THE LIVED EXPERIENCE OF BEING A CAREGIVER FOR A FAMILY MEMBER DEPENDENT UPON HEMODIALYSIS

by

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ABSTRACT

An identified gap in the literature exists regarding studies using an inductive approach that allow caregivers to describe the lived experience of caring for family members dependent upon hemodialysis for managing end stage kidney disease. This study used a purposive sample of six caregiver participants, male and female, with an average age of 36 using a descriptive, phenomenological approach designed to share experiences of providing care to a family member dependent on hemodialysis. The representative sample was recruited from a mid-sized hospital in the mid-Atlantic region of the United States. The investigator conducted face-to-face, semi-structured interviews with participants. Using the Giorgi method of data analysis, six major themes and 12 sub-themes were identified. Perceptions of the caregiver participants were that caregiving is hard work and stressful; however, caregivers found the experience meaningful. Caregivers identified they need a support system and the stress of caregiving interferes with their own health. Uncertainty regarding the indeterminate time a family member will use hemodialysis added stress to caregivers. Study limitations included a sample with one male participant, which may limit understanding of the male caregiver perspective and included participants who only spoke English. Study results should interest caregivers and healthcare professionals working with caregivers of family members dependent on hemodialysis. Further research should include the effects of exercise, spirituality, and the cultural differences for caregivers providing care for family members dependent upon hemodialysis. A longitudinal study examining long-term effects of caregiving with this population is warranted.
DEDICATION

This dissertation is dedicated in memory of my parents, Betty and Bud Kearney. Thanks for always believing in me and stressing the importance of education. I know you are proud of me.

This dissertation is also dedicated to my family. Thank you to my husband, David, for believing in me and showing this through your unending support and love for me while I pursued this educational journey. Thank you to my son Scot, who forgave my need to spend many hours in my home study office. Thank you to my son, Chase, who made the selfless decision to serve our country as an Army soldier during wartime. Thank you to my mother-in-law, Mary Turner, for your encouragement throughout the journey. You all serve as an inspiration to me every day.

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Chapter 1

Introduction

The number of individuals who are caregivers for a family member continues to rise as the population of those who are both elderly and chronically ill increases (Barry, 2010; Belasco & Sesso, 2002; Nguyen, 2009). Archbold, Stewart, Greenlick, and Harvath (1990) identified two variables that influence a family member’s ability to manage the challenges and responsibilities of caregiving for a family member who is chronically ill: mutuality and preparedness. Mutuality encompasses the ability of the caregiver to find gratification and meaning in the caregiving relationship (Archbold et al., 1990). Preparedness represents the evaluation of the competence or skillset of the family member to perform the activities associated with caregiving duties (Archbold et al., 1990). Caregivers frequently report being unprepared for their new role (Cangelosi, 2009). Some caregivers embrace the role and use the experience of caregiving as an opportunity to bond with their family member and build a closer relationship. Other caregivers struggle with family responsibilities and experience guilt or feelings of inadequacy (Cangelosi, 2009).

Challenges faced by caregivers caring for a family member with a chronic illness include physical exhaustion, poor social support systems, and ineffective coping mechanisms (Belasco & Sesso, 2002; Nguyen, 2009). The responsibilities of caring for a family member may interfere with a caregiver’s job or career and the treatments and medications may result in financial strain for the family (Nguyen, 2009). Some caregivers successfully manage the multifaceted aspects of caregiving for a chronically ill family member while others are overwhelmed by the challenges and are ultimately unsuccessful in their attempts to manage the complexities of caregiving. Caregiving can compromise caregivers’ physical, mental, and emotional health, which can lead
to physical illness and depression as the caregivers’ needs are neglected in favor of the needs of
the chronically ill patient (Belasco & Sesso, 2002; Nguyen, 2009; Schneider, 2004; Wagner,
1995).

The term *caregiver burden* describes a caregiver’s response to the chronic stress of
caregiving and includes feelings of being overwhelmed with the responsibilities associated with
caregiving (Belasco & Sesso, 2002; Burns, Archbold, Stewart, & Shelton, 1993; Cangelosi,
2009; Savundranayagam, Montgomery, & Kosloski, 2011). Characteristics manifested by a
caregiver experiencing caregiver burden include anxiety, emotional stress, fatigue, and
relationship changes between the caregiver and the family member (Savundranayagam et al.,
2011; Schneider, 2004).

Caregivers of patients affected by Alzheimer’s disease and non-specified dementia
represent the population most studied for the effects of caregiving and caregiver burden. A small
number of quantitative studies explore characteristics of caregiver burden and outcomes of
caregiver burden in caregivers of patients who use hemodialysis as a treatment modality for end
stage kidney disease (ESKD) (Martinez-Martin et al., 2007; Novak & Guest, 1989; Schneider,
2003; Schneider, 2004; Washio et al., 2012), which was the population for this study. Studies
with hemodialysis and ESKD patients primarily focus on either measuring caregiver burden in
general or exploring differing aspects of burden including contributing factors, characteristics,
and outcomes of burden (Belasco & Sesso, 2002; Novak & Guest, 1989; Washio et al., 2012).

Investigators have largely used quantitative measures to determine outcomes of burden
and examine dimensions of burden (Honea et al., 2008; Savundranayagam et al., 2011;
Schneider, 2004), without completely describing the nature of the experience as actually lived.
The measurement tools used in studies by Belasco and Sesso (2002), Novak and Guest (1989),
Schneider (2003; 2004), and Washio et al. (2012) are adapted from studies of caregiver burden in the Alzheimer’s and dementia, multiple sclerosis, and the general caregiver literature. It is unclear if the adapted tools adequately represent the factors, characteristics, and outcomes of caregiver burden specific to the hemodialysis patient population. Thus, there was a need to explore caregiving from a qualitative perspective for those who were providing care to family members with ESKD requiring hemodialysis to understand better the lived experience.

Chapter one encompasses the background, statement, and significance of the problem of caring for family members using hemodialysis as a treatment modality for ESKD. The purpose and nature of the phenomenological study is discussed and the research question is presented in chapter one. The framework informing the study is discussed in chapter one with the conceptual definitions, assumptions, limitations, and delimitations presented.

**Background of the Problem**

More individuals are living at home with chronic illnesses and require family caregiving (Barry, 2010; Cangelosi, 2009; Cantu, 2004). Medical technology was not always available and many individuals who were affected by chronic illness, specifically ESKD, did not survive (Cangelosi, 2009). With advancing technology, a growing number of patients have chosen hemodialysis as a treatment option for ESKD (Tong, Sainsbury, & Craig, 2008). Hemodialysis is not a cure for ESKD but one option for successful long-term management of the chronic disease. This long-term management frequently requires extensive family support and engagement. However, investigators have primarily studied caregivers of patients affected by Alzheimer’s disease and non-specified dementia and less is known about caregiving for patients with other chronic conditions (Montgomery & Kosloski, 2009; Savundranayagam et al., 2011).
The consensus in the literature is that caregiver burden is a multi-dimensional concept requiring the subjective input of the caregiver to comprehend fully the experience of caregiving (Caserta, Lund, & Wright 1996; Honea et al., 2008; Novak & Guest, 1989; Poulshock & Deimling, 1984; Savundranayagam et al., 2011). Poulshock and Deimling (1984) included financial difficulties, caregiver role strain, and feelings of embarrassment and overload in the conceptual definition of caregiver burden. Caserta, Lund, and Wright (1996) used a caregiver burden inventory (CBI), developed by Novak and Guest in 1989, to quantitatively identify dimensions of caregiver burden. Caserta et al. (1996) furthered the work of Novak and Guest (1989) when they evaluated the usefulness of the CBI in the Alzheimer’s and other dementia patient population. Five dimensions of caregiver burden are measured in the CBI and include: a) length of time the care receiver had been dependent upon the caregiver, b) the developmental stage in life of the caregiver, c) physical effects of caregiving, d) social effects of caregiving, and e) emotional effects of caregiving. Time dependence includes restrictions on the caregiver’s time, both daily and over time. These restrictions affect the perception of burden in a caregiver. The study by Caserta et al. (1996) lends credibility to previous work and supports the conceptualization of caregiver burden as a multidimensional construct.

Novak and Guest (1989) describe the developmental stage in the caregiver’s life as having a strong impact on the perception of caregiver burden. This is especially evident in relation to peers who are not caregivers and have time to engage in leisure activities while the caregiver performs caregiving duties and responsibilities. Another dimension is emotional burden, in which the caregiver develops negative feelings for the care receiver that includes anger or resentment (Novak & Guest, 1989).
In another quantitative study assessing the dimensionality of caregiver burden, Honea et al. (2008) separated caregiver burden into subjective and objective dimensions. The authors included physical activities associated with caregiving in the objective dimension and emotional reactions in the subjective dimension. In a dimensional analysis by Savundranayagam, Montgomery, and Kosloski (2011), three categories of caregiver burden are identified and include stress burden, relationship burden, and objective burden. This dimensional analysis by Savundranayagam et al. served as the conceptual framework for the dissertation study and is further explicated in the theoretical framework section of the study.

The caregiver’s characteristics associated with caregiver burden are based on quantitative studies (Johanna Briggs Institute [JBI], 2011; Martinez-Martin et al., 2007; Savundranayagam et al., 2011; Schneider, 2004). The characteristics include lower socio-economic status and female gender. Additionally, caregivers who are younger in age are affected more than older caregivers (JBI, 2011).

Several investigators measured precursors or factors contributing to caregiver burden through quantitative studies (Belasco & Sesso, 2002; Schneider, 2003; Schneider, 2004). The precursors of caregiver burden include caregiver fatigue (Schneider, 2003; Schneider, 2004), caregiver low educational attainment, and caregiver chronic co-morbid conditions (Belasco & Sesso, 2002). Other factors that contribute to caregiver burden, such as the use of home care technology (Silver & Wellman, 2002), caregiver’s lack of engagement in a regular exercise program (Hirano, Suzuki, Kuzuya, Onishi, Ban et al., 2011; King, Baumann, O’Sullivan, Wilcox, & Castro, 2002), and infrequent use of respite care (Huang, Shyu, Chang, Weng, & Lee 2008) have been studied and measured quantitatively in dementia, hemodialysis, and general chronic illness populations.
Wagner (1996) identified that precipitating and contributing conditions to caregiver burden are associated with disruption of the normal lifestyle and life routine. Roles within the family structure can evolve over time and result in a changing family dynamic (Montgomery & Kosloski, 2009). In a dimensional analysis of caregiver burden for caregivers of Alzheimer’s disease and other non-specified dementia, Savundranayagam et al. (2011) and Caserta, Lund, and Wright (1996) identify time on caregiving tasks and problem behaviors of the care receiver as precursors contributing to caregiver burden.

The outcomes of caregiver burden or the caregiver’s response to the challenges of caregiving include emotional stress or anxiety, imposition on the caregiver’s work or social life, and negative changes in the relationship between the family members (Savundranayagam et al., 2011). Schneider (2004) explored fatigue as an outcome of caregiver burden. Poulshock and Deimling (1984) emphasize the importance of exploring a caregiver’s subjective experience because the interpretation of the caregiving experience is different for each caregiver. Measured outcomes included self-reported health status of the caregiver (Belasco & Sesso, 2002), fatigue (Schneider, 2003; Schneider 2004), intent to institutionalize the care receiver (Savundranayagam et al., 2011), and increased mortality of caregivers (Schulz & Beach, 1999). The role of context is essential when considering outcomes of caregiver burden for a caregiver population. Studies with this population indicated that caregivers of family members who use hemodialysis experience burden; however, it is unclear if the experience was the same as those caregivers of family members with other chronic illnesses, such as dementia. Some investigators addressed the caregiver’s perceptions of quality of life while caregiving for their family member (Fan, Sathick, McKitty, & Punzalan, 2008; Ferri & Pruchno, 2009; Wicks, Milstead, Hathaway, & Cetingok, 1997). The unique and varied caregiver perceptions and interpretations of caregiving
support that existed indicate the importance of qualitative exploration of the caregiving experience.

In general, investigators cannot ascertain the entirety of an experience of an individual affected by caregiving for a family member through quantitative measurement (Poulshock & Deimling, 1984). Quantitative measures simply allow the participant to rank elements in a closed format and do not provide the opportunity to express the full range of the human experience. In some quantitative measures, not all elements associated with the experience were present thereby giving a false sense of full explanation of the experience. Qualitative measurement is best used when the nature of the research question is exploratory and in which the investigator uses open ended questions to explore the phenomenon. Additionally, qualitative research is conducted in the field with participants experiencing the phenomenon under study (Giorgi, 2009).

There was a gap in the number of qualitative studies that examine the context and the phenomenon of caregiving in those family members who care for another family member who is dependent upon hemodialysis. A qualitative study using naturalistic inquiry by White, Richter, Koeckeritz, Munch, and Walter (2004) examined family resiliency in families with a member who uses hemodialysis. The study emphasizes how the family’s coping mechanisms assisted in adjustment to the situation when caring for a family member using hemodialysis, and does not focus specifically on the lived experience of the caregiver. The investigators in the study identified the importance of the family members engaging in a positive life view or ‘bonadaptation’ to adapt successfully to the changes in family lifestyle when one member is dependent upon hemodialysis (White, Richter, Koeckeritz, Munch, & Walter, 2004).
Using a qualitative approach, Namiki, Rowe, and Cooke (2009) interviewed patients who were dependent upon home hemodialysis to determine psychosocial adjustment to the changes in their lives. The aim of the study was to understand the daily life changes in patients who have chronic kidney disease and use hemodialysis. Because the patients identified the importance of their caregiving partners and the need for a team approach to providing care for the patients, this study provides a beginning understanding of the caregiving experience.

