The Decision Making Process of Informal Caregivers of Dementia Family Members Regarding Nursing Home Placement

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The Decision Making Process of Informal Caregivers of Dementia Family Members Regarding Nursing Home Placement

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

By

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ABSTRACT

The purpose of this study was to understand the decision making process of caregivers placing their elderly family members in a nursing home facility. Experiential Learning Theory (ELT) was used, as well as the Critical Incident Technique (CIT). ELT was utilized in an effort to understand the learning that took place during the caregiving experiences, and CIT was used to better understand the critical incidents that led the caregivers to seek nursing home placement. A sample of twelve former informal dementia caregivers between the ages of fifty-seven and eighty-seven was drawn from the metropolitan Richmond, Virginia area. In-depth interviews were audiotaped and provided the primary source of data for this study. An interview protocol consisting of eleven open-ended questions derived from current dementia caregiving literature guided the conversation between the researcher and the caregivers in the sample.

A constant comparison method was used in this study. The findings revealed that there are a variety of reasons why informal dementia caregivers seek nursing home placement for their family members. Themes related to the decision making process to seek nursing home placement include (1) dementia related behaviors, (2) safety concerns, (3) emotional and psychological burden, and (4) unexpected medical intervention. Indicators of each theme found in this study suggest that providing informal care for an individual with dementia can be very overwhelming and challenging. Although there were some positive aspects associated with this form of caregiving, such as feelings of pride and self-worth, the overall consensus from this study was that dementia caregiving is a very difficult experience in which the primary caregiver had to ultimately seek formal placement in a nursing home for their family member for a variety of reasons.
Dedicated to my dad, Dr. Stephen Russell Merritt, who was the best role model a daughter could have ever asked for.
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CHAPTER 1
INTRODUCTION

Background

“The Graying of America” is a common phrase used to describe the reality that Americans are living longer. As the elderly population increases at a greater rate than ever in the United States, so do the caregiving demands for elderly individuals. Historically, older individuals have had their care provided to them by their family members (Velkoff & Lawson, 1998). This continues to be the trend as today’s aging individuals are living longer. It is estimated that in the United States, eighty percent of care given to frail or impaired elderly individuals is provided by family caregivers. The largest proportion of these family caregivers are spouses, followed by adult children and other family members, to include siblings, grandchildren, nieces and nephews (Bumagin & Hirn, 2001).

Today, with advances in medicine and medical technology, it is not uncommon for individuals to live well into their 80s and 90s. The fastest growing population in the United States is the oldest-old population, which consists of elderly individuals aged 85 and older. By the year 2030, it is projected that the older population will double from 36 million people in 2003, to 72 million people in the year 2030 (United States Census Bureau, 2005). With today’s decrease in mortality and increase in medical technology, the current life expectancy and longevity of the older population greatly increases the demands of caregivers in the United States.
Chronic Health Conditions

Providing care for an elderly individual can be a stressful and time-consuming commitment. Many elderly people are in poor health and have chronic conditions that affect their activities of daily living and functioning. About 80% of senior citizens in the United States have at least one chronic health condition, such as heart disease, and 50% of seniors have at least two chronic conditions (United States Census Bureau, 2005). With the increase in chronic conditions and other age-related occurrences, such as falls and injuries, it is often family members who take on the role of the primary informal caregiver. It is common for informal caregivers of elderly persons to seek long-term care institutionalization when they feel as though they can no longer care for an individual without professional assistance. Important factors that often lead informal caregivers to institutionalization include physical health, psychological functioning, and behavioral disturbance (Hope et al., 1998). Understanding which aging factors influence the decision to seek long-term care institutionalization raises questions regarding the decision making process of informal caregivers. It is important to have a clear understanding of the particular experiences and incidents that lead up to a final decision to seek long-term care institutionalization in a skilled nursing home setting.

Overview of the Study

Little is understood about the decision making process of placing elderly family members with dementia into long-term care facilities. Previous caregiver studies have shown that taking care of an elderly family member at home with dementia often leads to stressful situations for the informal caregiver. These stressful situations have negatively affected the psychological well-being of the caregiver (Dura et al. 1990). The informal caregiving role often has a profound impact on one’s livelihood, decreases one’s marital satisfaction, decreases their participation in leisure activities, and negatively affects one's perceptions of the quality of family relationships (Seltzer & Li, 2000). Family caregiving is a stressful role in which the person providing care is often faced with negative and harmful consequences (Aneshensel, 1995). Examples of these consequences include caregiver burden, caregiver stress, and depression. Often caregiving is typically unexpected and not
voluntary. Not only can the changes to one’s lifestyle as a result of caregiving be negative to the caregiver’s health, caregiving is also associated with a reduction in social involvement (Haley et al., 1987).

Many caregivers are not able to deal with the challenges of taking care of a family member in their home and opt for long-term care placement in a nursing home. Research has shown that it is the adult children, who are informal caregivers, who are more likely to place a parent into a nursing home (McFall, 1992). The reasons that many caregivers choose nursing home placement following informal caregiving at home is due to the high levels of stress and burden that many caregivers face (Colerick & George, 1986).

Aging Demographics

Gerontologists understand the importance and the need for informal caregivers in today’s aging society. Understanding the demographic profile of today’s aging population reaffirms this need. In the year 2000, there were 420 million people in the world who were aged 65 years and older, thus making up about seven-percent of the world’s population (United States Census Bureau, 2005). In addition, the average life expectancy in the United States has increased from 47 years in 1900, to 76 years in the year 2000 (United States Census Bureau, 2005). This drastic growth within the aging population demonstrates that people are living longer and living healthier lives, thus increasing the demand for eldercare.

A result of this increase in life expectancy and longevity within the aging population creates a need for dedicated caregivers. The backbone of today’s long-term care system is informal caregiving. Currently, the number of informal caregivers who provide some level of community long-term care is close to thirty million, with estimates of their unpaid care reaching between two hundred and seventy-five dollars and three-hundred billion dollars annually (Polivka, 2005). Although these caregivers provide care for others, they are often in need of care themselves. High levels of stress related to caregiving certainly affects these caregivers' health. Depression and anxiety are also commonly associated with caregiving (Gaugler, et al., 2001).

A 2002 survey conducted by the National Opinion Research Center reputed that many
caregivers are vulnerable with a high percentage of serious health problems (Polivka, 2005). The survey also provided a detailed look into the demanding tasks of informal caregiving, which included caregivers providing an average of 20.9 hours of care per week, including personal care, household tasks, and medical care. Proper training and education for informal caregivers is very important to ensure safety for both the caregiver, as well as for the elderly individual in their care. The findings of the survey made it apparent that there is a lack of necessary caregiver training. According to the survey, many caregivers did not receive instruction in the caregiving tasks, and fifty-six percent of the caregivers were taught nothing about activities of daily living care (Polivka, 2005). These statistics illustrate the lack of support and training for today’s informal caregivers. Proper education could lessen the burden caregivers face when caring for an elderly individual, thus reducing health conditions, such as stress, anxiety, and depression.

Elderly Care Demands

It can be assumed that a lack of preparation and training in caregiving techniques make an informal caregiver decide to seek long-term care institutionalization for the elderly individual in their care. A study which focused on relinquishing in-home dementia care found that increasing care demands, such as problematic behaviors, certainly impacted a caregiver’s decision making process to seek long-term care institutionalization (Gaugler, et al., 2001). Other factors which affected the decision to seek placement included stressors to the caregiver, such as role captivity and role overload, as well as conflict within the caregiver’s family, levels of socioemotional support, and the well-being of the caregiver (Gaugler, et al., 2001). More information needs to be known about the factors that contribute to the decision making process regarding informal caregivers seeking long-term care institutionalization, which is the focus of this research. This study sought to understand the influencing factors that informal caregivers face when placing a loved one in a nursing home. This study involved family members of the elderly population who cared for their loved ones in their home prior to an admission into a long-term care facility. It investigates the decision making process of the informal caregiver when faced with the challenging tasks of elderly dementia caregiving.
Rationale for the Study

This investigation was necessary in order to provide physicians, long term care facilities, staff, and social workers with an in-depth look into the decision making process of the informal dementia caregivers, leading to necessary interventions for their aging loved ones. Current research shows that there are many negative factors associated with informal dementia caregiving. Informal dementia caregivers are often faced with caring for an elderly individual who has limited mobility, and chronic health conditions, as well as cognitive impairments and possible problematic behaviors. In addition to the multiple health conditions that a primary caregiver must face when providing care, there are also negative factors that can affect their caregiving abilities. A caregiver’s perceived lack of help from family members or professionals can increase stress within the caregiver. Other factors include tension between family members and a feeling of being trapped in the caregiving role. Emotional exhaustion and impaired psychological and physical well-being can also negatively affect the caregiver (Gaugler et al., 2001).

This study sought to understand the decision making process of informal dementia caregivers regarding nursing home placement. In order to understand why the caregivers sought formal care, one must understand the negative and positive factors which are associated with caregiving. Previously included, there are many negative factors associated with providing care to an elderly individual. There are, however, positive factors associated with caregiving, which include feeling more useful, feeling needed, and having an opportunity to learn new skills. It is important to understand that many informal caregivers get enjoyment from providing care and being a companion to others. Many caregivers gain a sense of fulfillment through their caregiving obligations. However, there often comes a time when informal caregiving no longer works well. Caregivers may experience strain and disruption of work, social and family life, or have to deal with feelings of depression, anger, and anxiety (Aneshensel et al., 1995). This study sought to find out whether these types of experiences affected the decision making process to seek nursing home placement for their family members.
Caregiver Health Concerns

Many researchers have studied the link between caregiving for elderly persons, and an increase in caregivers' emotional or mental health problems (Koerner et al., 2008). Individuals who provide care continue to be at an increased risk for symptoms of depression and high levels of hostility and anxiety when compared to non-caregivers. Caregivers are also at risk for a loss of self, missed social opportunities, and compromised physical health (Koerner et al., 2008). Caregiving can be associated with a chronic stress experience due to the ability to create physical and psychological strain over an extended amount of time. Also associated with caregiving are high levels of uncontrollability and unpredictability, which has the ability to create stress in work and family relationships (Schulz & Sherwood, 2008). The physical and mental health of caregivers is certainly at risk depending on different aspects of the caregiving situation. Providing care to an elderly individual with behavior problems, cognitive impairments, and functional disabilities is commonly associated with feelings of caregiver distress and depression. In addition to physical and mental stress, caregiving can also be very financially stressful for caregivers due to families often being the primary source of home care and support for older relatives (Schulz & Sherwood, 2008).

Positive Caregiving Aspects

Although there are many negative aspects of informal caregiving, there are positive factors associated with the informal caregiving process, also known as caregiving benefits and gains. Examples of these positive factors include an added meaning to one’s sense of self, feeling more useful, feeling needed, and having an opportunity to learn new skills. Caregivers have also reported gaining a sense of fulfillment for carrying out an obligation, as well as enjoyment from providing care and being a companion to someone in need (Koerner et al., 2008). Other positive effects of caregiving include caregivers feeling good about themselves, having meaning to their lives, and strengthening their relationships with others. Perhaps this is because individuals in supportive relationships tend to be happier and healthier and live longer.
than individuals who are socially isolated (Schulz & Sherwood, 2008). It is through understanding the positive and negative factors that face informal dementia caregivers on a regular basis that one can begin to understand their decision to seek nursing home placement for the elderly individual in their care.

Gaining a better understanding of the informal dementia caregiving process can positively benefit today's aging society. This research sought to better inform physicians and helping professionals who are faced with referring aging residents to long term care facilities. They will now be able to better understand the issues that primary caregivers are facing while providing care for an individual with dementia in an informal setting. The physicians will be able to better understand medical changes that are taking place in the elderly individual, such as increased incontinence or a change in one’s cognitive functioning, based on the caregivers’ information. This study will better prepare long-term care administrative staff with an understanding of the care that the resident was receiving at home, and what issues lead to their necessary admission. Social workers and other members of the health care field will be provided with an in-depth look into the issues that informal caregivers face on a regular basis, as well as what to look for when the caregiver nears their breaking point and needs assistance with their caregiving role.

**Research Questions**

The intent of this study was to understand the decision making process of informal dementia caregivers regarding nursing home placement, when faced with the challenging tasks of elderly caregiving. This research was designed to provide an opportunity to hear the voices of informal caregivers of elderly individuals with dementia. The overall guiding research question “What are the influential factors that contributed to a decision of nursing home placement for informal caregivers?” was addressed through the use of the experiential learning theory. This theory focuses on education that takes place when one is directly participating in life events. Included in this theory is learning through the reflection of everyday experiences. This is a type of informal education, and through this education, informal caregivers were able to help make a decision as whether or not to
institutionalize the individuals in their care. This decision was mainly based primarily on the life events and experiences that were taking place in the informal caregiving process.

Three research questions that provided the framework for this inquiry included:

1. How do caregivers understand the transition of placing their loved one in a nursing home?
2. What does the decision making process mean to them?
3. How do caregivers cope with this transition?

**Design and Methods**

In order to address the research questions, this study was a qualitative study with in-depth interviews. Qualitative research was used due to the flexibility, as well as the expressive and significant nature of qualitative data. This form of research created emerging themes from the data through a structured framework, which were modified as data appeared. As data and themes appeared, and emerged, the interview questions were further revised in order to obtain more pertinent information that was important to the research. In order to enhance the credibility and reliability of the research findings, multiple methods of data collection were used.

The phenomenological research approach focuses on examining human experiences and understanding the meaning from these events and interactions. Detailed descriptions of the people being studied were used to understand behaviors and construct meaning (Bogdan & Biklen, 2007). Phenomenologists believe that there are multiple ways of interpreting others' experiences and these experiences must be examined well. This method involves studying only a small number of subjects though prolonged and extensive engagement in order to develop relationships and patterns of meaning. As part of this process, the researcher must be able to group and bracket the experiences of those interviewed (Creswell, 1994).

In addition to the phenomenological research approach, the critical incident technique was used in this study. This research technique focused on gathering and analyzing information about significant experiences from individuals’ lives (Flanagan, 1954). The use of
the critical incident technique in this study allowed the researcher the opportunity to gather facts from informal caregivers in order to gain knowledge on the decision making process to seek nursing home placement. The former informal caregivers interviewed were asked to identify those specific events during caregiving which had an important effect on the final caregiving outcome. The use of this technique was beneficial for the study because it provided an individualized report based on personal experiences (Flanagan, 1954). An open-ended method was used in this technique, which focused on one or more important events, and incidents, which took place.

**Definition of Terms**

**Alzheimer's disease:** Alzheimer's disease is a form of dementia in which plaques and tangles form in the brain which result in cognitive impairments, memory loss, and a loss of functioning throughout the body. Alzheimer's disease is a terminal disease with no known cure.

**Assisted-Living Facility:** Assisted-living facilities (ALFs) provide living arrangements to people with special needs to include assistance with eating, dressing, bathing, and taking medications. Assisted-living facilities are commonly private pay only, however, some facilities are income-based.

**Caregiver Stress:** Caregiver stress consists of physical, emotional, and/or financial strain as a result of the caregiving experience. Exhaustion, loneliness, and guilt are common feelings associated with caregiver stress.

**Continuing Care Retirement Communities:** These types of communities are for senior citizens and offer different housing arrangements based on care needs. There is often independent housing, assisted-living, and nursing home care on the same campus. These types of communities are often private pay only, with a required entrance fee, followed by monthly fees.
**Dementia:** Dementia refers to a number of syndromes which are characterized by diverse cognitive, behavioral, and emotional impairments. Cognitive impairments which may affect individuals with dementia include difficulty understanding or using words, memory loss, and failure to identify or recognize objects. Occupational and social functioning are often impaired, and behavioral disturbances may also be present. Dementia is prevalent in approximately six to ten percent of individuals aged 65 years or older. This prevalence increases with age, affecting approximately thirty-percent of individuals aged 85 years or older (Centers for Disease Control and Prevention, 2006).

**Elderly:** The chronological age of 65 years is the accepted definition of elderly or old person in most developed world countries. Currently, there is no standard numerical criterion for the United Nations (UN), but the UN has agreed that 60 or more years is the cutoff to refer to the older population (World Health Organization, 2009).

**Experiential Learning Theory:** The experiential learning theory consists of education that occurs through the direct participation in life events. Also included in this definition is learning through the reflection of everyday experiences (Beard & Wilson, 2006).

**Formal Long-Term Care Facility:** Long-term care facilities provide rehabilitation services for individuals who need professional assistance with their care. Health care, personal care, housing services, and social services are available to residents who reside in long-term care facilities.

**Informal Caregiver:** An informal caregiver is an individual who provides major care responsibilities and assistance to someone unable to care for themselves. Informal caregivers are often unpaid for their services and are often family members.
Long-Term Care: Long-term care consists of needing extended human help with Independent Activities of Daily Living (IADLs) or Activities of Daily Living (ADLs), due to physical, emotional, or mental problems. There are three types of long-term care: formal and informal care provided in the community, and institutional care.

Skilled Nursing Facility: Skilled Nursing facilities (SNFs) are facilities which provide rehabilitation services (speech therapy, occupational therapy, physical therapy), as well as medical services and 24 hour nursing care. Assistance with meals, dressing, bathing, and taking medications is also included. These extended care facilities are eligible for payment under Medicare and Medicaid, and also accept private payer sources.
CHAPTER 2
LITERATURE REVIEW

Introduction
The literature review for this research is comprised of both theory and empirical work. The theoretical framework for this study is based on the experiential learning theory. First, a historical overview of the experiential learning theory provides information regarding learning through the reflection of everyday experiences. A discussion of studies on informal caregiving follows. Studies related to caregiver stress and the decision making process to enter long-term care are provided to convey the current knowledge of transitional care.

Methodology of Literature Review
The researcher used the EBSCO search engine to search different databases. The databases used to collect literature review data included AGEline, ERIC, Pubmed, and PsycArticles. A total of 73 articles were found in the search. Those included in this review of the literature were vetted by using the research standards of the American Educational Research Association.

Experiential Learning Theory
The experiential learning theory (ELT) considers learning to be a cycle that begins with one’s experience, continues with reflection, and later leads to action which becomes a concrete experience for reflection (Demirbas & Demirkan, 2003). The ELT was developed by David Kolb and published in 1984 as part of his learning styles model. In ELT, there are four defined phases in the process of learning from experience. These phases include (1) concrete experience, (2) reflective observation, (3) abstract conceptualization, and (4) active experimentation. The learning styles of individuals are defined by their relative reliance on these four learning phases.
The framework of the ELT is holistic, to include affective, perceptual, behavioral, and cognitive strategies (Boyatzis & Kolb 1991). Kolb’s ELT offers a way to understand the different learning styles of individuals, as well as an explanation of how experiential learning applies to all individuals.

In the ELT, immediate or concrete experiences provide a basis for reflections and observations. These reflective observations lead to the formulation of abstract concepts and generalizations. Following this, the implications of concepts in new situations are tested through active experimentation (Demirbas & Demirkan, 2003). A cycle of these experiences ideally represents a learning cycle, in which the learner is able to experience, reflect, think, act, and ultimately learn. In addition to Kolb’s four-stage cycle as mentioned above, Kolb’s ELT model also has a four-type definition of learning styles. These learning styles explain the combination of the phases in his experiential learning process, which use the terms diverging, assimilating, converging, and accommodating. The learners’ preferences regarding the stages of Kolb’s ELT cycle do not make better or worse learners due to each individual having a preferred learning style (Demirbas, & Demirkan, 2003).

The ELT focuses on learning as a process in which one gains knowledge through a transformation of experience. This learning does not have to be solely an intellectual activity or an activity which the learner experiences alone. The purpose of experiential learning is to lead individuals through the various cycles of the ELT in order to ensure that critical links between the different moments in the learning process are made (Jong, 2006).

Kolb proposes that different people naturally prefer a certain single different learning style, and that there are various factors which influence their preferred style, such as one’s personal development. Kolb’s three stages of personal development include (1) acquisition, (2) specialization, and (3) integration. As an individual matures through these development stages, it is suggested that their ability to reconcile and integrate the four different learning styles improves. The development stage known as acquisition includes the time frame from birth to adolescence, and involves the development of cognitive structures and basic abilities. Following
acquisition is specialization, which includes early work and personal experiences of adulthood and schooling. Also included is the development of one’s particular specialized learning style, which is commonly shaped by social, educational, and organizational socialization. The third personal development stage by Kolb is integration. It is during this development stage, which occurs during mid-career through later life, that the presence of expression of non-dominant learning styles in work and personal life are taking place (Kolb, 1984).

**Experiential Learning Process**

In the ELT, people learn in a two-step process which requires the input and process of information. Some individuals prefer learning through concrete examples, while others have a preference for abstract concepts (Little, 2004). In processing the information, some individuals are better at processing through active experimentation, while others prefer to use reflective observation. Individuals who prefer to input information through concrete examples and active experimentation are known as accommodators. Accommodators prefer to learn through hands-on experiences, and they learn best through independent discovery. Divergers are individuals who prefer learning through concrete examples. These learners prefer to have information presented to them in a reasoned, systematic, and detailed manner. Assimilators are learners who prefer abstract concepts for the inputting of information and prefer processing information through reflective observation. These learners gain knowledge by watching and thinking and reflecting. Convergers prefer to learn through considering abstract concepts and then experimenting on what they have learned (Little, 2004).

Learning from experience is a natural means of learning which requires the opportunity to reflect and think about one’s experiences (Beard & Wilson, 2006). Informal caregivers of elderly individuals often experience situations during the caregiving process which allow them to learn informally through experiential learning. Situations which include experiencing caregiver stress and burden, as well as behaviors associated with dementia, allow informal caregivers opportunities to reflect and learn. It is important to understand that the informal caregiving process is often a major transition in one’s life. It is through the ELT that caregivers
can learn from change in order to better adapt to future change (Beard & Wilson, 2006). Because the ELT focuses on learning from processing one’s experiences, one must remember that informal caregivers learn from experiences at different times. An informal caregiver can learn from an event at the time it occurs, and they can also learn from a past event when reflecting on it later. Experiential learning can also take place from learning more about a past event when thinking about it more in-depth (Beard & Wilson, 2006).

Retrospective Learning

One type of experiential learning is retrospective learning. This takes place when one looks back at an event and analyses it. Individuals can look back on their experiences and closely recollect what happened, thus learning from their experience. In addition to learning from their experiences, they are also able to relate their experience to existing ones, thus finding new meanings in past experiences (Beard & Wilson, 2006). Regarding long-term care institutionalization, former informal caregivers may understand more about their actions to seek formal care upon the reflection of their past caregiving experiences. The purpose of this study is to use the ELT in an attempt to understand how the informal caregivers learned from their caregiving experiences, and how these caregiving experiences made them seek long-term care institutionalization.

Informal Caregiving of Elderly Individuals

As the population in the United States continues to age, there are a growing number of older adults with health impairments in the community who need assistance with their care. Although modern medicine, public health, and healthcare have been successful in increasing the life expectancy of today’s population, many older adults are unable to take care of themselves (Baumann, 2008). In today’s society, most people prefer to remain in their own home and maintain their independence. Unfortunately, a reduction in functioning and independence occurs as an individual ages, which can greatly affecting one’s independence and ability to be self-sufficient. Following this decline in health, family members may become the informal caregivers who provide assistance, thus enabling their elderly relatives to continue to live in the
community (Aneshensel et al., 1995). Although many informal caregivers are children taking care of their elderly parents, it is not uncommon for spouses to be informal caregivers as well.

