their spouse home with them.

This study's findings suggest that nursing home staff, family, clergy, and friends should be interactive and aware of how the community-dwelling spouse is feeling. Although the placement may have been recent or had been years ago, the data clearly showed that the emotions of sadness, loneliness, anxiety, and anger continue to be felt by the community dwelling spouse.

Implications for social change include that the nursing home staff could provide meals that are set up for the community dwelling spouse and their spouse. Some nursing homes do provide a meal if asked; but most nursing homes provide this at an extra

charge. As indicated in the present study, the husbands were not eating well. Providing meals would make sure that the male community dwelling spouse is provided a complete meal with their spouse. Many of the institutions charge a fee for an additional tray. In my opinion, this needs to be considered in the monthly cost that Medicaid pays and not an additional cost. If it is an automatic service to married couples, they may take more advantage of it, and based on this study, would help particularly the male community dwelling spouse have a balanced meal.

Family and friends need to be more involved either by phone or in direct contact with the community-dwelling spouse as most of them are alone most of the time. Friends seem to drift away especially if a spouse becomes more cognitively impaired. This is very concerning as the community spouse still needs that friendship as their spouse further declines. When placement occurs, the nursing home and physician to the resident spouse could educate the extended family that the community-dwelling spouse needs emotional support. Even though they may not be the Durable Power of Attorney to Healthcare (DOPA), if they are listed on the admission sheet, they could be contacted and informed that the community dwelling spouse needs to have more interactive support by calls and visits.

There is an opportunity for church friends and/or church fellowship to reach out more to the community dwelling spouse especially when that spouse is not attending church anymore. Many clergy will visit nursing homes to visit or to provide communion for the residents; but in this research study, the clergy and church fellowship did not visit the community-dwelling spouse that had attended their churches. Clergy and their church



fellowship need to be aware that the community-dwelling spouse needs that emotional support, and include them in their visits.

Perhaps a support group or caring friend for the community-dwelling spouse at the nursing home should be considered. Many of these participants are emotionally lost. They forge ahead on their own, but do not have anyone that they talk to daily. Since many of the participants showed that they reduce their social interaction to just their spouse, a caring friend that visits with them could start a friendship which could grow into a support group. Previous research had reported that psychotherapy (Dye, 1980) or telephone calls could be provided to caregivers after nursing home admission, which would allow psychological support (Davis et al., 2011). In addition, a “buddy system” has been suggested, in which new residents and their family are introduced to existing residents (Brown, 2012) but the therapy, buddy system, and the telephone calls are just temporary and at the transition phase. Gladstone (1995) suggested that community-dwelling spouse be offered counseling and support. A nursing home in Mahoning County has caring friends for the residents. They are volunteers that are trained by the nursing home staff. This concept could be adapted for the community dwelling spouse.

Mullins et al (2011) suggested a support group for community dwelling spouses at the nursing home, but it did not go into detail to as what would be covered in the group. Nursing homes should consider sponsoring a support group not related to the resident’s particular illness, for example Huntington’s; but rather, a support group for all community dwelling spouses that have their spouse residing in that nursing home. Many of the diseases that the resident spouses have do not have local support groups for the

community dwelling spouses. Husband (3) who had his wife in a nursing home for 8 years had attended a number of Huntington support groups soon after she was diagnosed, but he felt that he knew enough of the disease now, plus the closest support group was 3 hours away in Columbus, Ohio. Wife (2) felt lost and uninformed about her spouse's illness. She felt that the doctors do not take the time to discuss the spouse's health when they are in the nursing home. Often the community-dwelling spouse is not part of the doctor's visit as they are not scheduled at the nursing home. Having a support group could initiate changes in how the community dwelling spouse is treated. The community dwelling spouse would be able to vocalize concerns and the leader of the group could take that information to the nursing home staff.

An area for future research is the morals and values in institutionalized spouse relationships. Each of the participants was very committed to their spouse even if that spouse was verbally abusive, physical and/ or cognitively deficient. Some of the participants have not been able to communicate with their spouse for years. What keeps a person from reaching out to another when their spouse is terminally ill? Some spouses will terminate the marriage or find another mate when a spouse becomes diagnosed with a physical disorder that has cognitive and physical declines.