However, since the focus of the study was the patient, not the caregiver, the results included only the perspectives of the patients themselves and largely ignored the caregivers’ experiences and their perceptions surrounding the experience of caregiving.

In a hermeneutical study, Fex, Flensner, Ek, and Söderhamn (2011) explored the life experiences of family members of patients using advanced technology in the home, which included the use of oxygen therapy, peritoneal dialysis, and ventilators. Out of 11 participants in this qualitative study, only one had a family member who used hemodialysis. Fex et al. (2011) noted the participant’s (the caregiver’s) need to psychologically and physically support the patient, which raised some concerns and required balancing the relationship between the caregiver and family member. While life-giving, the use of technology radically changed the lives of the caregiver and the family member. The study by Fex et al. helps to identify the meaning of the experience for a caregiver who is living with an adult family member dependent on technology for medical problems in the home; however, it did not address the entirety of the caregiver’s lived experience or the perceptions and responses to the experience of caregiving in those who care for a family member dependent upon hemodialysis.

Overall, there was limited qualitative research examining psychosocial aspects of caring for caregivers who provide care for a family member using hemodialysis. This descriptive,
phenomenological study explored the lived experience of caregivers providing care to a family member dependent on hemodialysis as a treatment for ESKD. The investigator of this study focused on the caregivers’ perceptions and descriptions, which assisted in understanding the context and nature of the caregiving experience. This exploration of the lived experience was needed because it was not clear if the experience of caring for a family member dependent on hemodialysis was similar to the experience of caregivers of patients with Alzheimer’s disease or non-specified dementia described in the literature as representative of caregiver burden. While some quantitative studies did exist that identified that caregiver burden occurred when measured with caregiver burden inventories and scales (Savundranayagam et al., 2011; Schneider, 2003; Schneider 2004), it was still not clear what the lived experiences and perceptions were for the caregivers of family members who use hemodialysis.

The focus of this dissertation study was the exploration of the lived experience of caring through a descriptive, phenomenological approach. This study focused on the caregiver’s perspective about the experience of caring for a family member receiving hemodialysis as a treatment for ESKD to understand more fully all aspects of the experience.

**Statement of the Problem**

The problem that the investigator of this research study addressed was that there was an incomplete understanding of the human experience of caring, including the experience of caregiving that is perceived as a burden, for family members using hemodialysis as a treatment for ESKD. Previous qualitative research has primarily included an exploration of caregiver burden in family members of patients with chronic illness, such as Alzheimer’s disease, and limited exploration with family members of care receivers using hemodialysis (Cao et al., 2010; Fex, Flensner, Ek, & Söderhamm, 2010; Lingler, Sherwood, Creighton, Song, & Happ, 2008).
was unclear if family members caring for another family member who uses hemodialysis experienced caregiving in the same manner as those who provided care to family members with other chronic illnesses. In an effort to appreciate and understand the phenomenon, the investigator of this descriptive, phenomenological study sought to explore the lived experiences of caregivers providing care to a family member using hemodialysis.

While the literature is limited regarding caregivers of patients with chronic kidney failure an even greater paucity of literature existed specific to those dependent upon hemodialysis as a treatment for ESKD. Some quantitative exploration of the concept of caregiver burden, fatigue, and quality of life for the caregivers of chronic renal failure and hemodialysis patients is noted in the literature (Belasco & Sesso, 2002; Nguyen, 2009; Schneider, 2003; Schneider, 2004). What these few studies demonstrate is that caregivers could experience burden because of their caregiving duties and those who experienced caregiver burden were more prone to chronic illness, depression, and fatigue (Belasco & Sesso, 2002; Cangelosi, 2009; Nguyen, 2009; Schneider 2003; Schneider, 2004). Previous research in caregivers of patients with asthma, dementia, stroke, and cancer demonstrated that information and support for caregivers improved the caregiver’s quality of life; however, there was not similar research with the hemodialysis patient caregiver population (Tong et al., 2008).

The majority of knowledge about caregiver burden in the study population came from quantitative studies measuring causes of burden and demographics of caregivers through surveys and measures of fatigue and caregiver burden inventories or scales (Belasco & Sesso, 2002; Savundranayagam et al., 2011; Schneider, 2003; Schneider, 2004). Earlier quantitative research studies focus on measuring caregiver’s perceptions of psychosocial needs and changing roles within the family structure (Wagner, 1996) and adjustments in lifestyle (Barry, 2010; White et
al., 2004). As caregivers take on more of the physical responsibilities and emotional care of a family member experiencing kidney disease, role reversal occurs, leading to frustration and loss of role identity in the relationship for the patient and caregiver as the family member becomes increasingly dependent (Montgomery & Kosloski, 2009). Time needed to perform care tasks and problem behaviors of the care receiver, as well as stress levels of the family affected the relationship between the family members (Savundranayagam, et al., 2011). Additionally, uncertainty with the course of the disease, the realization that treatment is life-long, and worry over the patient’s health negatively affected the caregiver’s ability to cope with the chronicity and the trajectory of the condition, which can lead to caregiver burden (Burns et al., 1993; Wagner, 1996). In quantitative studies, using quality of life measures in the renal-specific population, other investigators addressed the caregiver’s perceptions of quality of life while caregiving for their family member (Fan et al., 2008; Ferri & Pruchno, 2009; Wicks et al., 1997).

A noticeable gap in the literature existed with qualitative studies regarding the lived experience of caregivers, including the experience of caregiver burden, of patients using hemodialysis as a treatment for ESKD. Studies more recent than those conducted by Wagner (1995) and White et al. (2004) could not be located in the literature. The factors and outcomes of caring for a family member using hemodialysis are contextually experienced by the individual caregiver. The efforts to offer support interventions and an improved quality of life began with appreciating and understanding the intricacies, successes, challenges, uncertainties, potential stressors, and burden in the experience of caring for a family member who uses hemodialysis.

**Purpose of Study**

The purpose of this descriptive, phenomenological study was to explore the lived experience of caregivers providing care to a family member using hemodialysis. The study
included a series of semi-structured interviews that were audio-recorded and transcribed. The investigator used field notes to aid in data analysis of the interview transcripts. The interviews included questions about the caregiver’s daily routine and care giving activities as well as their perceptions about their experiences and relationship with the care receiver, the impact of caregiving on their work or social life, and their emotional or physical health since providing care.

Recruitment for the study included approaching potential participants from a local hospital medical renal nursing unit in a medium-sized city in the mid-Atlantic region of the United States. The goal was to have a minimum of five participant interviews available for data analysis. The study included additional participants if needed to achieve data saturation. The researcher asked potential participants inclusion criteria questions and identified those caregivers who had the experience of caring for a family member using hemodialysis as a treatment for ESKD.

Six semi-structured interviews, which lasted approximately 90 minutes, were conducted and audio-taped with volunteer family members who met study inclusion criteria and who experienced the phenomena of caring for family members using hemodialysis as a treatment for ESKD. The study included using QSR NViVO® software to assist in organization of data of transcribed interviews. Analysis included the identification of pattern and themes that described the experience of caregiving for a family member using hemodialysis as a treatment for ESKD. Field notes enhanced analysis of interview transcripts.

**Significance of the Problem**

Chronic kidney failure and subsequent hemodialysis treatments can introduce uncertainty and unpredictability in the lives of patients and their caregivers (Belasco, Barbosa, Bettencourt,
Diccini, & Sesso, 2006; Molzahn, Bruce, & Sheilds, 2008). Quantitative research has measured precursors, characteristics, and outcomes of caregiving, including caregiver burden and much of the literature has been focused on caregiver burden in caregivers of patients with Alzheimer’s disease and non-specified dementia (Cangelosi, 2009). It was unclear if the essence of the experiences of caregivers in the dementia patient population was the same as the experiences of the population of caregivers for hemodialysis patients. A phenomenological approach was needed to explore and understand the experience of caregiving for caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD.

This study made an original contribution and added to the body of knowledge regarding the caregiving experience for family members using hemodialysis as a treatment for ESKD. From this research, interventional actions and support mechanisms to improve the quality of life for the caregiver can be implemented now that the experience of providing care to family members dependent upon hemodialysis is better understood and appreciated.

**Nature of the Study**

The qualitative research method is used to discern process, meaning, and value for an individual using their life experiences (Bogdan & Biklen, 2007). Researchers using the qualitative method seek to draw out individuals’ perceptions of their life experiences within the context of their lives to identify and assign meaning and value to the experience (Bogdan & Biklen, 2007; J. Walton, personal communication, August 20, 2011). The role of context in the human world cannot be understated (Giorgi, 2009).

Exploring phenomena using qualitative methods leads to understanding at a deeper level allowing life experiences to be the focus of the study (Bogdan & Biklen, 2007; Fawcett & Garity, 2009; Shank, 2006). A phenomenological approach aims to study everyday experiences
from the point of view of the individual without evaluation or judgment (Schwandt, 2001). For researchers to examine what life is like for these caregivers, the caregivers must be allowed to share stories of the experience.

This study used a descriptive phenomenological approach to examine the lived experience of caregivers who provide care for a family member receiving hemodialysis as a treatment for ESKD. The Giorgi (2009) method of descriptive phenomenology was used for this study. Giorgi (2009) developed his approach to phenomenology by combining the three traditions of phenomenological philosophy, science, and psychology. Knowledge of a phenomenon is the goal of qualitative research and, according to Giorgi (2009), using a combined approach offers a way to examine phenomena using scientific principles of sound research. The researcher chose the Giorgi (2009) method because of the straightforward nature of the data analysis process.

The aim of this study was for caregivers to describe their experiences and share the meanings of those experiences. Other qualitative approaches, for example case study and grounded theory were considered for this study; however, they were not chosen. Grounded theory and case studies did not allow an investigator to explore the lived experience of a phenomenon. A quantitative approach was not chosen for this study because although different aspects of caring have been measured and quantified; there remained an incomplete understanding of the lived experience of caring for a family member using hemodialysis as a treatment for ESKD.

**Research Questions**

This study allowed caregivers to share their daily lives and experiences. Using a phenomenological approach, this study enhanced current literature by providing experiential
knowledge of caregivers who care for a family member using hemodialysis as a treatment for ESKD. For this qualitative study the overall research question was: What is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD? Two sub-questions for this study are:

R – 1: What are the perceptions that caregivers have about the experience of providing care for family members dependent upon hemodialysis as a treatment for ESKD?

R – 2: What is the meaning that caregivers give to the experience of caregiving for family members dependent upon hemodialysis as a treatment for ESKD?

**Theoretical Framework**

**Phenomenological Orientation**

Qualitative research uses an inductive approach to enhance the understanding and increase the knowledge base of a discipline (Mitchell & Cody, 1993). In general, qualitative approaches to discovery are used to generate knowledge in absence of a theoretical foundation, rather than justify a pre-existing theory, which could jeopardize the investigation through preconceived notions of the phenomenon under study (Mitchell & Cody, 1993). Alternately, some scholars argue that all research is theory-driven, thereby constituting a dichotomy regarding the place of theory in qualitative research (Mitchell & Cody, 1993). Some studies may contain both inductive and deductive approaches (Mitchell & Cody, 1993). Mixed-methods research is an example where the investigator uses both approaches to explore a phenomena or a clinical issue.

Husserl supports the notion that a qualitative investigator can create a complete divergence of self from pre-existing constructs or ideas regarding a phenomenon under study (Mitchell & Cody, 1993). This divergence of self from previous scholarly thought (theory) is
termed *epoche* or bracketing. Bracketing is intended to free the mind of the investigator to be completely open to examining the phenomenon under study using an inductive approach, with fresh eyes.

Giorgi, who expanded on the work of Husserl, contends that there must be some theoretical framework to give perspective to the phenomenon under study and it is virtually impossible for the investigator to completely disengage thoughts from preconceived notions when conducting research (Mitchell & Cody, 1993). Therefore, Giorgi suggests that a qualitative investigator make his or her preconceptions known before embarking on the study and setting them aside (bracketing) during the study (Giorgi, 2009; Mitchell & Cody, 1993).

A philosophical orientation for this study included what Giorgi (2009) identified as curiosity around the human condition, which he described as universal. Phenomena are multidimensional experiences surrounding the human condition and phenomenologists study life experiences through the contextual lens of the individual (Giorgi, 2009; Wertz, 2008). Caregiving is an example of a multidimensional experience (phenomenon) that affects many people; however, differences in the lived experience can be seen within the context of the individual’s situation (Giorgi, 2009).

Humans construct meaning and understanding from perceptions of personal realities. The investigator begins the process of understanding and appreciating the individual’s situation with the naïve, which most often starts before theorizing according to some scholars (Giorgi, 2009; Wertz, 2008). From this perspective, making sense of a phenomena or phenomenon affecting humans does not necessarily follow a logical model of deduction, rather the use of an inductive inquiry helps the investigator to appreciate and understand how a phenomenon affects individuals within a particular situation, in this case the caregivers of family members’
dependent upon hemodialysis (Giorgi, 2009). However, Giorgi (2009) also distinguishes phenomenology as philosophy with phenomenology as a guide to scientific inquiry, which can lead to discipline specific knowledge. This distinction suggests that different disciplines have specific phenomena of central concern with some prior understanding. He further states that a theoretical perspective is necessary for discipline-specific discovery and science. Thus, this study used a phenomenological inquiry approach, which is inductive; however, a structural model depicting the concept of caregiver burden was presented, as to give a beginning understanding to the concept that was then bracketed as what was referred to as an external pre-supposition or clinical theory prior to interviewing participants (Gearing, 2004).

