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The Experience of Adult Children Caring for Aging Parents

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THE EXPERIENCE OF ADULT CHILDREN
CAREGIVING FOR AGING PARENTS

BY

KIMBERLY CONWAY

Dissertation Committee

Dr. Judith Lothian, Chair

Dr. Judith Lucas

Dr. Munira Wells

Submitted in partial fulfillment of the
Requirements for the degree of Doctor of Philosophy in Nursing

Seton Hall University

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DEDICATION

Author Jane Howard is credited with saying this: Call it a clan, call it a network, call it a tribe, call it a family. Whatever you call it, whoever you are, you need one.

This work is dedicated to my family. To my mother, who always wanted to become a nurse and instilled in me the passion of caring for others. To my husband George, and my children Christian, Matthew, Erin, April, and Rachael who supported the decision to continue my nursing education 100%. There were many times over the six-year journey I needed another pair of hands. Without hesitation, George pitched in. When I became impatient and despondent, my caring children assisted me when possible, and lifted my spirits. Having a grandmother who was constantly glued to the computer, I especially thank Zachery, Sarah, and Allison for reminding me that there wasn't anyone else who could spend precious time with them making cookies, planting flowers, or reading stories with them.

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ABSTRACT

Background: An estimated 35 million Americans are age 65 or older, and this population is expected to double within 25 years. When the normal progression of life for an aging person is interrupted, adult children are often suddenly faced with assuming care of their parent(s). Currently adult child caregivers of aging parents, work up to 100 hours per month at caregiving.

Problem Statement: A limited body of empirical studies exists on the caregiving of aging parents exclusively by their adult children. Despite the amount of time dedicated to parental caregiving little is known about the experience of this exclusive caregiver group. The question being asked is “What is the experience of adult children caregiving for aging parents?”

Method: A phenomenological approach was used to gain insight into the lived experience of an adult child caregiving for their parent(s). Interviews were conducted with six daughters and one daughter in law. Interviews were audio taped, transcribed and analyzed using traditional qualitative techniques. Themes were identified and presented through the use of storytelling and narratives.

Results: Assumption of caregiving tasks for a parent often occur unexpectedly. Adult child caregivers then undergo significant changes in their family life, employment, filial and social relationships. They experience a myriad of unpleasant emotions and loss, yet their viewpoints remain extremely positive.

Conclusions: Assessing the physical, educational, and emotional needs of caregivers gives nurses the opportunity not only to provide instructions, but much

needed holistic support and self-care instructions as well. These conversations can help improve the adult child's caregiving experience and that of their parents.

Chapter 1

INTRODUCTION

Aim of the Study

People in the United States are living longer. An estimated 35 million Americans are age 65 or older, and this population is expected to double within 25 years. The oldest old, who are 85 years or older are the fastest growing segment of the population. What is most concerning is that as age increases, so too does the risk to develop co-morbid conditions that can seriously endanger the health of the elderly. These comorbidities can complicate existing chronic conditions and decrease the quality of life for our senior Americans. (National Institute on Aging [NIA], 2007; Schultz & Martire, 2006). When the normal progression of life for an aging person is interrupted due to chronic illness, acute illness or terminal disease, adult children are often suddenly faced with assuming care of their parent(s).

Wolff & Kaspar (2006) estimate that 40% of adult children provide some form of assistance for their aging parents. The responsibilities of this new role can increase tension in the life and relationships of the adult child caregiver (Stone & Clements, 2009; Szinovacz & Davey, 2007), and contribute to loss of productivity and revenue for employers (Metlife, 2011). In addition, the National Alliance for Caregiving (NAC) and AARP (2015) report these key findings:

- American caregivers are predominantly female (60%)

- The majority (86%) of caregivers aged 50 or older care for a relative. Almost half (47%) care for a parent, with 8% reporting they care for a parent-in-law
- More than half (55%) of caregivers of those 50 years old or older are caring for someone age 75 or older.
- Nearly half of caregivers aged 50 or older has been in their role for an average of 3.7 years, with a quarter providing care for five or more years. Those caring for the oldest-old (85 years old/older) have been in their role for 4.6 years – longer than those caring for someone age 50 to 74 years of age.

Most existing literature is focused on family caregivers of relatives requiring terminal and palliative care, and on caregiving for persons with debilitating illnesses such as chronic obstructive pulmonary disease (COPD) and dementia disorders (Herbert & Schultz, 2006; Mannino & Kiri, 2006; Pinto, Holanda, Medeiros, Mota, & Pereira, 2007; Schreiner, Morimoto, Arai, & Zarit, 2006; Spence et al., 2008). Family caregivers encompass spouses, adult children, siblings, and nieces/nephews (Flynn & Mulcahy, 2013; Herbert & Schultz, 2010; Mannion, 2008; Schreiner et al., 2006; Spence et al., 2008). A limited body of empirical studies exists on the caregiving of aging parents exclusively by their adult children. This study aims to explore and describe the experience of adult children caregiving for aging parents at any stage of health.

Phenomenon of Interest

Adult child caregivers of aging parents, work up to 100 hours per month at caregiving. Seven out of ten caregivers are daughters. The majority of adult child

caregivers are in their 40's and 50's, 60% work fulltime, and approximately 17% are self-employed or own a business. Of the adult children that serve as caregivers, greater than 50% have their parents living with them, and over 13% live more than 10 miles away (Johnson & Weiner, 2006; Metlife, 2011; NAC & AARP, 2015). Despite the amount of time dedicated to parental caregiving little is known about the experience of this exclusive caregiver group. Because of potential influences on the adult child caregiver, a deeper understanding is needed of the experience of parental caregiving.

Justification for Studying the Phenomenon

The family caregiver, whether a spouse, adult child, or sibling acts as a consistent provider of home healthcare. This makes him or her a major constituent in the healthcare system (Evercare & NAC, 2007; Eynert & Burman, 1999; Feinberg, Reinhard, Houser, & Choula, 2011; NAC & AARP, 2015). The social, psychological, and spiritual distress levels of ill persons and their family caregivers are highly correlated and have been well documented (Feinberg et al., 2011; Murray et.al. 2010; Northhouse, Catapodi, Schafenacker, & Weiss, 2012; Tang, Li, & Liao, 2007). The NAC & AARP (2015) further delineates the updated profile of adult family caregivers as being single: meaning unmarried (20%), divorced (8%), or widowed (5%) with 38% of family caregivers having children living within or outside of the household. These current populations of caregivers face the same documented risks to their physical and emotional health. The “sandwich” generation are those persons who financially and emotionally support their own child(ren) while supporting

(physically, emotionally, or financially) their aging parents (Miller, 1981, p. 419). Miller (1981) states these adult child caregivers are “exposed to a unique set of unshared stresses” (p. 419). Other research studies support Miller’s (1981) findings identify these stresses as family strain (Strauss, 2013), financial stress and balancing employment (Eldh & Carlsson, 2011), and changes in filial relationships (Stone, Enyert, Middleton, Caughlin, & Brown, 2012). Studying the phenomenon of parental caregiving can provide an expanded awareness of the adult child/parent relationship. Findings can be utilized to help nursing recognize caregiver needs and develop supportive interventions and services to effectively enhance the experience of other adult child caregivers and the care recipients.

Research Question

What is the experience of adult children caregiving for aging parents?

Relevance to Nursing

The current data on the aging population show healthcare is being provided either in the person’s own home, within the adult child’s home or in long term care facilities (Evercare & NAC, 2007; NAC & AARP, 2015). Not all adult child caregivers are readily prepared for what faces them in taking on the responsibility of caring for aging parent(s). Not knowing how to provide care or make decisions creates feelings of frustration and helplessness (King & Quill, 2006). There are numerous studies on the specific consequences to the mental and physical health of caregivers. Herbert & Schultz (2006) identify the caregiver role as a primary stressor. Combining the care needs of the care recipient along with the caregivers’ own family

and personal needs creates role overload leading to dismantled social and family relationships, financial strain, occupational hardships and health deterioration such as various physical ailments, depression, isolation, and anxiety disorders (Coe & van Houtven, 2009; Kang & Marks, 2013; Khalaila, R., & Litwin, H., 2011; Strauss, 2013).

The Institute of Medicine [IOM], (2011) recommends "... to deliver more care in the community rather than the acute care setting." (p. 2). With statistics predicting the elderly population will double over the next 25 years (NIA, 2007), it stands to reason that the need for adult child caregivers will also increase.

The AARP Public Policy Institute, (Feinberg et al., 2011), reports 42.1 million family caregivers provide caregiving to adults with limitations in activities. The estimated value of their unpaid contributions to the U.S. healthcare system is 450 billion dollars. "If family caregivers were no longer available, the economic cost of health care and Long Term Services and Support (LTSS) would increase astronomically" (p.14). Investing in sufficient resources through federal and state policies to reduce caregiver strain, provides a positive return on investments by containing healthcare and LTSS costs (Feinberg et al., 2011).

There is a paucity of empirical information about the current experience of caregiving for aging parents. This knowledge is essential in order to develop nursing interventions to support these adult child caregivers. Results of this study may contribute information that will aid and prepare those who choose this caregiver role, initiate or encourage change in healthcare policy to promote better health outcomes

for caregivers, and provide descriptive evidence with the potential to enhance the experience of adult child caregivers.

Researchers Assumptions/Biases/Experiences

I have personally experienced the challenges of being an adult child caregiver when my mother was dying from lung cancer in 1994. I had just delivered my 5th child 1 month prior to my mother moving into my household. The other children's ages ranged from 3 to 13 years of age. Mom moved back to New Jersey from Arizona knowing she was dying and wanting to be closer to her family. We spoke about how wonderful it was to be together, for her to be able to hold her newest granddaughter, and we shared thoughts while making final arrangements. I was caring for an infant and a three-year-old child at home, afternoons were filled with sport activities and homework with the older siblings, as well as the other responsibilities of running a large household. After only 4 weeks, mom's health declined rapidly. She was becoming weaker, more tired and lethargic. It was a huge effort for her to breathe while walking from one room to another. Feeling extremely overwhelmed, and with mom's permission, I began the process of acquiring hospice intervention for assistance and called our pastor to make a visit. The next morning, I found mom in a coma and she died peacefully that afternoon. No hospice care started and she never saw the pastor. Mom was only 57 years old.

During this encounter with mom, my maternal grandmother was still alive. But neither of them could physically travel to see each other. Although she never mentioned it, I could sense mom deeply longed to see her mother and as her disease

progressed, she did not want to be left alone. I felt my purpose was to keep mom and my grandmother connected on a daily basis, and make sure either myself or my husband was in the house at all times. Although mine was a short caregiving experience, looking back, I became emotionally exhausted and my personal well-being was compromised by my trying to fulfill that purpose. Yet, I feel being able to be with my mother during a very intimate time in her life, gave meaning to my actions; and moreover, gave a sense of some comfort to the loss I was experiencing.

Chapter II

LITERATURE REVIEW

The Health Effects of Caregiving on Family Caregivers

Emblem Health and NAC (2010) define family caregivers as “those responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability. The care recipient may be a family member, life partner or friend” (p. 12). Caregiving according to Schultz (2013) may range from only episodic care, to include the assumption of primary responsibility for care tasks.

Advances in medical technology coupled with the trend towards community based healthcare support the likelihood for persons with chronic and or terminal illnesses to be cared for in the comfort of their home by their family (Herbert & Schultz, 2006; Spence et al., 2008; Vreugdenhil, 2014). There is little educational preparation in assuming the role of a family caregiver. Many family caregivers face a variety of responsibilities, obligations and demands they have never experienced such as medication administration, dressing changes, activities of daily living, symptom assessment, and surrogate decision making (Feinberg et al., 2011; Spence et al., 2008).

According to Herbert & Schultz (2006), caregiver stressors are directly linked to the level of disability, disease type, and tasks required for the care recipient. Studies involving caregivers of family members with COPD reveal role confusion and a conflict in priorities. Caregivers feel time is not their own, and therefore

perceive a lack of control in their life. Schumacher et al., (2008) report similar caregiver effects with caring for a family member with cancer. Some days' caregivers feel they are the spouse, child, or sibling; other days they are the nurse, doctor, or therapist. Due to the constant care needs of the care recipient, caregivers experience loss of concentration, lack of sleep, isolation and depression (Mannino & Kiri, 2006; Schreiner et al., 2006; Spence et al., 2008).

The perpetual daily activities of caring for aging parents can be physically fatiguing. In a majority of persons diagnosed with dementia, the effects such as deterioration of memory, changes in communication and language, reasoning and judgment, intensify over time rendering a person disabled and in need of constant care and safety supervision (Alzheimer's Association, 2014). Social activities for the caregiver such as visiting friends and family can become limited. There are financial worries such as expenses for a child's education, mortgages, decrease or loss of caregiver wages or those of the care recipient if they are the main source of income. Zarit, Reever, & Bach-Peterson (1980), in their seminal study, measured the stressors of "caregiver burden" and found caregivers have increased mortality, anxiety, and depression. Other research studies reveal similar results such as sleep interruptions, sleep deprivation and depression leading to poor concentration and impaired task performance in homemaking and their own personal care (Flynn & Mulcahy, 2013; Mannion, 2008; Schreiner et al., 2006; Spence et al., 2008).