Informal spousal caregivers comprise 38 percent of the nonpaid caregiving population in North America (Sussman & Regehr, 2009). Due to social and political pressures encouraging older adults to age at home and not in long-term care institutions, many spousal caregivers feel pressure to care for their partners at home for longer periods of time. The consequences of this action result in spouses of elderly individuals, particularly those with dementia, offering physical care, having to navigate challenging behaviors, providing emotional support continuously, and dealing with grief and bereavement. These spousal caregivers face difficult caregiving, in addition to the management of a complicated and resource-limited health and support system (Sussman & Regehr, 2009). Non-spousal informal caregivers also face these difficulties, but typically without as many health problems as an elderly spousal caregiver, and without the grief of facing the decline and loss of a life-long partner.

Informal Caregiving Roles

In addition to an increase in informal spousal caregivers, men particularly are now playing a greater role in the caregiving process. Many husbands are encountering role transformations as their wives need assistance due to illnesses. Sanders and Power (2009) examined the changes that occurred in the responsibilities, roles, and relationships of husbands who provided care for their wives with chronic health conditions. The husbands in this study had to learn how to form new types of relationships with their chronically ill wives. The results of the study suggested that husbands who are caregivers experience changes in the ways in which they adapt to their marital roles, and to the new roles which they assume when providing care for their wives. Because all caregiving experiences are different, it is important to understand the differences within all informal caregivers, whether male or female, spousal or non-spousal.

Within informal caregiving there are numerous physical, emotional, and psychological challenges. In addition to these challenges, informal family caregivers have different responsibilities and need to understand the knowledge, skills, and attitudes involved in
facilitating successful caregiving (Baumann, 2008). Providing informal care for an elderly individual may be seen as a caregiving career, due to the large amount of responsibilities it entails. This caregiving career has dual stages to include the first stage, the acquisition of and the preparation for the caregiving role. Following this is the enactment of care-related responsibilities and tasks within the home. An informal caregiver often continues to provide care following placement into a formal institution, known as supplemental or invisible care. A disengagement from the caregiving follows, which often includes the important steps of bereavement, recovery, and social reintegration for the informal caregiver (Aneshensel, et al., 1995).

**Informal Caregiving Demands**

In addition to the numerous physical, emotional, and psychological challenges of informal caregiving, there are also care demands that informal caregivers face. It is common for an informal caregiver to have five dimensions of care demands. These care demands can be very stressful for informal caregivers, and are often contributing factors to the caregiver seeking placement in a long-term care facility. These care demands include the activities of daily living (ADLs), problem behaviors, and the patient’s need for interaction and supervision. Also included is the time commitment involved in caregiving, and the activities which are needed to replace family and household activities formerly performed by the individual who now requires care (Goldstein, 1989). Providing ADL care for an elderly individual includes assisting with toileting, bathing, and dressing. This may be particularly difficult for an individual with dementia, should they continuously resist or struggle during ADL care. This can be very stressful for the caregiver.

Problem behaviors are common in the elderly population. Many informal caregivers tend to feel helpless and hopeless when the individual in their care becomes depressed (Goldstein, 1989). It is difficult for caregivers when they feel as though they are not appreciated. The elderly individual’s need for interaction and supervision is another large part of the informal caregiving process. Constant supervision can be time-consuming and exhausting. The time commitment involved in caregiving can be overwhelming for an informal caregiver.
Caregivers must constantly put their needs secondary to the elderly individual in their care. This can easily lead to feelings of resentment and caregiver burden. A final care demand for informal caregivers involves the replacement of the activities formerly performed by the individual who now requires care. Examples of these activities that may have maintained the household include shopping, cooking, housework, or managing the finances (Goldstein, 1989). In addition to having to provide personal care, the informal caregiver now faces extra everyday tasks which were previously not their responsibility.

Informal caregivers must deal with many factors attributed to advanced age during the caregiving process. It is often a combination of these factors which influence an informal caregiver’s decision to seek long-term care placement for the elderly individual in their care. As mentioned above, dementia is one of the prevalent conditions in elderly persons. Because dementia and the related behaviors are very difficult to control, dementia increases the risk of nursing home placement more than fivefold. Supporting caregivers through interventions, such as support groups, has been researched in hopes of delaying nursing home placement for individuals with dementia.

Mittelman, Haley, Clay, and Roth (2006) studied the improvement in informal caregiver well-being to a delay in nursing home placement of patients with Alzheimer’s Disease. The researchers found that patients with Alzheimer’s Disease whose informal caregiver received an enhanced counseling and support intervention experienced a reduction in the rate of nursing home placement compared to usual, non-support care. This study suggested that providing greater access to effective counseling and support programs could greatly benefit informal caregivers, patients with Alzheimer’s Disease, and society.

Gitlin, Corcoran, Winter, Boyce, and Hauch (2001) investigated the short-term effects of a home environmental intervention on upset and self-efficacy in caregivers and the daily function of dementia patients. They also sought to find if the effect of treatment varied by caregiver race, gender, and relationship to the patient with dementia. The intervention used in this study consisted of five 90 minute home visits by occupational therapists who provided education
and physical and social environmental modifications. The researchers found that caregivers who received the intervention reported fewer declines in patients’ instrumental activities of daily living, and less of a decline in self-care. There were also fewer behavior problems reported in the patients at the three month post-test. Additional results included the intervention spouses reporting reduced upset, women reported an enhanced self-efficacy in managing behaviors, and minorities in the study reported enhanced self-efficacy in managing functional dependency. These results suggest that the environmental program appeared to have a modest effect on dependence of the dementia patients’ instrumental activities of daily living (IADL). The results also suggest that certain subgroups of caregivers showed an improvement in self-efficacy and a reduction in upset in specific areas of caregiving.

Informal Caregiving Stress

Informal caregiving is closely related to caregiver stress. The stress and burden which an informal caregiver may experience can certainly be a factor in the decision making process to seek long-term care institutionalization. Mitrani et al. (2006) evaluated the role of family functioning in the stress process of informal dementia caregivers. Each dementia caregiver in this study was assessed on their sociodemographics, burden, depression, anxiety, and perceived health. Their family functioning was measured through the utilization of a multidimensional and observational instrument. The researchers concluded that family functioning significantly contributed to distress in the overall sample, and partially mediated the relationship between distress and objective burden. It was suggested by these researchers that family structural functioning is one contributor to the caregiver stress process. It is also suggested that interventions which target structural family problems may reduce caregiver distress.

In addition to family functioning, the life satisfaction of informal caregivers plays a very important role in the success of the caregiving situation. Borg and Hallberg (2006) studied the life satisfaction of informal caregivers in comparison with non-caregivers. These researchers found that one-fourth of the caregivers had support from other individuals, most frequently other family members, and also had help and advice from professionals. Lower life satisfaction in
informal caregivers was associated with unemployment, limited social resources, not sleeping well, and overall poor health. It was suggested by the researchers that the most important factors associated with lower life satisfaction within informal caregivers was having poor health and limited social resources. Most desired by the informal caregivers in this study was compensation or some type of payment for their caregiving services.

A review of the research studies previously discussed supports the importance of counseling and support interventions in delaying nursing home placement. Also supported is the effect of family structural systems on the caregiving process and experience. The effects of having a low life satisfaction within informal caregivers were also provided, thus demonstrating the need for more social resources within the informal caregiving process. Caregivers, when provided with interventions and additional resources, are less likely to suffer from caregiver stress and are more likely to delay long-term care placement.

**Formal Caregiving of Elderly Individuals**

Formal caregiving takes place in a variety of settings which include assisted-living facilities, continuing care retirement facilities, and long-term care nursing facilities. With today's population growing older and living longer than ever, it is very important to address the care needs of elderly persons who reside in these types of facilities. It is also important to identify formal caregiving settings, as well as the job duties and requirements of the formal caregivers who work within the long-term care field.

Today’s elderly population has grown because of improvements in health services, economic development, and education. Currently, the fastest growing portion of the elderly population in many countries is known as the “oldest old population”, consisting of older adults aged 80 and older (United States Census Bureau, 2001). These older adults commonly have chronic health conditions which greatly affect their abilities. According to the Center for Disease Control, approximately eighty-percent of individuals over sixty-five years old are living with at least one chronic health condition, and fifty-percent of these individuals have at least two chronic health conditions (Centers for
Disease Control and Prevention, 2007). These multiple chronic conditions increase their likelihood of disability and the need for professional services, like long-term care, to help them in maintaining their functional independence. Common chronic illnesses which face adults aged sixty-five years and older are hypertension, arthritis, hearing impairments, heart disease, cataracts, orthopedic impairments, and diabetes (Hill, Thorn, Bowling, & Morrison, 2002).

Medical Conditions Associated with Aging

In addition to the above chronic illnesses which are commonly associated with today's senior citizens, it is important to understand that a disability due to a cognitive impairment is also a risk factor for long-term care placement. Cognitive impairments typically involve a form of dementia. Dementia impairs one's memory, language, judgment, and abstract thinking, thus affecting one’s ability to maintain functional independence and activities of daily living (Hill et al., 2002).

Broken hips, weight loss, cancer, and pressure ulcers are other medical conditions which affect elderly persons and often lead to necessary admission into a long-term care facility. These types of age-related functional impairments often lead to necessary rehabilitation services, and can result in long-term care placement at a nursing facility. With an estimated five percent of United States’ adults over age 65 residing in nursing homes, it is important for facilities to be prepared for their physical, psychological, and behavioral needs (Hill et al., 2002).

Long-term Care Services

Long-term care encompasses many different services for the residents. One can define this type of residential setting as place which provides assistance with instrumental activities of daily living such as laundry, meals, household upkeep, organized activities, transportation, and medication supervision. There is a continuum of care which provides housing and social support, professional services, and assistance with self-care functions such as bathing, toileting, and dressing (Hill et al, 2002).
Frail elderly persons who are in need of residential care, such as a skilled nursing homes, commonly have three characteristics which differentiate them from independent older adults who live in the community. These characteristics include (1) being an advanced age, (2) having a disability, and (3) having limited resources to live independently in the community (Hill et al., 2002). Because disability increases as a function of the advanced aging process, it is important to be aware that the longer an adult lives, the more likely that he or she will become disabled. Chronic illnesses, such as cancer and heart disease, are a source of disability. These illnesses are a dysfunction or disease that lasts a long period of time, involves a period of remission and an increase of symptoms, and increases the likelihood of functional impairments (Hill et al., 2002).

Advantages and Disadvantages to Formal Caregiving

There are both advantages as well as disadvantages associated with the formal caregiving setting. Advantages of long-term care include 24 hour monitoring from trained and licensed nursing staff. Formal caregivers check on all residents in the facility during required rounds and are prepared to assist with any medical conditions at all hours of the day. Twenty-four hour assistance is important in a long-term care facility because residents need to be toileted in the middle of the night, as well as get required treatments, tube feedings, wound care, and medications. Another advantage associated with long-term care includes the family caregiver being provided with reduced responsibilities. Greater safety for older adults who are at a risk for falls, dizziness, wandering, and fainting is provided within the facility's safety interventions. Examples of these interventions include fall mats and bed alarms. The companionship of having other older adults around in the facility is another advantage of the formal caregiving setting. Often older adults who are residents are able to make friendships and have new relationships within the facility (Beckerman & Tappen, 2000).

The disadvantages associated with the formal caregiving setting include the impersonal institutional care that is provided in formal settings by strangers. It can be
difficult for new residents to become acclimated to unfamiliar people providing them with their care, rather than family members. Limits on independence and freedom are two disadvantages to formal caregiving, which is often a difficult adjustment. Within the formal caregiving setting, there are many policies and rules which residents and their family members must follow in order to protect the resident, and the facility. Examples of these rules include limited visiting hours and scheduled meal times. A loss of privacy is another disadvantage within the formal caregiving setting. Limited numbers of private rooms within facilities make privacy difficult (Beckerman & Tappen, 2000). Other difficulties include watching roommates die and regularly having to get adjusted to new roommates. Other privacy issues include shower rooms, the sharing of bathrooms, and a common lack of personal phones in each resident’s room.

**Formal Caregiving Requirements**

There are many job duties and requirements of the formal caregivers who work within the long-term care field. Using a team approach within long-term care facility staff allows for multiple disciplines to combine their training, experience, and perspectives in order to serve as a support system for one another (Hill et al., 2002). Disciplines within a long-term care facility include the nursing, housekeeping, dietary, recreational, administrative, and social services staff. The nursing staff consists of licensed and registered nurses, as well as certified nursing assistants. Medication passes and treatments are provided by the nurses at the facility, and certified nursing assistant provide care with bathing, dressing, eating, and toileting. The housekeeping staff must pay special attention to infection control and to the sanitizing process of the facility. Because a nutritionally sound and well-balanced meal is essential for residents in long-term care, food service provided by the dietary staff is very important. Specialty diets, such as diabetic diets, are prepared at the facility to accommodate the needs of the residents (Beckerman & Tappen, 2000).
Socialization in Long-term Care

Socialization is increased at long-term care facilities through the use of engaging activities. These activities seek to increase a resident’s social interaction and decrease their isolation (Hill et al., 2002). It is the administrative staff in a long-term care facility who makes sure that all policies and regulations are being following. Examples of these policies and regulations include following all Medicare and Medicaid guidelines, and followed the state and federal laws for long-term care facilities. The social services staff in a long-term care facility focuses on using a holistic approach, one that combines an understanding of the social, psychological, physical, and cultural situation of the elderly resident (Burack-Weiss & Brennan, 2008). Long-term care social workers often provide assistance with long and short term nursing home placement, as well as discharge planning and facility grievances.

As the population in the United States and throughout the world ages at a rapid pace, it is important to understand the formal caregiving process which takes place in long-term care. Psychological, medical, and social services for the elderly are provided, and older adults are monitored twenty-four hours a day. Each formal caregiver in a long-term care facility has care obligations which they are responsible for in order to ensure a safe and healthy environment for their residents. It is through this institutional model that residents are provided necessary and important care, such as assistance with eating, bathing, and toileting (Burack-Weiss & Brennan, 2008)

Caregiver Stress

Caregiving is typically unplanned, unexpected, and not entered into by choice (Aneshensel & Pearlin, 1995). Due to this commonly unforeseen obligation, the difficulty of providing care for an elderly individual is commonly associated with caregiver stress. This type of stress is very common for informal caregivers, particularly those caring for individuals with dementia. Senile dementia of the Alzheimer’s type and other progressive dementias are associated with many hardships (Dura, Stukenberg, & Kiecolt-Glaser, 1990). This is due to the unpredictability and rapid decline of such illnesses. Individuals with dementia typically have the
most significant behavioral impairments (Goldstein, 1989). These dementia-related behaviors often have large consequences on the daily lives of the informal caregivers. It is because of these behaviors, such as intense aggression, wandering, and forgetfulness, that many caregivers become stressed, as well as depressed (Dura, Stukenberg, & Kiecolt-Glaser, 1990). In addition to stress, caring for an individual with dementia is also associated with other negative outcomes, such as depression, anxiety, and diminished health (Mitrani et al., 2006).

Research in the field of gerontology over the past 40 years has shown that caring for an older person with a disability affects the well-being and health of the caregiver (Zarit & Femia, 2008). A wide range of programs and services are available to lessen the stress of today’s caregivers, especially those caregivers of individuals with dementia. Providing care for an individual with dementia is the most challenging type of caregiving, and is also the most frequently studied area of caregiving. In order to understand dementia and to succeed in caregiving, effective treatments for caregivers must be utilized. These treatments have four overlapping characteristics which include a psychological rather than solely educational approach, flexibility, multidimensionality, and sufficiency in the dosage or amount of treatment (Zarit & Femia, 2008).

**Psychological Interventions**

Psychological interventions allow caregivers to apply the general information they receive to their specific situation. New skills are able to be practiced and the caregiver receives feedback and develops plans to implement their new skills in future situations. Flexible interventions draw from a set of approaches without specific time restraints. Multidimensional interventions address multiple stressors and other risk factors that affect the health and well-being of the caregiver. The dosage of treatment intervention focuses on providing more treatment for a better outcome. Examples of this include follow-up counseling session that meet the caregiver’s needs. Ongoing support and treatment has been found to have positive outcomes, for both immediate and long-term time frames (Zarit & Femia, 2008).

Burns, Nichols, Martindale-Adams, Graney, & Lummus (2003) studied the effect of primary
care interventions on alleviating the psychological stress suffered by the caregivers of individuals with Alzheimer’s disease. Targeted educational models were used during the study which focused on patient behavior management and caregiver stress-coping management. The implications of the research suggest that brief primary care interventions may be effective in the reduction of caregiver distress and burden in relation to the long-term management of the dementia patient. The researcher also suggests that interventions need to focus on care recipient behavior, as well as caregiving issues, in order to reduce caregiver distress.

Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels, & OldeRikkert (2007) focused their research on understanding the effect of community occupational therapy on the quality of life, mood, and health status in dementia patients and their caregivers. Community-dwelling dementia patients and their caregivers aged 65 years and older received occupational therapy for a five week period, with a control group receiving no therapy. Behavioral and cognitive interventions were used which trained patients with assistive devices which compensated for their cognitive decline. The dementia caregivers’ interventions focused on the coping of behaviors and the supervision of the individual with dementia. The results of this study show that community occupational therapy improves dementia patients and their caregivers’ mood, quality of life, and health status, as well as improves the caregivers’ sense of control over life.

Primary Caregivers

Although there are informal caregivers who are not family members, family members tend to often be primary caregivers. This is due to the family typically being the closest and most influential interpersonal contact throughout the life span. When an older individual requires care, the person most likely to assume the responsibility is the spouse. Children or others typically provide the primary care when there is no spouse present (Goldstein, 1989). Having family members as caregivers certainly increases the risk of caregiver stress for a variety of reasons. Different family factors, such as communication patterns, marital cohesion, conflict, and boundary ambiguity are related to the caregivers’ emotional functioning (Mitrani et al., 2006).

Mendez-Luck, Kennedy, and Wallace (2008) examined the concepts of burden related to
giving care to older relatives with a sample of female caregivers in Mexico City. Semi-structured interviews were used in an attempt to better understand the caregivers’ experiences and feelings of burden. Although some of the caregivers viewed burden as a positive sacrifice that involved good will, initiative, and love, burden was also viewed very negatively by some of the caregivers. They stated that they felt emotionally and physically heavy from all of the work their caregiving entailed. They also stated that their lives were complicated by the caregiving, and that their lives were disrupted due to the difficult tasks involved, such as feeding and toileting. These results suggest that while some caregivers view caregiving as positive, many caregivers view their required tasks as tiring and stressful.

Caregiver stress is a consequence of a process that comprises a number of interrelated conditions. These conditions include socioeconomic characteristics, the caregivers’ resources, and the primary and secondary stressors in which the caregivers are exposed. Primary stressors in caregiving include the hardships and problems which are directly tied to caregiving. Secondary stressors are separated into two categories with one being the strains which are experienced in the roles and activities outside of caregiving, and the other being intrapsychic strains. These strains involve the reduction of self-concept. Coping and social support for the caregiver can be an intervention throughout the stress process related to caregiving (Pearlin, Mullan, Semple, & Skaff, 1990).

Caregiver Stress Consequences

Being an informal family caregiver is a stressful role with deleterious consequences for the individual providing care (Aneshensel & Pearlin, 1995). Caregiver stress can be associated with a lack of preparedness for the caregiving experience. Many family members feel as though they do not have the necessary knowledge and skills to provide the appropriate care for a person with a chronic illness, thus resulting in caregivers feeling unprepared and lacking confidence (Given, Sherwood, & Given, 2008). Without a large amount of guidance from medical providers, many caregivers feel as though they do not know how to assume the caregiver role, and that they are not familiar with the type and amount of care needed. Another concern of informal caregivers is the lack
of knowledge regarding understanding how to access and utilize the necessary resources for their
person in their care. These feelings of uncertainly and unknowing contribute to distress within the
caregiver (Given et al., 2008).

Yedidia and Tiedemann (2008) studied 40 family caregivers in order to understand the
spectrum of needs necessary for caregiving. The results of the study suggest that caregivers need
information about the services available to them, successful stress management and strategies,
and assistance with financial issues and insurance coverage. Caregivers also need support in
communicating with professionals, finding out information on diseases, and recruiting
competent help. The caregivers needed training to learn appropriate care tasks and ways to
communicate with someone with dementia. Legal advice and information about adverse drug
reactions were other issues that the caregivers wanted to further understand. These results show
that there are many issues and concerns that today’s caregivers should know more about in order to
provide good care. Without a clear understanding of the important issues mentioned above,
caregivers cannot meet the needs of the individuals in their care.

Williamson and Schulz (1993) examined the strategies Alzheimer’s disease caregivers
used in coping with specific caregiving stressors. The researchers found that the most commonly
identified stressors included were loss of the ability to communicate, memory deficits, and the
gradual decline of a loved one. Strategies related to coping with these stressors included taking
direct action when coping with memory deficits, seeking social support when dealing with the
decline of a loved one, and finding acceptance in dealing with the communication impairments
and decline of a loved one.

Chappell and Reid (2002) examined the distinction between caregiver burden and well-
being. The overall quality of life of caregivers was assessed using a path model in which burden
was conceptualized as distinguishable from well-being. The findings of this study suggest that
the quality of life of caregivers could become better, even with burden in their lives. Well-being
in this study was directly affected by certain variables which included perceived social support,
burden, self-esteem, and hours of informal care. Burden in this study was affected directly by
behavioral problems, frequency of getting a break, self-esteem, and informal hours of care, but was not affected by perceived social support. These findings show that perceived social support is strongly related to well-being, but unrelated to burden.

Stress in Formal Caregivers

Caregivers who work in a formal setting with older adults have many experiences with individuals who have physical, cognitive, sensory, and emotional problems. In long-term care facilities, these caregivers spend hours each day assisting older adults with different job tasks. For a direct care worker, most likely known as a nursing assistant, these tasks include bathing, dressing, feeding, and toileting the residents. For social services associates and nurse managers, these job tasks typically include assessing the older adult, developing care plans, counseling the family and the older adult, monitoring, reassessing, and evaluating the progress and care provided at the facility (Burack-Weiss & Brennan, 2008).

Working with older adults in long-term care can certainly be challenging. Although this type of occupation is a type of human service work which offers many rewards, it also presents many demands (Thompson, 1995). Like informal caregivers, formal caregivers also face stress and burden due to the demands of their caregiving.

When working with older adults in a formal setting, formal caregivers must understand the power of relationships. Differences of opinion and conflict are common within any intense relationship (Burack-Weiss & Brennan, 2008). When providing care to older adults, formal caregivers must commonly understand that there may be a refusal of care which can add stress to the caregiver’s relationship with the older adult.

Working with older individuals who are dependent due to illness and disabilities can create numerous stressful situations for formal caregivers. It is often difficult for elderly persons to come to terms with an unexpected medical diagnosis, the loss of independence, or the loss of control over their life. These individuals may be in shock or disbelief and may face such emotions as anger, sadness, and denial (Burack-Weiss & Brennan, 2008). Assisting these individuals as they go through the continuous aging process can emotionally affect the
caregiver, as they seek to provide comfort and the necessary services for the older individual. Anticipatory empathy provides the caregiver the opportunity to assist the older individual through one-on-one contact as one way to better understand the situation that the older individual is going through. This is beneficial for both the caregiver and the older adult (Burack-Weiss & Brennan, 2008).

**Common Stressors**

Common stressful issues that the former caregiver, as well the older individual, must go through include physical care, such are attempting to prevent falls and wandering, as well as clinical care issues, such as maintaining colostomy bags and changing dressings on wounds and bedsores. Former caregivers also must deal with bathing and toileting the residents in the facility, as well as monitoring medications. Dealing with incontinence is another stressful issue for formal caregivers. This is due to many elderly residents needing incontinence briefs and having a lack of control over their bowels and bladder (Bumagin & Hirn, 2001). Often these incontinence episodes are embarrassing for the elderly individual, and may make them agitated, which can add stress to the caregiver. It is not uncommon for the duties of incontinent management to become the focus of conflict between the caregiver and the care recipient (Bumagin & Hirn, 2001).