**Introduction: A Caregiving Model**

Caregiver burden from a theoretical perspective is often described as a multidimensional response to a negative appraisal of caring for another (Caserta et al., 1996; Nguyen, 2009; Savundranayagam et al., 2011). The development of theory around the concept of caregiver burden primarily focuses on stress responses of the informal family caregiver to specific factors. Stress inducing factors include a lack of caregiver knowledge about caregiving tasks or home care technology, lack of financial resources or other support systems, and the time associated with caregiving activities (Burns et al., 1993; Savundranayagam et al., 2011). Additionally, the caregiver may not have chosen or planned to assume the caregiver role as in many cases the care receiver experiences an unplanned illness event (Raina et al., 2004). Finally, the informal caregiver does not have the rights or privileges that formal care providers have such as payment for services rendered or days off from caregiving responsibilities (Raina et al., 2004).

Because informal caregiving is not a career choice formally recognized by society, caregivers may feel trapped by the role responsibilities and lack of rights and privileges (Raina et
al., 2004). The informal caregiver’s responses to stress inducing factors related to caregiving include caregiver fatigue (Schneider, 2003; Schneider 2004) and declining health status (Hirano et al., 2011; King et al., 2002). Specifically, caregiving is associated with increased mortality rates among informal caregivers who experience burden related to caregiving activities and responsibilities (Schulz & Beach, 1999).

**External Pre-Supposition: Structural Model: Predictors and Outcomes of Burden**

The framework that informed this dissertation study is the model by Savundranayagam et al. (2011) entitled *Structural Model: Predictors and Outcomes of Burden*. The model provided a beginning appreciation of caregiver burden and identified connections between essential concepts. The model is based on the experiences of patients with Alzheimer’s disease and their caregivers and incorporates existing research on predictors of caregiver burden and outcomes of caregiving burden (M. Savundranayagam, personal communication, February, 14, 2013). The model was chosen for this study because it provides a multidimensional perspective on the nature of informal family caregiving and some initial information about the experience of caregiver burden. However, the goal of this study was to provide a complete description from caregivers through their personal stories and experiences of the phenomenon of providing care to a different population, which included their perceptions and feelings. While the model provided some understanding, phenomenological exploration using an inductive approach was focused on the lived experience (Giorgi, 2009). While conducting the study, the investigator bracketed the model (set aside pre-suppositions) and examined the participant’s experience a fresh. The investigator then considered what was learned with what was already known about caregiving burden.
While the basis of the model came from research with caregivers for patients with Alzheimer’s disease, the model still encompasses elements essential to the experiences of other patient and caregiver populations, including caregivers of family members using hemodialysis as a treatment for ESKD. The elements include the interpersonal relationships that occur between the care receiver and caregiver and potential caregiver anxiety regarding the caregiving responsibilities (Savundranayagam et al., 2011). However, because caregiver groups are not homogeneous, Savundranayagam et al. stress the importance of exploring caregiver burden in different populations to examine relationships between predictors and outcomes of caregiver burden that are potentially related to ethnicity, socioeconomic status, and the care receiver’s medical diagnosis. The intent of this study was to examine the differences in the contextual experience of the phenomenon of caregiving for a specific population through an inductive approach.

Savundranayagam et al. (2011) developed the *Structural Model: Predictors and Outcomes of Burden* using a quantitative study of 280 spouse and partner dyads and 243 adult child caregivers of patients with Alzheimer’s’ disease and non-specified dementia. Study participants were volunteers from a caregiver registry in the Midwest. The respondents completed questionnaires that included information regarding demographics, care receiver’s functional status, and problem behaviors of the care receiver. Additionally, information was obtained regarding the caregiver’s health status, type of care provided to the care receiver, level of perceived burden, and intent to place the care receiver in a skilled nursing facility. Caregiver respondents rated the extent to which their lives had changed as a result of caregiving on a five-point Likert scale. Savundranayagam assessed the dimensions of caregiver burden and relationship between factors contributing to burden and caregiver outcomes and through this
analysis created the model that provides an explanation for caregiver burden. With the author’s permission, a graphic depiction in Figure 1 shows the *Structural Model: Predictors and Outcomes of Burden* by Savundranayagam et al. (2011) (Refer to Appendix A and B for the Letters of Permission from the Author to use the Model and the Letter of Copyright Permission from the Publisher).

Development of the *Structural Model: Predictors and Outcomes of Burden* is predicated on several assumptions and beliefs. One assumption is that the caregiver-care receiver dyads share an interpersonal relationship prior to the event requiring the change to the caregiver-care receiver relationship. A second assumption stated by Savundranayagam et al. (2011) is that the activities of caring for another person negatively affect other aspects of the life of a caregiver. An example of the second assumption is that caregiving may require an employment change or interfere with social activities or other interpersonal relationships. The third assumption is that emotional stress often accompanies caregiving responsibilities.

These assumptions reflect the current literature regarding patients using hemodialysis as a treatment for ESKD and their caregivers as well (Moulton, 2008; Schneider, 2003; Schneider, 2004; White, Richter, Koeckeritz, Munch et al., 2004). Specifically, Moulton (2008) addresses social isolation of care receivers and caregivers. The second assumption in the model addresses the negative effects of caregiving on the lifestyle of the caregiver. Social isolation can be the result of loss of leisure time because of caregiving responsibilities affecting lifestyle or changes in non-familial interpersonal relationships. This assumption occurs in context of the individual’s situation and incorporates the concepts of mutuality and preparedness in the lived experience.

An assumption in the model is that the caregiver and care-receiver dyads had a pre-existing relationship prior to the event that required the change to a caregiver relationship. Other
studies have focused on family relationships to explore caregiving and coping. White, Richter, Koeckeritz, Munch et al. (2004) explored family resiliency in a qualitative study. White et al. described the power of positive relationships and family integrity as essential to the development of positive coping mechanisms under adverse conditions such as chronic kidney failure. Exploration of family relationships is integral to a complete understanding of the phenomenon of caregiver burden.

Figure 1 Structural Model: Predictors and Outcomes of Burden

**Model Components**

In the current model, factors or variables contributing to caregiver burden are *hours on care tasks* and *problem behaviors*. *Hours on care tasks* is a universal concept within the phenomenon of caregiving. Hours on care tasks directly relates to the time a caregiver devotes to the duties of caregiving and the effects on a caregiver’s lifestyle or ability to work outside the home. The activities associated with *hours on care tasks* in the Alzheimer’s disease patient population may not reflect the same activities that caregivers provide in a different patient...
population (Savundranayagam et al., 2011). As an example, family members using hemodialysis as a treatment for ESKD may need more assistance with instrumental activities of daily living (IADL) such as meal preparation or medication management rather than dressing or bathing. Thus, it was important to identify the differences in the phenomenon of being a caregiver for a family member dependent upon hemodialysis to provide a complete description and understanding of the experience.

Problem behaviors are more specific to the population identified in the model. Problem behaviors may not be part of the lived experience of caregiving for a family member who uses hemodialysis. Problem behaviors identified in the model include behaviors such as wandering, irritability, and suspiciousness, which can interfere with the completion of activities of daily living (ADL) (Savundranayagam et al., 2011).

Savundranayagam et al. (2011) identified three dimensions of caregiver burden. The dimensions are stress burden, objective burden, and relationship burden. While these dimensions are identified as common to the caregiving experience, the unique lived experience of caregivers in differing situations needed to be explored. Stress burden in the current model addresses the perceived emotional effects of caregiving on the caregiver. Worry, anxiety, and feelings of hopelessness are included in the dimension of stress burden. In the hemodialysis caregiver population, stress burden reflects caregiver’s worry and anxiety about the care receiver’s well-being and overall health status (White et al., 2004).

Objective burden in the model reflects changes in the lifestyle and other relationships of the caregiver. Changes in social routines and ability to participate in recreational activities and relaxation comprise objective burden. Family members using hemodialysis as a treatment for
ESKD and their caregivers experience changes in lifestyle and daily routines when incorporating the hemodialysis treatments in their lives (White et al., 2004).

Relationship burden reveals the relationship between the caregiver and family member with a focus on family member behaviors (manipulative or demanding) that strain the relationship between the individuals. Encouraging compliance with medication regimens or dietary restrictions with an uncooperative care receiver changed the way a caregiver behaves toward the care receiver. For example, White et al. (2004) reported that one spousal caregiver whose husband was treated with hemodialysis as a treatment for ESKD described feeling like “the warden” (p. 368) when addressing her husband’s dietary restrictions.

In the model Savundranayagam et al. (2011) demonstrates a strong relationship between problem behaviors and stress, objective, and relationship burden affecting the outcomes of the model (caregiver’s self-rated health and intent to place the care recipient in a skilled nursing care facility). Hours on care tasks clearly links with objective burden in the Savundranayagam et al. study; however, as the patient population under study changes, the duties associated with hours on care tasks is expected to change.

The outcomes depicted in the model are caregiver self-reported health status and intent to place the care receiver in a skilled nursing care facility. Intent to place a care receiver in a skilled nursing facility is not documented in the caregiver literature for users of hemodialysis as a treatment for ESKD and it is not clear whether this was part of the caregiver burden experience for these caregivers. It is not known if microvascular changes in brain circulation of the patient leading to changes in behavior or cognition while the patient is on hemodialysis results in significant behavioral problems that lead a caregiver to place the family member in a skilled nursing care facility (Lewis, Dirksen, Heitkemper, Bucher, & Camera, 2011).
Declining caregiver health status during caregiving activities is well documented in the hemodialysis caregiver literature (Belasco & Sesso, 2002; Nguyen, 2009; Schneider, 2003; Schneider, 2004). In elderly spousal caregivers, increased physical or emotional strain of caregiving is identified as an independent risk factor for mortality (Schulz & Beach, 1999). Thus, exploring the nature of caring for family members using hemodialysis as a treatment for ESKD and episodes of declining caregiver health represented an essential part of this experience.

According to the model, the levels of perceived stress burden and relationship burden were significantly predictive of the outcomes of caregiver self-rated health and intent to place the care receiver in a skilled nursing care facility. Objective burden (lifestyle changes) is hypothesized by Savundranayagam et al. (2011) to correlate with the outcomes; however, objective burden did not show the predicted correlation with the outcomes of self-rated health status or intent to place the care receiver in a skilled nursing care facility. It was unclear if the concepts described in the model were reflective of the lived experience of caregivers of family members dependent upon hemodialysis. Exploration of the perceptions and lived experience of caregivers in this situation was essential.

Application of Model to a New Population

A question still existed regarding the transferability of the model to the hemodialysis caregiver population. During model development, Savundranayagam et al. (2011) examined caregivers of patients with Alzheimer’s disease and non-specified dementia. It was unclear if the experience of caregiving for family members with Alzheimer’s disease and dementia represented the essence of the experience for caregivers of other patient populations such as hemodialysis patients. Additionally, the experience of caregivers identified in the model regarding hours on care tasks is reflective of physical assistance the caregiver needed to provide to help the care
receiver with ADL (bathing, dressing, toileting, etc.). The specified activities are central to the caregiving experience for those using hemodialysis as a treatment for ESKD not necessarily because of the hemodialysis but because these care receivers often have co-morbid conditions that render them unable to complete self-care activities.

The caregiver burden related to hours on care tasks may be represented in the hemodialysis experience as the required monitoring of the care receiver for potential complications such as fluid overload, physical effects of toxin build-up, or issues with the arterial-venous access device (Moulton, 2008). It was possible that the experience of giving care to family members dependent upon hemodialysis as a treatment for ESKD includes hours of care or physical assistance when the care recipient experiences acute illness, after a difficult hemodialysis treatment, or an overall decline in their functional abilities. However, it was not clear if this aspect of caregiver burden from the model fit with the nature of the experiences for caregivers of family members using hemodialysis as a treatment for ESKD.

Problem behaviors, such as wandering, may not be applicable to the population of patients using hemodialysis as a treatment for ESKD. More information was needed to ascertain if this was an issue for some care receivers who suffer from Alzheimer’s disease or non-specific dementia as well as chronic kidney failure. Instrumental activities of daily living such as managing dietary restrictions, the use of home technology, medication management, financial concerns and impact of dialysis treatments, and transportation to and from a dialysis center are experiences that were more appropriate to examine in caregivers of family members using hemodialysis as a treatment for ESKD (Moulton, 2008). These experiences are not addressed in the structural model by Savundranayagam et al. (2011).
The experiences of an individual are important when attempting to understand a phenomenon (Giorgi, 2009). Savundranayagam et al. (2011) encouraged investigators to use the model as a guide to explore the model’s usefulness in other populations. This study focused on the lived experience of caregivers of family members who are dependent upon hemodialysis. The intent in examining the model by Savundranayagam et al. was to identify what was known and was not known about the experience of caregiving and caregiver burden and then to bracket the information (set it aside) until the experience was understood from the participant’s perspective. The model is factual and based on quantitative measures using caregivers of patients with Alzheimer’s disease and other non-specified dementia. In conducting phenomenology, the investigator continually examined biases and presuppositions’, suspending them so as to be open with what was shared by the participants (Giorgi, 2009; Mitchell & Cody, 1993). The theory was then used to assist with placing what was learned in context with the literature. In this study, the phenomenological approach offered an enriched understanding of the phenomenon of caregiving through personal storytelling.