Another perspective in the nursing literature reveals a negative effect of caregiver distress on the care recipient. Highly stressed caregivers can affect their

family member in several ways. The care recipient's adjustment to the illness may be disrupted. This can occur as he/she withholds expression of thoughts and feelings towards their illness, because they are fearful of upsetting their caregiver (Northouse, Templin, & Mood, 2001). Anxiety may increase in the care recipient because they see the added stress their care brings upon their care giver (Segrin, Badger, Dorros, Meek, & Lopez, 2007). There is also an increased potential for medication administration and other treatment errors by the caregiver when their concentration is impaired by multiple stressors (Lai, 2010). These unhealthy effects emphasize the importance of caregiver support.

The Adult Child Caregiver

Miller (1981) coined and defined the term "sandwich generation" as "adult children of the aging who are sandwiched between their aging parents and their own maturing children... a segment of the population roughly between 45 and 65 years of age" (p. 419). These particular caregivers are balancing several responsibilities such as spouse/partner, mother/father, grandmother /grandfather, and employee along with caregiving. The current literature reveals adult child caregivers with their own multiple roles are subject to numerous strains due to the addition of their newly adopted caregiver role (Herbert & Schultz, 2006; Flynn & Mulcahy, 2013; Spence et al., 2008; Vreugdenhil, 2014). The research identifies characteristics of these strains to include poor mental and physical health with family tension (Strauss, 2012), financial stress and balancing employment (Eldh & Carlsson, 2011), and changes in marital and filial relationships (Stone et al., 2012).

Millions of these family caregivers in the U.S. are recognized as an essential element of the healthcare team. At the expense of their own personal health and family relationships, the sandwich generation of caregivers contributes a direct financial impact on the healthcare system in the US. Their monthly out of pocket expenses are approximately \$5,531 per year (Evercare & NAC, 2009). The need for aging parents to participate in public assistance programs such as Medicaid, decreases as a result of their adult children providing their care. This allows healthcare dollars to shift from high cost institutional care, to lower cost community care (Feinberg et al., 2011; Vreugdenhil, 2014). Employers also feel the effects of parental caregiving. Employed caregivers need to make caregiver related phone calls, take time off during the day, and arrive late or leave early from work over the course of approximately 4-6 years (NAC, 2009). Caregiving issues also impact the careers and earnings of employees. It is reported that 63% of caregivers save less for their retirement than those who do not provide caregiving tasks (Evercare & NAC, 2009). Caregivers also make decisions to decrease hours from full to part time, pass up promotions, take early retirement or quit jobs altogether (Evercare & NAC, 2009).

Cultural Influence on Adult Child Caregivers

Filial caregiving among several cultures is a profound core value that shapes family relationships. In the Asian culture, according to Confucian belief, the first born son and his wife are expected to care for his parents and parents-in-law in their aging years. Buddhist teachings encourage service to others over oneself. With regard to parental caregiving, both Confucian and Buddhist principles include showing honor,

reverence, and obedience for fear of shame being brought to both households (Chan et al., 2012; Jones, Zhang, Jaceldo-Siegl, & Meleis, 2002; Wongsawang, Lagampan, Lapvongwattana, & Bowers, 2013;). In Japan, the eldest daughter or wife of the eldest son is expected to care for an elderly parent, even if it means leaving their employment to dedicate themselves to the family member (Chan et al., 2012; Hashizume, 2010; Jones et al., 2002). The attributes of respect, preserving family, and repaying parents are strong supporting motives for Asian adult children to care for their parents. Yet, negative outcomes among these caregivers are evident regardless of how venerable the intentions. A quantitative study by Tang et al., (2007) identify 75.9% of 170 Taiwanese caregiver subjects were at risk for depressive distress. These results are also found in other studies revealing negative associations between filial piety and caregiver burden (Chan et al., 2012; Khalaila & Litwin, 2011), and lack of protection from burden and depression (Lai, 2010). The Mexican & Latino cultures have their own expectations and beliefs about appropriate caregiving within the family. Female members provide most of the caregiving due to beliefs of gender specific roles of males and family honor. (Delgado & Tennstedt, 1997; Hodge & Sun, 2012; Wells, Cagle, Bradley, & Barnes, 2008). Religion, belief in God, and associated religious practices are very prominent within the Hispanic culture and these are motivating factors in caregiving (Hodge & Sun, 2012). The elderly Latino population is expected to quadruple by 2050. Higher birth rates among this ethnic minority provide younger adult child caregivers, but compared to their Caucasian counterparts they have fewer financial resources, lower financial income and less

access to healthcare. As a result, the elders can have greater cognitive and physical impairments forcing caregivers to provide higher levels of care without assistance, and placing caregivers at higher risk for unhealthy outcomes (Herbert & Schultz, 2006).

Summary

People are living longer in part due to advances in medicine and changes in healthcare policies. Along with advancing age comes age related health issues. There will come a point when older adults can no longer independently care for themselves and their child or children will likely become their caregivers. Several studies on family caregivers (Feinberg et al., 2011; Herbert, 2013; Lai, 2010; Mannino & Kiri, 2006; Northouse, Templin, & Mood, 2001; Schreiner et al., 2006; Schumacher et al., 2008; Spence et al., 2008; Vreugdenhil, 2014; Zarit, Reever, & Bach-Peterson, 1980) encompass a mixed sample population of spouses, children, family members, partners, and friends. These studies highlight the many physical, psychological, and social challenges of caregiving. What is missing is an in depth picture of the experience of providing care to an aging parent, from the caregivers' perspective.

Miller (1981) reported the disproportionate responsibility falling on the sandwich generation and the lack of assistive resources had become the norm; outside assistance was available only once the family experienced a crisis situation.

According to the most recent report (NAC & AARP, 2015) the current status of the adult child caregivers is not much different from what Miller (1981) reported 34 years ago. Adult children, predominately females, are supporting parents with medical care,

chores, errands, decision making and household finances. This impacts not only their employment and personal relationships, but makes them susceptible to physical strain, declining health, and financial hardships.

What is missing in the literature is an in-depth look at personal experiences of adult children who have cared for their aging parents. These personal stories may reveal narratives of growth and purpose, anguish and distress and the influence of culture. A study focused on the lived experiences of these caregivers will give readers an understanding of the essence of what it truly means to be in that particular caregiver role. This study will also provide nurses a deeper understanding of the caregiving experience. A deeper knowledge of the experience may provide direction for nurses to provide emotional and educational support to caregivers, as well as advocate for change in healthcare policies that will further assist caregivers with personal burdens.

Chapter III

METHODOLOGY

Phenomenological inquiry as defined by van Manen (1990) “is the study of the lifeworld- the world as we immediately experience it” (p. 9). Phenomenology asks “How does it or did it feel to experience a certain phenomenon?” This type of qualitative research is different from other research in that its purpose is to gain an understanding of the phenomenon, through the subjective and unique descriptions of the person’s lived experiences rather than by categorizing, theorizing, or quantifying them. Phenomenology should reveal the meanings within the phenomenon through the written interpretive descriptions given by the researcher based on what the participants share (Heidegger, 1962). The persons’ actual descriptions awaken the reader “to see” the deeper and fuller meaning of the experience. In principle, phenomenological inquiry is meant to add to our comprehension on the essence of being human (Munhall, 2012; van Manen, 1990).

Phenomenological research flourished during the early 20th century through the renowned German philosophers Edmund Husserl and Martin Heidegger. Descriptive phenomenology generated by Husserl, used philosophy as a rigorous science to engage deeply into participants’ perception of a phenomena (Husserl, 1965). The hermeneutic research tradition is associated with Heidegger. Heidegger (1962) believed hermeneutic phenomenology should focus on the understanding of “being.” van Manen (1990) interprets “being” as the fullness of human living. It is the way we can learn what it means to exist as a man, woman, or child in this world. He

considers this type of research to be a *human science* as its goal is to make sense of aspects of the lived human world.

Design and Approach

van Manen (1990) states “phenomenology does not problem solve” (p. 23). Instead trying to understand how humans experience being is what is important. van Manen (1990) further supports his beliefs by stating:

Natural science studies “objects of nature,” “things” and “natural events” and the “way that objects behave.” Human science studies “persons” or beings that have “consciousness” and that “act purposefully” in and on the world by creating objects of “meaning” and that are expressions of how human beings exist in the world (p. 3-4).

Influenced by Heideggerian philosophy, Max van Manen (1990) developed a human science approach to phenomenological research. Identified are six research activities van Manen (1990) suggests as a methodological structure for the researcher, that guides this study.

The first activity of phenomenological study is *turning to the nature of the lived experience*. The researcher orients to the phenomena; makes sense of an aspect of human living and formulates the research question. The research question for this study was to discover and interpret what is the lived experience of adult children caring for aging parents.

The second activity is to *engage in existential investigation*. The researcher examines the literature regarding the phenomena, explores personal experience, and

interviews those living the experience. A review of the literature and reflection on my personal experience of the phenomenon provided a foundation for further investigation.

The third activity of van Manen's (1990) model is *engaging in phenomenological reflection*. Thematic analysis is used to determine the structures of which the experience is composed. From the participants' interviews deep thematic descriptions and statements were isolated with the hope of bringing to light a better understanding of the phenomenon.

The fourth research activity is *to write and rewrite*. Rich descriptions of what participants say are gathered to bring out the essence of their experience. The descriptions from a participant are not acquired from one writing. Language was thoughtfully used and provided examples in an effort to retain the meaning of their experience, so the voices of the participants can be visualized by the reader.

Maintaining a strong and oriented relation is the fifth activity. The researcher should preserve a strong association to the phenomenon during the research and reflection. A strong focus was maintained on the phenomenon during the interviews. Journaling my thoughts unquestionably helped to keep my personal preconceptions and biases separate from the voice of the participants. My own thoughts and reflections were journaled immediately after leaving each interview.

Lastly, the sixth activity is *balance the research context by considering the parts and the whole*. The researcher must keep a focus between the parts and the whole in order to provide a clear description of the participants' experience.

Undeniably this was an area that needed constant oversight. As the data were collected the immense amount of content at times became overwhelming. I tried not to become so buried in each step of the research process (the parts) so that I would not lose sight of the research question (the whole). Admittedly, there were times this did occur to the point where my organization of thoughts and writing came to a halt for several days. Reorganization of the data into smaller segments and commitment to a flexible timeline to review the assigned segments, allowed me to make progressive strides in my research process.

Heideggerian philosophy and the research activities of van Manen (1990) were used to answer the research question of “What is the experience of adult children caring for aging parents?” Phenomenology as a philosophy “can not only guide your research but your interactions with others, your understanding of yourself and others, and can guide your practice” (Munhall, 2012, p. 25). The essential information gathered from this study about adult child caregiving will furnish healthcare providers with a deeply enriched understanding of the needs and consequences for this caregiver population.

Researchers Stance

As an adult child of 36 years, I cared for my 57-year-old mother until her death from lung cancer. Admittedly, growing up and being the eldest of three children, and a nurse, I had a take charge attitude. Even among my own friends, school activities, and social groups I was a leader. Of my two younger brothers, one (33 years old) lived in Georgia and therefore couldn't be present to assist with mom's

care. The youngest brother (25 years old) lived with and did care briefly for mom while they resided in Arizona. Once mom and my brother returned to New Jersey, my brother took a self-proclaimed sabbatical. Needless to say I felt abandoned. Didn't my mother raise three children? Wasn't this their mother as well that was dying? I couldn't understand why my brother in Georgia couldn't come up for at least one week or even one weekend to see his mother. According to one brother, since I was a nurse, I was much better equipped to handle her situation. I knew both my brothers loved their mother, so what was happening now? Perhaps it was too painful to see what was occurring and keeping their distance safeguarded them. So once again I took charge and kept my brothers updated on mom's progress; all while caring for my own family.

Fast forwarding, many years after my mother's death, I was asked by my pastor to consider being the faith community nurse of my parish and create a health ministry group. He felt there was a need for outreach from the congregation to parishioners in need. The yearly Gallup Poll rating honesty and ethical standards states "nurses have topped the list each year since they were first included in 1999" (Riffkin, 2014, para. 2). Anyone who is a nurse experiences family members, friends, and even strangers asking questions or seeking advice about an illness or medical situation. I noticed this had been happening to me with relative frequency from people within my parish congregation. I decided to accept my pastor's proposal.

Over the next few years, talking with personal friends and through my exposure to the congregation as a faith community nurse, I have heard many varied

stories of family's hardships, but the stories of people who were suddenly faced with caring for their parent(s) resonated with me. My own experiences began to surface and I felt a strong kinship with these people.

The Institute of Medicine (2011) reports our healthcare system is transforming to become more patient centered and needs to deliver care through a community based model. In the circumstance of the adult child caregiver, this will allow nurses to assess patients' and caregiver's need for health promotion, disease prevention, and services from other disciplines. This can prevent or limit crisis situations for the care recipient and/or the adult child caregiver. Still, I see more and more adult children facing the same situation as I did with caring for a parent. There is limited if any contact with a nurse to provide supportive interventions. I then question, are their experiences similar? If not similar, then what are the differences? Is there something that helps them cope with their situation? Simply, what are their intimate feelings about their whole situation? It is because of my own experience that this topic has become the center of my research. I hope to improve my own practice as a faith community nurse and a nurse educator, as well as impact the practice of other professional nurses.

Personal Assumptions, Biases and Beliefs

“The term *knowing* refers to ways of perceiving and understanding the self and the world” (Chin & Kramer, 2004, p. 2). To some degree, qualitative researchers pre-understand or know about their topic of research due to their own experience. My personal experience caring for my mother and my belief that adult children are

responsible for their parents, created an area of concern referred to as researcher bias and this had the potential to affect the analysis of my collected data.