Although nursing homes provide skilled nursing and medical care, as well as other professional support services for those with mental and physical disabilities, it is important to understand the stress that formal caregivers in such a facility face. Working with individuals who have communication, hearing, or vision problems, as well as those who suffer from dementia or other health problems takes a toll on caregivers. One must understand that psychological, emotional, and social support must be offered to caregivers in an attempt to reduce their stress and burden in order to improve their abilities to provide care (Naleppa & Reid, 2003).
Decision Making Process to Enter Long-Term Care

Family caregiving research has focused primarily on the relationship between the demands of being an in-home care provider and caregiver outcomes, such as burden and distress. There has been much less research focusing on transitions into or out of the caregiving role (Schultz, Belle, Czaja, McGinnis, Stevens, & Zhang, 2004). The placement of an elderly individual into a long-term care facility in order to ensure the coordination and continuity of care is known as transitional care. Transitional care consists of a broad range of environments and services which are designed for the safe passage of patients across care settings and between different levels of care. Maintaining a high quality of transitional care for older adults with chronic conditions is especially important for elders, and their family caregivers (Naylor & Keating, 2008). Poor communication, an incomplete transfer of patient information, a limited access to important services, and inadequate education of older adults and their family caregivers all contribute to gaps in care during transitions of elderly individuals.

Although being a caregiver can be very rewarding, it imposes many burdens on family members. Gaps in transitional care, as mentioned above, can be very stressful for the elderly patient, as well as for their family caregiver. The stress and burden of caregiving can certainly increase during the transition to a long-term care facility. It is important for nurses and social workers to tend to the emotional needs of the caregivers in order to assist them in minimizing their negative experiences during their difficult time (Naylor & Keating, 2008). Other implications for the support of family include focusing on the needs, preferences, and goals of the elderly patient and their family caregiver, and improving communication among patients and family caregivers. The lack of knowledge, skills, and resources of family caregivers is a strong barrier to effective care (Naylor & Keating, 2008).

It is estimated that as many as 90% of patients with dementia become institutionalized before their death (Yaffe et al., 2002). Prior to this institutionalization, most patients with dementia continue to live in their communities until family members are no longer able to provide their care. The decision to place a dementia patient into long-term care is complex, and is based on both patient
and caregiver characteristics. Other deciding factors include the sociocultural context of the patient and the caregiver (Yaffe et al., 2002).

**Transitional Care**

Transitional care for individuals with dementia care affect caregivers differently than non-dementia caregivers. Because nearly half of all nursing home admissions ages 65 years or older have dementia, it is very important to assess and understand the effects of a long-term care transition on the dementia caregiver. Schultz et al. (2004) sought to assess the impact of placing a relative with dementia in a long-term care facility on the caregivers’ health and well-being. The results of this study show that caregivers who institutionalized their relative reported their depressive symptoms and anxiety to be as high as they were while providing care in their home. These results show that the transition to institutional care can be very difficult for caregiving spouses, almost half visit their relative daily and continue to provide help with care during their visits. A clinical intervention for the caregiver that better prepares the caregiver for a placement transition may greatly benefit the caregivers.

**Predictors of Placement**

Yaffe et al. (2002) focused their research on determining the comprehensive predictors of placement among an ethnically diverse population of dementia patients. The results of their study show that both patient and caregiver characteristics are important determinants of long-term care placement for dementia patients. Interventions used in this study were directed at delaying long-term care placement, such as the reduction of caregiver burden or difficult patient behaviors. These interventions consisted of expanded in-home and community-based services, as well as case management. These interventions must take the patient and the caregiver into account as a unit in order to effectively work. The caregiver characteristics which were associated with patient admission into a nursing home included older age, being married, being functionally dependent, caregiving for at least 90 hours a week, having at least six depressive symptoms, and have a higher burden score on the scale used in the study. If the caregiver in the study had an annual income of less than $10,000 or was a daughter or daughter-in-law, the dementia patients
were less likely to be placed in long-term care. Ethic differences in the study sample showed that black or Hispanics were less likely to be placed in a nursing home. Dementia patients who lived alone and had greater ADL dependencies, lower scores on the mental scale used in the study, and had at least one difficult behavior were more likely to go to a nursing home. This study provides the interesting association between ethnicity and other characteristics and the risk of nursing home placement.

Gaugler, Kane, Kane, Caly, & Newcomer, (2005) studied the effects of the duration of caregiving on institutionalization. The researchers were interested in understanding how key care demands, such as dealing with problem behaviors, influence the institutionalization of the individual needing care. This study focused on having a better understanding of the wear-and-tear hypothesis, which suggests that the longer a caregiver remains in their role, the more likely negative outcomes will occur. Negative outcomes include caregiver distress and institutionalization for the care-recipient. The results of this study show that dementia played a large role in the caregivers’ decision to institutionalize this individual in their care after a certain duration of time. Also shown in these results is the importance of providing interventions early in the dementia caregiving process.

There are many predictors and risks for institutionalization for individuals who require care from caregivers, particularly those with Alzheimer’s disease (AD) and other forms of dementia. Significant risks for institutionalization include functional impairment, increased cognitive decline, behavioral disturbances, and incontinence. Other risks factors for institutionalization include increased assistance with ADLs, caregiver exhaustion and burden, and depression (Liken, 2001). With an individual with AD, families often feel uneasy prior to institutionalization and guilty following institutionalization.

Johnson, Schwiebert, and Rosenmann (1994) sought to understand the decision making process involved when an older individual is relocated to a nursing home. Identifying the factors influencing the placement of older adults in the nursing home was a purpose of this study, as well as describing the process in which this placement decision occurred. The researchers
explain that the relocation of older individuals to a more supportive environment, especially a nursing home, is a psychologically and physically stressful life event for both the older individual and their caregiver. Common effects of this relocation may include anxiety, depression, illness, and possible death. This findings of this study described nursing home placement as an arrangement of beliefs, family dynamics, and experiences related to the older adult. The factors which influenced nursing home placement in this study included health issues, caregiver issues, and a fear of living alone. The older individuals in the nursing home emphasized that the care provided to them at the nursing home is care that they would be unable to have if they were away from the facility in their own home. Caregiver issues from this study included family dynamics surrounding an older individual’s decision to move. Family members’ personalities or lack of capable family members caused them to come to a nursing home. Some subjects did not want to be a burden to their family members, and felt as though their family member may not be capable of taking care of them. The fear of living alone was an important issue in this study, due to subjects describing the fear that they had when being unable to take care of themselves.

Many factors, both positive and negative face today’s informal caregivers. Although providing care for an elderly individual can make the caregiver feel helpful and needed, it can also bring on feelings of stress and social isolation. Caregiver burden, which includes restricted social contact, the number of tasks performed, deteriorating physical or mental health, and the feelings of stress and strain, can lead informal caregivers to seek long-term institutionalization. Through understanding these experiences, in addition to other challenges faced by informal elderly caregivers, health care professionals can be better prepared to assist caregivers with their challenges. This research attempts to capture caregivers’ experiences and challenges in order to understand their decision to seek long-term care institutionalization.
CHAPTER THREE
 METHODOLOGY

Choice of Qualitative Research Methods

Qualitative research is characterized as research which seeks to understand, portray, and sometimes explain social phenomena. The data collected through qualitative research were obtained through studying experiences of individuals or groups, analyzing interactions and communications of participants, and through the collection and interpretation of different types of documents, such as texts and images (Flick, 2007). The researcher chose to use qualitative research methods for a number of reasons. First, qualitative research techniques were appropriate for this study because they allowed the researcher to include herself as an important part of the research process. Qualitative researchers access experiences, documents, and interactions in their natural context, and use concepts in their research process (Flick, 2007). They are able to understand the life experiences of the study participants through their data collection.

Qualitative researchers draw from these experiences and the organized patterns of behavior displayed and are able to generate theory, thus forming a study which takes place in the participants’ own environment. This field research helped the researcher understand daily life from the participants’ perspectives. The selection of the setting or social group used in the research was based on the researcher’s interests (Bailey, 2007). In this study, the in-depth interviews took place in the preferred setting of the former caregiver. This allowed the participants to be in a familiar setting,
rather than in a foreign place. The researcher wanted to have the participants feel comfortable and relaxed during the interview process, in hopes of being provided with a deep understanding of the decision making process of informal caregivers regarding nursing home placement. A second reason for using qualitative research methods is that they worked well with the theoretical framework used in this study. The experiential learning theory was used in this study because it focused on using experience as a way to analyze the interactions of people and their environments, thus linking action and thought, which leads to learning and understanding. Experiential learning makes sense of active engagement between the inner world of the person and the outer world of the environment (Beard & Wilson, 2006). The informal caregivers’ in-depth interviews allowed the researcher to understand their interactions with the elderly person who was in their care, as well as understand why they had to make the decision to seek professional caregivers. A third reason for using qualitative methods in this research was that open-ended interviews provided the participants and the researcher, an opportunity for reciprocal communication during the interviews, allowing for a dialogue (Bailey, 2007). The use of open-ended interview questions allowed the researcher to learn and understand the perceptions, attitudes, and beliefs of the informal caregivers. It was also beneficial because it allowed for flexibility, including the use of probes and follow-up questions, during the interview process (Bailey, 2007). The researcher was more informal during the interview process in order to make the participants feel at ease and talk freely about their experiences and points of view. Through asking questions and using probes such as “Could you explain that?” and “What do you mean?” the researcher was able to provide more details to experiences which responders are describing (Bogdan & Biklen, 2007). This type of questioning provided the researcher with an opportunity to establish rapport during the interview, with the hope of increasing the interview’s quality.
Qualitative Research in Caregiving

Qualitative research can be especially beneficial when studying informal caregivers of the elderly population. During the qualitative research process, the researcher was given the opportunity to generate useful knowledge, which enriched her understanding of the experiences that affected informal caregivers (Hollway & Jefferson, 2000). These face-to-face interviews allowed a dynamic interaction between the research and the study participants. These interviews provided communication between two people in which knowledge was generated through the posing of questions by the researcher regarding long-term care placement decision making, and the responses provided by the participants (Mauthner et al., 2007). Second, as mentioned above, in order for the researcher to gain an understanding of the personal experiences of the informal caregivers which led to their decision to seek long-term care placement, the setting of a study was very important. The use of descriptive research which takes place in a familiar setting increases the validity of the data collected, due to the researcher being provided with a more holistic picture of the caregivers and their everyday lives (Bailey, 2007). The researcher was then better able to capture the deep meaning of experience in the participants’ own words, and through the immersion into their setting. The familiar setting of the research defines the study in qualitative research, thus intimately linking the research to that particular location (Marshall & Rossman, 2006). In the case of this study, the familiar setting was the choice of the former caregiver being interviewed. Interviews took place in different settings, to include their personal residences and in the nursing homes where their family member resides. These settings were familiar to the study participants, which was appropriate for the necessary data collection. Third, qualitative methods allowed the researcher the opportunity to seek data that are not limited to short, closed-ended responses which provide little understanding as to what the informal caregivers’ decision making process entails. In-depth interviews, also referred to
as unstructured or open-ended interviews, typically gives the researcher the opportunity to spend a considerable amount of time with the study participants in their own environment asking questions, and recording their responses (Bogdan & Biklen, 2007). This open-ended format permitted the participants to answer the questions from their own frame of reference, rather than from one which is structured by prearranged questions. This often led to the participants of the study being able to freely express their thoughts around particular topics (Bogdan & Biklen, 2007). A fourth advantage to the use of qualitative methods in caregiving research is that personal interaction was used in an effort to provide the researcher with a better understanding of the informal caregiving experience. Personal interaction provided the researcher the opportunity to listen to the positive and negative experiences associated with informal caregiving, and to understand the difficult decision to seek long-term care placement in a nursing home. The characteristics of qualitative research described above explain the importance of using qualitative methods in assisting our understanding of the decision making process of informal caregivers regarding long-term care institutionalization.

**Phenomenology Research Approach**

Understanding the meaning of events and interactions to ordinary people in particular situations is the purpose of the phenomenological research approach (Bogdan & Biklen, 2007). This approach is not only a description of a phenomenon, it is also an interpretive process which involves the researcher making an interpretation regarding the meaning of lived experiences (Creswell, 2007). This research approach focused on the interpretive understanding of human interaction regarding the decision making process of informal caregivers seeking long-term care.

The principle founder of this approach was philosopher Edmund Husserl (Denzin & Lincoln, 2005). Husserl believed “that the relation between perception and its objects is not passive. Rather, human consciousness actively constitutes objects of experience. Consciousness, in other words, is
always conscious-of-something. It does not stand alone, over and above experience, more or less immaculately perceiving and conceiving objects and event, but, instead, exists always already-from the start-as a constitutive part of what it is conscious of” (Denzin & Lincoln, 2005).

In addition to Edmund Husserl, Alfred Schutz is another leader in the field of phenomenology (Denzin & Lincoln, 2005). Schutz argues that the social science field should focus on the ways that the world is experienced by its members. It is as though one must focus on the ways that they take objectives and events to be real in existence. This process allows experiences to be given shapes, thus resulting in knowledge (Denzin & Lincoln, 2005). The phenomenology approach used in this study was hermeneutical phenomenology. Hermeneutical phenomenology is research that is oriented towards lived experiences and interpretations of life (Creswell, 2007).

This phenomenological research approach was used because the researcher in this study sought to understand the meaning of informal caregivers’ events and interactions and understand how they affect the decision to seek long-term care. The researcher sought to understand which experiences affected their decision making, through the interpretation of these experiences. Understanding the human interaction of the caregiving process was important for this research approach. Caregiving can be a very stressful and negative experience frequently due to reasons such as dementia behaviors and chronic illnesses. The researcher realized that these experiences and interactions of the caregivers painted a picture of how ordinary people in particular situations were able to make an important decision that affected their life and the life of their loved one.

Focus of the Study

The focus of this study was understanding the decision making process of informal dementia caregivers regarding nursing home placement. The participants chosen for this study were former informal caregivers who had recently placed an elderly family member who was in their care into a
nursing home. The researcher chose this study focus due to understanding that informal dementia caregiving has a profound effect on the individual providing care, the person receiving the care, and the decision to seek nursing home placement. The literature related to informal dementia caregiving provides some explanations for this effect, but few studies about the topic have focused on understanding this decision making process.

As more and more individuals grow older, need assistance with their activities of daily living, and are becoming diagnosed with dementia, more family members are becoming informal caregivers. It is important to explore the experiences of these caregivers, in an effort to understand the events that lead up to seeking formal care for elderly family members. It is worthwhile to listen, be aware, and to understand the challenges that they experience.

**Research Questions**

In order to investigate the decision making process of informal caregivers regarding long-term care institutionalization, the researcher needed to have an understanding of the following research questions. These questions provided the framework for this inquiry.

1. How do caregivers understand the transition of placing their loved one in a nursing home?
2. What does the decision process mean to them?
3. How do caregivers cope with this transition?

**Methodology: Multiple Methods Approach**

In addition to the in-depth interview, field notes recorded before and after each interview by the researcher, and a reflective journal kept by the researcher were the multiple methods of data collection used during this study. The in-depth interviews, focused on the above questions, were the primary method of data collection. The field notes taken by the researcher consisted of what she heard, saw, thought, and experienced during each data collection session (Bogdan & Biklen, 2007). Field notes allowed for the meaning and context of the interview to be better captured. The tape
recorder used during this study was unable to capture the sights, impressions, and extra remarks said before and after the interview. The field notes taken from each interview served as a personal log which kept the researcher on track during the processing of the interview data (Bogdan & Biklen, 2007). The use of a reflective journal allowed the researcher an opportunity to use critical reflection and thinking in order to better understand the environment from which she was collecting data. She was able to use thick description throughout her field notes and reflective journal. This form of reflection permitted a more personal account of the interview. Speculation, feelings, ideas, and problems were written in this journal, which allowed the researcher to open up about her research journey (Bogdan & Biklen, 2007). The researcher also made notes regarding data saturation, when she felt as though she was no longer seeing or hearing new information from the interviews.

**Critical Incident Technique**

The critical incident technique (CIT) focuses on gathering qualitative information from incidents which one has experienced. This technique was first created and used in qualitative studies by J.C. Flanagan. Flanagan created the CIT as a means to gather information, such as factual knowledge regarding specific and significant behaviors, in order to make logical conclusions (Flanagan, 1958). When this technique was devised, it assumed a positivist approach and was used primarily in occupational settings (Chell, 2005). The technique uses unstructured interviews to capture the frames of reference, thought processes, and the feelings about a particular incident that has meaning for the participant in the study. When the CIT is used during an interview, it can be a form of storytelling (Boyatzis, 1998). During an interview, the study participant can be asked to describe what led up to a particular situation, who was involved in the situation, and what was the outcome of the situation. Through using the CIT during an interview, the interviewer acts as a journalist in order to attempt to minimize leading cues and get the interviewee to describe their
actual behaviors and statements (Boyatzis, 1998). It is imperative that the interviewee gives an account of what the particular incident means for them in relation to their present circumstances, their life situation, as well as their attitudes and orientation. The CIT is used during the investigation of relevant and significant events and occurrences which are identified by the interviewee in an attempt to gain an understanding of the particular incident from the interviewee perspective. This technique takes into account the affective, behavioral, and cognitive elements (Chell, 2005). When using the CIT, one must use research questions and ideas which focus on the objectives of the study. Locating appropriate study subjects and gaining access to them can require patience and skill by the researcher. During the CIT interview process, interviewees are typically asked to focus on four or fewer incidents that they have experienced about which they have intimate knowledge. The interviewer must attempt to gain useful information from the interviewee’s experiences. It is important to make sure that the interview is controlled and that probes are used to gather information. Clarification during these interviews is essential in order to not miss key information. Following the CIT interview is the transcription and analysis of the data. The CIT was selected for this study because it focused on gathering qualitative information from incidents that the former informal caregiver experienced during their caregiving, as well as during their decision making process to seek long-term care. The participants in this study were able to provide the researcher with an in-depth look at particular situations by allowing the former informal caregiver to share their story during the interview. The CIT allowed the interviewer to understand factual knowledge, thus leading to conclusions, based on the interviews.

Instrument Development

An interview protocol created by the researcher was used during this study. This protocol focused on gaining an understanding in the areas of interviewee background prior to nursing home
placement, the decision making process regarding nursing home placement, and stress and the informal caregiver. This interview was in an open-ended question format and sought to understand the experiences of informal caregivers.

Sample Selection

Purposeful sample selection was used in this study. The subjects of this study, twelve former informal dementia caregivers, were selected because they made the decision to seek long-term care for their elderly family member during the past year. These informal caregivers resided in the metropolitan Richmond area, were the primary caregivers to an elderly family member with a medical diagnosis of dementia for at least three months, and lived with their family member for at least one month while providing care.

Procedures

In order to obtain a sample, the researcher contacted the Social Service Directors in seven nursing homes within the selected geographic area. Of these seven facilities, five Social Service Directors were willing to participate in the study. These Social Service Directors were then mailed recruitment scripts which provided information regarding the study for potential participants with the researcher’s contact information. (Please refer to Appendix A for the recruitment script.) After receiving permission from family members at the facility, the researcher was provided with their contact information and set up the in-depth interviews over the phone. It is through these initial phone calls that interviews were scheduled in the settings of the participants’ choice. During the data collection, analysis, and summary, the researcher protected the identity and confidentiality of the study participants through the use of pseudo names. (Please refer to Appendix B to review the interview protocol which was used.) Following the written consent of the study participants, the
researcher collected data through the use of in-depth qualitative interviews which were audio taped and then transcribed by the researcher. (Please see Appendix C for the consent form.) At times, the interviews did touch on topics that brought out emotion in the study participants. This was an expected reaction, due to the sensitivity of the questions asked. The participants were provided with a list of counseling services and their contact information, should they need to speak with a professional counselor. (Please refer to Appendix D for this information.)

As mentioned above, the participants in the study had family members’ who resided in one of five participating facilities. Six participants had family members from facility A, one participant had one family member from facility B, facility C had two family members, facility D had one family member, and facility E had two family members. Through the use of multiple facilities, the researcher was able to have a variety of former dementia caregivers throughout the selected geographic area.

The researcher used trustworthiness throughout this study. It was very important to pay close attention to the four issues of trustworthiness: credibility, transferability, dependability, and confirmability. Credibility evaluates whether or not the findings of the research represent a plausible interpretation of the data. The data gathered from this study does explain how stress, dementia-related behaviors, and unexpected medical conditions do factor into the decision making process regarding the long-term care placement of individuals with dementia. Transferability is the level to which the findings of this study can be transmitted by the readers of this research beyond the study to another setting or context. It can be understand from the data collected in this study that stressful situations can lead individuals to seek additional assistance, and not just in the case of elderly individuals with dementia. One may transfer the findings of this study to another setting or context which involves a different form of caregiving. For example, an autistic child with unmanageable
behaviors may lead the parents to seek a specialized day care program for additional help. Similar to a dementia caregiver seeking long-term care placement, the parents of the autistic child may also need a break from their caregiving role. Dependability focuses on the value and worth of the data collection and analysis, as well as the generation of theory used in the study. The researcher collected her data primarily through the audio-tapes which were transcribed and analyzed. Through the collection and analysis of this data, in addition to the theoretical perspective of the ELT, the data provided from this study is dependable, and worthy of trust. In addition to dependability, confirmability explains how well the study’s findings are supported by the data collected in the study (Lincoln and Guba, 1985). The researcher of this study used a procedure to check and recheck her data throughout the study. This procedure consisted of replaying her audio-taped interviews, and reviewing her journals and interview notes, in order to make sure that she captured the meanings and emotions expressed during each in-depth interview.

In addition to using trustworthiness, the researcher also used an audit trail during this research study. An audit trail can be described as a transparent description of steps taken during research which began at the start of the research study and continued until the development and findings of the research are complete. The records included in an audit trail explain what was done during the investigation. Examples of these records include raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, instrument development information, and reflexive notes (Lincoln and Guba, 1985).

In this study, an audit trail was used to keep track of what the researcher had done during the study in order to increase the quality of her research, and of the study’s results. She kept every note that was taken during each interview, as well as saved every document written on the computer under a special file. The researcher also used a consistent audio-recording system for each in-depth
interview. Detailed descriptions were used in journal entries, and notes were written prior to and following each interview. During the data reduction and analysis, interview dialogue, journal entries and notes were compared constantly, in an effort to combine themes and reduce reiterations.

Member checking is a process in which each research participant reviews a summary of the data analysis procedure, as well as a summary of the final results of the research. Member checking took place with the participants of this research study in an effort to make sure that they feel as though the data was interpreted correctly regarding their personal experiences. Each member received a transcribed copy of their interview via mail to their home address. A follow up call or e-mail from the researcher confirmed that they received their transcriptions and asked if they agreed with the information collected during the interview. There were some clarifications that were made during these calls and e-mails which were noted by the researcher during her data collection and analysis. The family members interviewed during this study did appreciate this follow-up contact from the researcher. This technique was used in an effort to improve the validity, and accuracy of the study. In addition to member checking, this research study was peer reviewed by experts in the field of gerontology and education. The researcher of this study transcribed the data by hand, and also used a computer-based qualitative data analysis program. Please refer to Appendix A for the recruitment script, and Appendix B for the interview protocol.