**Methodology**

The qualitative paradigm is founded on the premise that global measurements and close-ended scales do not entirely capture the individual experiences of the caregivers. Furthermore, lived experiences are uniquely different for everyone and the phenomenological approach is essential for nurses to develop an understanding of the caregiving experience that allows the design of an individualized plan of care for the caregiver. The usefulness of caregiver storytelling that leads to understanding by nurses cannot be underestimated. More understanding was needed regarding potential outcomes of the experience of caring for a family member who is
dependent upon hemodialysis other than intent to place the care receiver in a skilled nursing facility.

A phenomenological approach allowed caregivers to more fully describe the caregiving experience when caring for a family member who dependent upon hemodialysis as a treatment for ESKD. An in-depth exploration of lifestyle alterations and changes inherent in the hemodialysis care receiver-caregiver relationship grants nurses, nurse practitioners, physicians, social workers, and case managers the opportunity to more fully understand and appreciate the life experiences of a caregiver in this study population (Molzahn et al., 2008). The dissertation study added to the understanding of the experience of caregiving for a family member dependent upon hemodialysis as a treatment for ESKD by using a qualitative approach and addressing experiences not explored or as well developed in the model.

**Definition of Terms**

The following conceptual definitions were used in the study:

- *Family member, patient, and care receiver* refers to the individual who is being cared for and who is using hemodialysis as a treatment for ESKD as a treatment for chronic kidney failure (Lewis et al., 2011).

- *Chronic kidney failure* is the condition wherein the kidneys are damaged over time due to chronic illness (for example, Diabetes Mellitus) or exposure to toxic substances. The kidneys cannot properly filter the blood to prevent toxin buildup in the bloodstream or produce waste. Often the trajectory of chronic kidney failure is ESKD (Lewis et al., 2011).

- *End stage kidney disease (ESKD)*, as determined by a physician through evaluation of laboratory values, is when the kidneys have completely stopped
working and the patient will need to go on dialysis (either peritoneal or hemodialysis) or opt for no treatment (Lewis et al., 2011).

- **Hemodialysis** as a treatment for ESKD typically involves the patient travelling to an ambulatory center several times a week for blood cleaning treatments. Some patients choose to perform hemodialysis at home (Gayomali, Sutherland, & Finkelstein, 2008). During the process of hemodialysis, the patient has two needles attached to tubing placed in a catheter, graft, or fistula located in an arm or leg. Blood is removed from the patient via one needle, filtered through an artificial kidney attached to a computerized machine programmed specifically to meet the patients’ needs for treatment, and returned to the patient via the second needle. This process can take up to five hours three times a week.

- **Caregiver** refers to the family member who has a previously established relationship with the patient. The caregiver is most closely involved and engaged in a variety of activities with and for the patient using hemodialysis either at home or in an ambulatory center (Belasco & Sesso, 2002). Caregivers do not necessarily have formal medical training although they often help manage the dietary and medication regimens required by the patient who has the illness (Gayomali et al., 2008).

- **Caregiver burden** refers to the response to caregiving and is often associated with overwhelming emotions, anxiety, and sense of responsibility felt by caregivers in which a pre-existing interpersonal relationship exists between the caregiver and care receiver. Oftentimes, the patient or care receiver displays problem behaviors and the caregiver engages in activities to support the care receiver.
Caregiver burden is a negative response to the caregiving experience and is characterized by emotional stress, anxiety, and feelings of being overwhelmed, physical fatigue, negative changes in the interpersonal relationship between the caregiver and care receiver, and imposition on the caregiver’s work or social life (Cangelosi, 2009; Nguyen, 2009; Savundranayagam et al., 2011).

- **Stress burden** refers to the perceived effects of caregiving on the caregiver. These effects are characterized by changes in the caregiver’s affect and mood including increased anxiety, emotional stress, and worry (Savundranayagam et al., 2011).

- **Relationship burden** includes changes in the interpersonal relationship between the caregiver and care receiver. The changes can include manipulative behavior by the care receiver (Savundranayagam et al., 2011).

- **Objective burden** refers to observable changes in the caregiver’s lifestyle, including work and social life. Changes can also include modifications in the caregiver’s daily routines (Savundranayagam et al., 2011).

- **Quality of life** refers to self-identified level of satisfaction with personal living conditions (Schneider, 2004).

- **Lifestyle changes** in the lives of a hemodialysis patient and his or her caregiver refer to changes in employment, physical environment, social support, financial status, medication management and special dietary regimen (Moulton, 2008). Frequent physician visits are included in these changes.
Assumptions

An assumption is a principle that is believed to be true without the benefit of proof or verification (Polit & Beck, 2008; Simon, 2010). The nature of a phenomenological study is to explore the lived experiences of participants. A critical assumption of phenomenology is that language reflects the thoughts and perceptions of the participants (Giorgi, 2009). Exploring perceptions and experiences was essential in understanding the life of a caregiver who is caring for a family member using hemodialysis as a treatment to manage ESKD.

An assumption in this study was that the volunteer participants would be thoughtful and truthful in their responses to interview questions thereby introducing authenticity through sharing of perceptions and experiences in the study. Confidentiality was maintained through careful anonymizing of participant responses and further contributed to authenticity in the study. The investigator of this dissertation study sought to understand the phenomenon of caring for family members using hemodialysis as a treatment to manage ESKD. Participants were selected according to experience with the phenomenon, their ability to identify the lived experiences as caregivers of hemodialysis. The appropriate method used to accomplish this experiential study was a qualitative descriptive phenomenological approach. In descriptive phenomenology, bracketing occurs because the participants interpret their own experiences (Hein & Austin, 2001) therefore, objectivity of the investigator can be strengthened through the use of bracketing. Bracketing (also termed epoché), involves the focused and deliberate acknowledgment of investigator bias and preconceived notions regarding the phenomenon (Giorgi, 2009).

Limitations

Limitations are potential weaknesses or caveats in a study that may be out of the control of the investigator (Locke, Spirduso, & Silverman, 2007). As this was a phenomenological study
exploring lived experiences of caregivers caring for family members using hemodialysis as a treatment to manage ESKD, the investigator relied on self-reporting via interviews as the data source. Limitations included the presupposition that participants were willing to answer the questions and told the truth about their experiences. This study provided a snapshot of caregivers’ experiences and feelings, which could have been different in the past or might be different in the future.

**Delimitations**

Delimitations are the boundaries of a study set up by the investigator (Simon, 2010). In this study, the researcher recruited adult caregivers of patients dependent upon hemodialysis as a treatment to manage ESKD within a specific geographic area. In this study the purposive sample was delimited to non-paid familial caregivers of patients using hemodialysis as a treatment to manage ESKD in a location readily accessible to the investigator, a mid-sized city on the mid-Atlantic coast of the United States. The familial caregivers were adults over 21 years of age. The familial caregivers were able to effectively communicate in the English language, verbally and in writing.

The philosophical or theoretical framework was based on Savundranayagam et al. (2011) *Structural Model: Factors and Outcomes of Burden*. Using the framework, the investigator explored the answer to the phenomenological question, what is the lived experience for caregivers who provide care to a family member using hemodialysis as a treatment for ESKD? The framework was a starting point to inform the study. The study results stemmed from the articulated experiences of the participants.
Summary

As more people develop chronic kidney failure and choose hemodialysis as a method of treatment, family members are called upon to provide essential care giving duties (Barry, 2010; Belasco & Sesso, 2002; Cangelosi, 2009). The lives of these familial caregivers are affected by medical treatments that create lifestyle changes and interrupt the established flow of life. These changes can result in emotional and physical distress for the caregiver and is often referred to as caregiver burden in the literature (Schneider, 2003; Schneider, 2004; Nguyen, 2009). However, less was known about the actual experience of caregiving for a family member dependent on hemodialysis to manage ESKD. This section introduced the problem and origin of caregiver burden and explained the importance of further exploration of the lived experience of familial caregivers.

The Savundranayagam et al. (2011) *Structural Model: Factors and Outcomes of Burden* was introduced as an informational framework model for the study. Chapter two provides an overview of the search process for literature on caregiver burden, presents the historical basis for research on this topic, and presents quantitative and qualitative studies related to caregiver burden in general and in the hemodialysis population.
Chapter 2

Review of the Literature

In chapter two, the investigator provides an introduction to the literature review, a description of the literature search process, a historical overview of the caregiving burden literature, and a review of existing qualitative and quantitative research regarding caregiver burden in general and as related to the caregivers of patients who use hemodialysis as a treatment for managing ESKD. In chapter one, the investigator expounded on the increasing incidence of patients choosing hemodialysis as a treatment option for managing ESKD. Dialysis treatments and required changes in lifestyle, diet, and medications affects the lives of a hemodialysis patient and the caregiver, interrupting the established flow of daily life.

The problem of being a caregiver and possibly experiencing caregiver burden when caring for another family member dependent upon hemodialysis as a treatment for ESKD was introduced in chapter one. Caregivers must commit to the changes in lifestyle that hemodialysis treatments require and the increase in responsibilities. The additional responsibilities and changes in lifestyle may result in feelings of being burdened with the added responsibilities of caring for a family member using hemodialysis.

Having a family member dependent upon hemodialysis as a treatment for managing ESKD can result in the experience of being burdened with subsequent emotional and physical distress for the caregiver who is responsible for daily activities surrounding the treatment. This is referred to as caregiver burden in the literature (Schneider, 2003; Schneider, 2004; Nguyen, 2009). The investigator presented The Structural Model: Predictors and Outcomes of Burden as an informing framework for this study (Savundranayagam et al., 2011).
During the literature review process, the investigator identified many studies that measured factors and outcomes of the experience of caregiver burden while providing care for a family member. The investigator identified a gap in the literature regarding studies in which participants specifically described the lived experience of providing care for family members dependent upon hemodialysis as a treatment for managing ESKD. The gap is that there are no descriptive phenomenological studies examining the lived experience of caregivers providing care for family members dependent upon hemodialysis. The investigator suggested that this gap assisted in establishing the need for the descriptive phenomenological dissertation study.

**Search Process**

The investigator conducted a literature search for specific studies on the topic of caregiver burden in patients who use hemodialysis. The investigator conducted a search of the literature on the following databases: PUBMED, Web of Knowledge and Web of Science integrated search software. The investigator performed a literature search on other data bases such as Google Scholar and CINAHL, which showed the same results as previously located on PUBMED and Web of Knowledge. The inclusion criteria for articles in this literature review included:

- quantitative and qualitative studies that were published in peer-review journals
- written in the English language
- focused on aspects of caregiver burden for family members using hemodialysis or the effects of caregiving for hemodialysis patients on the family
- focused on caregivers of patients who receive hemodialysis in differing settings

The investigator found several studies from investigators located in Europe and Asia that were written in English and published in peer-review journals and included these in the literature
review. Interventional studies were excluded from the literature review. The literature review revealed many resources on caregiver burden; however, only 17 studies were chosen for the literature review in this dissertation.

The 17 studies selected for review represented the core categories for the specific area of focus for this study, the caregivers of family members who use hemodialysis. When examined more thoroughly, many studies that were located in the original search were not specific to burden in caregiving for hemodialysis patients or were repeated quantitative studies. Also not chosen were additional studies that examined interventions to decrease burden. Some studies located in the literature search did not meet the inclusion criteria, for example they were not published in scholarly journals or were not written in the English language. Although they were located under the keywords caregiver burden, many studies addressed caregiver strain or caregiver stress instead of burden in caregiving and, therefore, were not used in the literature review. The term caregiver burden was chosen because the investigator determined that caregiver stress and caregiver strain were encompassed in the concept of burden.

The investigator performed a literature search using the following key words and various combinations of the keywords: nurses, nursing, qualitative research, quantitative research, phenomenology, psychosocial needs, caregiver, care giving, caregiver burden, hemodialysis, caregiver burden and hemodialysis, home hemodialysis and qualitative research, technology, and culture and care giving (Table 1 shows the search process and keywords used with numbers of articles located).
Table 1 Search Process and Key Words

<table>
<thead>
<tr>
<th>Search Engine</th>
<th>Keywords</th>
<th>Numbers of Articles Located</th>
</tr>
</thead>
<tbody>
<tr>
<td>PUBMED</td>
<td>Caregiver Burden in General, including caregiver strain and caregiver stress (including books, non-peer reviewed articles, interventional studies)</td>
<td>4147</td>
</tr>
<tr>
<td>PUBMED</td>
<td>Caregiver Burden, Stress, or Strain and Nursing (including books, theory papers and conceptual models, non-peer reviewed articles)</td>
<td>1479</td>
</tr>
<tr>
<td>Web of Science</td>
<td>Caregiver Burden, Stress, Strain and Nursing (including books, interventional studies)</td>
<td>791</td>
</tr>
</tbody>
</table>

The investigator instituted a keyword search for *caregiver burden*, which revealed over four thousand results in PUBMED. The investigator discovered that over 200 articles have been published in English and in peer-review journals on *caregiver burden* each year since 2004. In 2012, there were over 500 articles published on *caregiver burden*.