Striving to understand the experiences of the research participants, in this case the adult child caregiver, and keeping an open mind towards the data requires the researcher to take a stance of “unknowing” (Munhall, 2012). In order to be fully present while interviewing participants, researchers should clear their thoughts from their assumptions, former knowledge and bias, as well as personal beliefs. Munhall (2012) refers to this as “decentering.”

I began this study with a preconceived knowledge of the parental caregiving experience based upon my own involvement, although it was 21 years prior to this research. I expected to hear from the participants about stress, fatigue, scheduling and perhaps even financial concerns. Nevertheless, my experience was quite some time ago, clearly shorter, and mixed with possible presumptions. Our society has changed immensely in several areas since that time. The structure of families and how households are maintained, the unstable financial/employment climate, and, of course, healthcare delivery and preservation of health insurance have dramatically changed in the last two decades. Might these changes affect the experience I was looking to explore?

Writing out one’s beliefs is an approach that assists the researcher to develop enhanced awareness and possible bias towards the research topic. Bracketing does not ignore the researcher’s views, but allows one to express and review them in a continuous reflective process (Ely, Vinz, Dowing, & Anzul, 1997; van Manen, 1990).

I journaled my thoughts directly after conducting each interview. After transcribing the interview verbatim, I would read and re-read the transcript along with reviewing my journal notes. I bracketed and compartmentalized other thoughts within the transcripts. This allowed me to approach my topic openly and honestly and hear the voice of the current caregivers.

Trustworthiness

According to Lincoln & Guba (1985), trustworthiness of a qualitative research study is essential to evaluating its worth. There are several techniques used to support the trustworthiness of qualitative research: *credibility*, *transferability*, *dependability* and *confirmability*.

Credibility includes several methods to increase the probability that credible results will be found within a research study such as *prolonged engagement*, *member checking* and *peer debriefing* (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). *Prolonged engagement* is spending sufficient time in the field in order to understand the phenomenon. I conducted at least three interviews with each participant to gain insight into their lived experience as a caregiver. The time range of the interview was 45-60 minutes in length. One interview lasted approximately 90 minutes. One participant was a healthcare professional and used her home as an alternative office for her practice. She realized she had scheduled a client around the time of our scheduled second interview. I offered to reschedule but she declined. Reviewing her office schedule, she was not able to locate an amenable day or time to suit both our needs. Rather than withdraw herself from the study, the participant offered to delay

her client and suggested to have me conduct the second and third interview in one session. Rather than lose this participant from the study I accepted her offer. This interview lasted approximately two hours. I believe the time spent with the participants supports the credibility and truth of the data collected. I believe these interviews aided in the development of trust between myself and the participants due to the private and confidential manner in which they were conducted.

Member checking takes place when participants review the data and interpretation for accuracy and is considered an important aspect of the research process. Member checking “provides the opportunity to assess intentionality . . . [and] gives the respondent an immediate opportunity to correct errors of fact and challenge what are perceived to be wrong interpretation”

(Lincoln & Guba, 1985, p. 314). Conducting multiple interviews allowed me to review previous data with the participants, whereby they assisted me with clarification of their comments, and confirmed my interpretations. During the conversations I would ask questions such as “Could you explain that a little more?” or “What do you mean by (blank)?” or “Tell me a little more about (blank).” “Is this what you mean?” or “How would you say (blank) in your own words?” By validating the participants’ statements, the data became more credible.

Peer debriefing is the process of data analysis by a person other than the researcher (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). Multiple debriefing sessions with my chairperson both in person and via email were arranged to ensure that my analyses remained rooted in the data.

Transferability refers to the ability of the study findings to have meaning in other situations (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). For this study the experiences of caregiving for an aging parent, related by adult child participants, were written with deep, rich descriptions in hope that readers would understand the meanings and be able to associate these to other caregiving circumstances. Portrayals of the participants' experiences as themes were accomplished through (a) the quotes from the participants which supported the emerging themes and metatheme, and (b) the vignettes I chose to exemplify the experience of each participant.

Dependability demonstrates that research findings are credible. The findings are consistent and can be replicated. Lincoln & Guba (1985) posit there is no dependability if there is no credibility. In order for findings to be dependable the researcher needs to account for any changes in context/procedure within the study. Dependability was assured through the use of journaling, audio recordings and transcriptions. There were no changes in participant settings. A change in one participant's interview has already been described and it had no effect on the approach to this study. All other interviews were conducted as proposed.

Confirmability is the process over time in which the researcher creates an *audit trail*, documents the findings for replication and assures that responses from the participants are not shaped by researcher bias (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). Several methods of providing an audit trail were used in this study. I documented thoroughly in a journal, and research notes. Audio recordings were used during interviews and verbatim transcriptions of those recordings were

personally typed. Analysis of data was directly written on the transcripts and index cards were used to organize themes and list references from the transcriptions. These records all served as an appropriate audit trail for this study.

Participants

Phenomenological research dictates that it is imperative for participants to have actually experienced the phenomenon under investigation in order to aptly articulate its meaning (Polit & Beck, 2008; Streubert & Carpenter, 2011; Sokolowski, 2000; van Manen 1990). Participants for a phenomenological study were chosen because of their experience with the caregiving phenomenon. This type of sampling is termed *purposeful sampling* (Lincoln & Guba, 1985). Inclusion criteria for this study were that each participant was an English speaking, adult child over 21 years of age, and was currently caregiving, full or part-time to an aging parent or parents with a chronic, or terminal illness over a period of more than one year. The care recipient parent(s) were either residing within the adult child's home or within their own residence. All participants in this study contacted me individually as a direct result of reading my recruitment flyer (Appendix A).

To recruit participants for this study I distributed flyers to local churches within my northwestern New Jersey community. A letter of support (Appendix B) was received from the lead pastor. These churches included the recruitment flyer in their weekly bulletins or posted them on their community bulletin boards. Church pastors often come in contact with homebound or ailing parishioners and their extended family, where they may observe first hand any adult child caregivers. The

pastors agreed to mention the study at their weekend services and post the recruitment flyer. This recruitment setting is the first place from which I received three eligible female participants. I also contacted and received a letter of support (Appendix C) from the Area Director and Program Manager for the United Way of Northern New Jersey. She kindly posted my flyers in their announcement section of the website for the United Way Caregiver Coalition which covers five counties in New Jersey. This recruitment setting provided only one female caregiver who did not meet the study criteria. To further generate participant interest, flyers were also distributed via email by my family members and two personal friends to their academic colleagues and friends. That solicitation did yield three potential participants, two males and one female, but they did not meet the eligibility criteria. The recruitment flyer was also posted in a local senior center. From that setting, I received four eligible female participants. In total, 11 caregivers inquired about participation in this study. There were seven caregivers that met the eligibility criteria and participated in the study.

Table 1

Participant Demographics

Sample (n=7)	Age	Work	Marital Status	Parent	Parents Age	Caregiving Years	Recruit Setting
Marie	71	Retired Teacher	Married 5 children	Mother Lives with MK	94	5	Parish church
Karen	40	Chiropractor Part-time	Divorced 2 children living at home	Both Parents	Mother 85 Father 87	4	Senior center
Felicia	55	Special Ed Teacher	Divorced 2 children living at home	Both Parents	Mother 83 Father 85	1.5	Parish church
Julie	55	School Nurse	Married No children	Both Parents	Mother 82 Father 85	3	Parish church
Annie	21	Student Full-time	Single No children	Both Parents AM lives with parents	Mother 60 Father 54	1	Senior center
Brenna	45	Nurse Supervisor Part-time	Married 3 children; 2 living at home	Mother-in-law Lives part time with BL	Mother-in-law 70's	3	Senior center
Valerie	39	Student Full-time	Single One child living at home	Father	Father 85	10	Senior center

As shown in Table 1, there are seven participants in this study. All participants are female, with six daughters, and one daughter-in-law. Their ages range

from 21 to 71 years. One participant is retired, two work full time; two part-time, and two are full-time students. Three participants are married (two with children), two are divorced (with children), and 2 participants are single with no children. One participant cares for her father, one participant cares for her mother, another participant cares for her mother-in-law and four participants care for both their parents. Only two participants have their parent(s) residing within their home. The age range of the parents is 54 to 94 years. The years spent caregiving range from 1 to 10 years.

Protection of Human Subjects

Complying with the ethical standards for qualitative research requires addressing the standards for informed consent, anonymity, confidentiality, data treatment and publication, and the researcher-participant relationship. This study commenced after Institutional Review Board (IRB) approval from Seton Hall University was granted (Appendix D). To maintain ethical principles, I used the following strategies. Upon receiving notification of a potential participant's interest in being included in the study, I telephoned each individual to review the inclusion criteria. I used the recruitment flyer as a template for the conversation as the participant had this document in order to contact me and reference. Scheduling of three interviews and their approximate amount of time, information required from each interview for data collection, recording of each interview, and confidentiality were discussed. I answered questions from the participants regarding inclusion in the

study, and in closing I scheduled mutual arrangements for a date, time and place to conduct the first interview.

Before the start of the first interview, all participants were given a consent form revealing the purpose of the study and the nature of participation. It was made clear to participants that they are free to participate or not and they have the right to withdraw from the study at any time without penalty. There were no physical risks and no direct benefits to the participants. After reading the consent and again indicating interest in participation, the written consent was obtained.

Privacy and confidentiality of the participants was protected by using fictitious names for the participants, as identification within the study results, transcripts, and all other documentation by the researcher. The participants were anonymous to all but me. All data collected, field notes, logs, reflective journals, and audiotapes, were kept on a flash drive. Audiotapes were transcribed verbatim only by me and kept in a secure, locked cabinet within my own home. Storage will be maintained for a period of at least three years from the completion of the study.

Herbert & Schultz (2006) directly linked the level of disability, disease type and type of caregiving tasks for the care recipient to the stress levels of caregivers. I anticipated that during the interview process, participants might experience “normal” emotional discomfort such as crying, resentment or anger related to the expression of their feelings about their caregiving experience. Several, but not all of the participants did exhibit deep sentiment while conversing about their parent(s). Their voices became strained with their emotions or there were periods of silence during the

interview. There were participants who literally broke down and cried. Their melancholy was not about their own circumstance of rendering care for their parent(s), but about the profound change taking place in the parent(s) due to the inevitable course of aging. Although I had prepared information on hand, at no time during these expressions of emotion, did any participant require referral information for counseling or mental health support services.

Data Collection

The interview process is a method which allows people to voice their experiences related to a particular topic. In phenomenological research the interview serves two purposes. First, it is used to gather descriptive information that will help develop a deeper understanding of the phenomenon. Second, the interview may be used to develop a conversational relationship between the researcher and the participant (Munhall, 2012; Ryan, Coughlan, & Cronin, 2009; van Manen, 1990). Data were collected through two to three informal in-depth interviews lasting approximately 45-60 minutes with each participant over a 4-8week period. I audio recorded each interview using a digital recorder that was placed openly between the participant and myself. All interviews were conducted in private. Settings where the interviews were conducted were either the participants' home or another mutually agreed upon private area during weekdays. The time of the interviews was typically performed in the afternoons or early evening hours when participant errands or employment was completed for the day. Interviews were conducted until data saturation was achieved.

In accordance with the informal interview style described by Ryan et al., (2009), a conversation takes place between the interviewer and the interviewee about a particular topic guided by the interviewer asking broad open-ended questions as needed. A tentative interview guide (Appendix E) was used which contained general questions that were utilized as a guide. The initial interview statements and inquiries were as follows: Tell me about yourself. Tell me about your immediate family; are you married or have children? Describe your relationship with your parent(s). I felt these introductory type of questions would allow the participant to become more comfortable with being interviewed, provide me with background information, and most importantly facilitate the development of trust between myself and the participant.

The focus of the second interview was the actual lived experience. Questions posed were: “How did you come to be either the primary or shared caregiver? What caregiving responsibilities do you perform? How often do you need to assist your parent(s)?” and finally “What is it like being a parental caregiver?” The aim of these questions was to bring out the essence of the phenomenon of this study. If needed, I would clarify any data from the first interview as part of member checking. At the final interview I asked if there was anything the participant would like to add and if there was anything they would like to change. This was meant to be an opportunity for the participant to reflect and serve as a natural conclusion to our researcher/participant relationship. I also secured permission to contact the participants during my data analysis phase for any further clarification if necessary.

My own reflective notes regarding my thoughts or observations occurring during the interview were written down promptly after I left the interview. Audio recordings and my transcriptions of each interview were reviewed simultaneously for accuracy. I noted inconsistencies directly on the transcripts and before the start of subsequent interviews I reviewed these notes with the participants to clarify my transcription content.

Data Analysis

Phenomenology explores the experience of the phenomenon by allowing the essential meaning to be discovered in the data (Munhall, 2012; van Manen 1990). In phenomenology, data is generally analyzed through a process of coding, categorizing codes and finding themes (Ely et al., 1997; Tesch, 1990; van Manen, 1990). I personally transcribed the audio recorded interviews. I listened, read, and re-read the transcriptions for accuracy. This contemplative time, being immersed in the data of the participants' own words, is what Munhall (2012) refers to as "dwelling" (p. 145). This allowed me to have a deeper understanding of the participants' experience and assisted me in uncovering the meaning of their experience.