**Delimitations**

The delimitations of this study were the restrictions and bounds that the researcher set prior to the beginning of her study to narrow its scope. This study was delimited to dementia caregivers from the metropolitan Richmond, Virginia area. These caregivers had to have provided care to a family member who had lived with them for at least a month, prior to seeking nursing home
placement within the previous twelve months. The researcher focused solely on dementia caregiving due to the prevalence of dementia in today’s aging population. She focused on familial caregiving because family members are often the primary caregivers for elderly individuals living in the community. This study was delimited to nursing home placement, as opposed to other forms of long-term care, due to nursing homes being the primary form of placement for elderly individuals with advanced dementia.

Data Reduction and Analysis Procedures

The researcher downloaded the qualitative program NVivo to pull themes from her in-depth interviews. Also used to analyze her data and focus on commonalities and key themes in her data was the electronic tool titled Wordle. Wordle, found at http://www.wordle.net is a program that creates word clouds from provided texts. (A word cloud is design of words which appear the most frequently from a body of text.) The researcher inserted the answers to each in-depth question asked in her interviews with the former dementia caregivers. From this inserted text, Wordle formulated the main ideas from the text, leading the researcher to better organize her data and then start data reduction.

Analysis of Data

Because qualitative research is conducted through an intense and prolonged contact with an individual’s life situation, a qualitative researcher must gain a holistic overview of the context of their study. This holistic view must be systematic, encompassing, and integrated. The researcher must focus on using deep attentiveness, empathetic understanding, and a suspension of preconceptions, in order to capture data from the depths of the individuals in their sample. It is through this process that certain themes and expressions can be shared (Miles & Huberman, 1994). Analysis done on the words expressed during a qualitative interview can be clustered, subclustered, and segmented in an effort to compare, contrast, and present patterns.
Data analysis began following the first in-depth interview and continued throughout the entire data collection process. The researcher audio-taped and transcribed the in-depth interviews in an attempt to become very familiar with the former informal caregivers’ experiences, thus leading to emergent themes throughout the data. Because qualitative research is subjective, there are many factors that may negatively affect the quality of information collection, coding, and analysis (Boyatzis, 1998). It is because of this that qualitative researchers must use specific steps when analyzing interview transcripts. In interview studies, transcripts are the main data used (Bogdan & Biklen, 2007).

The data obtained from transcripts provided the researcher with the exact words used during the interview process. It is from these exact words that analysis began. After each interview, the researcher transcribed the data and used thematic analysis to seek emergent themes. Thematic analysis is a process which requires the researcher to find a patterned theme in their transcripts. This theme at a minimum describes and organizes the researcher’s possible observation, and at a maximum interprets the aspects of the phenomenon. This type of analysis has many purposes, to include a way of making sense of seemingly unrelated material, a way of analyzing information, and a way of systematically observing a person, group, or situation (Boyatzis, 1998).

The four stages a researcher uses thematic analysis include sensing themes, consistently coding the theme, developing themes, and interpreting the themes in the context of a theory or a conceptual framework, thus assisting in the development of knowledge. When initially sensing a theme, the researcher focused on her notes from her reflexive journal, which included what she observed and thought, and those notes which pertained to decisions made in the course of data analysis. The researcher came up with themes, such as the time commitment of caregiving, the challenges of caregiving, and positive aspects associated with caregiving, following the use of a
coding technique. Open coding was used to construct categories that described different caregiving experiences from the data collection. This raw data was reviewed and dissected into smaller pieces which were then examined and compared in an effort to identify resemblances and differences. It is from these comparisons that groups were formed, thus leading to different themes in the data. Following the development of these themes, they were then interpreted in the context of the ELT.

The stages of thematic analysis are very similar to experiential learning theory (ELT). As mentioned in the literature review, David Kolb’s (ELT) states that apprehension comes before comprehension, which then allows further apprehension, continuing in a learning cycle (Boyatzis, 1998). Codes consist of tags or labels assigned to different units of meaning of data compiled during the study. These codes can be words, sentences, and phrases connected to a specific setting. Focusing on the meaning of these codes is a very important part of the data analysis (Miles & Huberman, 1994).

The researcher of this study used five specific steps to develop themes and codes from the data collected during the in-depth interviews. First, the raw information from the interviews was reduced in an effort to process the pertinent data. This type of data reduction refers to the process of selecting, simplifying, and transforming data that appears in written field notes or transcriptions (Miles & Huberman, 1994). Second, themes were identified within samples of the data. Third, themes were compared across subsamples of data in order to identify similarities. Fourth, sets of statements to differentiate the subsamples were written, and fifth, the reliability of the codes were determined (Boyatzis, 1998). It was very important that the qualitative researcher in the study focused on the regularities, explanations, patterns, propositions, and possible configurations throughout the data analysis process (Miles & Huberman, 1994).
Additional Data Source Findings

In this study, member checking had two purposes. Primarily, the researcher sought to discuss the results of the interview with the interviewee, get their feedback, and clarify and discrepancies or errors. Secondly, the researcher sought to use the member checks as another source of data. The researcher mailed a copy of each transcribed interview to the interviewee and followed up with a phone call to verify the data in each interview. Most of the interviewees repeated the comments that were shared during the interview, with no additional experiences shared.

Of the twelve interviews which took place, there were few clarifications made through the member checking process. These few clarifications were documented and added to the original data prior to analysis. All caregivers agreed that the researcher had quoted and described their caregiving experiences accurately. Only one caregiver adamantly clarified that she did not have as much social support as she had originally mentioned in the initial interview. She wanted to make sure that the researcher knew that there was only one weekend in three years in which someone took care of her mother and allowed her a weekend off. Her original interview gave the perception that this was a regular occurrence, which was not the case. She wanted that cleared up right away in order to make it known that other than her husband, she had no other assistance in the home with her mother, with the exception of this sole weekend. The researcher added this information to her data, making a note in her reflexive journal.

The reflexive journal allowed the researcher to better understand the qualitative research process. The data collected in the journal greatly assisted the researcher and supported the data collected in the interviews. Each interview setting was both comfortable and private, thus allowing the caregiver the opportunity to safely share their experiences as well as allow emotion to show without others present. Observations written in the journal included the atmosphere of the setting,
whether it was formal or informal, as well as the feelings of the researcher during the interviews.

The researcher’s field notes made the interview data more credible, especially when writing about the body language and emotions of the interviewees while discussing the challenges of dementia caregiving. These individuals were so close to their family members and each spoke candidly about when they decided that they could no long provide care for their loved ones at home. Listening to their stories allowed the researcher to view the total dedication of these caregivers. Many of these caregivers were very willing to participate in the study with hopes of making a difference for future dementia caregivers faced with similar challenges.

When re-reading her journal entries, the researcher recalled getting emotional during many of the interviews, especially when the interviewees started to cry. When the male interviewees cried when describing the stress and sadness that they experienced when caring for their wives and mothers, it made the researcher weep as well. Seeing grown men get emotional was both difficult and uncomfortable for the researcher, due to her perception that most men do not tend to show emotion. Because the interviews were done in a private setting behind closed doors, the researcher understood that they were most likely more comfortable when providing her with true feelings and emotions relating to the difficult experiences in their life.

The journal entries do reflect the dedication and hopefulness of the caregivers interviewed regarding their decision to seek nursing home placement for their loved ones. Reading journal memos regarding their stories of struggle, emotional and psychological strains, health conditions, and relationship issues, as a result of their caregiving made the researcher relive each interview during the data analysis. The insights provided from the reflexive journal led the researcher to analyze the physical and emotional responses to the interview questions, in addition to the verbal responses transcribed.
Data Management Procedures

All data for this study was managed in a safe and secure setting. Each in-depth interview was transcribed and saved in a password protected Microsoft Word Document. Aliases were used for the individuals in the study in each interview, and each interview provided no identifiable information. All taped interviews will be destroyed following the conclusion of this research project in order to maintain complete anonymity of the study participants. All printed interview transcripts were locked in a file cabinet at the home of the researcher, as well as all field notes and reflexive journal entries.

VCU IRB approval was obtained prior to any research for this study taking place. All criteria for IRB approval were met. These criteria included minimizing risks, integrating a reasonable risk/benefit relationship, and maintaining an equitable subject selection. Also included was the completed informed consent process, and informed consent documentation. The confidentiality and privacy of all subjects involved in this study was maintained.
CHAPTER 4
DATA ANALYSIS AND FINDINGS

Demographic Information

This study consisted of twelve former caregivers who recently sought long-term care nursing facilities for their family members with a medical diagnosis of dementia. The sample was diverse due to the caregiver and family member relationships, ages of the caregivers, and the work statuses of each caregiver. These former dementia caregivers were between the ages of fifty-seven and ninety-one. Each individual was interviewed individually in the setting of their choice. Two elderly husbands, aged ninety-one and eighty-three, admitted their wives into a facility. Two elderly wives, aged eighty-three and seventy-six admitted their husbands into a facility. A third wife, fifty-seven years old, admitted an elderly husband into a facility. There were six daughters included in this sample, aged fifty-eight to sixty-three. Five daughters admitted their elderly mothers into a facility, and one daughter admitted her elderly father. The final participant in this study was a son who admitted his elderly mother into a facility. All twelve former dementia caregivers lived in the metro Richmond, Virginia area and had placed their family member into a nursing home in the same metropolitan area.

Although five of the caregivers were retired during their caregiving at home, three worked full time while providing care in their home. Two caregivers did not work at all during the time, and two other caregivers were forced to retire in order to continue to provide care for their family members. Table 1:1 provides demographic information for the sample.
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Table 1.1 Demographic information for the sample.
Biographical Sketches of the Dementia Caregivers in the Sample

Kittie

Kittie is a very strong woman, aged eighty-three, who provided care for her husband in their home for ten years. Her husband is eighty-seven years old with a medical diagnosis of dementia, and they have been married for sixty-five years. Kittie began providing care for her husband prior to the onset of his dementia, when he had colon cancer in 1999. Kittie is a cancer survivor herself, surviving stomach cancer while providing care in the home for her husband. Following Kittie’s cancer in 2004, her husband had a stroke after which a shunt was placed in his head to drain water from his brain. Although Kittie did not work at the time, providing care for her husband became a full time job.

Kittie’s husband was falling frequently and needed constant attention. She often received help from neighbors who would assist her when her husband fell in the home. She took responsibility for bathing and dressing her husband daily. She did have adaptive equipment added to the home to better accommodate her husband. With two grown daughters, Kittie had no one else at the home regularly assisting with the caregiving. She was often afraid to leave her husband alone in the home, for fear that he would fall, so she took him with her everywhere she went. In addition to the falls, Kittie dealt with her husband’s dementia behaviors as well. Confusion was his primary behavior; he would often get up in the middle of the night very confused and was prone to falling at this time. Her husband would often live in the past, often forgetful of the past twenty years.

During her caregiving, Kittie retreated from social outings and other enjoyable pleasures due to her duties as a caregiver. She stopped playing bridge, which was a big hobby of hers, because she had to take care of the bills, her husband’s health, and other obligations. Following a bad fall in which her husband broke his hip, Kittie had to seek placement in a nursing home for him. Although she did have hopes of bringing him home following
rehabilitative therapy, he currently remains in the nursing home as a long-term care resident due to the inability to walk, and the progression in his dementia. Kittie does feel a sense of relief following the relinquishment of her role as the primary caregiver, but also has a sense of guilt. She has started on anti-depression medication which has really helped her. She stated that it is very difficult to see her husband in his current state because he is very confused. She does feel as though she is extremely lucky to have her family as a social support system. She also feels as though she has had to give up a lot in her life in order to provide care for her husband, due to his poor health condition. When remembering their life together and all that they have been through, she was emotional at the end of the interview.

Bobbi

Bobbi is a fifty-seven year old wife of an eighty-three year old husband with a medical diagnosis of dementia. Bobbi herself is in very poor health, recovering from a broken arm and broken elbow during the time of the interview. She also has rheumatoid arthritis, as well a chronic spine and back disorder. Bobbi and her husband have been married for twenty-eight years, and she has not worked due to being on disability as a result of her poor health; her husband was the sole breadwinner. Although Bobbi herself has the above health conditions, she was the primary caregiver of her husband in their home for a year, prior to her seeking nursing home placement.

Bobbi’s husband had a severe stroke, which affected his short-term memory and led to cognitive impairments. Following a short-term rehabilitation stay, her husband came home and was unable to follow his routine activities of daily living. He was also very irritated and agitated following the stroke. He had mini-strokes which then created more memory loss, as well as seizures. Bobbi had no assistance in her home while caring for her husband, even though there were other family members who could have helped, they did not want to be disturbed. As the sole caregiver, Bobbi was afraid to leave her husband alone because he started falling frequently. She moved closer to town from the country in an attempt to be closer to the rescue squad and hospital, should her husband need help.
Following the move closer to town, Bobbi’s husband became more agitated, as well as verbally and physically aggressive; he also was very combative towards her due to the dementia. Falls during the night were very common, and Bobbi would often have to call the rescue squad for assistance in getting her husband off of the floor. Following these falls, Bobbi made the decision to seek long-term care nursing home placement for her husband. She was afraid that he would fall and break a bone, and she stated that she could not psychologically handle providing care for her husband, due to a lack of sleep and a sense of feeling worn out. She felt as though a nursing home would be in his best interests, especially because she was scared of his behaviors. Following the relinquishing of the caregiving role, Bobbi felt a sense of relief, but also a sense of sadness, because she was now separated permanently from her husband. Bobbi does have her church as social support, as well as friends in the community, which provides her with a sense of comfort.

Alfred

Alfred is an eighty-three year old man who admitted his eighty-one year old wife with a medical diagnosis of dementia into the nursing home. Alfred and his wife have been married for sixty-four years. Alfred initially became the primary caregiver following a car accident in which his wife was internally injured. Following the car accident, Alfred noticed that his wife was becoming forgetful and started having behavior issues. She was unable to be left alone and was getting very agitated. She was becoming depressed and wandering in the evenings as well, which was frightening for Alfred. She was also becoming verbally abusive and easily angered.

Alfred was cooking and getting meals for his wife daily, as well as being with his wife all day. Due to the demands of his caregiving, he started to withdrawal from playing golf and being around his friends in a social atmosphere. Accommodations were made to the house in order for him to keep his wife at home. A new bed was brought into the home, and bedrooms were moved around in an attempt to meet his wife’s growing needs. Alfred had assistance from hospice care. Hospice provided certain supplies and caregiver assistance in the home three days a week. Alfred would toilet his wife routinely, as well as bathe and dress her. She wore briefs as well so he
would change her briefs regularly as well.

Falls were taking place outside of the home. Alfred’s wife fell twice, which was a constant concern. Alfred would take his wife with him to go out to eat and would bring a wheelchair for transport. He was very happy to be able to take her out and have a good time, just the two of them. During one point in the caregiving, Alfred was the primary caregiver to both his wife, as well as to his daughter, who had broken her foot. This was a very stressful time for Alfred, as he had two people to take care of all day.

Alfred’s wife was admitted into the nursing home following a hospital stay due to another health condition. Following this hospital stay, both of her shoulders were dislocated. Alfred stated that there was no way he could take her home with this condition and that he knew long-term care placement in a nursing home was necessary. Alfred now visits his wife regularly in the nursing home, only missing a visit in order to play music or play golf. He is very stressed out about the health condition of his wife because he feels as though she is becoming more debilitated every day. Alfred does have a good social support system, which includes their children. He talks to them on the phone and they stop by to visit him.

Donna

Donna is a sixty-two year old woman who was the primary caregiver of her ninety year old mother, who has a medical diagnosis of dementia, for six years. Donna's father passed away seven years ago, and following his death, her mother went through a depression which led to her being admitted into a psychiatric hospital for depression. In addition to the depression, Donna's mother also had an onset of Parkinson's disease, which made increased care necessary. Donna did have some help from her brother when providing care for their mother, but he also has Parkinson's disease and was limited in the amount of assistance that he could provide. Donna did have caregivers from an agency coming in to the house, so that helped her, but she would still have to toilet her mother throughout the day and night. Although Donna was retired from her job, she had the full time job of coordinating everything from transportation to doctor's appointments, Meals on Wheels, and activities of daily living for her
mother.

In addition to coordinating her mother's care and activities, she also had to deal with her mother's difficult behaviors, which included fighting, pinching, and being physically abusive. The Parkinson's disease eventually made Donna's mother unable to walk, thus leading to her needing a wheelchair. The home in which they lived was not handicap accessible, thus leading to the placement of her mother in a nursing home.

Donna did not feel guilty at all about placing her mother in a nursing home, and she had a great sense of relief following her decision to seek a nursing home for her mother. She felt as though she was able to focus on her marriage and to finally do things with her husband again. Donna does feel a lot of stress currently because her mother is not doing well here at the facility as a result of her Parkinson's disease. She got very emotional when discussing her mother's current condition. She does have a social support system which includes her husband, whom she describes as a rock. She said that he provides her with moral support and strength.

John

John is a ninety year old man who placed his eighty-seven year old wife with a medical diagnosis of dementia into a nursing home. Married for sixty-one years, John did not have time to think too much about the nursing home placement of his wife because it happened as a result of his own admission into the hospital. Prior to his own health condition which led to hospital admission, John was the primary caregiver at home for his wife for two years. John bathed his wife, fixed all of her meals, dressed her, toileted her, and transferred her from chairs into her wheelchair on a daily basis. John was also responsible for giving all medications to his wife.

The couple have four grown children who would stop by and visit, but they never spent the night or really assisted him in the caregiving tasks. He states that they were just there for encouragement. John did have some assistance coming into the home; he had three different nursing assistants from a home health agency who would come for a total of six hours a day.
John's wife was falling at home, which was a concern of his. Although his wife never got injured from any of these falls, John was having to pick her up off of the floor each time she fell, which was a physical challenge for him. John is very thin man and rather frail at ninety years old; he stated that having to continuously pick up his wife was really hard on him. In addition to the falls, John also noticed that his wife's memory was failing due to dementia. His wife started getting confused easily.

Although John is very advanced in his age, he continued to have his own business as a contractor but had to retire due to the caregiving duties that his wife required. He did have other tasks that he was responsible for, including taking care of the home, cleaning, and grocery shopping. Because of his responsibilities, John was not getting a lot of rest in the evenings. He was often up during the night with his wife and felt that after two years, he would not be able to handle the caregiving for much longer. The decline of his health and hospital admission led to the long-term care placement of his wife. John was able to be discharged himself from the hospital, received rehabilitative therapy, and is now living at home with the help of a daily private duty aide.

Jan

Jan is a sixty-seven year old woman who placed her ninety-year old mother with a diagnosis of dementia into a nursing home following living with her for three years. Not only did Jan live with her mother in her mother's home, her husband did as well. The mother and daughter had been neighbors for thirty years and during the decline of her mother with dementia, Jan and her husband had to move in to provide care. Initially, Jan's mother had a bad fall while at home which resulted in a head injury. Following the head injury, her mother had another fall while at home alone in which she broke her leg. Her mother was showing signs of dementia at this point as well, getting forgetful. Jan took her mother to a neurologist and it was determined that she had Alzheimer's disease.

Following the broken leg, Jan and her husband moved into her mother's house under the impression that they would be there for about six weeks. Six weeks then turned into three years in which Jan balanced a full time job while taking her mother to day care
five days a week. She did have assistance from her husband who would help get the mother up in the mornings and ready for day care.

In the evenings and on the weekends, Jan's mother was there at the home, with Jan and her husband providing all nursing care. They did not have any family in the area and there were no friends that could help with the caregiving. There was never a time for a break from the caregiving, as they were very afraid to leave the mother alone in the home. At one point, they were gone for an hour and the mother drank an entire cup of rum, thinking that it was coffee. Following this frightful event, Jan vowed to never leave her mother alone by herself again. This was both time consuming and emotionally challenging.

Jan felt distance between she and her husband during this time period because they never got any time alone with each other, which was upsetting to her. There were no date nights or meals eaten out in three years. In addition to feeling distanced from her partner, Jan was never alone; her mother was constantly following her around the house and trying to help her with tasks, often getting in the way. This was very frustrating for Jan, especially because her mother had become so forgetful and confused, often doing tasks incorrectly due to her cognitive impairments.

Jan's husband was very caring and emotionally supportive during the entire caregiving time period. He reassured Jan that he never wanted her to have any regrets about the end of her mother's life, or ever feel guilty. He would reassure her that they were doing what was best for the mother. Deciding to place her mother into a nursing home ended up what Jan felt was best for her mother. Jan felt as though getting her mother up and dressed very early in the mornings and taking her to day care was getting to be too much for her mother; her mother was getting very exhausted and the constant trips to the daycare were taking a physical toll on her mother. Her mother's dementia had progressed as well, with her no longer recognizing her family members and getting very confused easily. The mother was fortunate that she did not have negative behaviors,
such as aggression.

Jan and her husband were relieved of their caregiving duties, such as bathing, dressing, and toileting her mother following her admission to a nursing home. Following the placement of Jan's mother into a nursing home, she did realize that the caregiving had taken a mental toll on her; she had withdrawn from her friends at work and she had been feeling as though there was no joy in her. She had such a hard time emotionally during the caregiving as she watched her mother change in all aspects; she could no longer talk to her, perform simple tasks, or even recognize her, which was very difficult for Jan to accept.

Jan was able to move back into her home with her husband following the placement of her mother into a nursing home. They were able to reconnect and start going out to eat again and doing the enjoyable activities that they were unable to do for three years.

Pauline

Pauline is a sixty-two year old daughter who had to place her eighty-five year old mother with a medical diagnosis of dementia in a nursing home. Pauline is married and did work full-time while caring for her mother in the home. Pauline first noticed her mother's dementia because her mother started forgetting things easily and was wandering around her apartment complex, as well as getting lost while driving. Pauline initially became the primary caregiver after her mother wandered out in the middle of the night and was found by a neighbor. It was at this point that Pauline moved her mother into her home with her husband. Pauline and her husband made many accommodations for her mother during the time she was in her home. She turned her dining room into a bedroom for her mother and moved furniture into storage.

Her husband was very involved in providing care for his mother-in-law because he had been taking care of his elderly parents prior to this caregiving experience. In addition to her husband, Pauline also had family members who relieved her of some caregiving tasks during the day while she worked. She had a cousin who would sit with
her mother during the day and fix meals and toilet, as well as twin aunts who would come over to the house on a daily basis.

Paula was grateful for the extra assistance because she was often tired after working full-time as a special education teacher. During the weekends when she did not work, she had very limited assistance, and she was constantly feeling as though she never got a break from the work at school and the caregiving work at home. She did feel overwhelmed at times because she never got time to herself, or alone time with her husband. Time management was difficult for Pauline because after work she had to relieve her cousin and then she had to feed her mother, bathe her, and get her ready for bed. At times her mother did not want to sleep, so Pauline would be up all night and then have to work in the morning, which was exhausting for her.

In addition to being tired, Pauline also struggled with health conditions as a result of the caregiving; her blood pressure was high, she was having trouble with her legs from lifting her mother, and she had put on extra weight as a result of eating under stress. After caring for her mother in her home for five years, Pauline decided that she could no longer care for her mother due to the stress and health conditions that she was having, and the fact that she was considering retiring from the school system. Pauline knew that she could not retire and provide care for her mother all day. She was unable to ever go out with her husband and she had socially withdrawn from her friends because she never had the time to get together with them, and they did not understand exactly what she was going through with her mother.

Following her mother's admission to a nursing home, Pauline felt a sense of relief. She did explain that there was also a void in her life initially, because she did not have anything to do in the evenings because she did not have to provide care for her mother. She is very satisfied with the decision that she made to seek long-term care placement for her mother in a nursing home. Her mother has a much better appetite than she did while at home with Pauline, and she is much more mobile, often walking around the facility
and visiting with the staff. Although her dementia has progressed and she does have days were she is lower functioning, overall, her mother is doing very well.