The increase in publication on this topic shows an increased awareness of the issue of lay caregivers’ experiencing burden when caring for family members and the importance of exploring the phenomenon. Prior to 2004 there were as many as 191 articles published annually and as few as one article published in 1985. A keyword search for *caregiver burden and nursing* revealed 1479 results. In PUBMED, the keywords *caregiver burden and hemodialysis* revealed the majority of articles cited were quantitative studies. The combination of *caregiver burden, nursing, and hemodialysis* showed nine quantitative studies in PUBMED.
The Web of Science is a citation index or citation database that identifies how many times an article or study was cited and by whom it was cited (K. Hierholzer, personal communication, March 13, 2013). The oldest reference to caregiver burden as a phrase or topic heading is noted in 1990 in the Web of Science (Pruchino, Michaels, & Potashnik, 1990). The search terms caregiver burden and nursing in all years, in all databases for the search revealed 791 results. Narrowing the results down to specific research areas within nursing revealed 31% of the 791 articles discussed general nursing themes and none of these were focused on hemodialysis treatments. Searching with the terms caregiver burden, nursing research, and dialysis revealed one article dated in 2004, while searching with the terms caregiver burden, nursing, and dialysis revealed six quantitative articles.

In the quantitative literature, a systematic review by Tong, Sainsbury, and Craig (2008) explored interventions for caregivers of patients with chronic kidney disease. Schneider (2003; 2004) measured the construct of fatigue as a factor and result of burden in caregiving. Several investigators explored burden in caregiving by using the Caregiver Burden Inventory or Caregiver Burden Scales (Akinci & Pinar, 2012; Belasco, Barbosa et al., 2006; Caserta et al., 1996; White Richter, Koeckeritz, Lee & Munch, 2002; Wicks et al., 1997). These studies were used in the literature review.
There was support for exploration of caregiver burden using qualitative methods (Bastawrous, 2013; Poulshock & Deimling, 2004). The investigator found several qualitative studies examining various aspects of patients who use home hemodialysis technology (Fex et al., 2011; Namiki et al., 2009; Wise, Shatell, Klicko, Burdan, & Showers, 2010). One qualitative study article discovered addressed the differences in the relationship between caregivers and
patients who use home hemodialysis as compared to the same dyads with the patient using in-center hemodialysis (Wise et al., 2010). These studies were used in the literature review.

Tong, Palmer et al. (2013) conducted a qualitative interview study with patients who used in-center hemodialysis and their caregivers, which explored the beliefs and expectations associated with the possibility of using home hemodialysis instead of in-center hemodialysis. Fex et al., (2011) explored family life with a member who uses advanced technology in the home. White, Richter, Koeckeritz, Munch et al. (2004) explored resiliency in families where one member uses hemodialysis. These studies were used in the literature review.

**Historical Overview**

Florence Nightingale, a champion of proper nursing care for soldiers during the Crimean War, is widely considered the mother of modern nursing. Nightingale’s research on caring focused on nutrition, proper air ventilation, and nutrition for soldiers (Nightingale, 1969). Nightingale recognized that, “Every woman…has at one time or another…charge of the personal health of somebody” (Nightingale, 1969, preface). Nightingale’s comments were made based on the historical context of family members caring for one another in times of illness and crises.

During the 1960s, changes in the family structure, along with the increased geographic mobility of family members, and increased presence of women in the workforce resulted in a change in the patterns of informal caregiving by family members for each other (Scharlach, 2008). The challenges did not preclude family members from providing care for one another; however, the manner in which they provided care changed (Scharlach, 2008). Scholars and clinicians recognized the construct of a caregiver’s experience of burden in response to the increased stresses on informal family caregivers, acknowledging the challenges inherent in the changes in the family structure and family dynamic (Scharlach, 2008).
Resulting from the focus on a caregiver’s experience of being burdened and stresses inherent with informal family caregiving, investigators developed an increased interest in research and formation of self-help support systems (including books and support groups) to decrease the experience of being burdened associated with caregiving activities (Scharlach, 2008). In subsequent years, investigators conducted a variety of studies on caregiving.

The recent literature on caregiving included theory development (Montgomery & Kosloski, 2009; Tsai, 2003) and a focus on managing technology in the home (Silver & Wellman, 2002). Other investigators have focused on the measurement of caregiver burden when caring for family members who have different chronic illness conditions or diseases such as coronary bypass surgery, cancer, and dementia (Halm, Treat-Jacobson, Lindquist, & Savik, 2007; Honea et al., 2008; Kim, Chang, Rose, & Kim, 2011).

Some investigators have performed quantitative measurements of factors or outcomes of burden such as measuring fatigue (Schneider, 2003; Schneider 2004) and measured caregiver strain or burden (Sullivan, 2007). Schneider’s (2003; 2004) research focused on caregivers of patients using hemodialysis. Research by Löckenhoff, Duberstein, Friedman, and Costa (2011) focused on assessing personality traits and caregiving in general. Several investigators developed self-help guidelines for those experiencing stress and burden related to caregiving activities and responsibilities (Brody, 2008; Cangelosi, 2009; Cantu, 2004).

Investigators addressed the challenges and the effects of family members caring for one another from different viewpoints. Investigators have focused on the quantitative measurement of burden. The focus of some investigators was assessment of relationships between the caregiver and care receiver (Namiki et al., 2009; White, Richter, Koeckeritz, Munch et al., 2004). Over time, some investigators have changed the focus of caregiving research. Several
investigators have explored the development of public policy, state and federal statutes, and laws that protect the caregiver’s employment and increase resource funding for the family (Braithwaite, 1992; Montgomery, 2002).

According to Montgomery and Kosloski (2009), providing support systems for caregivers has implications for social policy changes. Changes in Medicare policies, institution of new laws, and the increase of governmental and private funding sources over the last decade eliminated the option of using institutionalization for many chronically ill patients (Huang, Shyu, Chang, Weng, & Lee, 2008). Even as the focus of caregiving research changed and acknowledging the focus on measuring factors and outcomes of burden, there remained a gap in the investigation of the lived experience of being burdened when providing care for a family member who uses hemodialysis.

**Quantitative Studies**

**Caregiver Burden in General**

Archbold et al. (1990) identified *mutuality* and *preparedness* as two variables that can influence a family member’s ability to manage the challenges and responsibilities of caregiving. *Mutuality* is the ability of the caregiver in finding gratification and meaning in the caregiving relationship and is associated with a mutual emotional closeness between the family members (Archbold et al., 1990). The concept of *preparedness* includes the evaluation of the skillset of the family member to perform the tasks and activities associated with caregiving duties (Archbold et al., 1990). Role theory provided a foundation for exploration of these concepts.

Archbold et al. (1990) used role theory as the basis for the development of measures in a longitudinal study. The hypothesis being tested in this longitudinal study was that higher levels of preparedness and mutuality are associated with lower levels of caregiver strain. Archbold et
al. defined caregiver strain as the caregiver’s perceived difficulty with fulfilling the caregiver role. The 78 caregiver – care receiver (patient) dyads were recruited from a large health maintenance organization (HMO) in the Pacific Northwest region of the United States. The patients were aged 65 years or older and had recently been discharged from the hospital.

In the study, Archbold et al. (1990) used the *Family Caregiving Inventory*, a structured interview instrument that measured predictor variables related to mutuality, preparedness, and measures of caregiver role strain. The dyads were interviewed twice, once roughly six weeks after the patient was discharged from the hospital and again at nine months after discharge from the hospital. Archbold et al. decided that the length of time for the initial interview was appropriate because it was long enough for the dyads to recuperate from the initial health issue for which they were admitted into the hospital. At nine months, Archbold et al. predicted that the dyads had settled into a routine and had enough time to see changes in daily routines and lifestyle alterations from previously established patterns.

In the study, the requirements for the giving of care to a patient were that the patient needed assistance with activities of daily living (bathing, toileting, eating, dressing, etc.), medications, ambulating, or household chores. The patients were not identified by disease type or condition in this study. In the study, Archbold et al. (1990) used the *Family Caregiving Inventory*, which is a structured interview instrument that measured seven predictor variables related to mutuality and preparedness and nine measures of caregiver role strain. Archbold et al. collected data via interviews with the caregivers and patients using two instruments specifically designed to capture the varying perspectives of the dyad. Two investigators travelled to the participant’s homes or other negotiated place and, after obtaining informed consent, conducted simultaneous interviews with the participants in separate rooms.
Archbold et al. (1990) proposed that a mutually positive relationship between the caregiver and patient lessened the caregiver’s perception of being strained when providing care. An inverse relationship between quality of life and caregiver burden was demonstrated in other studies (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002; Wicks et al., 1997). In the study, Archbold et al. found that higher levels of preparedness and a positive relationship between the dyad participants resulted in lower levels of reported caregiver strain. The study by Archbold et al. complimented previous studies by showing that the better a caregiver is prepared to manage a patient’s needs in the home, the less the caregiver perceives being strained with the added responsibilities of caring.

In a conceptual paper that provided a theoretical perspective, Montgomery and Kosloski (2009) examined caregiver burden from the perspective of changing role identity in the relationship between the caregiver and patient. Using role theory as a foundation, Montgomery and Kosloski proposed that as time passes in a familial relationship where one member of the dyad is a caregiver and the other a care receiver, roles within the relationship change. As an example, if a daughter becomes involved in activities requiring an increasing time commitment as well as crossing over to include personal care needs, over time the daughter may see herself as less of a daughter and more of a caregiver. This change in role identity from daughter to caregiver can be distressing, resulting in the daughter’s perception of being burdened (Montgomery & Kosloski, 2009). Montgomery and Kosloski did not explore burden further in this article beyond the relationship between burden and role change.

The study by Archbold et al. (1990) focused on the skills preparedness and mutual emotional investment in the relationship between the family member who is providing care and the care recipient. Montgomery and Kosloski (2009) speculate that this was incomplete because
other factors can contribute to the determination of satisfaction in caregiving. Montgomery and Kosloski cite that societal culture and the individual family culture also provide norms with which to determine the extent of perceived burden in caregivers who provide care for family members. The study by Montgomery and Kosloski did not focus on the quality of the relationship or emotional closeness between the caregiver and recipient, rather the investigators simply used time as a factor in their conclusions about the development of caregiver burden. Perhaps a study in which both time and relationship quality is examined may prove helpful in determining the utility of role theory in the study of caregiver burden.

In a classic study advocating examining the concept of being burdened using subjective independent measures, Poulshock and Deimling (1984) recognized that the literature on family caregiving was measured quantitatively. Poulshock and Deimling also used quantitative measurements yet proposed that caregiving is subjective and contextual; the impact of caregiving is dependent on the individual’s situation. The structured interview question study designed by Poulshock and Deimling included 614 families, stratified for geographic area of residence, race, and household configuration. The patients were not identified by disease type or condition in this study.

Study findings showed that caregiving burden is contextual. A patient’s requirements for assistance in ADLs are independent of the requirements for assistance when cognitively impaired (Poulshock & Deimling, 1984). There was a strong relationship between depression in the caregiver and negative caregiver-patient relationships with $r = .40$. This gives rise to the question of depression being an effect of caregiving or an antecedent to poor a caregiving relationship.
Although this study used structured interview techniques and quantitative statistics, Poulshock and Deimling (1984) support the use of qualitative measures to further examine the subjective nature of the concept of family members being burdened when providing care for another family member. Bastawrous (2013) agreed with the use of qualitative methods to explore perceptions of being burdened in caregivers because quantitative measures do not capture the essence and contextual elements in the concept of being burdened.

**Caregiver Burden Related to the Caregivers of Patients Who Use Hemodialysis**

The experience of being burdened when caregivers provide care to a family member who uses hemodialysis to manage ESKD is universal. This was demonstrated by a study that sought to validate an English language instrument that measured caregiver burden for use in Turkish populations. As well, a Brazilian study examined caregiver burden and quality of life in caregivers of patients who use hemodialysis (Akinci & Pinar, 2012; Belasco & Sesso, 2002). Additional studies have been conducted in Northern Taiwan investigating the use of respite care and the role of culture in the choice of using respite care (Huang et al., 2008). Japanese investigators examined caregiver burden in caregivers of patients using hemodialysis (Washio et al., 2012).

Studies have approached the caregiver’s experience with being burdened in different ways (Akinci & Pinar, 2012; Belasco, Barbosa et al., 2006; Caserta et al., 1996; Schneider, 2003; Schneider, 2004; Wicks et al., 1997). Several studies have quantitatively examined burden using the *Caregiver Burden Scale* or *Caregiver Burden Inventory* (Akinci & Pinar, 2012; Belasco, Barbosa et al., 2006; Caserta et al., 1996; Wicks et al., 1997). Other approaches focused on one aspect of burden such as fatigue (Schneider, 2004).
The Caregiver Burden Scale used in many studies is a measurement instrument designed to globally quantify burden in caregivers using several dimensions. The instrument, developed by Swedish investigators Elmstahl, Malmberg, and Annerstedt in 1996, used a multidimensional approach to measure overall burden in caregivers. The instrument was initially validated using a longitudinal study involving 150 Swedish caregivers of patients who had experienced a stroke (Elmstahl, Malmberg, & Annerstedt, 1996). Reliability was confirmed in another 23 patient-caregiver dyads.

Elmstahl et al. (1996) note that the caregiver burden scale showed good construct validity and test-retest reliability according to the statistical analyses, and several dimensions of burden among caregivers could be distinguished. The five dimensions identified in the study by Elmstahl et al. (1996) included general strain, isolation, disappointment, emotional involvement, and environment. The dimensions showed strong reliability with kappa values, .89 to 1.00 and with internal consistency showing Cronbach's alpha, .70 to .87 (Elmstahl et al., 1996). Other studies have shown that the strength of this instrument lies in the multidimensional nature in measuring burden (Belasco, Barbosa et al., 2006).