Phenomenological themes may be understood as the *structures of experience* (van Manen, 1990, p. 79). They capture an aspect of the phenomenon one tries to understand. For my thematic analysis, I used the 10 step approach by Ely et al., (1997) to guide my data analysis.

1. Study and restudy data to develop intimate knowledge. I selected specific

phrases or words from the data that appeared to have significance to the phenomenon.

2. Note initial impressions. I wrote in the margins of the transcriptions any thoughts I had on that particular section of the conversation.
3. List tentative categories. I labeled my own words or phrases into descriptive categories.
4. Refine categories examining steps two and three. I returned frequently to the data for any possible revisions.
5. Group data under categories and refine categories if needed. At this point I began using colored index cards to differentiate each category.
6. Select verbatim statements to link with categories. I returned to the data and highlighted participant statements according to the category color.
7. Review results and revise step 6 if needed.
8. Write theme statements from participants and link in and across categories.
I listed participant statements according to which interview (1st, 2nd, or 3rd), page and line on the appropriate category card.
9. Integrate findings about each person.
10. Compare findings for commonalities, patterns, and unique happenings.
Each category card was reviewed and participant statements were grouped if specific words or thoughts were expressed.

Data collection was continued until I determined that data saturation had been achieved. Saturation was reached when no additional data were discovered, and no new themes emerged (Streubert & Carpenter, 2011).

The goal of data analysis was to richly describe the experience of adult children caring for aging parents. This qualitative research brought to life, through the voice of its participants, the essential aspects of the phenomenon for these individuals. The data analysis resulted in the emergence of nine subthemes, four themes, and one metatheme that capture the essence of the experience.

Chapter IV

INTRODUCING THE PARTICIPANTS

Vignettes

Although the participants share some commonality, the participants each have unique circumstances and therefore their individual voices should be heard. For that reason, I have created a vignette for each participant in this study. These vignettes are based upon interview data with quotes representing the participants own words. My purpose in creating vignettes is to bring the participants to life and allow the reader to gain a better understanding of their unique experience of caregiving to parents.

Marie. I'm Marie and I have been married to my wonderful husband for 46 years. I am 71 years old, a retired teacher with four grown children, and five grandchildren. My mother has always been a very independent woman. My father died at 49 years old, leaving my mother with five children. I was the oldest and the youngest was only two years old. After the death of her second husband around 2003, she was still on her own for a good seven years. I started to notice she became forgetful with her medications and eating. Because mom lived in the same town, I'd stop by daily before and after work to check in on her. She also had lovely neighbors who would look in on her as well.

Then came the call. She had fallen on the floor, a neighbor found her and she needed to go to the hospital. It was a very emotional time for the family. Nobody knew what they wanted to do, yet everybody didn't want me to make all the decisions. Nobody wanted her to go to a nursing home, yet I don't think they fully

realized the situation. My siblings just kept putting things off, and I knew I couldn't keep doing what I had been. I was starting to have some medical issues myself and "going to mom's home after work to make her dinner, then going to my home to make dinner again was taking its toll on me. I couldn't be two places at once." I knew it would be easier for a lot of reasons for mom to come and live with me. So I "took the bull by the horns" and decided to retire, mom moved in with me. I didn't realize how much I didn't know about this venture. I thought all I'd have to do is provide mom with a roof over her head and give her medicine. I received little to no guidance from healthcare workers. And whatever I did learn was from friends and my own mistakes. It was scary at first but I'm okay now.

Five years have passed since that decision. Mom is 94, cognitively intact and although somewhat physically limited, maintains some independence. My main responsibilities for mom are handling her medical compliance and being a companion. Right now she is able to manage her own physical care. I drive her to all her doctor appointments and liaison with the physicians, take her out of the house for a change of scenery, provide all her meals, and try to keep her functional with small chores at home that she can tolerate to help her mind and body stay active.

Karen. I'm Karen and I am 45 years old. I work three days a week as a Chiropractor. My office practice is about an hour away from my home. And "my other job is caring for both my parents." I am a single parent with two children ages 18 and 20. My 18-year-old is a high functioning autistic and goes to another county for school. I still need to be very watchful of his whereabouts and activities. My 20-

year-old attends college out of state. My dad and mom are 87 and 85 years old respectively and live five miles away from my home in a multilevel 100-year-old farmhouse on 3.5 acres. It was their summer get-away until they retired.

They were both very active and social up to four years ago. Mom is declining physically with her medical issues of rheumatoid arthritis, and failed back surgery. Dad has also had two strokes and cardiac issues. Since I work in healthcare, I may have a better advantage than most people. With their [parents] medical issues I know what to watch out for, I know what to ask or direct the physicians to do. Many caregivers don't have this knowledge and learn on their own.

Three to four times a week I go to their house to help clean, vacuum or do help with laundry. I also maintain the 3.5 acres by mowing the grass and in the winter, clearing the driveway of snow. All this is in conjunction with multiple doctor appointments for both of them, taking them grocery shopping, going to church, and any other errands they may need done. These excursions require I take both their walkers with me. Getting them out of the car with their stroller rollers as I call them, increases time significantly but I look at it as their getting exercise.

I do have three older brothers. One brother lives in the same town as me, the other 45 minutes away and the third lives in Philadelphia. I've thought about moving them in with me. My home has a big unfinished addition that could be converted to a studio apartment. I just don't have the money to do it. Finances are very tight since my divorce four years ago. My life and work schedule has been adjusted so I can do

what is needed now for them. “Everything is planned accordingly. I just hope everything goes according to the plan.”

Julie. I’m Julie and I’m a 55-year-old high school nurse. I’m married and have no children of my own but plenty of nieces and nephews! I am the second oldest of five siblings. There is one brother and four sisters. My siblings all live about an hour away from mom and dad; I live up the road from them. “I have been a caregiver forever.” I remember helping out at home with my youngest sister because mom was going to school to become a nurse. My father, the youngest of his siblings would take one of us every day and me every weekend to see his mother whom he was helping. Eventually my grandmother moved in with my family and I helped with her physical care as well. My mother and father are 82 and 85 years old. I’m much closer to my dad than my mom. He has some health issues associated with age but dad is aging faster since he’s helping to care for mom.

Mom has been ill with kidney disease since she was a child. “All we ever heard growing up was your mother’s going to die, your mother is going to die. She was supposed to die in childhood because she had 4+ albumin in her urine since the age of 7.” As a result, mom’s had many medical and surgical problems over the years. My dad is just aging rapidly caring for mom. So I have a routine of helping with food shopping, doing laundry, and cleaning the house. I’ll help her bathe and get dressed when dad needs to take her to appointments. In the winter I’m there at four a.m. for snow removal before I go to work because I don’t want my dad to do it. Otherwise

I'm called for any emergencies, which can be frequent based upon their definition of an emergency. My husband and I help to maintain the house and the yard.

My mother is also a nurse and has accomplished much in her career. Mom's very bright and completed two masters' degrees and started to pursue her PhD in nursing. Having a mother who is a nurse and being a nurse myself has been a point of contention with caregiving decisions. As intelligent as mom may be, I feel she makes poor health choices and I struggle with that. I've learned a lot about myself over the last three years of caregiving for my parents.

Felicia. I'm Felicia and I'm 55 years old. I have two college age children, a daughter and son 19 and 21. One lives at home the other is in school out of state. I have been a single parent for 17 years. A lot of what takes up my time is teaching special education students in high school for 28 years. And then there's my mom and dad who live 3 blocks away from me. I do have three siblings, one brother and two sisters who all live an hour away from my parents. The house where my parents live was originally a summer house, a cabin they bought in 1966. By the early 1970's they moved in year round and have been there ever since. They just celebrated their 60th wedding anniversary. Mom is 83 and dad is 85 years old. And for the last 58.5 years my mother took care of my father like the old traditional marriage, waiting on him hand and foot.

Suddenly mom started getting these "episodes" and everything changed. Dad is trying to care for her while he has his own medical problems to deal with. They both have diabetes and high blood pressure. But mom still has these occurrences of

electrolyte imbalances that come out of nowhere. She has been to many doctors yet there is still no diagnosis. I'm not a medical person and I always have to ask so many questions to make sure I'm doing the right things for mom. I have to ask. Rarely does anyone, nurses or doctors anticipate giving me information in advance.

Mainly I'm the person to take mom to the doctors and help regulate her medical care which includes seeing that she keeps taking her medications. If dad is not up to driving with her to shop, I'll do the food shopping. I get their mail and the newspapers and do their laundry regularly. I assist mom with showering and dressing because she's so unsteady. Their house is not in the best condition and I do the best I can. My son helps with the yard and snow removal. We're in touch physically or by phone every day and my son helps as often as possible. My life can be hectic and unpredictable. Organization of both houses is not my strong point but it's a constant work in progress.

Annie. Hi, I'm Annie. I'm 21 years old and a full time college student. I have a brother who is 36 and a sister who is 32. Both are married and have children and live on their own. Mom is 60 and dad is 54 years old. I'm single, have no children, and still live with my parents, so "I end up doing most of the work to help them." My brother lives next door but we just see him and his family usually on Sunday's for dinner. My sister and her family rarely come to visit my parents.

Mom has hypertension and diabetes and recently lost strength in one arm, like a neuropathy since having chemotherapy last year. Dad has cardiac problems since he had a heart attack at age 47, seven years ago. My parents are Spanish from Argentina

and their culture has a huge effect on their overall health. Mom feels God is punishing her, and dad has this manly complex where he thinks he's invincible and doesn't need medication and doctors. I have to stay on top of the medical side of things which can be overwhelming with the both of them. I am going to nursing school but I don't know everything. If I don't know what to ask, I just hope the nurses and doctors will tell me.

Since I live at home I'm helping them every day. In the mornings I don't leave until my dad takes his medicine. I go to his doctor appointments with him and I check his defibrillator/pacemaker every month. When I come home, I do the cooking for all three of us. I always help with the house cleaning and the laundry. Mom sometimes needs help with bathing and dressing.

"I manage the best I can." My parents are very supportive of me finishing school. Mom had me late in life at age 39 and she always tells me I am "the child meant to be."

Valerie. I am Valerie and I live with my husband of 10 years and my 4-year-old son who has special needs. I have one older sister who is 54, and one older brother who is 52, and I am 39 and going to school full time. My sister and I share caregiving for my mother and father but the greatest amount of care is done for my father who is 86. My parents have been divorced for over 30 years and happen to live in the same senior citizen building. I live approximately 20 minutes away from their apartments. My sister lives about the same distance from another direction. My brother has been estranged from the family for a number of years.

At age 75 after my dad had heart surgery he began showing signs of dementia. You know, the fire department arrives to the building because dad left something on the stove, then walked out to go to the local market. More signs have progressed over the years, and he was finally diagnosed with Alzheimer's and dementia. Now what? I've heard about Alzheimer's but do I need to do anything? And if so what is it? I can't bring him home with me, so can he stay where he's been living? Thank goodness a social worker gave me some starter information. Other than that I've learned along the way on my own. I was clueless at the beginning of this.

I go to visit and check on him after school 3-4 days per week for 6-8 hours and on weekends. He needs to have all his medication set out in their bottles, on the table in a certain order, otherwise he gets upset. I make sure he's stocked with food and he's very specific about his food. Otherwise he'll refuse to eat. And then of course there's the laundry and cleaning of the house and generally making sure he's physically okay.

Dad is now 86. I have been caring for him for 10 years. "You learn to do anything and everything to make things work."

Brenna. I am Brenna and I share caregiving for my mother-in-law. I'm 45 years old, married, work part-time and have 3 children. Two are at home and one is away at college. All of my family lives in Ireland. My sister-in-law is the other person who helps with caregiving. She is not married, has no children, and my husband is her only sibling. "Ya ya" as we affectionately call my mother-in-law, lives

one week at my house and the other week at my sister-in-law's home. She is a widow and lived on her own for quite some time.

Ya Ya sustained a bad fall at home while entertaining a friend of hers, and injured one knee and both shoulders. She was not the same person after that. The family noticed her forgetfulness and it came to the point that we couldn't trust her to live alone anymore.

Because she's my mother-in-law I run all my ideas through my sister-in-law first. I'm a nurse for over 25 years and I've suggested to my sister-in-law that mom see a neurologist about the forgetfulness. My sister-in-law has never followed up, so she's never been officially diagnosed. If I see or hear about things that will help with mom's care, I'll tell my sister-in-law. Otherwise I don't know if she would get any of that information.

Ya Ya is very pleasant and can do most of her personal care. She'll sit outside, listen to the radio or help with laundry. She will read the same little book about the saints over and over and when I bring her something different, she'll tell me she hasn't finished that book yet. Basically I help her with bathing and dressing. I prepare her meals and she'll accompany me on errands. Things are not as bad as I know they're going to get. "Oh, did I mention that my mother-in-law only speaks Greek!"

Chapter V

FINDINGS

Themes

There were four themes that emerged from the data along with corresponding subthemes.

1. It Was Meant to Be
 - a. Who I am
 - b. Our upbringing
 - c. Because of proximity
2. My Changing World
 - a. Self-neglect
 - b. Limited social life
 - c. Resentment
 - d. Anger
 - e. Guilt
3. Loss of What Was
 - a. Parents become your children
 - b. Fallen idols
4. On Call 24/7

It Was Meant to Be. It was meant to be, was the first major theme to emerge from the data. The participants in this study revealed it was not unexpected that they

became the caregivers. Initial analysis of their statements revealed three subthemes: *Who I am, our upbringing, and because of proximity.*

Who I am. Annie described how she was chosen for caregiving.