In practice, the referral base to psychologists should not be based only on the resident's need, but the need of the community-dwelling spouse. A patient with the cognitive deficits as these participants would never been referred for counseling; but their spouse could be referred. Social workers need to be aware how a community-dwelling spouse who has a spouse with cognitive deficits should be referred for counseling.

## Conclusion

The community-dwelling spouses in the present study were very committed to their spouse and many of them visit twice daily or stay for hours in a day. They sit next to their spouse quietly, calmly; but yet are very sad, lonely, anxious, and angry. Male community dwelling spouses that have more traditional marriages appear to be struggling more than female community dwelling spouses. Many children who do not reside locally are not a daily support to the community-dwelling spouse. Friendships decline with age; but even more so, for those that have a spouse in a nursing home. If the resident spouse has a cognitive disability, friends withdraw and make excuses to the community dwelling spouse for their reason of withdrawal. Unless the community-dwelling spouse continues to attend their church on Sunday, church friends and clergy do not appear to visit the community dwelling spouse or their spouse.

Nursing homes make sure that the resident spouse's needs are being met; but the community-dwelling spouse is forgotten. They are included for holidays and care meetings for their spouse; but the emotions of the community dwelling spouse are not part of the equation.

Many children move away from their childhood homes and begin their own families. The child may not be able to cook meals, help shovel, or mow grass; but they could call more than once a week to check on the community dwelling spouse, especially a male community dwelling spouse that has a spouse with cognitive decline.

While writing this final chapter, one of my participants had passed. His passing affected me tremendously as his affect and mood described how sad and lonely he had

been for the last eight years without his spouse. His words resonate about how he felt he had already lost her. It still saddens me as this spouse died of a broken heart because the spouse he had loved for over 30 years had already left him eight years ago. I am blessed to have had him in my study.

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## Appendix A: Interview Questions

1. Tell me about what your life was like for the 2 years before your spouse entered the nursing home?

Follow up:

- a. Did you see your friends during this time? How often?
- b. Did you see your family during this time? How often?
- c. What medical condition resulted in placement? How has it affected your

relationship with your spouse?

2. Tell me about your relationship with your spouse at this earlier time.

- a. Activities together? Separately?
- b. Sleeping together?
- c. If spouse was capable, how divide household tasks?

3. Tell me about what your life since your spouse entered the nursing home?

Follow up:

- a. Do you see your friends now? How often?
- b. Do you see your family now? How often?
- c. Tell me how you are feeling emotionally, in general.

Do you have days when you feel sad or blue, Why do you think you feel this way?

Do you have days when you feel worried, concerned, or times when you can't get worrisome thoughts out of your head? Why do you think you feel this way?

Do you have days when you feel angry? Why do you think you feel this way?

4. Tell me about your relationship with your spouse.
  - a. Activities together? Separately?
  - b. Used to be together in bed, how do you feel about living separately? Your intimacy now compared to before your spouse was admitted?
  - c. How do you manage household tasks?
  - d. How are you taking care of your own health? (appointments, eating, sleeping)  
Is this different from when your spouse was at home?
  - e. Do you discuss your feelings or important decisions with your spouse now?
5. How do you travel to the nursing home? How do you feel when you can't travel to visit?
6. What do you miss the most about your spouse not being at home?
7. What do you see for your future as a couple? For yourself?

## Appendix B: Flyer

Recruitment Flyer: May be posted in Long-term Nursing Care Facilities

# I would love to hear your story!

I am a doctoral student conducting a research study on how you, the spouse that remains at home, are emotionally handling having your spouse in long-term nursing care.



Are you 65 years and older?

Been married for at least 30 years?

Live alone?

If so, I would love the opportunity to talk with you at the nursing home or a location that is more amenable to you. The time and location would be arranged to suit your convenience.

An index card is provided that you can drop off at the social worker's office or you can contact me for more information.