Akinci and Pinar (2012) conducted a methodological study to determine the validity and reliability of a Turkish translation of the Caregiver Burden Scale, developed by Elmstahl et al. in 1996. Akinci and Pinar used a total of five translators who spoke English and Turkish and who were familiar with both cultures, to translate the scale forward and backward to identify discrepancies in meaning in the scale prior to the caregiver’s exposure to the document for completion.

One hundred and sixty-one family caregivers for patients using hemodialysis were surveyed using the Caregiver Burden Scale appropriately translated for the Turkish language and
to reflect cultural sensitivity (Akinci & Pinar, 2012). The Maslach Burnout Scale and Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), also appropriately translated and revised to meet cultural standards, were used in this study (Akinci & Pinar, 2012). The mean age of the caregivers was 45 years old and the majority of caregivers were married females. The study results showed that familial caregivers in Turkey experienced similar changes in lifestyle when a family member is using hemodialysis as compared to those in other countries.

In this study, Akinci and Pinar (2012) found that Turkish caregivers experienced a decreased quality of life, which correlated with a higher level of caregiver burden. The inverse relationship between quality of life and caregiver burden has been substantiated by other studies (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002; Wicks et al., 1997). Akinci and Pinar showed that the Turkish translation of the Caregiver Burden Scale was valid and reliable in this population.

Belasco, Barbosa et al. (2006) used the Caregiver Burden Scale and the Cognitive Index of Depression along with the Medical Outcomes Study 36-item Short Form health survey questionnaire to measure caregivers’ quality of life when caring for patients who use either hemodialysis or peritoneal dialysis in this descriptive study. For this study, the Caregiver Burden Scale was translated into Portuguese and adapted for the Brazilian culture and population of caregiver and patient participants who were then interviewed by the investigators (Belasco, Barbosa et al., 2006). The investigators used subjects 65 years old or older who attended four outpatient dialysis clinics in the city of São Paulo, Brazil.

The investigators interviewed a total of 201 caregiver-patient dyads. Belasco, Barbosa et al. (2006) compared caregivers who provide care for elderly patients using dialysis with those who provided care for non-elderly patients using dialysis. One limitation of this study was that
the study focused on the age of the patient, not necessarily the physical health status of the
caregiver or relationship between the individuals as in previous studies (Archbold et al., 1990;
Montgomery & Kosloski, 2009; Schneider, 2004).

The analysis showed that the individuals most affected by burden were caregivers who
provided care for elderly patients using peritoneal dialysis. The investigators found that patients
using continuous ambulatory peritoneal dialysis (CAPD) required caregivers to participate
multiple times a day in the exchange procedure required by CAPD. The statistically significant
effects were seen in decreased quality of life and significant experience of burden (Belasco,
Barbosa et al., 2006) further emphasizing the inverse relationship found in other studies (Belasco
& Sesso, 2002; Wicks et al., 1997).

Novak and Guest (1989) developed a Caregiver Burden Inventory as a way to assess
caregiver’s needs and level of burden. Using previous scales and results from previous studies,
the investigators developed the Caregiver Burden Inventory by interviewing caregivers of
patients with dementia and Alzheimer’s disease. The participants were recruited from
community health care professionals including directors of long-term facilities, physicians, and
care coordinators (Novak & Guest, 1989). One hundred seven caregivers were interviewed in
their homes using open-ended and fixed-choice questions. The two hour interviews also
included the caregiver’s demographic information. The five factors identified in this
multidimensional view of caregiver burden included time burden (i.e., hours in the day required
to provide care), developmental burden (i.e., social and emotional development of caregiver),
physical burden (i.e., sleep and illness), social burden (i.e., getting along with others in the
family), and emotional burden (i.e., resentfulness, anger, and embarrassment) (Novak & Guest,
1989).
The statistical analysis showed that the reliability Coefficient Alpha for all five factors ranged from .73-.86 and accounted for 66% of variance in the data set (Novak & Guest, 1989). The variance could be attributed to the caregiver’s relationship with the family member and whether the family member was living in the home or in an institution. For example, caregivers who cared for a family member living in an institution scored lower on the burden scale than caregivers of family members who lived at home. Other caregivers were noted to have the same total raw scores; however, the factor weight was different depending on the living situation and duties of care. Novak and Guest (1989) supported the use of the Caregiver Burden Inventory as a way to measure burden in caregivers and as a starting point for health care professionals to identify appropriate resources to alleviate burden for these caregivers.

Caserta et al. (1996) investigated the utility of the Caregiver Burden Inventory to support a multidimensional view of caregiver burden in a descriptive quantitative study. The study sample was recruited from a mailing list of caregiver support groups and the client lists of three adult day care centers in northern Utah (Caserta et al., 1996). The investigators gave a questionnaire to or interviewed 160 respondents for this study. The instrument is divided into five dimensional categories including time dependence, developmental, physical, social, and emotional burden experienced by caregivers (Caserta et al., 1996). Fatigue is one aspect of the physical dimension and is further explored by Schneider (2004).

The developmental aspect of the Caregiver Burden Inventory referred to the length of time of caregiving and measures the effects of long-term disruption in caregivers’ lives (Caserta et al., 1996). The reliability coefficients for the five dimensions ranged from .69 (social) to .87 (developmental). Caserta et al. (1996) found that functional impairment is a factor of the dimension of time and spousal caregivers spent increased time and experienced more
developmental burden than non-spousal caregivers. Additionally, physical health is not as highly correlated with physical burden as initially expected (Caserta et al., 1996).

Caserta et al. (1996) found that the Caregiver Burden Inventory is useful to assist nurses and care managers to focus interventions on the area needed most by caregivers. This instrument provided a starting point for the measurement of burden in caregivers; however, it did not provide details on the lived experience of being burdened. This measurement instrument did not address the relationship between the caregiver and family member for whom care is provided as seen in previous studies by Archbold et al. (1990) and Montgomery and Kosloski (2009).

Wicks et al. (1997) used an exploratory descriptive design with a convenience sample of 96 caregivers of kidney transplant candidates to examine caregiver quality of life and subjective burden. The investigators recruited the sample from a University transplant service in the mid-south. The research question driving this study addressed the quality of life and experience of burden in family caregivers of patients using hemodialysis and peritoneal dialysis prior to receiving a kidney transplant. Following previous reports of an inverse relationship between quality of life and subjective burden, Wicks et al. developed a research question focused on the manner in which the patient and caregiver illness factors affected the experience of burden and the quality of life for these caregivers.

In this study, Wicks et al. (1997) invited participants to complete a demographic data form, the Caregiver Burden Interview, and the General Quality of Life measure. Wicks et al. (1997) found that a caregiver’s quality of life scores were good to excellent in 92% of caregivers who were employed full-time. Scores for the type of dialysis used showed caregivers of patients using continuous ambulatory peritoneal dialysis (CAPD) or in-center hemodialysis reported their quality of life as good to excellent in 87% and 73% of the time respectively. This is in contrast
to the study by Belasco, Barbosa et al. (2006) that found caregivers of patients using CAPD experienced lowered levels of quality of life. Perhaps this is because of the increased age of the patient in the Belasco, Barbosa et al. study. The Caregiver Burden Interview and General Quality of Life measures are global measures and a snapshot of subjects’ opinion and experience at a moment in time. Use of global instruments can be a limitation in this study.

The reasons for the high quality of life ratings may lie in the chosen mode of dialysis. In CAPD, the patient is responsible for self-administering the dialysis treatments at home. In-center hemodialysis involves the patient travelling to an ambulatory center for professional nursing care and administration of the dialysis treatment. In either of these situations, the family caregiver does not have direct involvement or responsibility for the dialysis treatment unless other health or psychological issues dictate their participation in the process. Wicks et al. (1997) postulate that the quality of life scores may have been higher in this sample because the patients who were awaiting transplant were more compliant with the chosen treatment modality and healthier overall. In this study, the caregivers who reported higher quality of life scores experienced less burden as previously noted in the literature (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002).

The Modified Caregiver Strain Index is another instrument used to measure stress or strain on a caregiver, which is the starting point for caregiver burden (Sullivan, 2007). This instrument is a self-administered 15-item index that allows ‘yes,’ ‘no,’ and ‘sometimes’ answers. The instrument is scored using two points for ‘yes’ answers, one point for ‘sometimes’, and zero points for ‘no’ (Sullivan, 2007). Statements are uncomplicated in nature and easily understandable by lay readers. Some examples of the statements include:

- My sleep is disturbed
• There have been family adjustments

• I feel completely overwhelmed (Sullivan, 2007)

The internal reliability of the instrument is reported to be .90 with test-retest reliability coefficient of .88 (Sullivan, 2007). The strengths of the instrument are that it is easy and takes little time for caregivers to complete.

One limitation of this instrument is that there is no categorical breakdown of the scoring on the instrument so the answers must be evaluated by a professional health care provider. The instrument does not give categorical markers for low, medium, or high levels of burden and a health professional must use his or her own professional judgment along with other assessment findings to determine the level of burden experienced by the caregiver (Sullivan, 2007). Another limitation is that some long-term caregivers reported disliking the dichotomous nature of the answer choices (Sullivan, 2007). However, using this easily administered instrument, nurses and care managers can quickly determine the need for follow up in areas that rank higher for the caregiver.

Other investigators have examined singular factors or outcomes of burden (Schneider, 2003; Schneider, 2004). Physical fatigue is recognized as part of the multifactorial experience of burden (Schneider, 2003; Schneider, 2004; Wicks et al., 1997). Schneider (2003) explored the construct of fatigue as a cause and as a result of burden in caregivers. Schneider (2004) modified the Fatigue Severity Scale, originally used for multiple sclerosis patients, for use among caregivers of hemodialysis patients and assessed its usability to determine the level of caregiver fatigue.

Schneider’s (2004) purpose in the descriptive study was to test the Fatigue Severity Scale on a non-medical population. Study subjects completed the Short Form – 12 and the Center for
Epidemiologic Studies Depression Scale (CESD) in addition to the Fatigue Severity Scale questionnaires and submitted the forms to the investigator. Of the 80 subjects whose questionnaires were satisfactorily analyzed, Schneider showed that physical fatigue may be experienced more than mental fatigue in those providing care for family members using hemodialysis.

The Fatigue Severity Scale has been previously established as having high internal consistency. In this study, Schneider (2004) found that the Cronbach’s α = .94, which showed the scale to be highly correlated with physical fatigue in caregivers of patients who use hemodialysis. In a commentary on Schneider’s work, Porock and Oliver (2005) proposed that physical health of a caregiver is only one aspect of the multidimensional construct of burden in caregiving and this study did not address length of time for caregiving activities, which could influence fatigue. Other studies exploring fatigue as a standalone concept in the caregiver population for hemodialysis patients could not be located in the literature.

The Fatigue Severity Scale can assist health care providers to determine the level of physical fatigue as a feature of caregiver quality of life and offers standardization to link caregiver burden with physical symptoms. Schneider’s (2004) work in the area of measuring fatigue will assist nurses and care managers to recognize one sign of potential burden in caregivers of patients with chronic kidney disease. Schneider proposed that understanding the nature of caregiver burden and fatigue may allow nurses and care managers to propose interventions to improve a caregiver’s quality of life.

Tong et al. (2008) report that there are several random controlled trials (RCT) exploring support interventions for caregivers of patients with dementia, stroke, and cancer. In a
systematic review, Tong et al. reveal only three studies that fit the inclusion criteria for an applied intervention for informal caregivers of patients with chronic kidney disease.

The inclusion criteria were:

- **Study design:** Any study reporting the development or evaluation of an intervention for informal caregivers of CKD patients including dialysis
- **Population:** Informal caregivers of adult and pediatric patients with CKD
- **Intervention:** Information and education, psychological or social support
- **Outcomes:** Physical status (fatigue, health problems), psychological status (depression, anxiety), caregiver burden (strain, perceived burden, adjustment issues), patient outcomes (relationship with caregiver, attitudes, physical and psychological health)

Narrowing the literature review from 1178 initial articles to 24 articles that focused on caregivers of dialysis patients, three articles fit the inclusion criteria previously listed. The three included articles focusing on caregivers of patients with chronic kidney disease did not address the concept of being burdened or support interventions to improve caregiver quality of life or decrease the caregiver’s sense of burden. Rather, the caregiver’s knowledge of care giving was addressed (Tong et al., 2008). This knowledge was assessed using pre- and post-test design using an educational intervention and participatory action research that was used in creation of an informational booklet for patients and caregivers (Tong et al., 2008).

Cultural comparison of family resiliency showed culture plays a major role in resiliency (White, Richter, Koeckeritz, Lee et al., 2002). White, Richter, Koeckeritz, Lee et al. (2002) found that although there were studies addressing care giving issues in the hemodialysis population, none addressed the issues from a cultural perspective. White, Richter, Koeckeritz,
Lee et al. (2002) explored family resiliency in 68 hemodialysis patients and their families using a cultural lens. For this study they used a descriptive comparative survey design across three ethnically diverse samples.

The investigators chose three ethnic groups including Anglo-American, Mexican-American, and Korean-American patients and caregivers for examination in this study. Subjects were initially contacted while undergoing their dialysis procedure in the ambulatory dialysis center. The investigators gave participants and their family members questionnaires to complete in their homes or complete at the center.

Anglo-American, South Korean-American, and Mexican-American cultural perspectives and values of care giving and family resiliency were explored to determine differences in life views and what the meaning and impact was of a serious chronic illness to individuals of the respective culture (White, Richter, Koeckeritz, Lee et al., 2002). In this descriptive comparative study, the research questions addressed perceived differences in stressors of chronic illness, resources, and resiliency of family members between members of different cultural groups. Research questions also addressed the same concepts in hemodialysis patients and their family member caregivers.