I feel there's a reason for me doing this. Ever since I was a child I've wanted to be a nurse. I felt better prepared to take care of my mother once she was diagnosed and had her surgery. Mom had me at a later age. She was 39 and she always tells me I was the child meant to be. (p. 6, lines 3-6).

Marie recalls a different way of how caregiving became part of her life at an early time; such as during a family crisis when her father became very ill and lost his job. "I was the oldest so I had to go to work. My mother couldn't go to work because well she has this baby and she hadn't been to work since 1938!" This incident caused Marie to leave college so she could provide financial support for her family. "When I went to tell the dean I was going to leave school the dean cried with me. It was meant for me to do that."

All of the participants have siblings. Karen recalls how even though she's the youngest; she was always the person her brothers would go to for decisions about her parents even before she started caring for them.

It always kinda falls on me. What are we gonna get them for Christmas? What about this and that? When dad was in the hospital after his first stroke, what are we gonna do about dad? So I just started doing what was needed. (p. 4, line 22; p. 5, line 1).

Our upbringing. Upbringing was expressed by the participants in terms of how they grew up seeing their parents caregiving for other older relatives, caring for their siblings, or by learning to show respect to elders through caregiving. Marie recounted memories of her mother after the birth of her brother who is almost 16 years younger. “Growing up I just thought she was wonderful and when she had my brother, she was just a mother. In my mind, my idea of a mother is about the nurturing of others.” Julie recalled how her father would visit his mother.

Every day my father would go and see his mother who lived in town, across town, and he would take one of us with him every single day. And she was an immigrant who spoke Italian. She was a widow since he was six years old and he was the caregiver in that family even though he was one of the youngest children. (p. 1, lines 18-21).

Brenna offered similar sentiments. “I think it’s part of our upbringing. We both had grandparents around when we were young.” Brenna also explained how caring for her mother-in-law was expected.

My father-in-law died young. So it was always a given we would look after her when she couldn’t do it herself anymore. It was like an unspoken rule. And my husband knows it’s the same if, God forbid, my parents were the same. Both sides of the family are very family oriented. For us it’s a natural thing to do. (p. 11, line 23; p. 12, lines 1-3).

Julie’s upbringing also taught her caregiving was a responsibility.

Whether it's my generation, my sister and her kids, we're still responsible. My parents have made it a point to make us understand it's our responsibility. Because my father took care of his mother, out of six children he was the only one, and my mother out of four children was the only one that would take care of my grandmother...they demanded that. Without saying it and it was expected and that's what we did (p. 2, lines 25-27; p. 7, lines 8-12).

Because of their *upbringing*, participants felt very strongly that automatically assuming the caregiving of older family members is absent from our society. Karen stated "I feel... everybody is not necessarily as respectful as they should be to their elders in caregiving. In the Asian community it is taught you serve the grandparents first. I think now it's the [attitude] typical hurray for me to hell with you." Brenna mentioned the same situation about previous generations of both hers and her husband's families. "So they didn't live together but they were right next to each other. Very family oriented. I think a lot of that is missing these days."

Because of proximity. Participants were asked how did you come to be either the primary or shared caregiver? As children grow up and begin their own families or careers, circumstances may have them live quite a distance away from their parents'. While others circumstances cause them to settle down very near to the childhood home. Marie and her mother lived separately in the same town for many years. Out of four siblings, Marie is the only one who lived nearby her mother. When her mother became ill and could no longer live on her own, Marie knew she should live with her, but her siblings needed to figure that out.

It was a very emotional thing [mom's living predicament]. Nobody [siblings] knew what they wanted to do and everybody didn't want me making all the decisions. But nobody was offering to take her. They just kept putting it [a decision] off and putting it off. I finally said I can't be in two places at once anymore. (p. 16, lines 16-18; p. 16, line 21; p. 18, lines 6-7).

Julie also lives "just down the road" from her parents and has three of four siblings who live 25 minutes to one hour away. "I get the day-to-day kind of stuff or if there's an emergency. It's because we are physically close in proximity." Karen's caregiving situation came about in reverse. Karen's parents retired to their summer home after Karen married, which was nearby Karen's home. "Technically my parents live out of state but where they're located they're just over the border. They're close enough but far enough." Karen has one sibling living in the same town, one approximately an hour away, and another who is three hours away. Felicia's three siblings live just less than an hour away, while Felicia also lives just "down the road" from her parents. The family home has existed for more than 50 years. Due to life circumstances, Felicia moved back to her parent's area. "So all their [parents] daily stuff falls on me. Cause I'm the closest. It's proximity. Definitely need and proximity."

The theme *it was meant to be* captures the essence of what these participants are expressing; caregiving for them was inevitable. The person they became, their upbringing, and choice of where to live, innately prepared them for the caregiver role.

Whether because of fate, destiny, or God's will, they would still have been the one to care for their parent(s).

The Current of Destiny by Yelda B. Moers

I don't know much
About the world
But I know what I feel
When I feel the current
Of destiny
Take me.

My Changing World. The second major theme, my changing world, described the impact caregiving of parents had on the lives of the participants. Although the caregiving responsibilities varied depending on the physical, medical and mental status of the parent(s), participants expressed similar experiences in the following subthemes: *self-neglect*, *limited social life*, *resentment*, *anger*, and *guilt*.

Self-neglect. In order to include parental caregiving tasks in the routine of life, participants conveyed how other responsibilities to self were deliberately put aside. Karen noted "It's a caregiver personality that you always put somebody else first. I just wish I would do more for me" Marie admitted "I neglect my own health, I just do." And Julie stated "I'm not getting the activity that I used to do because they're in need. I'm not taking care of myself." Karen has tried to create time but that means rearranging time. "At night I'm too tired. We have stepper machines downstairs. In order for me to do that I need to get up and downstairs by 5:30 in the morning. Sometimes it just feels too good to be in bed." Felicia emphatically expressed "I try

to fit in a walk and exercise. I try to do things for me. Some days are better than others.”

Limited social life. Julie explained whenever she has something planned her parents call with a need. “I’ve got my day planned, my two days off a week, things planned with my husband, and every single weekend something happens.” Another example given by Julie related to a three-week planned vacation with her husband that she left because her mother was in the hospital.

My mother was having a problem for a week or two. The day I was going to the airport, my dad calls to say we have to take mom to the hospital. I’m gone on vacation for three days, mom needs surgery. My husband’s on vacation for three weeks without me, this is our time together. I’m very resentful sitting at the hospital. (p. 6, lines 12-14, 19-21).

In order to plan and take any personal time away, Felicia said “...it’s like I have to put in an out of office memo. I couldn’t just leave.” Marie revealed she can’t leave her mother for more than 3 hours before mom starts to call and wonder why Marie is not home with her.

I can’t plan anything for myself with friends during the day. Mom gets irritable. I had a friend who called me several times to have lunch with her. I’d try but kept cancelling. Eventually she stopped calling me. When you’re retired you’re supposed to meet people for lunch, or go for walks and I can’t. (p.6, lines 13-16; p. 7, lines 6-7).

Resentment. A particularly difficult theme participants conveyed was the uncomfortable feeling of resentment they sometimes harbored towards their parent(s). Marie mentioned how resentful she felt after she planned for her sister to spend time with their mother. “But my mother wants me to be with her for all this. But there are times, I didn’t really want to do that today.” Karen’s expressed resentment this way: “... they [parents] are appreciative, but sometimes the more you do the more they expect. And then you explode for no reason.” Julie’s resentment shows when she reacts to last minute non-health related calls from her parents. “I get resentful sometimes. Oh God are you kidding me, really now? Like I’ll say that.” Felicia revealed “I’m getting called in the middle of the night and then you’re trying to function during the day, you’re not such a happy person.”

Participants also admitted to feeling resentment towards their siblings and spouses. One of Karen’s brothers lives a distance away and he will call her inquiring about his parents. “...you’re checking in with me? They’d love to hear from you. I don’t want to talk to you because you’re not here to help and you’re not going to be able to help.” Felicia recalled a time involving her brother. “I hear my brother is up so why didn’t he stop at the house? He was only a mile away. I don’t like that person I’m becoming.” Felicia continued with a statement she made one day when sibling feelings were tense. “It must be nice to just be able to just go!” Felicia went on to describe a particular time when she and her siblings were together at their parents’ home.

There was one time when there was a bit of a tension thing because people had things planned, and then I feel like why the hell am I the one always on hold? I can only do it [go away] if you're available? Why isn't it that you can only go if I'm available? You get those resentment feelings. (p. 12, lines 9-12).

Felicia also told of how she felt when a sister brings unhealthy foods for her diabetic mother.

I'm here all week thank you very much, it's bad enough they don't need it [sugary foods] I'm dealing with the repercussions of this, that's great! You're the happy little daughter and then at night who is getting the call that mom is throwing up or is dizzy, or her sugar is through the roof? (p. 7, lines 13-16).

Annie also felt resentful to both her siblings. "He thought that just coming to the house and showing moral support, he could wash his hands and feel good at night. My sister didn't even visit. She just basically came to the hospital and that was it." Brenna voiced feeling resentment towards her husband saying:

I would be at home with her [mother-in-law] more than he [husband] would. In the beginning whether it was the language, or she's not processing I've gone to my husband and said it's your mother, you need to take care of her, I need a break. There is the issue with downtime. Sometimes I really have to tell my husband to come up and take her. (p. 5, lines 19-22).

Anger. Participants spoke about how *anger* can slowly build until it's too late. Karen recalled. "They [parents] could say something or look at you the wrong way and then you explode for no reason." Julie struggles with the health decisions her mother makes. "She doesn't hear what I have to say when she calls me to fix a problem and then I get angry because she doesn't make sense." After her mother's surgery Annie felt anger towards her siblings.

I was in school 12 hours a day and it angered me because he [brother] couldn't even bring over a meal. I'm angry because I'm like, I know you guys are married and have children but I feel like they should be doing a little more. (p. 5, line 9; p. 5, lines 14-15).

Guilt. After experiencing a strong emotion, many participants conveyed a sense of *guilt* about their feelings, towards their parent(s), and family. Julie talked about the few times she actually said no to parental requests, "Maybe once or twice [saying no] and if I do I feel extremely guilty. I've even felt guilty about going to Mass." Annie expressed her guilt this way, "I mean I do get annoyed at times and lose my patience, but I'll go back and apologize to them and they'll apologize to me. Mom understands my feelings." Karen spoke about how her parents can't physically do certain tasks that were once a regular routine and now ask her to do them. "I can only do so much for so long. And then you feel guilty because you're like, you just want them to be happy." Valerie verbalized her guilt in this way:

We do a lot of arguing, a lot of laughing. I usually don't touch the subject for that day. I'll call him the next day and say, Hi Dad. How are you? I

can't abandon him. We're all he has. I couldn't live with not being there for one of my parents. After they've been through everything with me. (p. 5, lines 3-6; p. 9, lines 3-4).

Felicia mentioned having the same guilty feelings towards her mother.

That feeling would come over me. I feel guilty where I wish I didn't grumble. I've come home and beat myself up. Sometimes I wish I'd have been more pleasant. Or I wish I didn't rush out of the house. (p. 12, lines 1-3). As much as you say I love my mother and I'll do this forever with a smile, and of course you will do it forever, but the smile may not always be there. And then you have the guilt when you go home. And then it's too late to call, should I go back up there? Should I just let it be? It's the Catholic guilt. (p. 6, lines 6-9).

Three participants voiced guilt towards family members. Karen still feels guilt even if a sibling assists her. "I feel guilty if I'm not there. Why do I have to check on them? Because I have too. Maybe it's a control issue. Will they do things the same way?" Felicia speaks on how guilt affects sibling relationships. "I remember thinking later on, how could this happen? We've really been a close family. When you are kids you fight...But how it affects you, it can really affect your relationships. I'll feel very guilty." Julie talked about her guilt feelings regarding her husband.

When they call can you come over and do this, I'm in the middle of something with my husband and I kind of feel, oh God I don't want to give

the time up from my husband to have to go to my parents' house when I was just there yesterday for three hours! I feel guilty, I'm torn. (p. 8, lines 10-13).

These participants are at various stages in their life such as retirement, employed and raising their own children, single and going to school. Add in the responsibility of parental caregiving, and the impact appears to deeply effect the caregiver's personal lives. The emotions of *resentment*, *anger*, and *guilt*, along with the admission of *self-neglect*, and a *limited social life* voiced by these participants, is represented by the second theme of *my changing world*.

The Rope of Hope... by Leo Thomas

We, living with an expectancy
of a life that is mostly worry-free.
Yet life's demands, often spoil our best laid plans.
Leaving us only with scattered pieces of reality.

Loss of What Was. The third major theme, the loss of what was, came from several participants making statements about losing their parent(s). Not in the sense of loss through death, but loss of what their parents once were, or represented in their eyes when the participants were children. Experiences were expressed in the subthemes *parents become your children* and *fallen idols*.

Parents become your children. Depending on the amount of caregiving required or the physical and mental state of the parent(s), some participants felt there

was a definite role reversal. Valerie said “Like he’s not that big person I thought he once was. Now I have to be that person for him.” This is how Marie described her transformation. “I realize that okay so here I am in this place and now I’m a very different person. I’ve sort of become the mother to my mother because that’s what happens, that’s what happens.” Julie told of how her mother has taken on a childlike characteristic.