Regarding social support, Pauline is very happy that she has her husband of forty-two years. He has been with her through all of the caregiving and says that she couldn't have found a better guy. She is also very appreciative of the family members who assisted her while caring for her mother in her home; they often come to visit now at the nursing home.

Neda

Neda is a fifty-eight year old daughter who cared for her eighty-two year old mother with a medical diagnosis of dementia in her home for a year and a half prior to seeking nursing home placement. Neda initially became a caregiver in her home after realizing that her mother was having memory problems. During the funeral of her father, Neda's mother asked her who was getting buried. This was the key turning point that made Neda realize that something had changed about her mother. Following the funeral, Neda would bring over labeled food and labeled medications for her mother, who lived an hour away. Her mother had become very forgetful, often neglecting to eat and take care of important tasks, like her banking. Neda would come by the home numerous times a week. Concerned, Neda took her mother to the doctor, who confirmed that her mother had dementia. Neda's mother had a bad fall in the home which resulted in cutting her head. Neda realized that it was unsafe for her mother to be left alone, and it was at this point that she moved her mother into her home and became the sole caregiver.

Neda did not have additional help in the home assisting her with the caregiving. She was a single mother of a teenager, and was also working full-time while providing care for her mother. She had no friends or family who would come over to help, only a sister who lived in South Carolina who didn't visit often. She enrolled her mother into an adult daycare program and would take her in the morning prior to work, and bring her home in the afternoons. Her mother did have behaviors which were very hard to deal with; she would often become confused, mad, and frustrated. She
would wander throughout the house, often taking pictures off of the walls. She would wander throughout the night, sleeping very little, and Neda found herself sleeping on the sofa in the living room in an effort to monitor her mother more closely.

Neda constantly felt as though she was not able to give her mother the care she deserved. The daycare would tell her that he mother was not clean enough and then Neda would feel as though she was not doing a good job. The daycare threatened to report Neda to the department of Social Services, and she felt helpless because she felt as though she did not know how to provide proper hygiene for her mother. She realized that she needed to put her mother into a nursing home after an appointment with a geriatric psychiatrist. He recommended placement for her mother because of the stress that Neda was having from the caregiving. In addition to the doctor's recommendation, Neda stated that her mother's behaviors also played a part in her admission. Because her mother was unable to bathe herself, feed herself, or communicate her needs, she felt as though professional care was necessary.

She initially felt very guilty following the placement because she felt as though her mother had always taken care of her, but that she was not able to take care of her mother. There was sense of freedom following the placement too, but guilt was her primary feeling. She did feel sadness and disappointment that she could not do more for her mother. Currently, she does visit her mother regularly and enjoys their time together; she feeds her mother and sits with her multiple times a week.

Dana

Dana is a sixty-seven year old daughter who placed her eighty-seven year old father with dementia into a nursing home after being his primary caregiver. Dana initially began providing care for her father by running errands, picking up medications, and going to the grocery store for him. Dana realized that her father was having memory impairments when he was out driving one day and got lost. Dana took her father to a neurologist who then diagnosed her father with dementia. Her father had apparently been having mini-strokes that were affecting his
memory, unaware to anyone in the family. He began to routinely repeat himself and was often confused about what was going on. Dana then started spending more time at her father’s home, eventually staying there while caregiving for him in his home. Dana had still been working when she initially began taking care of her father, but had to quit her job in order to become a full-time caregiver. Because of her father’s confusion, he was not able to be left alone in the home. Dana would have to coordinate who would stay with her father at home, should she have to run errands or take care of her own personal tasks. She was afraid to leave her father at home alone for fear of his safety.

She did have other assistance helping at times with her father, to include two private duty nursing aides who would come in a few times a week. Dana also has a husband who would help her at times do tasks like putting her dad to bed, but it was usually Dana who did most of the work. She does have a sister who lives in Northern Virginia, but she would not visit too frequently and seldom helped Dana. She was responsible for the toileting of her father, as well as the bathing, dressing, and grooming. Because of her father’s large size, is was very difficult for her to get him in and out of the bed, as well as off and on the toilet, and into the shower. She has a very difficult time getting him to comply with safety issues as well. Her father regularly refused to use his cane, then his walker, thus leading to a wheelchair.

Dana did rearrange the home in an effort to accommodate her father’s wheelchair, trying to make him more mobile and independent in the home. She also had the bathroom renovated in order to take out the bathtub and put in a walk-in shower. The den and living room were switched in an effort to allow her father an accessible place to relax, and a hospital bed was brought into the home.

Her father’s confusion and dementia continued to be an issue, and her father was falling routinely within the home, which was a constant worry for the family. Her father would fall getting out of the bed trying to use the urinal, fell backwards into the bathtub, and he fell into the shower headfirst. Her father was having behavioral episodes as well, which included being verbally abusive to his wife. His incontinence increased, and he lost control of both his bowels and his
bladder. The behaviors and incontinence did not influence Dana’s decision to seek long-term care, but rather the falls and the injuries sustained from the falls.

When reflecting back on her decision to relinquish her role as the primary caregiver of her elderly father, Dana says that although it was not an easy decision, she knows that she made the right decision because she was very worried that he would severely injure himself from a fall at home. She did feel a sense of relief following the placement of her father, because she knows that she had to put caring for her father before her husband, kids, and issues that were going on in her life at the time. She said that she was at the point where she could no longer care for him, and that there was so much stress from the situation. Dana did state that she has an excellent social support which includes her husband of forty-four years, as well as a daughter-in-law who she is very fond of, which helped her greatly.

Jim

Jim is a seventy-two year old son who was the primary caregiver of his eighty-nine year old mother who has dementia. Jim initially became aware of his mother’s dementia when he noticed that she started forgetting things and was becoming very confused. He became very concerned with her condition and took her to the doctor, thus leading to a diagnosis of dementia. His mother would repeat herself and would also lose her train of thought easily. She began wandering out of the house and around the neighborhood, which was a big concern for Jim.

Jim did have some social support during the caregiving of his mother at home. He has an extended family which includes two cousins who assisted him, as well as a few aunts in the family. Jim’s mother did injure herself cooking on the stove one day and burned her hand. Following this accident, the family pulled together to cook for her and to bring her meals in an effort to keep her from ever cooking again. His mother was a danger to herself in regards to bathing as well. She would often leave the bath water running and would flood the house, creating a very hazardous environment for herself. Falls were taking place frequently also. Jim’s mother fell in the parking lot of a doctor’s office one day, and another day she fell and broke her finger. He tried to prevent her from falling in the home, but it was a constant worry.
neighbors were always attentive and helped Jim and his mother when needed, and the local ambulance would come and help out as well when there was a dangerous situation that had occurred.

The biggest concern for Jim in regards to his mother’s safety was her wandering. She would leave the house during the day, as well as in the middle of the night. the neighbors would often find her, or Jim would have to go looking around the neighborhood, searching for his mother. Jim knew that someone needed to be with his mother at all times in order for her to be safe. This was difficult for Jim because although he was retired, he did have other responsibilities, taking care of his grandchildren. He did have a sitter come in for eleven or twelve hours a day, but his mother needed twenty-four hour care.

Jim stayed up until three and four in the morning every night for a week in order to make sure that his mother did not wander off and this week helped Jim make the decision to seek long-term care placement. He realized that something else had to be done to make sure that his mother would be in a very safe environment, and in order for him to get sleep at night and be able to function properly.

The decision to seek a nursing home for his mother was very difficult for Jim. He did really wanted her to be able to be at home, but he realized that he could no longer handle the responsibility of being her caregiver. He states that he knows that someone needs to be with her at all times due to her dementia, for her safety. He became very emotional during the interview when explaining how he felt really needed as the primary caregiver. He said that she knows that he is still needed and that it is difficult to have her in a facility because she took care of him and he in turn took care of her for as long as he could. He knows that she is getting meals and that she is safe and being cared for, and he said that that takes a load off of him. He is just frustrated that he wasn’t able to do more to help his mother. He is feeling less stressed because he was constantly worried about her when she was home, afraid that she was going to fall or leave the bath water running in the house. Jim stated that now knowing his mother is ok and in a facility has really decreased his stress level.
Jim did and still does have a great social support system. His children and daughter-in-laws and extended families all helped out during his caregiving. He did receive a lot of support from his church members as well, especially because many of them had gone through similar situations with their parents.

Peggy

Peggy is a sixty-two year old only child who has lived with her eighty-five year old mother for the past twenty-six years, following the death of her father. Her mother has a diagnosis of dementia and Peggy started providing care for her mother in their home following the progression of the dementia. Peggy is married and she and her husband have always had her mother living with them for twenty-six of the twenty-seven years that they have been married. Peggy’s mother was very productive and active up until the time she began to have falls. With these falls came injuries which included two broken arms. In addition to her falls, she also had an onset of dementia which increased her need for caregiving. Peggy had health problems of her own which included getting back surgery and needing a lengthy recovery time. Her husband did help provide care for both Peggy and her mother during her recovery, but once it was time for Peggy to go back to work, she continued to be the primary caregiver of her mother. Peggy did have two daughters who helped her out during the caregiving process, but they lived about an hour away and could only help out at certain times. Balancing caregiving with working full-time was difficult for Peggy, but it did help that she had understanding bosses who worked with her and allowed her time off when needed.

Peggy and her husband made many accommodations to their house for her mother during the year and a half that her dementia progressed and her health was failing. These included the widening of doors, adding shorter steps, and making sure that the home was handicap accessible. She also got her mother a hospital bed to make her more comfortable. Peggy admits that the part that she didn’t prepare for was the dementia aspect of caregiving. Peggy did have a caregiver come into the home twice a week to help her with the bathing, but she continued to toilet her mother daily, get her ready for the day in the morning, help her with meals, and get her ready for
bed in the evening. Peggy’s husband did help her out during the day with the preparation of breakfast, but he made it clear that he was not going to sit with Peggy’s mother all day, which made Peggy very resentful. Peggy’s husband would work out or run errands because he was retired, and he did not mind leaving Peggy’s mother alone in the home by herself, even though it was a safety issue.

Peggy’s mother started to have behaviors which were very severe. She believed that someone was trying to poison her food and would not eat; she was becoming very paranoid. She was taken to the doctor who did blood work and it was affirmed that she had dementia. Caring for her mother without these behaviors was difficult enough; Peggy and her husband would have to pick up her mother off of the floor numerous times because she would try constantly to get up. In addition to this, Peggy’s mother was having delusions and hallucinations. One night when her mother became increasingly delusional, and began shaking violently, Peggy had to call the rescue squad and have her admitted to a psychiatric hospital. It was from that hospital that her mother ended up getting admitted to a long-term care nursing home.

Peggy felt and continues to feel an enormous amount of guilt associated with the nursing home placement of her mother. It was very traumatic to have to call the paramedics and to have her mother admitted into a psychiatric hospital, and to not have her able to return home has been very difficult for Peggy. This is the first time while they have been married that Peggy’s mother has not been with them in the home, and it did take some time to get used to that. She also has a lot of extra time for herself now that she does not have to assist her mother in the mornings and evenings with care. She is happy that she has her house family and her work family. She has her daughters and husband there for her who understand all that she has been through with her mother, and she is able to share what is going on her life with her friends at work, who care about her and want her to be happy and healthy.

**Crystal**

Crystal is a seventy-seven year old wife who cared for her seventy-seven year old husband who has dementia. They have been married for thirty-six years. Crystal started out being
a caregiver initially because her husband had other health conditions in which he needed her assistance with his car. For two years, he was not well in the home and he did not do much of anything around the house. He would attempt to cut the grass but would fall in the yard. He would try to help out and while washing dishes one day, he fell in the kitchen and had to crawl to the phone to call the rescue squad for help. Another time when her husband was trying to get the clean clothes off of the clothing line, he fell and hit his head on one of the house steps. Crystal said that her husband would often get dizzy and fall, and his legs would give out easily, thus creating a safety concern.

Crystal was very busy in the home, caring for her husband, as well as having to do all of the tasks that he was not able to do. She did all of the cooking, as well as the other necessary household tasks. Following a stroke, her husband was admitted into the hospital, and then into a long-term care facility. Crystal could not consider bringing him back home once he was admitted because it was just too much work for her. Her husband was incontinent and she was not able to handle toileting him in their home.

Crystal’s husband does have a diagnosis of dementia and does get confused at times. He does not have many changes in his behavior, according to Crystal, and he tends to just get forgetful at times. Crystal says that his dementia is a result of the stroke that he had prior to coming to the nursing home. The dementia was not a factor in her decision to seek nursing home placement, rather the incontinence and the lack of mobility of her husband. He is in a wheelchair and unable to walk, so Crystal knew that she could not provide care to him at their home.

Crystal does live alone and does not drive, however, she does talk to her children on the phone a lot, and she considers them her social support. She is also active in her church, and talking about her experiences and the stressful situation that she was in with her peers at church did make her feel better.

Initial Caregiving Experience

Caregiving for an elderly individual can begin initially due to a variety of situations. Often the start of caregiving, especially dementia caregiving, can be the onset of inappropriate behaviors,
such as wandering and becoming aggressive. Other informal caregiving situations may begin as a result of a fall, stroke, or accident. The caregivers in this study were asked to describe what initiated started their dementia caregiving experience. When the researcher designed her study, she was expecting to have dementia behaviors as the primary response for the onset of the caregiving. From the first interview, she was made aware that dementia behaviors were only one of three main causes for the initial caregiving. One main cause found in the caregiver’s response to the question of what led to the initial caregiving, was a trip to the hospital following an unexpected health condition, such as a stroke. Four caregivers in the study sample described having to become the primary caregiver following an unexpected admission to the hospital.

Bobbi, began caring for her husband at home following a severe stroke in which he was admitted to the hospital. Prior to this stroke, her husband was working on their farm and was totally independent. Bobbi responded to the question of how she initially became a caregiver:

Well, it started when my husband had a severe stroke, where it affected his short-term memory, he also lost the ability to retain a lot of his best interests in life and loves in life by the memory impairments. He had to learn to walk again, which he succeeded, he had to learn my name again, he knew I was his wife, but for three weeks he didn't know my name and through progress, going to Sheltering Arms hospital and getting Occupational Therapy, Speech Therapy, and Physical Therapy, for approximately three weeks. He was sent to Hanover Health Care for a short period of time for more therapy, then he reached a point that I felt I could tend to him at home and then home health came in, with therapy, and a nurse, an aide, and then he started uh, just going around the house trying to recognize different things, some things he did, because they were things of his past and loves of his past.

Bobbi continued to care for her husband in their home until his dementia behaviors and other health conditions, such as diabetes, became too much for her to control.

A stroke was also what led Kittie to begin providing care for her husband. Kittie’s husband was very independent in their home, often going to grandchildren’s baseball games and playing golf with his friends. Kittie explained what happened to her husband the day of his stroke, which led to an unexpected hospital admission:

Alright, ah well in 2004, my husband had a really, really bad stroke and couldn’t talk, he couldn’t move, he was really in bad shape. So um, he was in the hospital for a week I think it was that then they put him in the hospital on Parham road on the 4th floor, for therapy, and he was over there for I would say maybe three months and they got him up and walking and they gave him all the therapy; they had the speech therapists and they had the, all the
therapists there showing him how to use the bathroom seat and uh, I would go over there every day and my daughters would come over there and come and we were always there, Kittie was able to bring her husband home following the hospital admission, but once he got home, his dementia began and progressed rapidly.

Falls are very common and prevalent in the elderly population, especially for older adults who have dementia and limited safety awareness. In addition to a hospital admission, within the sample of this study, there is a theme of falls which led to initial caregiving situations in this study. Three caregivers in the study became the primary caregiver as the result of their elderly family member having a fall.

Jan recalled when her mother fell one evening:

My mother was eighty-five years old and living in her own home. She awakened in the middle of the night to go to the bathroom. She fell in the bathroom and hit her head. Following the fall, she complained that she had been sleeping a lot and we realized that she possibly had injured herself, asking her the questions “what year is it, who is the President, etc” and she didn’t know, so we took her to Patient First and they sent her to the hospital and did a CAT scan, it was a minor concussion. They told us that if she had any memory problems, we should take her to see a neurologist. When we took her to see a neurologist, they diagnosed Alzheimer’s Disease at that time.

Jan’s mother fell again and broke her femur. It was then that Jan and her husband had to move into her mother’s home; Jan then became the primary caregiver, in addition to working full-time outside of the household.

Peggy lived with her mother for many years prior to being a caregiver. It was not until a bad fall in her home, that Peggy began caring for her mother in the home. Peggy explained what brought on the initial caregiving:

From 1997 to about 2007, she was the active person and then she started having some issues with falling and back pain and so forth. In 2007 she fell and she broke her left arm, and the following year in 2008, she broke her right arm, and after she broke her right arm, she pretty much wasn’t able to walk because she couldn’t manage a walker with an arm that wasn’t functioning, so then she started the round of being in the wheelchair and from the wheelchair, she had back issues, um, that were causing her some problems. In 2009 when she broke her right arm, she stopped walking.

Once her mother stopped walking, Peggy had to provide total care for her mother, which included transferring her to and from the commode, bathing her, dressing her, and assisting with all of her
meals.

A third theme which led to the initial caregiving experience for the individuals in this study includes dementia behaviors. Five caregivers in the study became the primary caregiver as a result of their family member’s dementia behaviors. Neda had a mother who lived fifty miles away. She shared her first experience when she realized that her mother had dementia:

Well, my mom lived by herself after my father died. Following his death, her mother died, and while we were sitting at her funeral, she wanted to know who was sitting in that box, and I thought to myself, something is really wrong. I had not noticed anything but forgetfulness before.

Following the shock of realizing that her mother did not understand whose funeral she was attending, Nancy began visiting her mother more frequently, bringing her meals and distributing her medications, until it became too much. She then moved her mother into her own home and provided care for her, while working full-time, for eighteen months.

Pauline did not realize that her mother was having any cognitive impairments until her mother started behaving differently. She shared her experience which led to her becoming her mother’s primary caregiver:

Well with my mom, I didn’t expect this, you know it comes all of a sudden, because she had retired from her job, she was an operating room technician, and she was driving and active in church and all kinds of things, but when I saw it coming on it was because she was forgetting to eat, getting turned around in driving from where she was supposed to be and the reason why I brought her to my house was because she was walking out of her apartment, like in the middle of the night.

Pauline moved her mother into her home for fear of her safety. She provided care for her mother while working full-time. Eventually her mother’s behaviors got worse and it was very difficult for her to continue to provide care.

Jim, an only child who is very close to his mother, noticed that his mother was having difficulty remembering things, and he was very concerned about it. Jim explained how the dementia began, thus beginning his caregiving for his mother:

Um, well, we first realized that it was coming on with her forgetting things and starting conversations about one thing and end up talking about something different, farfetched, and just not being able to talk, you know, hold a conversation relative to what we are talking about and uh, we carried her to the doctor and he checked and after he talked with her, he
said that she was at the onset of dementia. So, uh, he prescribed some, some pills I think he gave her and she was taking those and uh, we were trying to tell her what was going on and uh, at first she wouldn’t accept it, that this was happening, and then she stopped taking the pills. We would give her the pills and she would uh, put them in her mouth under her tongue and drink the water down and we would leave and then find the pills over in the corner, or in the trash someplace, so we realized that she wasn’t taking the pills and we just went along with whatever was going on and trying to get her to take the pills. Sometimes she would and sometimes she wouldn’t, uh, after it started getting worse.

Jim was very uncomfortable with his mother’s memory problems and became her primary caregiver.

He was constantly monitoring his mother, worried about her safety all the time.

Dana, initially became the primary caregiver for her father when she found out that he had dementia. Her father got lost one day while driving down a familiar road and he had to pull the car over and call his family for help. Dana remembered this first experience with her father’s forgetfulness:

It started with his driving and he got lost. He pulled over to the side of the road and he didn’t know where he was, and then the second time, he accidentally hit a gentleman from behind, and after that he made up him own mind that we wasn’t going to drive. Mother and I were both concerned that it would be a fight about taking his permit and all, but he said “no, this is it” because twice now he had had incidents—so he made that easy for us, he gave that up. We took him to the neurologist, the physician referred him there and he said that he thought it was a form of dementia. He couldn’t say Alzheimer’s, but he did think it was due to the strokes that he had.

Dana cared for her father, toileting him, transporting him to doctor’s appointments, and making sure that he was fed until she could decided to seek nursing home placement. His forgetfulness did get worse, followed by stubbornness and verbal abuse towards his family.

As shown in the above caregiver reflections, there are numerous events or actions which take place that can lead to a family member becoming a primary caregiver. Although each situation was different, they all led to the same result of an individual with dementia needing a caregiver to monitor them at all times. Hospital admissions, falls, and behaviors greatly affect the lives of both the caregiver, and the individual with dementia, thus often leading to challenges in which assistance is necessary.
Assistance with Caregiving

Often caregiving can be very time consuming. When providing informal care for an individual with dementia, assistance from family members and friends often provides a break from stressful and demanding tasks. The researcher sought to understand the extent of the assistance that the caregivers in this study received. Common forms of assistance which appeared from these interviews were primarily family, friends, and home health care.

Family assistance was a common form of assistance throughout the interviews in this study. Eight of the caregivers did receive some form of assistance from the members of their family. Although the amount of family assistance did vary, overall, the caregivers were able to expect cousins, aunts, uncles, children, and spouses to give them a break from their caregiving obligations. Jim explained the assistance that he received from his extended family during the time he was the primary caregiver for his mother.

Well, I have two cousins who are still in here with me helping and it’s tremendous support, and from her sisters also. She has two sisters now here in Va. who will help out and they do the best they can. They are younger, maybe two years younger than she is, and the little that they can do, they do, and the whole family was pulling together to help her and we could always get somebody to do what needed to be done and to go over and help her out.

Jim also had assistance with his mother’s cooking and meal preparation from his family, which he was grateful for:

So we started cooking for her and finding out what she wanted to eat, fixing her meals. We made sure that everything was more or less "table ready". We would have cold cuts in the afternoon and then prepare her food in the evening.

Knowing that he could rely on his family to help him with the cooking was a great relief for Jim, who was still responsible for his mother’s doctor’s appointments, making sure that she was dressed, cleaned, and toileted, as well as safe.

Pauline was especially grateful for the help and assistance that she received from her husband, who lived in the home with Pauline and her mother. She was also very lucky to have help from her cousins and aunts. She explains their assistance:

Yes, my husband was involved because he has elderly parents. He’s an only child and I’m an only child, and you have to have that relationship like family, so it didn’t bother him to have my mom come, so he was very supportive and all, then my aunties, they were just excellent,
they were there almost on a daily basis. They helped me with the laundry and all of that, they were just there. I was still teaching and I retired last year. I had a cousin who agreed to come in and stay with mama during the day and take care of her until I came home from work.

Peggy had two grown daughters who were able to help provide assistance with her mother. Although they did not live in the same town, she was very happy when they would come over and give her a break from the personal care duties. She explained how her daughters helped her:

Yes, and my daughters would come down periodically. My older daughter came down for 4 or 5 months to give her grandmother a shower to help her get into the shower and then it progressed into she could no longer get into the shower and then we had to get the caregiver and she had a caregiver from Oct of 2009 until she was admitted to St. Mary’s hospital. She had that caregiver 2 hours a day, twice a week.

In addition to family members, one caregiver in this study had a friend who would help her with her caregiving tasks. Bobbi reflected on the help that she received from a friend:

She also helped with the garden and in the season of the summer, so she did stay with him so I could go to the grocery store and take care of legal business; She was a very dedicated lady who I had known for practically my whole life.