Using valid and reliable measurement instruments, the investigators measured the perceived differences between chronic illness stressors, resources, and family resiliency in Anglo-American, South Korean-American, and Mexican-American groups of participants. South Korean-American families scored lower on resiliency scores and perceived more stress related to illness than the other two groups (White, Richter, Koeckeritz, Lee et al., 2002). None of the mean group scores were ranked above the moderate range, according to White, Richter, Koeckeritz, Lee et al. (2002). A consistent finding was that the groups ranked relative/friend
support as low and each group expressed reticence to seek assistance from others to manage the stressors of caregiving.

The study did not address the concept of the experience of being burdened directly; however, relationships within the family can affect family resiliency (Montgomery & Kosloski, 2009). Cultural values also contributed to the potential experience of being burdened when providing care for a family member (White, Richter, Koeckeritz, Lee et al., 2002). Further exploration using qualitative phenomenological measures could provide more information on family relationships affecting resiliency and the caregiver’s experience of being burdened.

Studies have consistently shown that there exists an inverse relationship between quality of life and burden in caregiving (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002; Wicks, et al., 1997). Although helpful in quantifying and determining the extent of burden when providing care, these foundational studies offer a global measurement of burden. Measuring fatigue using a scale is a starting point; however, measurements do not address the lived experience of fatigue or being burdened when providing care to family members using hemodialysis.

Qualitative study on the topic of burden would offer more information on the issue of how life changes affect the caregiver’s experience of being burdened. Nurses can use this information to recognize the signs and symptoms of burden in caregivers and assist the family caregiver to locate resources to decrease the burden experience. Further exploration using phenomenology provided more information regarding the lived experience of being burdened a caregiver, including the experience of caregiver burden.
Qualitative Studies

Caregiver Burden in General

Cao, Chung, Ferreira, Nelken, Brooks et al. (2010) conducted a qualitative descriptive study using semi-structured interviews to explore the changes in a wife’s activities following her husband’s stroke. Ten participants were interviewed for an hour via face-to-face or telephone setting. Several questions asked the participant to describe a typical day and to describe the activities she was engaged in prior to her husband’s stroke (Cao, Chung, Ferreira, Nelken, & Brooks et al., 2010). The investigators transcribed audio-taped interviews in which the participants described the changes in their lives, their daily struggles, and daily physical activities to the interviewer.

Cao et al. (2010) found the participants discussed the changes in their role within the family structure. One participant shared that she felt more like a maid than a wife (Cao et al., 2010). Montgomery and Kosloski (2009) discussed role change theory in caregiving as the change in family roles that occur over time in the relationship between spouses. The participants described changes in their activity levels. Pre-stroke, the spouses were focused on recreational and leisure activities while the post-stroke activities were approached as therapeutic with a focus on the patient (Cao et al., 2010).

Several wives reported feeling less enjoyment when participating in post-stroke leisure activities without their husbands. The wives described caregiving as a full time job and some wives reported feelings of being burdened (Cao et al., 2010). Cao et al. (2010) suggested that a family centered approach to physical activities during stroke rehabilitation can decrease the burden experience in caregivers.
Caregiver Burden Related to the Caregivers of Patients Dependent on Hemodialysis

Investigators used a qualitative design to explore family resiliency in the families of patients who use hemodialysis (White, Richter, Koeckeritz, Munch et al., 2004). White, Richter, Koeckeritz, Munch et al. (2004) used naturalistic inquiry to explore resiliency in 15 families whose members were on hemodialysis. A purposive sampling approach was employed and participants were recruited with the assistance of dialysis center staff. The investigators did not limit the number of family members allowed to participate. The patients and caregivers were interviewed three times, twice separately and a third time together several weeks later.

The investigators asked questions designed to highlight stressors on the family. Family resiliency is influenced by the relationships between the individuals in the family and the cultural values in the society in which the family resides. This study focused on the dynamics in the family, not individual caregivers or the experience of being burdened.

In the study the authors identified strategies and resources that assisted in improving the “bonadaptation” (p. 363), or the positive life view of families. Social support, in the form of close friends and family members, was shown to improve family resiliency (White, Richter, Koeckeritz, Munch, et al., 2004). Some participants reported that maintaining an open communication style and working together as a team helped them improve their relationships and achieve happier lives. Other social supports that the participants reported as helpful were the dialysis nurses and ambulatory staff as well as other dialysis patients (White, Richter, Koeckeritz, Munch, et al., 2004). White, Richter, Koeckeritz, Munch, et al. (2004) identified that some participants achieved a sense of control over their lives and environment through self-education about chronic kidney disease and dialysis.
“Going forward” (p. 357) and maintaining family integrity in light of difficult circumstances were affected by the support systems provided when the nurse and care managers advocate for patients and their families (White, Richter, Koeckeritz, Munch et al., 2004). Although role theory was not used in this study, the previous work done by Montgomery and Kosloski (2009) and Archbold et al. (1990) could provide a point of reference when interpreting the relationships between family members and the reasons a family is or is not resilient when confronted with serious chronic illness of a member.

Tong, Palmer, Manns, Craig, Ruospo et al. (2013) conducted a semi-structured qualitative interview study with thematic analysis using a purposive sample. The investigators interviewed 22 patients and 20 caregivers of patients who currently use in-center hemodialysis to explore the beliefs and expectations associated with the possibility of using home hemodialysis instead of in-center hemodialysis. The participants were recruited by their primary care physician from four dialysis centers. The interview study using semi-structured questions was conducted in four cities in Italy where home hemodialysis is not currently a treatment option. Three positive themes and four negative themes regarding the use of home hemodialysis were identified.

One of the negative themes described family burden in managing the home hemodialysis process. In this theme the patients described not wanting to impact their family member with the time constraints of the treatments and responsibilities the treatment requires (Tong, Palmer, Manns, Craig, Ruospo et al., 2013). The caregiving family member responded that the responsibility of managing home hemodialysis treatments for a family member would be overwhelming because of a lack of training, the lack of knowledge of how to manage an emergency situation, and increased responsibility and accountability for the treatments.
The theme of *family burden* can be linked with the concept of being burdened when providing care for a family member who is dependent upon hemodialysis. The caregiver is educationally prepared by health care professionals prior to the initiation of home hemodialysis. However, the caregiver may still feel burdened with the added responsibility although Archbold et al. (1990) report that preparedness alleviates burden.

Changing roles in the family, resiliency, and sociological culture also can be linked with family burden (Archbold et al., 1990; Montgomery & Kosloski, 2009; White, Richter, Koeckeritz, Munch et al., 2004). In the family burden theme, the patient is reluctant to ask the family member to make a significant personal sacrifice for them. In cases where a family member takes on more responsibility for managing the care of a patient using home hemodialysis, role changes can occur, which can lead to strain in the relationship with the caregiver experiencing feelings of being overwhelmed (Montgomery & Kosloski, 2009). Cultural expectations often drive the decision to provide care for a family member. In some cultures, it is an expectation that a sick family member will be cared for by the others regardless of the relationship or skill preparation (Huang et al., 2008).

Fex et al. (2011) conducted a hermeneutic study using Gadamerian methods to explore the meaning of living with an adult family member who uses advanced medical technology in the home. Four nurses assisted in recruitment of the participants. Of the 11 caregivers interviewed, only one lived with a family member who used hemodialysis. The remaining patients used technology associated with oxygen delivery, ventilators, or peritoneal dialysis (Fex et al., 2011).

Fex et al. (2011) discovered a dichotomy for caregivers living with a family member who uses advanced medical technology. The caregiver reported feelings that led the investigators to
interpret the meaning as the caregiver feeling both separated from and connected to their technology dependent family member. The element of connectedness was shown in participant’s comments about being at home to monitor the technology used and adjusting the home environment to accommodate the technology. The element of separateness was shown in participant’s comments about role changes in the relationship and participating in activities without the family member (Fex et al., 2011).

The dynamics within the family can contribute to this dichotomy as the members assume different roles (Montgomery & Kosloski, 2009). Montgomery and Kosloski (2009) proposed that the change in familial roles must be secondary to an initial relationship between the two individuals such as spouse-spouse, adult child-parent, etc. Assisting one’s family member for a short time may not impact the caregiver; however, the longitudinal quality of chronic caregiving can alter the family dynamic in time and leave the caregiver with dichotomous feelings (Fex et al., 2011; Montgomery & Kosloski, 2009). Further exploration of the construct of separateness-connectedness and the role of changing family dynamics can be accomplished using phenomenological methods and may be reflective of the caregiver’s experience of being burdened.

Wise et al. (2010) conducted a mixed-method study on caregivers and patients who used short daily home hemodialysis (SDHD) for six months at the time of the study. The investigators used grounded theory to analyze the open ended interview questions asked of 13 caregiver-patient dyads. The investigators enlisted the assistance of nurses and social workers at ambulatory hemodialysis centers in various regions of the United States. Wise et al. (2010) identified four coping profiles including thriving, surviving, martyrdom, and seeking another option.
Wise et al. (2010) identified the domain *martyrdom* as the caregiver’s self-sacrificing behaviors accompanied by increased burden and resentment with the care situation. In the concept of martyrdom, the caregiver defers his or her own needs in favor of the patient’s needs and becomes resentful. The investigators report that martyrs felt more of an obligation to the caregiving role than desire to be with the patient or feelings of admiration for the patient (Wise et al., 2010). The investigators found that the power in the relationship between martyrs and patient dyads was asymmetrical and the couples did not have skills for communicating openly and honestly (Wise et al., 2010).

Martyrdom associated with increased burden reflects a decreased quality of life for the caregiver as seen in previous studies (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002; Wicks, et al., 1997). The domain of martyrdom can be reflected in the concept of the experience of being burdened. Martyrdom is influenced by the family dynamic, physical health, and role assumption by the caregiving family member (Wise et al., 2010). Wise et al. (2010) found that poor communication skills contributed to the ineffective coping mechanism of martyrdom noted in the caregiving relationship. Caregivers, who experience their own health issues and poor communication skills, may resent the time dedicated to the patient and exhibit martyr behavior further destroying the relationship and rendering the family dynamic in chaos.

For caregivers who are fatigued or who experience role changes, exploration using a phenomenological design may provide more information to capture all aspects of the lived experience of being a caregiver and providing care for a family member dependent upon hemodialysis. Wise et al. (2010) suggested that prior to initiating SDHD, the quality of the couple’s relationship is assessed using the Personal Assessment of Intimacy in Relationships (PAIR) inventory. The lower scores of this inventory indicate that couples should seek
counseling prior to starting SDHD to improve communication and decrease the incidence of burden (Wise et al., 2010).

**Literature Gap-Qualitative Studies**

Much of the literature on care giving in the patient receiving hemodialysis and caregiver population is quantitative (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002; Caserta et al., 1996; Schneider, 2003; Schneider, 2004; Tong et al., 2008; White, Richter, Koeckeritz, Lee et al., 2002; Wicks, et al., 1997). Although there was support for qualitative studies on the concept of caregiving and caregiver burden (Bastawrous, 2013; Poulshock & Deimling, 2004), there was limited qualitative research around the topic of the caregiver’s lived experience, including those experiencing caregiver burden, when providing care for a family member dependent on hemodialysis (Fex et al., 2011; Tong, Palmer et al., 2013; White, Richter, Koeckeritz, Munch et al., 2004; Wise et al., 2010). Qualitative studies on the lived experiences of caregivers who care for patients with other chronic illnesses, and may experience burden, such as stroke can be found in the literature (Cao et al., 2010).

There seemed to be a gap in phenomenological research regarding the lived experience of providing care for family members dependent upon hemodialysis to manage ESKD. Researchers from a variety of disciplines have contributed much to the exploration of the caregiver’s experiences in the literature especially in the areas of caregiver burden. Nurse’s scholarly efforts are underrepresented in the caregiver literature. The dissertation study addressed the gap in qualitative studies.

**Summary**

The literature showed an inverse relationship between caregiver quality of life and the burden of caregiving (Belasco, Barbosa, et al., 2006; Belasco & Sesso, 2002). Family members
experienced role changes while the family structure changed in response to chronic caregiving (Montgomery & Kosloski, 2009). In this chapter, the investigator addressed the literature review highlighting the literature search process, the historical perspective of caregiving, quantitative studies that measure precursors, characteristics, and outcomes of burden, and qualitative studies related to psychosocial aspects of caregiving and caregiver burden.

The investigator presented quantitative and qualitative research performed on the topic of caregiver burden in general as well as research related to caregivers who provide care for family members dependent upon hemodialysis. The investigator noted that there were several studies measuring precursors, characteristics, and outcomes of caregiver burden; however, no research studies describing the lived experiences of caregivers for family members who are dependent upon hemodialysis to manage ESKD were present in the literature. This dissertation study fills a noticeable gap in the literature. Chapter three discusses the research method and design that will explore the research question.
Chapter 3

Method

Chapter one explored how medical treatments for a family member, specifically hemodialysis, can create lifestyle changes and interrupt the established flow of life for the family. Having a family member who is dependent upon hemodialysis can result in emotional and physical distress for the family member who is responsible for daily activities surrounding the treatment and overall care of the patient. This is often referred to as caregiver burden in the literature (Schneider, 2003; Schneider, 2004; Nguyen, 2009).

Chapter two addressed the qualitative and quantitative caregiver literature with a focus on the literature search process and historical perspective of caregiving. Quantitative studies measuring precursors, characteristics, and outcomes of burden are addressed. Qualitative studies related to psychosocial aspects of caregiving and caregiver burden are discussed.