With my mother losing her memory she becomes very self-absorbed. Which I believe is what happens to them, they become children again, her needs have to be met before others. I’m not physically living with them but they’re like my children. (p. 10, lines 24-25; p. 10, lines 4-5).

Several participants confirmed specific incidents where they felt their identities reversed. Marie explained how at times her mother wouldn’t listen to her.

The hardest thing for adult children is that dependence. I see myself in charge of her medicines and meals. For 20 some years she didn’t answer to anybody, for her if she decided she didn’t want to take a particular medicine, you know. When she was alone and I made meals for her, she wouldn’t eat it. I’d get there in the morning and she wasn’t feeling right. Did you eat your dinner? She’d [mother] would say no, I had a half gallon of ice cream. We do sometimes argue about it. (p. 9, lines 9-10; p. 2, lines 14, 24-26; p. 3, lines 6-9).

Julie had a similar experience when her parents don’t always listen. “So you’ve [mother] got this problem you’re telling me about, you want a solution, I’m telling

you what the solution is, but you're not following my advice." Karen meets resistance when her parents want to maintain their previous lifestyle but they are not physically capable.

They're very resistant to change. Now why do we have to create work? Because this is how they've lived their life. We had flowers outside. We did this and we did that...we need a crew. We can only do so much for so long. (p. 7, line 12; p. 7, lines 6-9, 11-12).

Similar to a young child, Brenna's mother-in-law requires almost constant supervision because of her memory deficit. "She can't be trusted alone. She forgets too much. She completely forgets things like if she's eaten."

Fallen idols. When participants spoke about the physical or mental deficits of their parent(s), several reflected mournfully on the former occupations, or capabilities they admired about their parent(s). Julie recounted with pride her parent's accomplishments and how active her mother was with all her children's activities when Julie and her siblings were children.

She was a PhD student at Columbia and has a double Masters. My father only went to two years of college and was accepted to law school. He didn't go because he had five kids, but he became chief of police. She would run around and do everything for the church, and she was a den mother. She was an unbelievable mother and my father was great too. She's [mom] done all this for me and look at her now. You realize you can't take her as the mother you had. That's a loss. My heart is breaking for both of them because

they were so strong. (p.2, line 18; p. 4, lines 26-27; p. 11, lines 24-25, lines 1-2).

Marie lamented “What I see that mom...isn’t able to do, is an aberration and I miss my other mom.” Karen reflected “My dad worked since he was 12 and built his first garage. He was in construction. But it’s hard to see dad, who could fix anything not be able to do that now.” Annie stated “I always say I have my mom home, but I don’t have her home. She lost a lot of what she was.” Valerie revealed how she feels “depressed” with her loss.

It’s hard to see your parents go through that change. Whatever you thought of them as a kid, you imagine that same person. And to see it change so rapidly, it’s life changing. My dad was a master carpenter... and now it’s like I’m lucky if he can pick up a screwdriver and a hammer. (p. 7, lines 3-5, 7-8).

Felicia recalled in detail about her mother. Especially about her accomplishments and abilities.

She’s a really very intelligent woman. And it’s very sad to see that’s been taken away. She graduated college as salutatorian of her class. She lived in Paris the first six years of her life, then came here and went abroad again. She’s written and kept diaries all her life. She’s a historian. She used to take care of all the finances. She can’t calculate that well anymore. It’s sad, it’s really sad. You still love her regardless of where she is and what she has to

offer. But I feel loss when she knows what she can't do. (p. 5, lines 15-19, 24; p. 6, lines 1-2).

The third theme, *loss of what was*, reflects a deep anguish conveyed by these participants. The parent(s) who they depended upon growing up, is now dependent upon them, as their *parents becomes their children*. The role reversal alters the parental image to a *fallen idol* as the parent's previous abilities decline.

I'm Still the Child by Jerry Ham

A child shall lead them I had heard it said.
The thought, Lead who? went through my head.
Childish thoughts that now seem strange,
Looking back, how things have changed.

My parents are strong, they'll always be there.
Dad looked so wise sitting in his chair.
To raise their children, the patience it took.
But they had had it, when they got that look.

We look back now, and laugh and cry.
Sometimes we'll give a wistful sigh.
The good old days? Not true, we know.
But they were there to help us grow.

Now I'm grown and it falls on me.
Am I really the child she hoped I'd be?
I get impatient and want to scream.
Some days seem like a horrible dream.

I help her stand, then guide her feet.
I cook her food, then help her eat.
A child shall lead them, and yes it's true.
I'm still the child, and so are you

On Call 24/7. Regardless of whether the parent was undergoing a time of health and wellness, irrespective of any help from siblings, being at work or even if these caregivers were away, they can never stop thinking about their parent(s) and wondering if they would receive an urgent message for help. The fourth theme emerged as participants considered themselves *on call 24/7*.

Marie talked about how her mother will look for her, and only her, after a few hours of not being in the house. “That’s the hardest thing for adults. I think among caregivers it’s that total dependence. If she needs something she’ll call only me. He’s [MK’s husband] there but she won’t tell him.” Marie recalls the times even when her mother was living on her own, Marie was “going to mom’s home after work to make her dinner.” Karen gave two examples of how her parents are always on her mind whether she’s physically with them or not.

I’m taking my daughter back to college out of state. I’m thinking how are they [parents] going to get to church. My brother is on vacation. They’re gonna have to watch it on TV unless they get a neighbor to take them, which they won’t. It’s stupid stuff. (p. 8, lines 13-16). We all went to my niece’s wedding. I didn’t have a good time. My dad just had his second stroke, so I was concerned. I was concerned if they were eating. I was trying to make them happy. (p. 1, lines 1-2).

Julie thinks about her parents first, and how if need be, they may affect her plans for the day. “I think if something happens and they [parents] need something, okay well nobody [siblings] is in the area to help them. So my husband has to do certain things on his own, I’m on call. We’re both on call.” When Felicia was initially asked how often she helps her parents she responded with this statement, “It’s constant! You have to really be on-call. If I’m not going to be home, I have to put in an out of office memo. I can’t just leave.” Felicia continued when asked how do you know when they need you? “Oh God, I have to check in. I call and speak to them

every day. I'm back at work now so I don't call every morning, but I call every afternoon before I leave." Felicia also stated "If she's [mother] sick I'll get a call at 2 o'clock in the morning. What am I going to do? Let him [Felicia's father] hold her head while she's vomiting? He can barely walk to the bathroom himself. When she's sick it's around the clock." Brenna shared how her mother-in-law can never be left alone and sometimes it could be dangerous.

She can't be trusted. She forgets too much. She completely forgets things like if she's eaten. You could feed her breakfast and a ½ hour later she's looking for food saying she hasn't eaten all day. She loves to go sit outside. I heard the dog crazy barking...she was walking away, waving a stick, saying something in Greek and I looked up the driveway and there was a bear! (p. 1, line 23; p. 2, lines 1-3; p. 8, line 20; p. 8, lines 22-23; p. 9, lines 1-3).

The fourth theme, *on call 24/7* captures the new reality for the participants... caregiving never really stops. There may be a break in the caregiving routine with the help of a sibling, or the distraction of work. But who knows the routine best? Or what if something goes wrong? The caregivers have their parents on their minds at all times.

I am a Caregiver by Lin M. Watkins

I am a caregiver	And most of the time	And when I take
it's what I do	we do just fine	that necessary break
24/7	But once in a while	I've got to remember
I'm here for you.	I need my own time	it's for both our sake
I can't take care of you	I'll always be here for you	
unless I take care of me	so don't you fret	
So I work very hard	Together we're making	
At being guilt-free	memories of us I'll never forget	

Metatheme

A metatheme is considered to be drawn from the entire body of the data and it is also referred to as an overarching theme. (Ely, Vinz, Downing, and Anzul, 1997). Further analysis of the themes of this study revealed one metatheme that captured the essence of the experience of caregiving for an aging parent: *I am Blessed*.

I am Blessed. Despite the emergent calls, the changes in personal/family plans, the adjustments in work schedules, the planning with siblings, the emotional roller coaster of feelings, and all the time and effort to provide the care needed by their parent(s), participants still communicated an unwavering sense of fulfillment, joy, and feeling blessed. Annie: "It is rewarding. I feel good about doing it." Karen: "I feel it's an obligation, but I wouldn't change it for the world. I feel that I'm so blessed at whatever capacity they [parents] are in. I am very blessed that they're both in my life." Marie: "You know you hear about people whose parents have died, and

they think I should've told my mother this or that. I'm not going to have that problem. I mean there's been the adult companionship which is great." As a retired person with particular physical ailments, Marie spoke about the blessing of her husband's assistance. "I talked to him about having my mother move in and there was never a hesitancy. I'm very, very blessed. I know other women who want their mothers and don't have that [spousal support]. Julie: "We [all siblings] were told my mother was going to die when I was a kid. And the fact that she's here for 80 something years is a blessing." Felicia summed up her caregiving experience this way.

It's gonna sound crazy but I'm blessed. There's a real closeness. Now more with my father than there ever was. It's like we're in this together. And it's a privilege to do this [caregiving] for my mother, it really is. Do I get tired? Absolutely! Don't I want to see her in a home...? Absolutely not! If I can be part of her day to make her happy, I'm lucky. I'm blessed to see those smiles. (p. 13, lines 8-22).

Blessed in Aging by Esther Mary Walker

Blessed are they who understand
My faltering step and shaking hand
Blessed, who know my ears today
Must strain to hear the things they say.

Blessed are those who seem to know
My eyes are dim and my mind is slow
Blessed are those who look away
When I spilled tea that weary day.

Blessed are they who, with cheery smile
Stopped to chat for a little while
Blessed are they who know the way
To bring back memories of yesterday.

Blessed are those who never say
“You’ve told that story twice today”
Blessed are they who make it known
That I am loved, respected and not alone.

And blessed are they who will ease the days
Of my journey home, in loving ways.

Chapter VI

DISCUSSION

The literature was further reviewed to determine whether the findings of this study support or extend prior research and in what way the findings add to the body of knowledge related to adult children caregiving for their parents.

Our upbringing. The findings of this study suggest that American culture and upbringing values the care of aging parents by their children. Previous research provides background information on *upbringing* were studies on parental caregiving within different cultures which include Asian (Chinese, Thai, Philippine, and Japanese), Mexican, and Swedish. Filial piety, as parental caregiving was termed in the Asian studies, is a core value of the Asian culture (Chan et al., 2012). It defines the obligations between children and parents. Goals of the family are given priority over individual pursuits (Wongsawang et al., 2013). Caregiving in Japan is considered a woman's responsibility. According to Hashizume (2010), "Caregivers prioritized the needs of their husbands and the elderly and valued their well-being highly" (p. 834). A study in Sweden revealed participants felt caring for parents was a natural task (Jansson, Almberg, Grafstrom, & Winblad, 1998); and parental caregiving by Mexican women met the obligation of cultural familism (Wells, Cagle, Bradley, & Barnes, 2008). Six of the seven participants in this study were born in the United States; only two parents of the participants immigrated to America. This study reveals American adult children also felt providing care to their parents was part of their *upbringing*.

Because of Proximity. The participants in this study became caregivers because of their proximity to their parents. Some either reside together with their parents or their homes are “just down/up the road” from each other or a few miles apart.

There is some support in the literature for this finding. A study by Merrill (1996) looked at siblings transitioning to the role of a parental caregiver. Some of the adult children became the caregiver because their sibling(s) could not or would not assume the care or no other alternatives were available. Those who took on the care of their parent were more available because of either the flexibility of work, not having children, or *proximity*. Strauss (2012) reports “An adult child caregiver living closest to a frail or sick parent is often chosen among siblings to care for a parent” (p. 49).

Self-Neglect. The participants in this study missed their normal routine of eating healthy food or doing regular exercises and fell behind on scheduled healthcare appointments. There is evidence in a study by Pereira & Rebelo-Botelho, (2011) stating *neglecting self* occurs due to lack of recognition for the caregiving work that is done. Friends and relatives see apparent reality and think everything is okay. “I take care of you, of all of you and no one looks after me? I’m taking care of them and I don’t look after myself!” (p. 2452). It is worth noting that although the participants in this study talked about self-neglect, it was verbalized in a different manner. Some participants did not express a need for recognition from their siblings or children. Their self-neglect was a result of their own lack of planning, or being tired. Karen

says with regard to daily exercise, “I’m tired at night, and sometimes it just feels good to stay in bed.” With regard to recognition from their own children Felicia states, “They’ve always been good because they grew up with my mother and father. My son will go up and mow the lawn and then stay to watch T.V. with them.” Karen remarked self-neglect is part of being a caregiver. “It’s a caregiver personality that you always put somebody else first.” Even though siblings of the participants didn’t freely offer assistance, Karen tells her own daughter, “They [brothers] like to control, but if I needed them at 2 o’clock in the morning, they would be there.”

Limited Social Life. In this study, Marie expressed her disappointment about not being able to socialize with friends now that she’s retired. Julie feels the impact when trying to spend time with her husband. Research has shown caring for a chronically ill or disabled older person has a variety of negative consequences on the caregiver. This is directly related to the amount of support and level of caregiving needed for the care recipient (Strauss, 2012). The subtheme of *limited social life* is one of those consequences. Pereira & Rebelo Botelho (2011) also reported “We lost our personal life...most of it depends on my mother’s schedule (p. 2451). “If I’m at the supermarket and meet someone I know; I like to chat for a while. Not anymore” (p. 2451). A quantitative study of women by (Stephens, Townsend, Martire, & Druley, 2001) measured inter-role conflict of 278 daughters who had the primary responsibility of caregiving. These women were also wives, mothers, and employees. These women were asked if they had less time for leisure in the past year of caregiving. Leisure was defined as seeing friends, going out to dinner, reading, or just

doing nothing. A five-point scale was used with potential scores ranging from 8-40. Higher scores indicated more restricted activity. The average level of activity restriction was 30.4 ($SD = 6.4$, range = 15-40). Unlike some of the participants, Karen, Valerie, and Brenna, are still raising and involved with their children. Their parental caregiving tasks can either positively or negatively affect their family life. Kang (2006) documented caregiving restricted the life of the parent-child dyad.