Receiving help from friends during the caregiving process was not present throughout the interviews with the exception of the above example. Family provided the most support, with home health care being the second most utilized form of assistance. Home health care was present throughout the interviews, with five caregivers relying on professional help from a home health care agency for various forms of assistance. This assistance included therapy, bathing, dressing, and other help with activities of daily living.

John was fortunate to have his family come and provide encouragement, as well as a home health care agency that provided nursing services. He explained the hours of assistance below:

Most of the time, the children, four children, would stop by, and they would talk to her and you know, give her encouragement, but they never spent the night. I was the caregiver in the evening. After about a year or eighteen months I did have care advantage home health care; three girls would come, six hours a day, two hours at a time.

Dana explained that her family did hire home health care for assistance with her father. It was a challenge to continue to have them come into their home because her father did not like strangers in the home, and the home health care was extremely expensive. She explained this situation below:
Mother had two ladies to come in, we tried to keep Daddy at home as long as we could and when we became wheelchair bound, first we went through the cane, then we went through the walker, and of course each was met with him being dead-set against any of it. He didn’t feel like he needed the help, then we had two ladies come in and they stayed probably about six months. My mother went into the hospital because she had an ulcer and so we had the ladies come in and they just got real expensive, real expensive.

The above forms of assistance that the informal dementia caregivers in this study received reflects the need for additional help during the challenging process of providing care for individuals with dementia. Bathing, dressing, and toileting these individuals, in addition to providing meals and monitoring their behaviors can be very overwhelming for caregivers who do not have appropriate forms of assistance, thus commonly leading to feelings of stress and burden. As noted in the above quotes, the caregivers were grateful for the extra assistance that they received, even if it was only for a small amount of time. The importance of having someone relieve them of their duties temporarily was very beneficial for them.

Caregiving Challenges

There are many challenges when providing care for an individual with dementia. Common themes from this study regarding the challenges involved in caregiving include constant worry regarding safety, the social withdrawal of the caregiver, and the physical and emotional health of the caregiver.

Many caregivers have realistic fears that a fall or other injury will take place that will injure their loved one. This is due primarily to dementia affecting one’s cognitive ability to make good decisions and have safety awareness. Because many of these caregivers already experienced a fall or other health problem with the person in their care, there was often a constant worry regarding their family members’ health. Each of the twelve caregivers interviewed in the study sample expressed constant worry regarding their loved one’s safety. Because each of the caregivers in the sample had their loved one experience either an unexpected hospital admission due to illness or accident, a fall, or a challenging dementia behavior, they were all constantly on guard and worried about the safety of the family member in their care.

Pauline explained the worry and anxiety that she had while providing care for her mother,
which led to her mother moving into her home:

I had constant worry, because I tried, she’d say, “Oh, I’m going to be alright” so, we tried her staying at home you know in her appartment staying in her surroundings because at first my cousin was there with her during the day time in her own appartment, so I was trying to keep her in her own surroundings, but then at night if I didn’t stay all night, that is when she would wander, so I found myself staying all night, and then I would have to get up and to go work and all so it was better for me to bring her home.

Pauline was worried that her mother would wander out of her apartment, because she had done that in the past. Although her mother would reassure her that she was fine, Paula was emotionally drained from fearing for her mother’s safety on a daily and nightly basis.

Bobbi was very worried because her husband would have regular falls at times, and she was always worried that he would hurt himself. She stated that:

He would get up and fall during the night and I would have to call the rescue squad which was Henrico rescue squad and they were only approximately 5 min away and they would pick him up and put him back in the bed and check him out and sometimes I did ask them to take him and get him checked out.

These falls were ongoing and Bobbi feared that her husband would end up breaking a hip and not being able to walk, should he have a severe fall.

John was also worried about the safety of his wife. He is a very thin man who was regularly picking his wife up by himself. He too was very worried that she would have a bad fall and hit her head or break a hip. He explained the difficulty of assisting her when she would slide out of her chair and onto the floor:

Oh it was terrible. Well I would pick her up, she wouldn’t fall, she would slid up and getting her from the bed to the chair, I would get my arms up under her and get ready to move her and she would raise her arms up and slip right out from under me. And then I would have to lean down and pick her up and put her in the chair. Oh yeah, it was too hard on me after awhile. Yeah, it was a little difficult but we made it.

In addition to the constant worry regarding safety, eleven of the twelve interviewed caregivers in this study identified some form of social withdrawal as a challenge of caregiving. These former dementia caregivers shared experiences in which their caregiving greatly affected their lives, to include their jobs, their personal hobbies, and their relationships with others. There were feelings of resentment, isolation, and sadness as a result of their involuntary social withdrawal.
A change in one’s job was a common pattern during these interviews. Although Crystal was retired, once her husband was unable to assist her in tasks around the house, she suddenly had little free time due to her obligations. She explained:

I’m retired, but I have other tasks that keep me busy. In fact, I almost did everything, even when he was there. He wasn’t able to do anything. I did the laundry, he didn’t do any of that, he didn’t cook, he didn’t cut the grass, like I said the doctor refused to let him cut the grass.

Dana worked and had to cut back due to being the primary caregiver of her father. This was certainly an adjustment because she has also been busy taking care of her grandchildren when her father’s health started to decline. She spoke about this time in her life:

I used to do the books, but I stopped in order to keep my grandchildren and I did cut that back, I only had them maybe one day a week just to keep up with them because I was going to the store, getting the clothes, and doing this and that. I just didn’t have the time, so I did have to cut back on that.

Alfred was a very active man prior to the mental and physical decline of his wife’s health. He explained how he adapted his hobbies to include his wife, thus leading to the end of his hobbies, following her decline:

I used to, I played golf, and I’m active and I do a lot of stuff that I shouldn’t be doing and I used to golf with a bunch of guys, and it got so I would take her and she would drive the cart and she liked it, and I liked it too. Then that changed, it got so she couldn’t drive the cart. I would take her with me but she would just sit there, and then that lasted so long then I had to withdraw.

Alfred has started playing music again, which is his hobby, and now enjoys playing golf again, now that his wife is in the nursing home.

Kittie did not work at the time she was her husband’s primary caregiver, but she did have many other tasks that she was responsible for in addition to taking care of him. She also had to interrupt her hobbies and pleasures to make sure that he came first. She explained:

Oh yes, I had a lot of obligations, that is true and uh, I really stopped a lot of my pleasures in life. The other thing I did for my own pleasure is play bridge once or twice a week, and that is all I did you know. Yes, well after he had a stoke I had to take care of all the bills, everything, everything, so in addition to taking care of my husband I also had to handle taking care of the home.

Kittie did seem frustrated during the interview, and sad, that she had to put her pleasures and hobbies on hold in order to take care of her husband. She is a very understanding wife who is now able to
play bridge and enjoy free time, now that her husband resides in the nursing home.

The physical and emotional health of the caregiver is a theme from the interviews that is very important. Throughout these interviews, the entire sample of twelve caregivers explained that taking care of their personal health was a challenging factor when providing care for their family member. They often had to put themselves second to their loved one, setting themselves up for illness and a decline in their health. Bobbi had her husband with dementia who was recovering from a stroke in their home, while she had her own health concerns. She explains her health battles:

I was not working because I had health problems and I had been on disability and I have back problems; scoliosis, Rheumatoid Arthritis, which had crippled me in 1984. I took the treatments and the therapy, and I fought that battle and went back into remission.

Jan explained that caregiving for her mother with dementia was very emotionally challenging. She rarely had time for herself and was never alone during the evenings and weekends when her mother was not in daycare. She explained how she felt with the constant neediness of her mother:

Challenging, mostly I would say emotionally challenging. That was the most difficult part because my mom depended on me for everything. She has lost the ability to make any kind of decisions and she became almost glued to my side. She was very insecure if I left the room even. So, if I would go into the kitchen, she would follow me into the kitchen. If I went outside to water the lawn she would just sit by the window just so she could watch me. And I think that she became a little afraid and I was the one thing in her life that was solid that she could hang on to. She knew that she was losing it, she would voice her concerns about not being able to remember things, and we could watch her and see that she had no clue about what she was trying to do. now for me, it became very stifling. We have also been very very close but she always distanced herself, but now all of a sudden, she wanted to be right with me every section constantly asking me “what are you doing,” wanting to help when she couldn’t, so emotionally the whole thing, the biggest challenge was the fact that I was being stifled, I was trapped, and I had the thoughts and feelings that come about when you are in that situation for any length of time, which also brings on a guilt that you have as well.

Pauline felt very similar to Jan, although in addition to emotional stress and anxiety, Pauline was also having physical health problems as a result of caring for her mother. It is because of these health conditions, in addition to her never having time for herself, that she decided to choose a nursing home for her mother. She explained her physical difficulties related to caregiving:

I didn’t have any time for myself, I had just started to have my blood pressure go up, my legs, I was having a lot of problems with my legs because mama was like dead weight, you
know she wasn’t doing anything for herself so it was like she just shut down on me, but the day that I decided that I am going to have to make some more arrangements, it is because it was wearing on my health.

Pauline made the decision to seek a nursing home for her mother, and has since joined a gym and is feeling better and healthier. She contributes this to her decision to seek placement in a facility for her mother.

Caregiver Time Commitment

Providing care for an elderly individual with dementia can be very time consuming. Often, caregivers feel as though they would not be able to handle being an informal dementia caregiver for an extended amount of time. This study found common themes associated with this inability to provide care for an elderly individual for the long term, which included safety issues for the elderly individual, exhaustion of the caregiver due to role overload, and the issue of incontinence.

Safety issues continue to be a common concern when providing care to an elderly individual with dementia. Often a caregiver feels as though they can not leave their family member alone, for injuring themselves. This was a common concern among the caregivers who participated in this study. Of the caregivers interviewed, every caregiver felt as though the safety for the family member in their care was a large concern.

Donna, explains the time that she and her husband left her mother alone for an hour and a half while they took some friends to the airport. Her mother drank a cup of rum thinking that it was coffee, which was horrifying to Donna. She explained the experience:

One weekend, we had some friends visiting from out of state and they stayed at our house, which was empty. When they were going home, we both took them to the airport that day and I said to mom “I’m going to the airport and when I get back we can go and do the shopping” At this point she was still mobile and would go out with me. When I got back from the airport, we were only gone about an hour and a half, when we got back, my husband said “now what are you going to do now” and I said that I would make my mom a cup of coffee and then go to Krogers. So I walked
into the living room and she was sitting on the sofa with a mug in front of her. I told her that I was going to make her a cup of coffee and she told me that she had just had one and that it wasn’t very nice. In the bottom of the mug, there was a dark brown liquid in it. I knew that she took her coffee with milk and I smelled the mug and I couldn’t place it and I asked my husband and he sipped it and it was dark rum, and she had had poured herself a whole mug of rum and drunk the entire mug of it without realizing that it wasn’t coffee, and that was the day, the moment that we learned the “oh my God moment” that we can’t ever leave her alone.

This experience made Donna realize that she could never leave her mother alone unattended again. Prior to seeking nursing home placement, Donna made sure that either she or her husband were always with her mother at all times.

Jim was also afraid to leave his mother alone for fear of her safety. He made sure that either he was at the house or members of his family. He explained the difficulty of maintaining his mother's safety:

Being a caregiver means being there, and as I said, for me, or my cousins, all of us have our own families. It was always a challenge to be there for her. The neighbors would call us at 10 or 11 at night because Mom would go out on the porch at 12 or 1:00 at night and they have lights in the area, but just the fact that she is out there and if she decided to take off, then she’s gone, you know. It’s the safety factor.

The exhaustion of the caregiver due to a role overload was a very common theme found in this study. Each of the twelve caregivers interviewed in the sample explained specific situations in which they felt as exhausted as a result of the tasks necessary in the caregiving role. Bobbi has a difficult time balancing the medical aspect of providing care for her husband. She was responsible for maintaining his diabetes, as well as making sure that his bathing and dressing were taken care of. She explained her role overload:

He had the behaviors, the physical problem, being diabetic, and cardiac issues, as well as everything that goes along with the stroke. A nurse would come and check the Cadmium (blood thinning medication) to make sure that that was regulated but I was dispensing medications to make sure that they were given on time. If I didn't have Meals on Wheels I could not have functioned because I was having so much other stuff to do.

Betty was fortunate to have extra assistance with her caregiving, to include a nurse from a home health agency, as well as Meals on Wheels, which provided meals for her husband
on a regular basis.

Dana, in addition to Bobbi, also felt that caregiving would be too difficult to continue for a long period of time. She has a husband, as well as children and grandchildren, and caring for her dad kept her extremely busy. She also has an elderly mother who would assist her at times. She explained the tasks that overwhelmed her when providing care:

I definitely think that it would be hard to provide care for a long period of time, but I was kind of sharing it with Mother, I was the gopher, I would take him to the doctor, I would take Mother to the doctor, I was the transport, chauffer, that sort of thing.

Neda was also dealing with feelings of exhaustion due to role overload. She had no assistance in the home and limited social support. She felt as though she could not provide her mother proper care because she had never been trained on how to provide proper personal care. She explained her feelings of frustration:

I was frustrated because I didn’t feel as though I was able to give her the care she deserved. You know, it’s embarrassing to her to have to have someone bathe her, especially your daughter…and then the day care would say that she wasn’t clean enough and then I would feel like I’m not doing my job if they say I’m not doing my job…and her nails weren’t cut properly and the day care would say “We are going to report you to Social Services” and then you think, well, what do you expect me to do? What more can I do? If this is on my lap, I want her to be cared for but I don’t know how to do it.

Pauline was working full time as well as providing care for her mother in her home. She would get her mother up in the morning, and every evening, she would make sure that she was fed, showered, and dressed, and that all of her care needs were met. This was very exhausting for Pauline, especially because she worked forty hours a week and was not able to have private time with friends and family. She explained how she wanted to retire, but not have to provide care all day for her mother following retirement:

I was thinking about retiring, and I thought, well I can’t retire and do this all day, you know, I just can’t do that. My husband and I had no time alone, you can’t go any place, you know you are invited out to dinner or something, we couldn’t even go out to dinner, you know, once in a while we would get my cousin to come in the evening, if it was a special occasion, but for five years we couldn’t do anything, so that had to be
challenging because someone had to be there, we couldn’t leave, without, you know, especially in the evening and during the day, you know, it was out of the question because both of us had to work.

A third theme that was present when the caregivers were asked whether providing care for their elderly family member with dementia would be too much to handle for a long period of time, was the issue of incontinence. Incontinence is very common in individuals with dementia, as they slowly lose their ability to maintain control of certain bodily functions. Incontinence can also take place as a result of other medical illnesses. Two of the former dementia caregivers interviewed spoke about the difficulties of providing care for an individual who is incontinent, and explained how the incontinence made them realize that they would not be able to continue to provide care for their family member for an extended amount of time.

Kittie's husband became incontinent due to a bout of colon cancer. Below she described the difficulty of providing care:

My husband was wearing Depends all the time at home because he had gotten to the point where ever since he had the colon cancer surgery, they reconnected him but he had had diarrhea ever since and he was on diarrhea medicine ever since and sometimes he couldn’t make it to the bathroom in time. So he felt secure wearing depends, so he was used to wearing those before he came into a nursing home. As far as having too much to handle for long periods of time, it was the incontinence and not being able to lift him and get him in the tub.

Crystal also had the time difficulty with her husband. She felt as though caregiving was too much to handle for a long period of time due to his incontinence as well. She explained that following his stroke, she was unable to deal with certain care tasks:

Well, he was in a rehab facility and the social worker recommended that I take him home, but I told her that I could not do that because I can’t lift him and you know, and I couldn’t care for him because he is incontinent and I just couldn’t do it. It’s just too much work.

The identification of the constant worry regarding one’s safety, the caregiver role overload, and the issue of incontinence in the caregiver interviews allows the researcher to better understand certain caregiving situations. It is because of these situations that these caregivers felt as though they could no longer provide care for an extended period of time for their family member.
Situations Leading to Placement

There are many different reasons why dementia caregivers seek placement for the individuals in their care. The interview responses from this study show four main themes, to include an accident which led to the physical harm of a resident, the emotional toll on the dementia caregiver, the hospital admission of the elderly individual with dementia, and difficult behaviors. Many of the caregivers interviewed had two or more of the above concerns take place during their caregiving. Eight of these caregivers were very concerned about the falls and possible injury to their family members, which led them to seek long term care.

A fall in the bathroom which injured her father was the deciding factor in which Dana sought nursing home placement for her dad. She explained the fall and when she made this decision:

So, he fell into the bathtub, and that was the first time that we decided…I think, I think that putting him in the nursing home was best for him because he was going to hurt himself severely, because like he fell backwards into the tub, so they took the tub out and they put the shower in and he fell headfirst into the shower, you know so it’s like, it was not an easy decision, but he couldn’t bathe, and he didn’t like the caregivers’ help to come in and be at the house, he didn’t like strangers at the house, and if it was me or my sister, that was fine, but he didn’t like bringing anyone else in. So, um, I think that made the decision; we knew that Daddy couldn’t stay at home.

Seven caregivers interviewed revealed the raw emotional toll that the caregiving experience took on them. The constant worry and stress involved in caring for an individual with dementia led to stress in other aspects of their lives as well. The emotional toll of dementia caregivers led many of the caregivers interviewed to seek nursing home placement. Bobbi felt as though it was in the best interests of her husband, as well as for herself. She explained the emotional and psychological toll of providing care for her husband:

It was a very difficult decision to make, but I knew that it was in his best interests because if he kept falling, there would be broken bones, and psychologically, I was getting to a breaking point of being so worn out, couldn’t sleep, and making sure that he wasn’t getting up and falling and I knew that the legal rams of it too. The decision was in his best interests. I didn't want someone from social services to say that I was neglecting him.

Jan also felt the emotional toll of providing care for her mother. The dementia behaviors, in
addition to the large amount of care that her mother required drained Jan and also changed her outlook on life, thus leading to her seeking a nursing home for her mother. Jan's life lacked the joy in once had, and she explained how others noticed this as well:

And also the mental toll on me. I did not realize how much I had changed and was not until after several months after she got admitted that I noticed. It's a grieving period that you are going through and my husband said “oh, I have the old Jill back now” and at work they said to me “you’re like you used to be” you know, so it was only other people telling me how much I had changed. Well living under a cloud; I have normally a pretty happy and upbeat personality so I suppose that you could say that I was quite morose. I would go in, hello, do my job, and go back to mom. There was no joy in me, it was all gone. It was all gone and it’s a difficult thing to explain.

The emotional toll that the caregiving had on Neda led to a geriatric psychiatrist recommending placement for her mother. Neda took her mother to an appointment and after hearing Neda explain the stress that she felt and the frustrations with the caregiver, the psychiatrist told her that Neda would need to be his patient, as well as her mother. She explained this meeting:

I don’t think that I realized it, because I didn’t want to realize that she needed to be in a facility. When I took her to the geriatric psychiatrist…we would go once every couple of months, at the last visit, he just said “You’re my patient now” because I have to help you deal with dealing with your mother, because she needs to be in a facility. So at that point, I sought out a facility to put her in.

In addition to physical harm and the emotional toll of dementia caregiving, a hospital admission led four caregivers in this study to seek nursing home placement. These hospital admissions were for a number of medical conditions, to psychological and behavioral problems, a hip fracture, a stroke, and a head injury. Among these caregivers is Alfred. Alfred was caring for his wife with dementia when she had an onset of another health condition which led him to call the paramedics. Following her hospital admission and treatment, he realized that she would not be able to come home. He explained the situation below:

One day I heard a noise and it was my wife, so I go into her room and she had a strange facial expression, so I called 911 and when I called 911, hospice quit at that point. So the rescue squad came and they took her and from that point on she was in the hospital for about two weeks, and I don’t know what they did but they, her arms were very large. Well, she had five or more doctors but I never could find one doctor who talked
to me. She had a stripe on her back from her neck to her buttocks, striped, and uh, at that point I really thought that that would be the end of everything. When she got out of the hospital both shoulders were dislocated; there was no way I could take her home.

In addition to Alfred, Kittie explains the night that her husband fell and broke his hip and was admitted to the hospital. Prior to the fall, she was caring for him at home. After the fall and surgery, she was no longer able to bring him home, thus leading to nursing home placement. She explained:

They took him to the hospital and he had broken his hip in three places. So they had to do surgery on him and they put in a plate and you know, and while he was in the hospital at 2:30 in the morning, I got a call from the hospital saying that his heart rate was one hundred and sixty and he was right on the verge of a heart attack. They had to put him in the heart unit, and I got over there like 8:00 in the next morning and the cardiologist came in and said you were right there at a heart attack, it was a good thing that he was in the hospital. They gave him the medication and all and then it came time to make the decision of where to put him.

Hospital admissions and difficult behaviors are common in dementia. Of the twelve caregivers interviewed, five stated that difficult behaviors did influence their decision to seek nursing home placement for the elderly family members in their care. Bobbi stated that she was frightened by her husband behaviors, and that in addition to him being very hard to care for, she also felt as though he was getting too angry at their home and too aggressive. She explained:

Actually, I became scared, because he was so aggressive, and I guess the adrenaline, and he was so strong, and the verbal, it is just as bad as the physical, it worried me to no end. These behaviors did influence my decision to seek a nursing home, because I was scared.

Wandering and confusion led Neda to seek a nursing home for her mother. Her mother was not sleeping through the night, thus greatly affecting Neda's sleep patterns. She explained the accommodations she made for her mother:

She would walk around the house at night and my bedroom is on the second floor and her’s was on the first floor, so I just ended up sleeping on the sofa so that she wouldn’t go up and down the steps and hurt herself. My activities were planned around her. She wandered a lot. She tried to wander outside but I had the doors locked so she couldn’t get out.

Like Neda's mother, Jim's mother would wander around the house as well, also going
outdoors, which was especially scary for Jim. He explained her wandering and how it led to his decision to seek nursing home placement:

Yeah, uh, that and during the daytime, when she decided to take a walk, my neighbors would see her in places that the usually didn’t see her and they would stop and they would walk her back down to the house and that helped a lot because I could just sit back because it had gotten to the point where she would hear me but she wouldn’t really listen or do what I would ask her to do.

Peggy's mom had delusions and hallucinations due to her dementia. These were very hard to witness, as well as deal with for Peggy. She described an instance when her mother acted out with difficult behaviors:

She was already on one medication to help her control the shaking, but she was going into the other delusion episodes where things were really out of whack, and I had just gotten the prescription filled and had tried to give her some one Friday night when she went into one of these wild delusions where she was insistent she had a husband, this mystical man that she married and he was having a heart attack and she had to get to the hospital and she tried to get out of bed.

Positive Aspects Associated with Dementia Caregiving

Five caregivers in this study identified positive aspects associated with dementia caregiving. These aspects included spending special private time with their family member and getting to know things about them that they were unaware of, as well as a sense of pride and self-worth through providing care for someone who you love. Dana explains that although providing care for her dad was very challenging and difficult, there were positive aspects as well. Dana got very emotional during the interview when reflecting on the time that she and her father would visit, and he would share stories about his childhood that she hadn't heard. She reflected on this experience:

I liked it from the fact that he and I would discuss (starting to cry), I didn’t think that it would be emotional, he would tell me about growing up, you know, things that I hadn’t heard, that was good.

John and his wife, married for sixty one years, shared a lot of time together before and during the caregiving. John felt proud that he was able to provide such intense care for his wife without having to have someone move into the home with them. Like his wife, John is elderly as well, and never questioned the fact that when the person you love needs help, you provide it and try to do the
best job possible. When asked about the positive aspects of caregiving, John explained:

Definitely yes, well, there was nobody else to take care of her and I knew that I had to do it. It’s just a normal thing, and I didn’t mind it a bit, I loved it, because I thought so much of her.