Doctoral Student:

Barbara Hunt, Walden University

## Appendix B: Index Card

\_\_\_\_\_ I allow Barbara Hunt to contact me in order to participate in her  
dissertation project. Email: [barbara.hunt@waldenu.edu](mailto:barbara.hunt@waldenu.edu)

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

Best time(s) to reach me: \_\_\_\_\_



## Appendix C: Demographic Sheet

Name: \_\_\_\_\_ Birthdate \_\_\_\_\_

Spouse's name \_\_\_\_\_ Date of Admission \_\_\_\_\_

Are you your spouse's Durable Power of Attorney (DPOA) for Healthcare? \_\_\_\_\_

Reason for placement \_\_\_\_\_

Type of placement (Please circle):            Long-term            Skilled (Short-term)

Number of years married \_\_\_\_\_

Do you have children? \_\_\_\_\_ If so, how many? \_\_\_\_\_

Do you live alone or with family? \_\_\_\_\_

## Appendix D: Consent Form

## CONSENT FORM

You are invited to take part in a research study of the emotional impact of having a spouse in long-term nursing care. The researcher is inviting spouses who at least 65-years old, have their spouse in long-term care, and have been married to their spouse for at least 30 years to be in the study. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Barbara Hunt, who is a doctoral student at Walden University.

**Background Information:**

The purpose of this study is to learn the emotional impact that a spouse who has their loved one in long-term nursing care feels.

If you agree to be in this study, you will be asked to:

Meet for an hour interview with researcher at the nursing home or another location that is best suited for the participant.

Permit the researcher to audiotape the interview, and take notes during the session.

If all the interview questions are not covered within the hour scheduled, another interview time will be scheduled.

Once the researcher has analyzed and interpreted the interview, the researcher can provide the interview results to the participant with the hope of clarification of any misunderstandings the researcher incurred.

Here are some sample questions:

Tell me about what your life was like for the 2 years before your spouse entered the nursing home?

- a. Did you see your friends during this time? How often?
- b. Did you see your family during this time? How often?
- c. What medical condition resulted in placement? How has it affected your relationship with your spouse?

**Voluntary Nature of the Study:**

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at \_(will need to type each nursing home name)\_\_. If you decide to join the study now, you can still change your mind later. You may stop at any time.

**Risks and Benefits of Being in the Study:**

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue, stress or becoming upset. Being in this study would not pose risk to your safety or wellbeing.

By participating in this study, it will give you the opportunity to share your feelings about having a spouse residing in the nursing home. It will give professionals the insight and possible ideas in caring for others in the same situation.

**Permission**

As the Durable Power of Attorney (DPOA) of Healthcare of my spouse, I give permission to Barbara Hunt to confirm my spouse's placement date, reason for placement (medical condition), and type of placement from the nursing home.

**Payment:**

Volunteer participation is being asked and no compensation will be provided.

**Privacy:**

Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by a locked box that is kept with the researcher. Data will be kept for a period of at least 5 years, as required by the university.

**Contacts and Questions:**

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone or email or her faculty advisor: Dr. Lee Stadtlander at 406-451-6412. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1 612-312-1210. Walden University's approval

number for this study is IRB # 01-02-15-0139917 here and it expires on January 1, 2016

The researcher will give you a copy of this form to keep.

**Statement of Consent:**

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant \_\_\_\_\_

Date of consent \_\_\_\_\_

Participant's Signature \_\_\_\_\_

Researcher's Signature \_\_\_\_\_

After the study ends, if you wish to discuss any emotional issues that developed from the interviews, you may call:

Crisis Intervention Hotline (free and available 24-hours) 330-452-6000

## Appendix E: Letter of Cooperation from a Research Partner

Community Research Partner Name

Contact Information

Date

Dear Barbara Hunt,

Based on my review of your research proposal, I give permission for you to conduct the study entitled “The Emotional Impact that the Elderly Spouse who has a loved one in Long-Term Nursing Care” within the Insert Name of Community Partner. As part of this study, I authorize you to post flyers, and to utilize a room with the facility to interview participants to your study. Individuals’ participation will be voluntary and at their own discretion.

We understand that our organization’s responsibilities include: Provide a private room that is amenable and quite. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization’s policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student’s supervising faculty/staff without permission from the Walden University IRB.

Sincerely,

Authorization Official

Contact Information