Resentment. Day in and day out performance of caregiving tasks will eventually take its toll on someone. And that someone is most often the caregiver. In this study, Karen and Annie expressed their resentment when siblings “called to ask them” or failed “to visit” their parents. Merrill (1996) revealed an all-out battle over two days between nine siblings regarding their mother’s care. “You don’t do anything. I want to hear what you are going to contribute. What will you do?” (p. 408). Felicia was the most verbal in her resentment towards siblings when she’s not afforded the luxury to “just be able to just go” when planning time away either alone or with her family.

The findings of this study are consistent with what is reported in the current literature related to adult children having *resentment* towards their parent(s) and siblings. Wongsawang et al., (2013) reported resentment from a daughter towards her sister. Why doesn’t she ever take care of mom? Why do Om and I always have to be with mom? She always say she has meetings” (p. 340). The literature supports the emotion of *resentment* when participants voice displeasure at the lack of assistance from siblings. “No one shows much eagerness on their own to accept the

responsibility of taking care of the elderly parents. They don't want any kind of disturbance in their personal family life" (Dhar, 2012, p. 247). "Regardless of the system that we thought we had in place ...one of us always thought we were doing more than the others." (Sanders & McFarland, 2002, p. 70-71).

Guilt. Adult children who try to balance employment and caregiving, who at times need to choose work and family life over their parent(s), express *guilt* (Edlh & Carlsson, 2010; Hashizume, 2010). Participants in this study expressed their guilt differently. Their guilt was not from choosing work or family over their parent's needs, but surfaced at times from frustration with their parent(s) while providing the caregiving. Annie's mother takes longer to accomplish certain house cleaning chores. "I get annoyed and lose my patience." Felicia feels guilty when she "grumbles" after having a disagreement with her parents or siblings. Julie's parent(s) call at inopportune moments and she "just wants to say no" to the request, especially when she was just at her parent's home recently. Valerie's father at times becomes angry with her and they will argue. "I don't touch the subject for a day. I'll call him the next day and say hi dad, how are you? I can't abandon him. I couldn't live with not being there for one of my parents."

Parents Become Your Children. Julie will try to make other caretaking suggestions she feels are more appropriate for her mother's wellbeing. Brenna has to constantly be aware of her mother-in-law for her own wellbeing and safety. Spence et al., (2008) found caregivers lose their relational identity with assuming the role of caregiving. Participants in this study reflected on the many roles they shouldered

depending on the care their loved one needed. They were not just the spouse, child or sibling anymore. Now they were the parent, along with being a nurse, doctor, or psychologist.

In the instance of caring for a parent, the participants in this study expressed how their parent(s) became more physically and with some, mentally dependent; the participant's adult child role identity reversed to that of being a parent. Assuming the identity of the parent caused the participants to feel accountable for care decisions. Marie's mother while cognitively intact can be very stubborn when she insists on Marie being with her while others are visiting. Karen will re-prioritize her mother's requests when they don't make logical sense. This is similar to the findings of Spence et al., (2008), who reported that caregivers state, "It's like having another child sometimes because you are sort of responsible and I feel he's my responsibility. I feel that he is not anyone else's responsibility" (p. 370).

Fallen Idols. In this study, seeing the parents who formed you, who you adored as a young child, the parent who could make everything right again, now have limitations and are unable to care for themselves, deeply saddened the adult child caregiver. Participants in this study reflected on their memories of admiration about parents' personal accomplishments. Both Julie and Felicia spoke about their parent's intelligence and educational accomplishments. Marie, Karen, Annie, and Valerie all were deeply saddened with the memories of their strong parents, who could do anything, but were now so physically or mentally impaired or dependent. Pereira & Rebelo Botelho (2011) findings include a participant reflecting on the transience of

life. “That’s what had been so painful for me that it brings tears to my eyes and makes me want to put myself in his shoes: I’ll go through this instead” (p. 2453). A qualitative study by Sanders & McFarland (2002) reports the personal challenges and emotional reactions of adult children caring for a parent with Alzheimer’s. “We go through life thinking that our parents are invincible” (p. 68). The statements by participants in this current study are similar to those in the literature.

I am Blessed. In this study the caregivers revealed an enjoyment of the caregiving experience. Karen, Julie, Marie, and Felicia all used the word blessed as a positive gain. Marie loves that she has an “adult relationship” with her mother and Felicia feels she’s much closer to her dad because of sharing some of the care for her mother. A positive theme entitled “gains in relationships” emerged in a study by Netto, Jenny, & Philip (2009). In their study, caregivers experienced an improvement in their relationship with the care recipient. The positive caregiving relationship is also revealed in a study by Butcher, Holkup, & Buckwalter (2001). “It gives us a bond that would not be there otherwise” (p. 49). Another study by Sanders (2005) reported 81% of the participants experienced a positive gain as a result of caregiving. The caregiving experience had become a “blessing” and the participants were able to “re-evaluate” their lives both personally and professionally (p. 68). Jones et al. (2002) report challenges in parental caregiving stimulated what is termed as personal growth. “Because you have gone through many difficult things, you become a strong person” (p. 207). Peacock et al. (2010) also reported themes of personal growth as a sense of peacefulness, and closer relationships as an outcome of caring for a loved one.

In this study, Karen emphatically stated “I wouldn’t change it for the world. I’m so blessed at whatever capacity they are in” (p.7, lines 18-19), Jones et al. (2002) reported these caregiver statements “I wouldn’t exchange it for anything else” and “God has a purpose for giving me this problem” (p. 207). While some literature supports such statements, this study provides a deeper understanding.

What This Study Adds to the Literature

The sub-theme of *guilt* in this study was not reported in the same context as other studies. Guilt has been reported to be felt when the caregiver has to make a choice between their job roles or family over the care recipient (Edlh & Carlsson, 2010; Hashizume, 2010). To the contrary, several participants in this study expressed their guilt as a result of how they reacted to an unpleasant encounter with their parent while providing care. Participants expressed it was due to frustration waiting for a parent to complete a task on their own, the parent has called more than once in a short period of time, or simply having an argument. There was not a situation where a choice needed to be made between the adult child’s personal life roles and the demands of parental care except for social connectedness.

The burdens of caregiving still dominate the literature. Fewer empirical research studies focus on the positive aspects of caregiving, where caregivers emerge stronger as a result of the caregiving experience. There is a particular lack of research with regard to the positive gains of caregiving exclusively for the adult child caregiver. Of the five research studies cited to support this study’s findings in *I am Blessed*, only two had adult children as the sole participants. The majority of research

studies involving caregivers include spouses, siblings, and friends as the participants. This study's metatheme *I am blessed* adds to the discussion of more holistic themes of adult child caregiving experiences.

Chapter VII

SUMMARY, CONCLUSIONS, IMPLICATIONS

This chapter reviews the purpose and findings of this study. The contribution that this study makes to nursing knowledge will be discussed. Implications of the findings about adult children caregiving for aging parents will also be included in the context of nursing practice and future research.

The aim of this study was to elicit and understand the experience of adult children caregiving for their aging parents through their rich, personal descriptions. The method of choice for this study was phenomenology. By using this method, the experience was explored with seven participants immersed in the phenomenon. Data were collected and described using the participant's own words. Four themes and one metatheme were identified. The findings were compared with existing literature. The findings of this research provide a deeper understanding of the experience of the adult child caregiving for an aging parent.

Conclusion

This phenomenological study revealed four themes regarding the adult child caregiving for an aging parent. *It was meant to be* expresses how participants were not surprised to be in their caregiving situation. The consequences that can occur through caregiving is disclosed in *my changing world*, the participants' expressions of deep sadness through *loss of what was*, and the caregivers' very heightened responsibility of being *on-call 24/7*.

There were total of ten subthemes that emerged, most of which were similar to findings from previous studies. Taking care of others is part of *our upbringing* corresponds with the literature about filial piety and the responsibility of caring for parents (Chan et al., 2010; Jansson et al., 1998; Wells et al., 2008; Wongsawang et al., 2013). Most participants in this study became caregivers *because of proximity*. Prior studies report children living the closest are the ones who care for their parents (Merrill, 1996; Straus, 2012). Existing literature states *self-neglect* occurs due to lack of recognition (Pereira & Rebelo-Botelho, 2011). A finding in this study revealed self-neglect was part of being a caregiver and participants knew they could call siblings for assistance if needed. Research has shown caregiving has a various negative effects; one being a limited *social life* (Pereira & Rebelo-Botelho, 2011; Stephens et al., 2001; Strauss, 2012). Findings in this study were consistent with the literature. Participants in this study expressed their lack of time with friends and family. Caregivers in this study disclosed feeling *resentment, anger* or *guilt* with their siblings and their parent's physical decline. The literature supports these emotions as a result of providing constant caregiving tasks (Dhar, 2012; Merrill, 1996; Sanders & McFarland, 2002; Wongsawang et al., 2013). This study expressed the participant's loss of identity in *parents become your children* and *fallen idols*. The findings are supported in the literature when one assumes the role of a caregiver (Pereira & Rebelo-Botelho, 2011; Sanders & McFarland, 2002; Spence et al., 2008).

The metatheme, *I am Blessed* captured the essence of the experience for these adult child caregivers, and is supported in the literature (Jones et al., 2002; Netto et

al., 2009; Peacock et al., 2010; Sanders, 2005). All of these participants expressed a higher level of personal gain from their parental caregiving experience. Their relationships were much closer than they ever anticipated with their parent(s). For this particular group of participants, still having their parents as part of their lives, no matter what their capability, was a blessing and a privilege.

Strengths and Limitations of the Study

The use of a phenomenological approach for this study is a strength since it is the design of choice to achieve the goal of discovering a deeper meaning of the experience from those who were living it. The in-depth multiple interviews allow the participants to voice their experience. Therefore, the study's aim to richly describe the experience was met.

Diverse participant demographics of age (21-71), employment (one participant is retired, two work full time; two part-time, and two are full-time students), the occupations, marital status/children, parent cared for, parent(s) age (54-94), and caregiving years (1-10) also lent strength to this study's findings.

Trustworthiness was achieved by following the criteria for maintaining trustworthiness by Lincoln and Guba (1985). Non-structured interviews were conducted with each participant, providing ample time for in-depth description of experiences until saturation was achieved (45-60 minutes). Member checking was also done during interviews which assisted me with clarification of their comments, and confirmed my interpretations. Coding of data was written directly on the transcripts. As themes emerged, they were organized on index cards with references

to the transcripts. Validation of my analyses were done during several sessions with my chairperson. Finally, I returned to the literature to search for similarities and differences in previous data with my current findings.

Certain inclusion criteria may have also provided limitations. The study was open to English speaking daughters and sons of any ethnicity providing care to parents throughout at least eight counties in New Jersey. There were no male (son) participants. All participants in this study were female (6 daughters and 1 daughter-in-law) and lived in only three counties in New Jersey. Participants were White, with three being of Irish descent, two were of Italian descent, one was Polish and another was Hispanic. A more diverse cultural background, and living in different geographical areas may increase the knowledge of the experience of caregiving based on cultural upbringing, cultural religion, economics, and available resources. Whether these groups' experiences are similar to those in this current research, needs further study.

Implications for Nursing Practice

According to van Manen (1990) "phenomenology does not problem solve" (p. 23). However, the rich descriptions from these adult children caregiving for their parent(s), and the four themes and metatheme that emerged give us a deeper understanding of the experiences. These research findings have potential implications for nursing practice.

While conducting the interviews for this study, none of the participants were currently faced with a crisis situation with their parent(s). However, in describing to

me how they came to be the primary caregiver, their parent had experienced a life threatening event (heart attack, stroke, severe electrolyte imbalance, renal failure) which rendered the parent unable to independently care for themselves any longer. King & Quill (2006) report not all adult child caregivers are instantaneously equipped to take on the parental caregiving responsibility. Lack of knowledge creates anxiety, frustrations and helplessness. As noted in the vignettes, several participants expressed their lack of knowledge, with regard to how to proceed with their parent's care.

Felicia: "I'm not a medical person and I always have to ask so many questions to make sure I'm doing the right thing." Annie: "I don't know everything." Valerie: "I was clueless at the beginning of this."

Very little information or any direction was given by healthcare professionals about possible services for either themselves or their parents. Marie: "I received little to no guidance from healthcare workers. And whatever I did learn was from friends and my own mistakes." Annie: "I have to ask. Rarely does anyone, nurses or doctors anticipate giving me information in advance. If I don't know what to ask, I just hope the nurses and doctors will tell me." These statements indicate the lack of healthcare's response to caregivers' need for training and readiness, self-care instruction and ongoing support in caregiving.