Although Neda had many challenges with her mother’s wandering, lack of appetite, and constant confusion, she explained that there were positive feelings associated with providing care for her mother:

I guess there were positive feelings, it was fun sometimes to have her around the house, but she just couldn’t communicate as well as…well, she was my best friend before, she was absolutely my best friend, and it’s hard to see that happen, you know, your best friend go to a totally different person.

Pauline also had many issues with her mother’s wandering and dementia behaviors, but she did enjoy the company of her mother in her home and explained how appreciative her mother was of the care that she provided:

Yes, I did and then before she got to the point that she is now, she would always say thank you if you were to do something or give her something and she was like that with my cousin, she was real appreciative and thankful and my cousin said, “I couldn’t have found a better person to sit with during the day because she is very good to work with.”

Peggy’s mother was also very appreciative and was also sharing her feelings and emotions. There were constant hugs and words of kindness, which made providing care for her mother a lot easier during the difficult times. Peggy explained these feelings:

She was always open to say “Thank you” “I appreciate it” “I love you and those are the moments you feel appreciated. So, I was fortunate to have a mother who, she collected children like you would collect birdhouses, that is how she collected children. It’s a good thing that I am not a jealous person because I would be jealous of all these other people she gives attention to. But she is a very loving person. My husband feels that I’m not as loving as my mother, that I’m cold. My mother was always there with a hug, so she would always pull me close and hug me and tell me she loved me while I was taking care of her. And, before that also, you know, not just when she needed me, you know, other times also. So, appreciated, yes, and some of it I did out of appreciation for her, to appreciate your mother, and like I said, some of it I did because that is what I saw coming up, you take care of your mother.

Negative Aspects Associated with Dementia Caregiving

In addition to positive aspects related to dementia caregiving, there are many negative aspects as well. Each caregiver interviewed in this study experienced many difficult situations which
made the caregiving process extremely difficult. Donna felt a strong sense of expectation while providing care for her mother, rather than appreciation. She explained these feelings:

I felt a sense of duty, I do, of course, love my mother but sometimes it got to be a little much because I was around making sure to be with her all the time and to help my brother when the agency girls had left. So it wasn’t like “I know that mom is appreciative, and she is showing it” it was more like “this is what I have to do because I am the daughter” because she expected it. There was definitely frustration because there is this expectation, and a lack of appreciation.

Kittie had a hard time taking care of the physical aspects of providing care for her husband. Being eighty-three years old, she had many hard jobs such as bathing and dressing her husband. She explained these challenges, which were seen as negative aspects of caregiving:

Well at times there were, I felt like I….there were days that I went through when I didn’t know if I could do this much longer but then the next day it was better, you know, you live everyday and then the next day is better than the day before, so that is the way I handled it, but there were days where I thought, and my children thought that it was getting to be too much for me, you know, because, not that, I’m not a weak 83, you know, so, a lot of people my age could not have handled what I handled.

The caregivers in the study agreed that another negative aspect of dementia caregiving was having to witness the devastating decline due to dementia of their loved ones.

Pauline explained feeling this loss:

Yes, yes, that is the devastating part that you know, sometimes when I see her you know and I can’t even have a conversation, you know we would go shopping together and we were tight! When I got married, I still would have to have my mom go with me shopping, she always shopped for me and I just miss those things, we used to travel together and all like that, so there is a down side when you can’t have a conversation and sometime I’ll remember or think of something and I’ll think “I wish I could tell mama this because she would have known this person.” Yes, it is sad, it is really devastating. I know that for others in the family, it is really devastating because you don’t get any response back and it is sort of depressing.

**Caregiver Role Relinquishment**

Numerous feelings were associated with the caregivers’ role relinquishment. Included are feelings of guilt, relief, reluctance, a return to normalcy, and a sense of loss and death.
Feelings of guilt are certainly associated as a negative aspect of caregiving. Four caregivers felt a great sense of guilt in no longer being able to be the primary caregiver for their loved one. Having to rely on a nursing home to provide the care that they used to provide was a very difficult transition. Peggy felt guilty when she realized that nursing home placement was necessary for her mother. She explained below:

The negative feelings are the guilt. The guilt about having to place someplace, you know, about not being able to do it all myself. That is what my guilt is, that is what I have to settle with. And, no, I’m not seeing any counseling or anything, I have not sought counseling, although, there are those who think I should (laughing) but you know, it’s a tough thing and you have to go through it and you just have to know that they are in…when you hear your mother say “God, why am I still alive? What are you keeping me here for?” you, know and then somewhere along the line, you begin to question “yeah, why are you? why are you?”

Neda also felt a strong sense of guilt following her mother’s admission. She admits that she withdrew from visiting her mother, which bothered her. She explained:

I got into a pattern that I was surprised that I got into. I didn’t visit her as much as I should have, and I don’t know why. I guess it just hurt to see her the way she was. At first when she went into the facility, all she would say was “I want to go home, take me home, take me home” and that was really hard, so my visits were less frequent once she started begging to go home. It was hard, it was guilt.

Feelings of relief when relinquishing the caregiving role were common among the caregivers interviewed. Nine caregivers interviewed felt a great sense of relief through the relinquishment of their caregiving role. Many felt as though they could finally have a break from the bathing, dressing, cooking, and monitoring of their family members. Many also felt relieved in knowing that their family member would finally be safe in the setting of a nursing home, where dementia is common and there are interventions in place to monitor their safety, such as locked doors and alarms. Dana explained feeling relieved following the admission of her father into a nursing home:

I was relieved! Because I mean, I still do his clothes, I still come up here and read the paper to him I still do that, but I know that he is being washed, I know that they have three main meals that they are feeding him, I know that he is getting his medication, so I know that I am
the supplement on that, I do the clothes, and the treats, and the stuff like that, the newspaper, I’m like supplementing him.

Like Dana, Donna also felt a sense of relief following the placement of her mother in a nursing home:

Yes, and also after the whole process was over, I felt a whole lot better about her being here after she got over you know being so aggressive, then I felt a lot of relief and a lot of good feelings about her being here.

Kittie also felt a sense of relief, mixed with guilt, following the placement of her husband into a nursing home. She was hoping that he would one day be able to come home, following intense rehabilitation for his broken hip, but the nursing home placement ended up being permanent. She was distraught when coming to the conclusion that she would never be able to live with her husband of sixty-five years again, but also relieved that he would be safe and cared for by professionals. She explained:

Yeah yeah in a way you have a sense of relief and also a sense of guilt. You know you both of em kinda of work together there but I guess I was relieved because I knew that he was being taken care of and I knew that if he fell he would have someone to pick him up and I wouldn’t have to call somebody or 911 in the middle of the night or something like that you know so there was a sense of relief.

Pauline, like Kittie, was relieved that her mother would be safe under the care of professionals. Pauline was also relieved that she could take care of herself, as well as her health. She was not sleeping at night and was having physical problems as a result of her caregiving tasks. Relinquishing her role as the primary caregiver was seen as both a benefit to her mother, as well as to herself.

It was a relief. It was a relief, it is really a relief, you know it wasn’t because a lot of people hold on for monetary purposes, and I said no, it’s not about that, I want her to be safe, I want her to be in an environment where she can do some things. It is a relief, you can sleep at night. Before I couldn’t sleep at night. I was always tired and broke down, you are constantly doing things, if you are not doing meals, you are doing clothes, if you are not taking care of them you are doing something, I mean I was on my legs so much that I had to end up getting cortisone shots in my hip.

Jim agreed that his mother’s safety was a primary concern:
Ok, knowing that she was getting the meals, that she is safe, and that she is being cared for, it takes a load off of me. I can come and visit her and we take her out and just knowing that even though she complains a lot, she’s comfortable, and that she is receiving the best care that we know of, we are satisfied, we are very satisfied with the facility, and with what is going on.

Feelings of reluctance are also common with the role relinquishment amongst caregivers. Four caregivers in the study shared feelings of reluctance when relinquishing their caregiving role. Jan initially felt a strong sense of reluctance following the admission of her mother into the nursing home. She explained:

Well my reluctance to give up the role, my reluctance to put her in the nursing home was a sense of “I can’t believe that anyone can take of her as well as I do because nobody will love her the way I do” so you know, that was part of not wanting to let her go in, but on the other hand I knew that it was time. I remember that I got to the point where it was like “ok, there are three of us here, my husband, myself, my mother, at what point am I being unfair to my husband, requiring that we live here with my mother. This is something else to consider, at what point do you say, “hang on a minute, we have done enough for Mom” now it’s our turn.

A return to normalcy was what four of the caregivers felt when relinquishing their caregiving role. There was a sense of appreciation amongst them regarding finally being able to return to their hobbies and their old routines. One caregiver was excited to be able to return to his hobbies of golf and playing music, while another was able to reconnect with her husband, as well as her coworkers, and enjoy going out to eat which she greatly missed. Pauline was able to work on getting in better shape and exercising. She had put on weight as a result of eating while being unhappy trying to balance being a wife, working full-time, and being her mother’s primary caregiver. Pauline explained:

My legs are better now, because I am not on them all the time, and once I retired I started going to Curves (gym) and exercising and getting my energy back, so now I can do some things. My husband and I are going out to eat and doing things together. Oh yeah! We spend a lot of time together and that is good too. I know that it was confining for him because we had a small space and he was restricted almost to the bedroom when family came over. It can be a lot, but now we are on a honeymoon!
Donna felt as though care for her mother came first, and the rest of her family came second. She was not able to enjoy time with her husband and needed to make him a priority. She felt a sense of relief as well as a return to normalcy following the admission of her mother into a nursing home. She explained:

Yes, there is a sense of relief on my part because I could have my own life back. At first I was coming every day of the week and that got to be too much; it was taking too much away from my marriage, my husband, and doing things with him. And now I usually come Monday, Wed, Thurs, and Saturday. This week I am coming Monday, Wed, and Fri because we are going out of town because it’s my husband’s birthday. You can’t come every day, you can’t.

Two caregivers in this study shared a sense of relief, mixed with loss and death when describing their role relinquishment. Bobbi described being sad and missing her husband lying in the bed next to her, following his permanent admission into a nursing home:

It was relief, and also it's like death cause you're separated and it's just like someone has died because they are in one place and you're in another place, you're separated, and you go through that grieving type period like if it's a death and I would constantly wake up in the mornings and reach over and he wasn't there.

Peggy also described feelings of being lost following the admission of her mother into the nursing home after living with her for twenty five years:

I felt a little lost. You know, because it was, it was taking my time, you know, and I guess one of the biggest reliefs was not having to get her ready for bed. You know, because I was tired at 10:00 at night. You know, I was getting up between 5:30 and 6:00 in the morning on Tues, Wed, Thurs, and Friday, I would get her up before I went to work to go to the bathroom, and then she would go back to bed, and then a little longer, my husband would do the insulin and the breakfast thing. So, you know, I was doing maybe 45 min. to an hour’s work before I was leaving the house to do 8 hours.

Stress and Depression within the Caregiver

Providing care for an individual has been linked to stress and depression. It was important in this study to focus on the role that stress and depression had on the caregiver, and whether stress and
depression factored into the decision to seek long term placement in a nursing home. Of the twelve caregivers interviewed in this study, nine stated that stress was certainly a factor in their decision to seek nursing home placement. Four of these nine caregivers agreed that depression, in addition to stress, also factored into their decision to seek long-term placement in a nursing home. For Bobbi, stress factored in greatly in her decision to seek placement for her husband in a nursing home. She was constantly worried and stressed that he was going to fall and break a bone because he had been falling regularly in the home. This stress and constant worry kept her up many nights, leading to fatigue. Like Bobbi, Jan also felt stressed out constantly due to her caregiving duties. She also became depressed at the situation she was in. She felt trapped while caring for her mother, and explained an instance where she wished her mother was dead. This emotional quote shows the hard and challenging side of caregiving. Jan stated that:

I was sitting with her one day, one afternoon in her living room feeling trapping after she had come home from day care and I had come home from work and I was sitting there looking at her and for an instant, it flashed through my mind I wished she were dead. And then I realized what I had thought and the horror of what I had thought was just awful and then once I kind of got used to have thought it, I kept on thinking it you know, for a week, I understand it but I don’t like it, it is reality, and that was another change in me and I was changing in little increments, and that was a change within myself that I thought “Oh my God, this is what I’ve come to.” Now I am happy to say that I am thankful that I never lost my cool with her and she never knew this but God it was hard. Now I went through a severe depression after that for about three weeks and I was well aware of that and I don’t know whether I kind of emotionally went to another level and it kind of smoothed out but that was a really tough time, living through that, because she was a love.

Jan knew that she needed to put her mother in a facility for numerous reasons, which included her feelings of stress and depression. She was exhausted and drained from living with her mother for three years as the primary caregiver.
Stress did play a part in Kittie’s decision to seek nursing home placement for her husband. She did go to the doctor because of her depression during caregiving. She explained the experience below:

I was depressed at times, actually I went to the doctor one time and he said uh, I really think you need to be put on an antidepressant and I said well I wasn’t really thinking about going down that route you know, I hate to feel like I have to depend on something and he said well I have some samples here and I want you to try them and I want you to tell me, because I did cry really easily, and I started taking them and it really has helped me, I was really surprised, so, I’m still taking them.

Pauline had a lot of stress in her life when her mother was living with her, while she was working full-time. She explained the stress that she experienced, as well as the toll that it took on her health:

It has gotten to be real stressful and like I said, the stress was affecting my health, blood pressure, weight gain, a lot of weight gain because you know sometimes you feed your stress and especially when you can’t go anywhere. And it was like you didn’t call anybody, I would talk to my friends once in awhile but it was not often like I used to because we used to plan to do things together but then I couldn’t do that so there was no need, and you know people don’t want to hear your song all the time, so you isolate yourself really. I was feeling down with depression, and you don’t want to take it out on them because it’s not their fault so you just ask, “When will I get a break?” So I had to make that decision and I didn’t feel bad about it because I knew that that was what I had to do and I know that now I’m glad.

Jim was constantly stressed and worried about his mother and her condition, thus affecting his emotional health, and how he shared his feelings of stress with other people. He explains the stress in his life at the time he was providing care:

Yeah, and I was constantly worrying if she was going to fall or did she leave the bath water running, or did she leave the stove on and it was always a care of what is going on. Knowing that she was ok decreased my stress. I would say I was concerned, but I wouldn’t say I got distressed, for the most part, I think one way or another, I had talked with enough people about what was going on, I had friends who would come and help out also, so I had a lot of help.
Social Support

Social support is crucial during dementia caregiving. It was important to understand if the caregivers in this study had a good social support system available for them which allowed them to communicate with others about their stressors. All caregivers interviewed did have some form of social support which helped them in dealing with the challenges of dementia caregiving. Bobbi had a good social support through the church and its community members. She explained the helpfulness of these people:

There were ladies at church and even men, that came by and they would sit there and talk to him and they would help him with relating back and talking and that would give me some time to go and lay down and rest sometimes and they would just sit there and talk to him while I would just go and be quiet somewhere.

Neda explained how staying connected through talking to friends, as well as her uncle, helped her:

I guess I would talk to my friends on the phone, but I really didn’t want them to come in and talk with her. Just talking on the phone with folks and um I had my mother’s brother, my uncle helped me, he’s a minister and he helped me through a lot of it, although it was very difficult on him to see his big sister go through this. He didn’t visit as much either. I did confide with him more than anyone else I think and he kept her for me overnight one time.

Jim explained how his family and friends in church provided relief from the stress of caring for his mother with dementia:

Yes, my kids were there and they would help out, daughter-in-laws and everybody. The grandkids were tremendous, they would go over and see her too and that would lift her up during the day. Um, the neighbors, would help out and go and visit my mom, so different people coming in, our church, different members of our church would go in an see her and that was a tremendous amount of help which relieved me, which helped a lot. Yeah, we would talk about my feelings and experiences and some of them had been through the same thing with their relative so they knew what I was going through and they could coach me through, they would talk with me about that.

Peggy described her social support system, which included two families:

Well, I have two families, one is my house family and one is my work family and I don’t have friends in the area, I don’t have people I call all over the country. I have my children,
my husband, and my mother, but I found that my work family was um, a good, I don’t want to say, a good place, but they were caring enough to sit and talk for a few minutes and to listen. It was my work family that helped me in that respect, they were kind of my counselors that I could say things to that didn’t come back to me, because they really don’t care about the big picture, they just care about me and it’s not about me or my mother or my husband, they care about “What’s Peggy doing today? Is Peggy going to be ok with her job today?

Peggy was able to confide in friends and work, while relying on her husband at home. She stated that this greatly helped her in dealing with the challenges that she faced while providing care for her mother.

Data Analysis of Critical Incident Statements across Participants

The researcher focused on understanding critical incidents through the use of in-depth interviews during this study. A critical incident is often described as a significant experience which negatively or positively contributes to an outcome. The researcher sought to understand critical incidents which were described by the participants of this study, and the effect that these critical incidents had on their dementia caregiving experiences.

Dana experienced her father having numerous falls in the home, which commonly resulted in injuries. She had made accommodations to the bathroom, as well as to other areas in the home, in an attempt to keep him safe. A critical incident which resulted in Dana considering placement for her father in a nursing home was a bad fall in the bathroom. Dana explains the experience which made her critically think about her father’s future:

Well, like I said, he started falling out of the bed because he would get up in the middle of the night to go to the bathroom and he would not use the urinal. Um, he decided that when he would go to the bathroom, he would pull up on the grab bars, and one time he pulled up and he fell into the shower. So, he fell into the bathtub, and that was the first time that we decided…I think, I think that putting him in the nursing home was best for him because he was going to hurt himself severely, because like he fell backwards into the tub, so they took the tub out and they put the shower in and he fell headfirst into the shower, you know so it’s like, it was not an easy decision, but he couldn’t bathe, and he didn’t like the caregivers’ help to come in and be at the house, he didn’t like strangers at the house, and if it was me or my
sister, that was fine, but he didn’t like bringing anyone else in. So, um, I think that made the decision; we knew that Daddy couldn’t stay at home.

Jan had a critical incidence which resulted in her realizing that she could never again leave her mother alone in the home. Following a short errand with her husband, Jan returned to find that her mother had swallowed an entire cup of rum without realizing it. Jan was very worried for her mother’s safety and made the decision to make sure that her mother was monitored twenty-four hours a day. Jan explains the critical incident which occurred that made her realize that she must continuously focus on her mother’s safety:

In the bottom of the mug, there was a dark brown liquid in it. I knew that she took her coffee with milk and I smelled the mug and I couldn’t place it and I asked my husband and he sipped it and it was dark rum, and she had had poured herself a whole mug of rum and drunk the entire mug of it without realizing that it wasn’t coffee, and that was the day, the moment that we learned the “oh my God moment” that we can’t ever leave her alone.

Neda also had a critical incident which made her realize that her mother’s safety was in danger. Neda explained in the in-depth interview that she was constantly making food for her mother and bringing in over to her home. She was concerned that her mother was getting lost while driving, so she took away the car. The incident that really made Neda realize that her mother needed constant care was when she found empty cat food cans from which her mother had been eating. Neda explains the critical incidents which resulted in her mother needing continual care and supervision:

Um, she got lost, she drove, so I took her car away from her. I have a younger sister, but she lives in Louisiana so she didn’t really play a role in her caregiving, because of the distance. Um, but I just kept seeing her, every time that I would visit I would just see that she wasn’t eating, and then I would find cans of cat food open, and I think she was eating cat food instead of the food that was prepared for her. So, doctor’s care, MRI…I guess everything led to, she has dementia.

Pauline had an experience which scared her greatly, thus leading to her mother moving in with her and her husband. Pauline reflected on two incidents which occurred in which her mother left her apartment in the middle of the night and was found wandering throughout the neighborhood by her neighbors. These two experiences made Pauline realize that her mother could never be left
alone again, and could no longer live on her own. These experiences led Pauline to move her mother into her home. Pauline reflects on the moment when she realized that her mother was a danger to herself due to her dementia:

The first night she walked all the way out of her apartment into the yard, and she happened to be spotted by a friend of her’s who was up in the middle of the night because she has asthma and she saw my mother and then she called me. And then the next incidence was a girl across the hall was going to work and mama was out in the hallway about 5:00 in the morning and she called me and I said “uh oh, we can’t do this anymore, I am going to have to move you in.”

Peggy, like Pauline, also took care of her mother in her home for many years. Peggy reflected on an incident which occurred during her caregiving in which her mother’s psychotic behaviors and delusions became too difficult to control. Following the advice of the psychiatrist, Peggy called the police and rescue squad in an effort to control her mother’s behaviors. This incident made Peggy realize that she could no longer handle her mother in her home, thus relinquishing her caregiving duties. Peggy remembers the evening her mother had to be removed from her home, thus leading to an admission at a local psychiatric hospital:

So, on the night that she had all these delusions that she had to get to Bill, I was advised to call the ambulance and have them take her to St. Mary’s psychiatric hospital. So I nodded to my husband to please call. Where upon you end up with the entire Hanover County Fire Department at your door. So the entire neighborhood knows that something is going on at your house and they took her to St. Mary’s that night.

Jim realized that something had to change regarding his caregiving responsibilities following a week of monitoring his mother at night to make sure that she did not wander out of the house. He was exhausted and physically drained when he realized that he could no longer continue to be the primary caregiver for her. Jim explains the experience that made him understand that he had done all he could to ensure the safety of his mother:

Um, after I guess staying up until 3 or 4 in the morning for a week making sure that she didn’t go outside and wander off, because Mom, she might go to bed early, but she would wake up at 2 in the morning and decide that she wanted some milk or something and then she would go and sit on the porch. I was monitoring her, and it was killing me. I would be dead
during the middle of the day so I just thought, “we have to do something,” and it, it was just too much.

Alfred had a critical experience which involved his wife going into the hospital with a health condition. When it was time for his wife to be discharged from the hospital, the doctors noticed that she had two dislocated shoulders. Hearing this information and experiencing the challenges that he had at home while caring for his wife, prior to her hospital admission, made him realize that he could never take her home again. Alfred explained what happened while in the hospital with his wife:

Well she had five or more doctors but I never could find one doctor who talked to me. She had a stripe on her back from her neck to her buttocks, striped, and uh, at that point I really thought that that would be the end of everything. When she got out of the hospital both shoulders were dislocated, and there was no way I could take her home.

Kittie desperately wanted her husband to be able to come home following rehabilitation for a broken hip. It was only after she experienced him consistently unable to walk during his rehabilitation sessions that she realized that he would never be home with her again. Although she had been so hopeful and positive, the realization that she would not be able to physically handle him at home as his caregiver was difficult for her to grasp. Kittie remembers when she realized that her husband’s permanent nursing home placement was necessary:

Uh, after he broke his hip and was placed over here, they worked with him for I’ll say one hundred days, and never could get him back up to walking. They tried and tried and they couldn’t do it. And that is when I realized that he is going to have to be a permanent resident. So, up until then I was hoping I could bring him home.

The critical incident technique used during this study focused on the experiences of the dementia caregivers interviewed. Each caregiver provided the researcher with detailed information that was significant to the outcome of this study, thus leading the researcher to better understand situations and experiences that led to the nursing home placement of their family member.
CHAPTER 5
DISCUSSION

Introduction

This study sought to understand the decision making process of informal dementia caregivers seeking nursing home placement. Because of the challenges that dementia caregivers face during the caregiving process, the researcher interviewed twelve former informal dementia caregivers who recently placed their family member with dementia into a nursing home, in an effort to understand their experiences. These caregivers were asked questions which related to different experiences, such as the initial reason for which they became caregivers, the challenges associated with the caregiving, and the issues of stress and depression during the caregiving. Through the use of the experiential learning theory, the researcher sought to understand how the caregivers learned from their experiences, and if this learning assisted them in the decision to seek a nursing home. The caregivers relived the time when they were the primary caregivers for their family members, and shared these experiences, often with emotion, with the researcher during in-depth interviews which lasted about an hour each. It is during these interviews that the researcher was able to realize that although the caregivers each provided assistance to different family members with dementia, their experiences were very similar when dealing with falls, dementia behaviors, hospital admissions, and other common stressors associated with this form of caregiving.