The current research report from NAC & AARP (2015) documented these key findings:

- More than eight out of 10 caregivers providing care to someone 50 years or older years say they could use more information or help on caregiving topics (84%).
- Caregivers most often want information about keeping their loved one safe at home (43%) and about managing their own stress (42%).
- One in three caregivers of someone 50+ years says a health care provider, such as a doctor, nurse or social worker, has asked about what was needed to care for their recipient. Only 16% say a health care provider has asked what they need to care for themselves.

As of November 14, 2014 New Jersey Governor Chris Christie, signed the Care Act into law. One of the three major provisions of this law requires hospitals to provide in-person instruction on caregiving tasks that need to be performed at home post hospitalization.

What does nursing know better now about the adult child caregiver?

Depending on the acuity of the care recipient, these caregivers need to be prepared for the tasks of care and the potential impact on their lives. NAC & AARP (2015) report there is a greater demand for these types of dialog than there are actual discussions taking place. This creates a gap in nursing care. At a very basic level, nursing can identify the dynamics of families and those who need the most support. As noted in the literature review, race and culture have a notable impact on caregiving. Nursing should ascertain any culture care nuances, caregiving experiences and challenges.

Assessing the physical, educational, and emotional needs of caregivers gives nurses the opportunity not only to provide instructions, but much needed holistic support and self-care instructions as well. Asking direct questions such as, Are you a caregiver? What are you doing to care for yourself? can evolve into a very informative discussion between the nurse and the adult child caregiver. These conversations can help improve the adult child's caregiving experience and that of their parents. Nurses can connect family caregivers to services, resource groups and also support public policies, such as those lobbying for money that will support caregivers at home.

Recommendations for Future Research

Based on the results of this study, more qualitative research is needed to advance the body of nursing knowledge. This study has at least one participant from a minority ethnic culture. Replication is needed to include more ethnic and gender diversity. This may require recruitment from known demographic cultural areas. Along with ethnic diversity, future research should focus on adult sons caregiving for a parent. It would be most helpful to hear a male perspective on his experience and compare it to female counterparts. Does being a nurse influence one's parental caregiving experience? The literature lacks studies of adult child nurse caregivers for parents. Two of the participants in this study were nurses and their experiences were similar to those reported in the current literature. But what about the male nurse? And does the practice area affect the experience of a nurse?

More research is needed about the adult child caregiver who is a nurse. There are few studies in the literature that look at the caregiving experience through the eyes of the care recipient. This study described the theme and subthemes of *loss of what was*. What is the parent feeling and thinking about their children caregiving for them? How do they perceive the child-parent relationship?

Chapter VIII

REFLECTIONS

Participant Reflections

Some of the participants in this study felt they had a positive experience going through the interview process. Several mentioned they were nervous before starting, wondering what questions would be asked. But once they started to open up and speak, I could physically see their body's relaxing and the words began to flow. Often during the time together someone would reveal how no one ever asked what their life was like; and how talking about it in the open was so "therapeutic." That was Joan's favorite word especially when she would come to tears on how she felt about her mother. After her first tearful session, she later had tissues ready for our interview in case she needed them! Felicia's face lit up with enormous pride while telling me about her mother being a valedictorian and all the traveling she did. As a healthcare professional herself, Karen knew the importance of evidence based research and was happy to contribute to the literature. Participating in the study gave them opportunity for self-reflection. Marie would remember information she felt might be useful after we completed an interview and she told me how much she looked forward to our next time together.

Personal Reflections

The road to compiling this dissertation met several hurdles. Once my proposal was accepted, I felt I would have no problem recruiting participants. One of my strategies was sending the recruitment flyer to a national organization that had the

ability to reach hundreds if not thousands of caregivers in five counties of New Jersey. I prepared myself for the fact that I may be traveling a lot or spending time on the telephone in case the driving distance was too great. I was so excited to begin. And I waited, and I waited, and I waited. The road stopped at this first hurdle. The reality was I received only one participant through that contact and she did not meet the participant criteria. I immediately felt defeated, totally crushed. I began to get a few emails from people, but my spirits remained deflated as one after the other didn't meet the criteria. Approximately four weeks later I received an email from an interested person. While I was calling her to reply, I remember thinking she'll probably be another person that doesn't meet the requirements. To my delight that was not the case and I enthusiastically scheduled my first ever interview! My hopes were renewed and slowly more people began to contact me. Soon my calendar was filling up with interview appointments.

My next hurdle was the interview itself. I had never done this before. I remember discussing techniques in my qualitative classes, but now I was facing the reality! I was going to actually interview someone. Just as I mentioned previously how I noticed the participants relaxing once they began speaking, I experienced the same reaction. Once the conversation started I was totally engaged in their stories. But don't let me give the impression that everything was perfect, not by any stretch of the imagination. When I started to relax, I started to talk, and talk, and talk. There were a few moments when I said to myself "you need to be more silent." I have to

admit, being quiet was quite difficult. I realized this situation one evening as I was transcribing an interview.

As I'm still transcribing interviews while listening to the recordings, I realize how difficult it was not to speak too much during the conversations. And especially hard not to ask leading questions that would prompt the participant for a particular response. I'm listening to the recording and thinking: Should I have said the question this way or that way? Practice, practice, practice. (Reflective memo, 2015).

Once I started to concentrate more on letting the participant speak, my silence became easier.

While I actively listened to my participants comments I sometimes thought about my own experience as a parental caregiver. Munhall's (2012) term "decentering" came to my mind. Was I being fully present during these interviews? I wrote out my thoughts directly after the interviews in a journal that I kept. My answer was reflected in my notes after one particular interview.

I saw genuine tears today from the participant while talking about her mother. The release of emotion reminded me how I reacted to the injustice of losing a mother so early in life. I downright cry when I speak about the last days and weeks in my own mother's life. And she's been gone for 21 years! (Reflective memo, 2015).

I began to question myself. Was I doing this data collection right? Once I returned home, I would search my textbooks to re-read about interviewing, I believe,

because I wanted to be so perfect in what I was doing, I was actually making myself more prone to making a mistake. And then I read this. Munhall (2012) believes the researcher must also reveal and reflect on their beliefs in order to approach their topic honestly and openly. I began to change my approach to reviewing the data before the next interview. I read the prior transcription and referred back to my reflective journal. I spent time thinking about both mine and the participants' thoughts and perspectives on the topics discussed. I believe this helped me approach the next interview with a more open mind, and improved my listening skills. I am now more confident with conducting interviews and have a much better idea of how to separate my feelings and be a more active listener.

The last hurdle was the actual writing of the meaning of the data. I knew my transcripts by heart and could recite comments almost verbatim, but how was I going to communicate to outside readers the sentiments, the emotion, or the concern I heard in the participant's voices through the written word? Once the themes emerged, I typed the words and phrases in an internet browser and searched just to see what might be listed. I noticed the predominant results were web sites and blogs devoted to caregivers. The creators of the sites were caregivers themselves. The one thing that caught my eye was dedicated areas for poetry. One of the support tips given on these websites was to keep a journal of one's thought or write poetry to express feelings. I began reading the poems and realized this is how I could best convey my participants' deep, innate sentiments; poems written by caregivers for caregivers. That is why I chose to use poetry to describe each theme.

Final Thoughts

This doctoral journey has been an incredible life experience. Trying to balance my academic pursuit with my personal life caused me to make many difficult choices which included declining time and activities with my family and friends. I kept telling myself it will be worth it in the end. I learned just how much motivation and self-direction is required on the part of a qualitative researcher. Admittedly now, I have already reaped the sense of remarkable personal growth and accomplishment.

I cannot end this writing without voicing how I feel about the participants in this study. “I think I felt included in the participants lives since they were being so open with me” (Reflective memo, 2015). Their willingness to contribute and share their experiences with me goes beyond measure. We met not knowing each other, not knowing what would be forthcoming in our conversations.

Looking back at my own feelings having been an adult child parental caregiver, I could relate to the theme of *resentment* towards my brothers while caring for my mom. And *loss of what was* reminded me of how chemotherapy stole away my physically strong and very intelligent mother. It reduced her to barely being able to walk, forgetting one moment to the next, and could not finish articles she tried to read (Reflective memo, 2015).

These women showed me a profound compassion for the role they have chosen. They are genuinely and deeply committed to their parents. *I am blessed* for having made their acquaintance.

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Appendix A

RECRUITMENT FLYER

Invitation to Participate in Caregiver Research

Are you an adult with either full or part-time responsibility caregiving for an aging parent(s)? Would you be willing to participate in a study to describe what this experience is like for you?

Kimberly Conway MSN, RN-BC, CRN, a doctoral student at the Seton Hall University College of Nursing in South Orange New Jersey, is seeking participants to enroll in a study entitled:

“The Experience of Adult Children Caregiving for Aging Parents”

1. The purpose of this study is to explore and describe the experience of being an adult who is currently either partially or fully involved with primary caregiving responsibilities for a parent or parents with a chronic or terminal illness. The researcher would like know what this experience is like from the adult child’s point of view.
2. Participation consists of a series of three, audio-taped interviews lasting approximately 45-60 minutes each taking place over a flexible 4- 8week timeframe.
3. Participation in this study is strictly voluntary; you can withdraw from the study at any time.
4. All the information you share during the interviews will be kept confidential. Your identity will only be known to the researcher. You will be referred to by your initials during the interviews and all your audiotaped interviews will be identified by coinciding initials.
5. All audiotapes will be transcribed only by the researcher and kept on a secured USB memory key. All study materials will be stored under lock and key by the researcher to maintain strict confidentiality.

In order to participate in this study you must:

Be over the age of 21

Speak fluent English

Be an adult child who has caregiving responsibilities to one or both parents for at least 1 year.

To hear more about the study, please contact the researcher:
Kimberly Conway MSN, RN-BC, CRN
973-668-1398 or email
kimberly.conway@student.shu.edu

Appendix B

LETTER OF SUPPORT



Our Lady of Fatima Church

184 Breakneck Road • P.O. Box 242
Highland Lakes, N.J. 07422
973-764-4457

June 10, 2015

To Whom it May Concern:

I give permission to Kimberly Conway to put flyers into our Church bulletin as needed for her work on her doctorate.

Sincerely,

Rev. Msgr. Robert B. Carroll

Rev. Msgr. Robert Carroll
Pastor

Appendix C

LETTER OF SUPPORT

United Way of Northern New Jersey

P.O. Box 1948 | Morristown, NJ 07962
tel: 973.993.1160 | fax: 973.993.5807 | UnitedWayNNJ.org



June 12, 2015

Kimberly Conway, MSN, RN-BC, CRN
Seton Hall University
College of Nursing
400 South Orange Avenue
South Orange, NJ 07079

Dear Ms. Conway:

United Way of Northern New Jersey would be pleased to post your **Invitation to Participate in Caregiver Research** in the announcements that are sent to our *United Way Caregivers Coalition* members. The announcements go out by email, and limited postal mail, to the over 2,400 members of our five *Caregivers Coalitions*. Our membership includes approximately 1,200 family caregivers, as well as almost 1,300 service providers to caregivers.

As our mission is to promote knowledge of and action around caregiving issues to ensure all caregivers identify themselves in this role and have access to the resources, services, education, and other support needed to sustain them as caregivers, we welcome efforts to better understand the experience of family caregivers.

We wish you the best with your study.

Sincerely,

A handwritten signature in cursive script, appearing to read "Carol E. DeGraw".

Carol E. DeGraw, MSW, LCSW, DRCC
Director, Health Impact Area
973.993.1160, x202

Appendix D

SETON HALL UNIVERSITY IRB APPROVAL

REQUEST FOR APPROVAL OF RESEARCH, DEMONSTRATION OR
RELATED ACTIVITIES INVOLVING HUMAN SUBJECTSAll material must be typed.

PROJECT TITLE: The Experience of Adult Children Caregiving for Aging Parents

CERTIFICATION STATEMENT:

In making this application, I (we) certify that I (we) have read and understand the University's policies and procedures governing research, development, and related activities involving human subjects. I (we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) obtain written approval of significant deviations from the originally-approved protocol BEFORE making those deviations, and (2) report immediately all adverse effects of the study on the subjects to the Director of the Institutional Review Board, Seton Hall University, South Orange, NJ 07079.

Kimberly Conway 6/5/2015
RESEARCHER(S) DATE

Kimberly Conway MSN, RN

**Please print or type out names of all researchers below signature.
Use separate sheet of paper, if necessary.**

My signature indicates that I have reviewed the attached materials of my student advisee and consider them to meet IRB standards.

Judith A Lothian 6/5/2015
RESEARCHER'S FACULTY ADVISOR [for student researchers only] DATE

Judith A Lothian

Please print or type out name below signature

The request for approval submitted by the above researcher(s) was considered by the IRB for Research Involving Human Subjects Research at the June 2015 meeting.

The application was approved not approved by the Committee. Special conditions were were not set by the IRB. (Any special conditions are described on the reverse side.)

Nancy J. Ruszelski, Ph.D. 6/24/15
DIRECTOR. DATE
SETON HALL UNIVERSITY INSTITUTIONAL
REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH

Appendix E
INTERVIEW GUIDE

Interview One: I'd Like to Get to Know You

Tell me about yourself...

Tell me about your family (if married or have children)

Describe your relationship with your parent(s)?

Interview Two: Caregiving Situation

How did you come to be either the primary or shared caregiver?

What caregiving responsibilities do you perform?

How often do you need to assist your parent(s)?

What is it like being the primary caregiver?

Interview Three: Final Thoughts about Caregiving

What is the effect on your life? What might have changed?

Moving forward, what would you like to see happen?

Is there anything you want to add about your experience?