The researcher interviewed the former caregivers in this study to generate knowledge about
issues that are common in informal dementia caregiving. In-depth interviews were the primary
time source of data, as well as member-checking, and a reflexive journal in which observations were
recorded. An interview guide comprised of eleven questions based on the current dementia
caregiving literature addressed the following issues: how the caregiver initially entered the
caregiving role, the time commitment associated with caregiving, the challenges of caregiving,
identifying one’s role in the caregiving process, identifying stress and depression within the
caregiver, and the role of social support during the caregiving process.

During data analysis, the constant comparison method was used beginning with the first
interview and continuing through the last interview. In order to identify initial themes, data reduction
was used. Seven core categories related to the decision making process to seek nursing home
placement in the sample emerged from the data analysis: medical intervention, behavior
management, emotional and psychological drain, social support, social withdrawal, role overload,
and role relinquishment.

This chapter reviews the theoretical link between the Experiential Learning Theory and
dementia caregiving, as well as the use of the Critical Incident Theory in relation to the decision
making process to seek nursing home placement. This chapter also examines the study findings in
relation to the existing knowledge on providing informal care for elders with dementia and the
decision making process to seek formal placement. The delimitations of this research are then
explained, followed by recommendations for further research.

Theoretical Links:

The Experiential Learning Theory and Dementia Caregiving

The findings that emerged from this study on dementia caregiving were consistent with the
experiential learning theory. First, the data analysis showed that the caregivers used their
experiences as a way to analyze the interactions of people and their environments, thus linking action and thought, which leads to learning and understanding. This learning and understanding greatly assisted the dementia caregivers in making their decision to seek long-term care placement in a nursing home for their family members. Because experiential learning makes sense of active engagement between the inner world of the person and the outer world of the environment (Beard & Wilson, 2006), the majority of the caregivers interviewed reflected on their day to day experiences in determining that they could no longer provide care for their family member, thus leading to nursing home placement. The individuals interviewed in this study were involved in numerous situations in which they learned as a result of their experiences. An example of this includes a caregiver who tried multiple times to make accommodations to her home in an effort to keep her father safe, especially during bathing. It was from these difficult attempts to bathe him, including two instances when he fell, harming himself, that she made the decision, based on the active engagement in caregiving, that she could no long provide care for her father, and sought a nursing home.

This example relates well when understanding the experiential learning theory (ELT) because this theory considers learning to be a cycle that begins with one’s experience, continues with reflection, and later leads to action which becomes a concrete experience for reflection (Demirbas & Demirkan, 2003). Aside from the caregivers whose family member had a hospital admission leading to nursing home placement, the dementia caregivers in this study used the ELT and followed the following phases (1) concrete experience, (2) reflective observation, (3) abstract conceptualization, and (4) active experimentation prior to making their decision to seek a nursing home. The framework of the ELT is holistic, to include affective, perceptual, behavioral, and cognitive strategies (Boyatzis & Kolb 1991). Kolb’s ELT offered a way to understand the different learning
styles of individuals, as well as an explanation of how experiential learning applied to the dementia caregivers.

Through using the ELT in this study, immediate and concrete experiences provided a basis for reflections and observations. These reflective observations led to the formulation of abstract concepts and caregiving generalizations. Because the ELT focuses on learning as a process, the caregivers were able to gain knowledge through the transformation of experience. The purpose of experiential learning is to lead individuals through the various cycles of the ELT in order to ensure that critical links between the different moments in the learning process are made (Jong, 2006). Through the use of the experiential learning process, some caregivers in the study learned by active experimentation, while others learned from their caregiving experiences through hands-on situations and independent discovery.

Because learning from experience is a natural means of learning which requires the opportunity to reflect and think about one’s experiences (Beard & Wilson, 2006), the informal dementia caregivers of elderly individuals learned a lot through often difficult experiences thus leading to learn informally through experiential learning. These experiences include the extensive time commitment associated with caregiving, the challenges of caregiving, to include dealing with difficult behaviors, the emotional and psychological toll of dementia caregiving, and a lack of assistance during the caregiving process. Because being an informal dementia caregiver is a very time consuming role with many negative aspects, it is through the ELT that dementia caregivers can learn from change in order to better adapt to future change (Beard & Wilson, 2006).

As mentioned above, the ELT focuses on learning from processing one’s experiences. During this study, the experiences shared show how caregivers can learn from experiences at different times. Some of the informal caregivers interviewed shared with the researcher how they learned from an event at the time it occurs, while others learned from a past event when they reflected on it later. This study validated that experiential learning can also take place from learning more about a past event when thinking about it more in-depth (Beard & Wilson, 2006). This type of learning,
retrospective learning, was seen often throughout the in-depth interviews completed during this study. The individuals interviewed looked back on their experiences and closely recollected what happened, thus learning from their experiences. In addition to learning from their experiences, they were also able to relate their experience to existing ones, thus finding new meanings in past experiences (Beard & Wilson, 2006). This was the case when the caregivers were sharing feelings of a return to normalcy following the relinquishment of their caregiver role. Many reflecting back on their experiences shared that they did not realize at the time just how stressed out they really were, until they were able to return to their day to day routine, following the admission of their family member into a nursing home.

The Critical Incident Technique and the Decision Making Process

The critical incident technique (CIT) was an appropriate technique to use for this study because it focused on gathering qualitative information from important incidents which one has experienced. J.C. Flanagan created the CIT as a means to gather information, such as factual knowledge regarding specific and significant behaviors, in order to make logical conclusions. (Flanagan, 1958). Because this technique uses unstructured interviews to capture the frames of reference, thought processes, and the feelings about a particular incident that has meaning for the participant in the study, it worked well when analyzing the in-depth interviews of the dementia caregivers in this study. The use of the CIT during an interview as form of storytelling (Boyatzis, 1998), was particularly helpful in understanding the dementia caregivers’ decision to seek nursing home placement.

During the interviews, the caregivers were asked to describe what led up to their becoming the primary caregiver, who was involved in the situation, who assisted them during the caregiving process, and how did they come to the decision to seek nursing home placement for their family member. Through using the CIT during an interview, the researcher acted as a journalist in order to attempt to minimize leading cues and get the interviewee to describe their actual behaviors and statements (Boyatzis, 1998). She asked open-ended questions which allowed the caregivers to explain situations that they experienced leading up to their decision to seek professional care. It was
imperative that the dementia caregiver gave an account of what the specific experiences meant to them in relation to their present circumstances, their life situation, as well as their attitudes and orientation during the interview. The researcher was then able to fully understand the critical incident that they experienced, as well as the outcome of the situation, which was the nursing home placement.

The CIT was appropriate to use during this study because it takes into account the affective, behavioral, and cognitive elements of the dementia caregiving process (Chell, 2005). Prior to using the CIT, the researcher created research questions and ideas which focused on the objectives of the study. She then located appropriate study participants, the dementia caregivers, and asked them to focus on a limited number of incidents that took place during their caregiving experience. The findings of this study show that many critical incidents led to the nursing home placement of their elderly family members. Jan, for example, knew that it was time to place her mother into a nursing home when her mother began to show physical signs of exhaustion relating to her daily routine of getting up early and having to go to an adult day care program for eight hours a day. For Bobbi, she knew that she had to seek nursing home placement following her husband’s debilitative stroke. Dana feared for her father’s safety after a head injury occurred while he was showering, thus leading her to seek a safer environment for her father. These examples of the findings show critical incidents that took place in which the informal dementia caregiver realized that they could no longer provide the care that their family member needed, thus leading to nursing home placement.

The CIT was selected for this study because it focused on gathering qualitative information from incidents that the former informal caregiver experienced during their dementia caregiving, as well as during their decision making process to seek placement in a nursing home. The participants in this study were able to provide the researcher with an in-depth look at particular caregiving situations by allowing the dementia caregiver the opportunity to share their story during the interview. The CIT allowed the interviewer to understand the factual knowledge which led to the conclusion of nursing home placement, based on the caregiver interviews.
Key Comparison of Study Results

Difficult behaviors are common in dementia. Of the twelve caregivers interviewed in this study, five stated that difficult behaviors did influence their decision to seek nursing home placement for the elderly family members in their care. These caregivers had a very difficult time dealing with behaviors which included wandering, aggression, confusion, and agitation. These results are similar to a study regarding the effects of caregiving duration on institutionalization (Gaugler et al., 2005). This longitudinal study focused on determining how the duration of caregiving interacts with key care demands, such as the severity of problem behaviors, in regards to the institutionalization of individuals suffering from dementia. The results of the study show that more recent caregivers were more likely to institutionalize individuals with dementia than study respondents in different stages of the caregiving career. This study’s results also showed that providing care to an individual with dementia reflects on their decision to seek nursing home placement, especially when dementia behaviors are present. The duration of time that the caregiver provided care did not have an impact on the nursing home placement.

The caregivers interviewed in this study had mixed emotions when dealing with caregiver relinquishment. As mentioned, there was a strong sense of relief for nine caregivers in the study. For four caregivers interviewed in this study, there were many feelings of guilt associated with the admission to a nursing home and the relinquishment of their role. In a study which focused on the support of family caregivers during the long-term care placement process for elderly individuals (Nolan & Dellasega, 2000) caregivers also felt a sense of guilt when having to relinquish their caregiving role. In addition to the guilt felt, these caregivers also felt a sense of loneliness, sadness, and stress, similar to the caregivers in this study. The above study also shares caregivers’ feelings of frustration during the caregiving experience, as well as the importance of social support during the transitional period.

The emotional and psychological toll of dementia caregiving was certainly noticeable during this study's data analysis. In a study which focused on chronic stress and depression disorders in
elderly individuals (Stukenberg & Keicolt-Glaser, 1990) there was a focus on the hardships associated with providing care to an individual with dementia. When reviewing studies of depression in dementia caregivers, it was noted that depression rates ranged from fourteen percent to eighty-one percent of the caregivers in the sample. This is very similar to the results of this study, which show that seven of the twelve caregivers interviewed admitted that the emotional and psychological toll of caregiving led them to seek nursing home placement for the family member in their care.

This study’s results showed that the placement of an individual with dementia into a nursing home often takes place as the result of a sudden or unexpected happening. This was also the case in a study regarding critical incidents which precipitated the institutionalization of family members with Alzheimer’s disease (Liken, 2001). In both studies, at least eighty-percent of caregivers reported moving their relative to a nursing home as the result of an unplanned event, such as a fall, injury, or hospital admission. Many of these caregivers expected the possible admission of their relative to a nursing home in the future, but were caught off guard by the sudden need for placement. Another commonality between these two studies is the sense of role overload and loss of sense of control over the caregiving situation. In both studies, many of the caregivers tried numerous alternatives in an attempt to keep their family member at home, such as accommodations to the home and bringing in home health care, but the loss of control and feelings of overload forced them to seek nursing home placement. These two studies also had similarities which included the dementia caregiver feeling socially isolated and withdrawn from their pleasures in life. This was a common theme as caregivers dealt with the long hours of dementia caregiving, the lack of necessary assistance, and the stress and strain on their personal and professional lives.

**Limitations of the Study**

The limitations of this study included the income and payer source of the informal caregivers.
in this sample. This was an anticipated problem, due to some caregivers with limited assets not being able to utilize community interventions and services that may be costly, such as home health care services. Another limitation to this study was the small sample size, with a sample of twelve former informal dementia caregivers. Since this study type is nongeneralizable the findings of this study are specific to study participants and the setting involved. The retrospective view of the participants' decision making process was also seen as a limitation due to the different experiences each participant had when looking back and reflecting on their time as informal dementia caregivers. A final limitation included not having the dementia patient’s perspective and their view of the decision making process. By not having this information included in the study, one could only see one side of the story involving the placement into a nursing home.

Implications for Practice

The data collected from this research can be beneficial to both current and future caregivers. One implication for practice includes targeting community members through different faith based social agencies such as Jewish Family Services, Catholic Social Services, and Lutheran Social Services. Information seminars can provide individuals with a better understanding of dementia and the dementia caregiving process. Seminars can focus on providing basic caregiving techniques such as how to give proper baths and personal care to another individual. Tips on how to deal with the difficult behaviors associated with dementia, as well as how to successfully handle feelings of caregiver stress and burden can also be provided.

A second implication for practice includes county and city social service departments providing informative materials for today’s dementia caregivers in their offices, as well as caregiver support services. An example of informative material would include brochures on research-based information such as how to balance dementia caregiving, family, and work. A possible checklist for new dementia caregivers would also be helpful, and could include making sure that they speak with a health care provider to learn more about dementia, and that they explore their options regarding
what assistance is available to them. Another informative research-based brochure available free at service departments could include one hundred important pieces of information that every dementia caregiver should know. Examples of information provided could include the importance of the caregiver maintaining good health and eating well and exercising, as well as the importance of having a support system.

The data from this study revealed that many caregivers are not aware of the challenges that they face with dementia caregiving. It is through educating our future caregivers with courses, as well as providing our current caregivers with necessary support and information, that the dementia caregiving process will be better understood by all.

**Recommendations for Future Research**

It is apparent that today's elderly population is growing and living longer lives than ever before. With an increase in age comes an increase in the possibility of dementia and dementia-related issues such as falls, aggressive behaviors, stress, and depression. Informal dementia caregivers need a better understanding of ways to deal with the challenges of dementia caregiving. Although the results of this study suggest factors that lead to the placement of individuals with dementia, there is certainly a greater need for increased exploration into the decision making process of informal dementia caregivers regarding nursing home placement. The researcher suggests conducting a study which focuses on better understanding the dementia caregiving process. The first part of this study could follow elderly individuals after the diagnosis of dementia. In-depth interviews with the elderly individual, if possible, would provide insight into the dementia process, allowing them to express their feelings following diagnosis, the challenges which they are facing, and how they are coping with these challenges. It is very important to understand and learn from individuals at the onset of dementia, following through as they progress through the disease process.

The second part of this study could focus on family interviews throughout the stages of
dementia. Having a better understanding of how the family is coping with the decline of their family member will provide future dementia caregivers with an idea of what to expect when their family members’ decline. The in-depth interviews which took place during this study provided the researcher with a vast amount of knowledge regarding the challenges associated with providing this type of care. Many of the caregivers were unfamiliar with the warning signs of dementia, and many did not know about the behaviors associated with dementia. In addition to this, the lack of social support that some caregivers experienced, in addition to trying to balance work and family, was very challenging. Future research, like the proposed study above, is needed in order to understand the viewpoints of both the elderly individuals with dementia, as well as the dementia caregiver. Because many caregivers of elderly individuals are family members, there is often a lack of necessary knowledge regarding important aging issues. Future research is needed in order to focus attention on understanding these caregivers and what they should reasonably expect while providing care for an elderly individual with dementia.

In addition to need for research studies which focus on understanding the individual with dementia, as well as their caregiver, the researcher also proposes additional qualitative studies which focus on the stress and burden associated with dementia caregiving. This is suggested in an effort to understand the emotional situations that these type of caregivers experience.

More studies that use in-depth interviews in an effort to understand the voices of former dementia caregivers would be beneficial. There are many issues related to the balance of work, family, and dementia caregiving that are very common, often leading to feelings of depression and despair. The researcher observed many different emotions during her in-depth interviews, leading her to believe that the emotional side of dementia caregiving was not typically addressed or treated as a priority by the caregiver. As mentioned above, in-services and training on what to expect
during the dementia caregiving experience may better prepare caregivers for the possible negative emotional toll commonly associated with dementia caregiving. Future research would allow the opportunity to collect data which focus on the mental and emotional health of the dementia caregiver, which based on this research, is woefully lacking.
I am a doctoral student under the direction of Dr. Paul Gerber in the School of Education at Virginia Commonwealth University. I am conducting a research study to understand the decision making process of dementia caregivers regarding nursing home placement.

I am recruiting former dementia caregivers to participate in semi-structured interviews. During these interviews, they will be asked to share their experiences regarding the decision to seek nursing home placement for their family members. These interviews will take approximately one hour.

Your participation in this study is voluntary. If you are interested in participating in this research study, please call me at (804) 690-5053.

Sincerely,

Rebecca Merritt
Appendix B

Interview Protocol Form

Interviewee (Title and Name): ________________________________

Interviewer: ________________________________________________

Survey Sections:

_____ A: Interviewee Background

_____ B: Prior to Nursing Home Placement

_____ C: Decision Making Process Regarding Nursing Home Placement

_____ D. Stress and the Informal Caregiver:

Other Topics Discussed: ________________________________________

___________________________________________________________

Documents Obtained: _________________________________________

___________________________________________________________

___________________________________________________________

Post Interview Comments or Leads:

___________________________________________________________
Informal Caregiver Interviews

Introduction

Introductory Protocol

*In addition to note-taking, I would like permission to audio tape our conversations today. Please sign the following release form. To ensure confidentiality, only the researcher completing this study will have access to these audio tapes. Once the study is completed, the tapes will be destroyed. You must also sign a form created to meet our human subject research requirements. This form states that (1) all information will be confidential, (2) your participation in this study is completely voluntary and you may stop participating in the study at any time if you so desire, and (3) the researcher does not intend to inflict any harm during this study. Thank you so much for your participation.*

*The researcher has planned to have this interview last no longer than one hour. During the interview, there are several questions that need to be covered. If the allotted time begins to run out, it may be necessary to interrupt you in order to continue with the necessary line of research questions.*

You have been selected to speak with me today because you have been identified as a former informal caregiver. This research study focuses on the decision making process of informal caregivers regarding long term care institutionalization. The particular interests in this study are the factors that lead up to the informal caregiver seeking formal care. Understanding the experiences of these caregivers, how the caregiving affected their life, and the challenges of the caregiving experience will provide the researcher and the field with an in-depth look into the informal caregiving experience. It is important to note that this study does not aim to critique or evaluate your former caregiving experience. The researcher is trying to learn more about the informal caregiving process and what drives the informal caregiver to seek greater assistance with providing care to an elderly family member.

A. Interviewee Background

A1 I'm interested in learning as much as possible about what it's like to be a caregiver who has had to place a loved one with dementia in a nursing home. I'm interested in hearing about your experience (how long you provided care, what happened in that process, and what led up to the nursing home placement). Would you begin by describing your experience?

A2 Often caregiving can be very time consuming. Can you describe other assistance that you received from family members or friends? Can you please describe the extent of their help?

A3 Critical incidents can be thought of as crucial experiences which one gained knowledge and made conclusions. Please explain if there was a critical incident that took place initially thus resulting in you becoming a caregiver.
A4  Caregiving can be very challenging. Please describe if there were challenges when caring for your elderly family member? Please explain if you were managing other tasks at home in addition to your caregiving, such as working outside the home.

B. Prior to Nursing Home Placement

B 1  Being an informal caregiver can be very time consuming. Please explain if you ever felt as though caregiving would be too much to handle for a long period of time?

B 2  Many different situations lead caregivers to seek nursing home placement. Please describe how you realized that your loved one needed to be placed in a nursing home. Please explain how you felt when you realized that placement was necessary.

C. Decision Making Process Regarding Nursing Home Placement

C 1  Dementia caregiving often involves dealing with difficult behaviors. Please explain how you dealt with the challenges of dementia caregiving. Please explain if any behaviors influenced your decision to seek long-term care.

C 2  There are both negative and positive aspects of caregiving. Please explain if you felt as though you were important and needed during the caregiving experience? Please explain any negative feelings associated with the caregiving.

C 3  Identifying one's role in the caregiving process is common. Please explain how it felt to relinquish your caregiving role.

D. Stress and the Informal Caregiver

D 1  Providing care for an individual with dementia has been linked to stress and depression. To what degree has stress factored into your decision to seek long-term care institutionalization?

D 2  Social support is crucial during caregiving. As a caregiver, how were you able to cope with the stressors of caregiving? Please explain if there was a good social support system available for you which allowed you to communicate with others about your stressors.
RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: The Decision Making Process of Informal Dementia Caregivers Regarding Nursing Home Placement

VCU IRB NO.: HM 13062

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to find out the decision making process of informal dementia caregivers regarding long-term care institutionalization.

You are being asked to participate in this study because you are a former dementia caregiver who placed the elderly family member in your care into a long-term care facility within the past year.

DESCRIPTION OF THE STUDY

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

Participation in this study will entail answering a series of open-ended questions related to your caregiving experience, and your decision making to seek long-term care placement. The interview will take about one hour of your time, and approximately 9-12 other former caregivers will participate in this study.

Examples of the questions you will be asked include:

1. Providing care for an individual with dementia has been linked to stress and depression. To what degree has stress factored into your decision to seek long-term care institutionalization?

2. Social support is crucial during caregiving. As a caregiver, how were you able to cope with the stressors of caregiving? Please explain if there was a good social support system available for you which allowed you to communicate with others about your stressors.

The meetings will be tape recorded so we are sure to get everyone’s ideas, but no names will be recorded on the tape.

Significant new findings developed during the course of the research which may relate to your willingness to continue participation will be provided to you.
RISKS AND DISCOMFORTS

Sometimes talking about these subjects causes people to become upset. Several questions will ask about things that have happened during your caregiving experience may have been unpleasant. You do not have to talk about any subjects you do not want to talk about, and you may leave the interview. If you become upset, the researcher will give you names of counseling services to contact so you can get help in dealing with these issues. The researcher is not responsible for the expense of these services.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but, the information we learn from the caregivers in this study may help current or future caregivers in dealing with certain caregiving experiences.

COSTS

There are no costs for participating in this study other than the time you will spend in the interview.

CONFIDENTIALITY

Potentially identifiable information about you will consist of interview notes and recordings, and audiotapes of interviews. Data is being collected only for research purposes. The data will be stored in a locked filing cabinet, with only the researcher having the key. Any identifiable data will be stripped prior to data analysis. All taped interviews will be destroyed following data analysis. A data and safety monitoring plan is established.

We will not tell anyone the answers you give us; however, information from the study and information from your interviews and the consent form signed by you may be looked at or copied for the research or by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

The interviews will be audio taped, but no names will be recorded. At the beginning of the session, all caregivers will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. After the information from the tapes is typed up, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the researcher without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions;
**QUESTIONS**
In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:
Dr. Paul Gerber, VCU Professor  
(804) 828-1332

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 113  
P.O. Box 980568  
Richmond, VA  23298  
Telephone:  804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at http://www.research.vcu.edu/irb/volunteers.htm.

**CONSENT**
I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

<table>
<thead>
<tr>
<th>Participant name printed</th>
<th>Participant signature</th>
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Name of Person Conducting Informed Consent  
Date

Discussion / Witness ³

(Printed)

________________________________________________ ________________  
Signature of Person Conducting Informed Consent  
Date

Discussion / Witness

Principal Investigator Signature (if different from above)  
Date ⁴
Appendix D

Potential risks of this study include emotional or psychological distress as a result of asking former caregivers to discuss the care of an elderly person close to them. This may be stressful or trigger emotional content. The researcher has provided this list of organizations able to help them process any feelings, if necessary. The researcher does not assume responsibility for any costs associated with this care or with these services.

The following resources are recommended counseling services:

Dominion Behavioral Health (804) 270-1124
Chapman Senior Care (804) 741-7500
Counseling by Jewish Family Services (804) 282-5644
References


Centers for Disease Control and Prevention (2006). Dementia and Its Implications for Public