The Structural Model: Predictors and Outcomes in Burden by Savundranayagam et al. (2011) was used to inform this study. Investigators used qualitative research as an approach to explore the everyday lives of people (Polit & Beck, 2008). The literature review in chapter two highlighted a gap in the research literature. Noted throughout the literature there were quantitative studies measuring contributing factors and outcomes of caregiving; however, a noticeable gap in the qualitative literature existed regarding the lived experience of caring for a family member who is dependent upon hemodialysis to manage ESKD (Wagner, 1995; White et al., 2004). In phenomenology, investigators value the experiences of the individual and use participant information to develop a deeper understanding of those experiences (Giorgi, 2009; Polit & Beck, 2008; Streubert & Carpenter, 2011). The purpose of this descriptive,
phenomenological study was to explore caregiver’s lived experience when providing care for a family member who is dependent upon hemodialysis.

**Method**

Research methods are chosen based on the research question (Giorgi, 2009). The qualitative methods of inquiry are used when the investigator appreciates and values people’s voices and experiences. The investigator uses qualitative research methods to discern description and meaning of an experience (Giorgi, 2009). In this dissertation study, the research question addressed the lived experience when providing care for a family member who is dependent upon hemodialysis.

The research method chosen was a qualitative approach. Phenomenology is a philosophy in which a person seeks to understand a phenomenon such as an object, a feeling, or an experience, from the perspective of the individual undergoing the experience of the phenomenon (Giorgi, 2009). Individual participants share stories of their experiences through written or verbal communication methods, providing insights and an emic perspective to help others understand what the experience of the phenomenon is like for them. Objective analysis of a phenomenon is not the purpose of phenomenology. The focus of descriptive phenomenology is how the individual experiences and makes sense of the phenomenon and how the individual makes sense of the experience (Giorgi, 2009).

**Appropriateness of the Design**

Informed by the *Structural Model: Predictors and Outcomes of Burden*, this study used phenomenology to examine the context and perceptions of caregivers who experience the phenomenon of providing care for a family member who is dependent upon hemodialysis. This study filled a gap in the literature and made an original contribution to the body of knowledge, as
there was no apparent published research regarding the lived experience of caregivers who provide care for a family member dependent upon hemodialysis to manage ESKD.

The current literature has examined caregiver burden by measuring elements or factors contributing to burden in a caregiver. The quantitative research included factors such as fatigue (Schneider, 2003; Schneider 2004), quality of life in a caregiver of a family member who is dependent upon hemodialysis (Belasco & Sesso, 2002), and the influence of exercise on the subjective sense of burden (Hirano et al., 2011). Poulshock and Deimling (1984) emphasized the importance of garnering information to appreciate and understand the caregiver’s perspective of the experience of caregiving because of the uniqueness of the caregiving experience for every individual. Because researchers have conducted a significant number of quantitative studies, the descriptive phenomenological approach was chosen to better examine the lived experience of caring for a family member who is dependent upon hemodialysis to manage ESKD.

Other qualitative approaches that could have guided this study included a case study approach or a grounded theory approach. The case study approach often uses a single informant in an in-depth, longitudinal study to examine data surrounding the issue under study (Glesne, 2011). Other situations where a case study is used include when the investigator is interested in examining an organization or a flow of processes in an organization. Frequently, case studies are done when a situation is considered unique, which can make it difficult for an investigator to transfer the information or results of the study to other situations (Glesne, 2011).

The investigator in this dissertation study was focused on the caregiver’s lived experience of providing care for a family member who is dependent upon hemodialysis. This situation was unique because of the hemodialysis technology being used by the family member. The investigator was focused on the phenomenon of the lived experience in the context of caring for
a family member who is dependent upon hemodialysis. A case study was not an appropriate approach to use to describe the lived experiences of individuals.

A grounded theory approach was considered, but not chosen, for this study. Grounded theory uses inductive data to develop theory (Charmaz, 2006). The grounded theory approach concludes with an abstract theoretical understanding of the experience (Charmaz, 2006). The focus of this study was not on theory development; rather, the focus of the dissertation study was to examine the nature and perceptions of the lived experience of caregiving for a family member who is dependent upon hemodialysis to manage ESKD. Therefore, a grounded theory approach was not deemed appropriate for this study.

**Research Question**

The research question being addressed in this descriptive phenomenological study was:

What is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD? Two sub-questions for this study are:

R – 1: What are the perceptions that caregivers have about the experience of providing care for family members dependent upon hemodialysis as a treatment for ESKD?

R – 2: What is the meaning that caregivers give to the experience of caregiving for family members dependent upon hemodialysis as a treatment for ESKD?

Through a descriptive phenomenological approach, these questions assisted in discerning the emic perspective of the lived experiences of this unique caregiver population.

**Sample**

The investigator enrolled a purposive sample of volunteer family members who experienced the phenomena of caring for a family member who is dependent upon hemodialysis to manage ESKD. The investigator anticipated that recruiting up to ten participants for the
interview process, and more if needed to result in saturation of the data, to answer the research question and all other pertinent questions arising from the data. The investigator asked the participants open ended questions during a private, audio-taped interview to elicit responses of the lived experiences of caregivers in the study population.

The investigator delineated the following inclusion and exclusion criteria for the study.

**Inclusion Criteria**

- Caregivers of family members who are dependent upon hemodialysis
- Residents of central Virginia
- Able to communicate both verbally and in writing using the English language
- Willing to participate
- Male and female caregivers
- Age more than 21 years

**Exclusion Criteria**

- Age less than 21 years
- Not willing to participate
- Non-family members

**Sampling Strategy**

The investigator acquired Institutional Review Board approvals from University of Phoenix and a local Health System. Additionally, the local Health System hospital provided approval to conduct research on the premises (refer to Appendix C for the PRN form). With the assistance of the nurse manager who served as the institutional gatekeeper, the investigator located potential participants in a medical renal nursing unit and in-patient hemodialysis unit.
located in a hospital in a mid-sized city in the mid-Atlantic region. The investigator was assisted by the nurse manager of a renal nursing unit to identify potential participants. The nurse manager (gatekeeper) did not determine eligibility of participants or obtain informed consent. The role of the nurse manager was only to assist the investigator with obtaining access to potential participants. The nurse manager initially approached the caregiver, introduced the study, left a recruitment brochure with the caregiver (see Appendix D, Recruitment Brochure), and asked permission to give the caregiver’s viable phone number or email address to the investigator.

After receiving viable phone number or email address of caregivers willing to discuss the study, the investigator approached the individuals regarding the study in person. The investigator reviewed the inclusion screening criteria with the caregiver who indicated interest in the study. The inclusion screening criteria were specifically designed to identify a caregiver who provided care for a family member who is dependent upon hemodialysis to manage ESKD. If, through the discussion and review, the individual caregiver met the inclusion criteria, the investigator pursued a brief introduction of the study. (See Appendix E for details on the Introductory Script).

The potential participant had an opportunity to ask questions at the time of the screening to determine level of interest in the study. When a caregiver indicated an interest in being a participant in the study, the investigator negotiated a time and place for further review of the informed consent process, signing of the informed consent form, and the formal audio-taped interview.
Informed Consent

Informed consent is essential in human research and must comply with ethical principles (Marczyk, DeMatteo, & Festinger, 2005). The purpose of this descriptive, phenomenological study was to explore caregiver’s lived experience of providing care for a family member dependent upon hemodialysis as a treatment for ESKD, including the existence of caregiver burden. The investigator anticipated that a minimum of five participants was required to answer the research question and all subsequent pertinent questions arising from the data. An additional participant was interviewed to achieve data saturation.

The nurse manager of the renal nursing unit at the Health System Medical Center served as the institutional gatekeeper (see Appendix F for Letter of Support and Appendix C for the PRN form). The nurse manager identified caregivers of family members who were in-patients (potential participants) admitted to the renal nursing unit. Potential participants were approached by the nurse manager and asked if they would be willing to have a researcher discuss a study about being a caregiver for a family member who is dependent upon hemodialysis with them. The nurse manager gave the recruitment brochure to the family caregiver (see Appendix D). The nurse manager asked permission to give the caregiver’s name and a viable phone number or email address to the investigator. The investigator retrieved the names and a viable phone number or email address of those caregivers who wanted more information about the study. The nurse manager did not have access to data or results of the study. The researcher did not give the nurse manager information regarding who participated in the study.

The researcher contacted the family member to arrange time to discuss the study in person. Following the initial discussion and if the potential participant agreed to participate, the investigator arranged time for the interview. The researcher obtained informed consent at the
time of the interview (see Appendix G, Informed Consent). The investigator distributed contact information for the investigator in the form of an email address and phone number at the time of the initial contact with the participant indicating interest in the study. The contact information was in written form. The study procedures included following the requirements for University of Phoenix Institutional Review Board (IRB) and the local Health System Institutional Review Board (IRB).

The process to obtain informed consent consisted of an explanation of the study and the role of the participant in the study (see Appendix E for details of the Introductory Script). The investigator introduced the study, highlighted important elements of the informed consent form, and reviewed the entire consent form with participants prior to the interview. The investigator highlighted the withdrawal process and confidentiality section, and reinforced the coding process to ensure confidentiality. The investigator reviewed and highlighted the interview and audio-taping procedure for the interview, the importance of the investigator’s taking field notes, and process for taking a break or ending the interview should the participant become too upset by the discussion to continue at that time. Appendix G details the required Informed Consent form and Appendix I details the readability of the Informed Consent form. Appendix E details the Introductory Script.

Expectations of participants included signing the informed consent forms, agreement to the interview place and time, and audio-taping of responses when answering questions regarding his or her lived experiences of caregiving for a family member who is dependent upon hemodialysis. Participants answered open ended questions in an audio-taped interview format that were designed to elicit truthful responses to the experience of caregiving for a family member who is dependent upon hemodialysis as a treatment to manage ESKD (refer to
Appendix H for details of the Interview Schedule). The interview time was approximately 90 minutes (including time to review the informed consent form and have questions answered) and interviews occurred in a conference room in the hospital with the time negotiated between the participant and investigator. An additional 15 minutes (approximately) was allocated for summary transcript review by the participant. Using the participant contact information (viable phone number or email address), the investigator contacted the participant to arrange a meeting to review the transcripts. The meeting took place within five business days of transcription of the audio-tapes. The total time a participant was asked to devote to the study was approximately 105 minutes.

The investigator continued the interview as long as the participant felt comfortable in speaking about his or her lived experiences. The risk of psychological or physical stress was minimal to the participant; however if a participant became upset during the interview process, the investigator offered a break from the interview or concluded the interview upon request of the participant. The study protocol included providing tissues and a beverage to the participant during the interview or a break in the interview if the participant desired.

If, in the rare event, the participant experienced an increased emotional difficulty during the interview the investigator would have discontinued the interview and encouraged the participant to seek assistance from his or her physician. This event did not occur with participants in this study. The benefit of this study’s findings was enhanced understanding of the caregiver’s lived experience of caregiving for a family member who is dependent upon hemodialysis. There may be no direct benefits of participation to the participant.

If the participant desired to cease participation in the study, he or she was instructed to notify the study investigator in writing stating the desire to cease participation in the study. If
notified, the investigator would acknowledge this request in written form and keep a hard copy of the cessation request and reply correspondence in the study files. Using the interpretive alphanumeric coding document, the information provided by the participant to the date of cessation would be destroyed upon cessation of the participant in the study. There was no consequence as a result of non-participation in or withdrawal from the study. Participants contacted the study investigator either by email or phone call with any questions or concerns during or after the study. No participants decided to withdraw or cease participation in this dissertation study.

A symbolic gesture of compensation to the participant for the time devoted to the research study was offered to participants (Research Ethics, nd). The interview took approximately 90 minutes and required that the participant travel to the meeting site. The investigator offered a token of appreciation to the participant upon completion of the interview in the form of a $10 gift certificate to a local gas station. The gift certificate assisted the caregiver with the purchase of gasoline to travel to the interview site. The amount of the gift certificate was nominal. If the amount was unduly high, it could unfairly target participants in a lower socio-economic status. Many people desire to be compensated for their time and efforts and in light of the costs associated with the purchase of gasoline, the amount of the gift certificate was appropriate for this study’s participants.

Confidentiality

The investigator maintained confidentiality of the study records including audio tapes, transcripts of the interviews, participant information list, and field notes. Information provided through audio-taped interviews, transcripts of the interviews, and field notes was coded alphanumerically. The investigator kept a participant information list (paper copy of the
interpretive coding document that includes the participants’ name, viable phone number or email address, and alphanumeric code) in a locked, secure location separate from the audio-tapes, transcripts of the interviews, and field notes for management of the study, such as being able to locate and destroy data of a participant who has withdrawn from the study. This participant information list was an interpretive coding document and was the only document that had names, viable phone number or email address, and assigned codes for participants. After the participant information list was typed and printed, the computer version of the document was deleted from the word processing software program on the computer. The investigator did not keep a copy of the participant information list (interpretive coding document) on the computer.

During the interview process, the investigator introduced the participant with an alphanumeric code for audio-taping purposes. The investigator transcribed the interviews using the alphanumeric code as the only identifier. The investigator kept alphanumerically coded, hardcopy interview transcripts in a locked, secure location for three years. The investigator will keep alphanumerically coded field notes in a locked, secure location for three years with the coded hardcopy interview transcripts and audio-tapes. The investigator will destroy the audio-tapes after three years. The audio-tapes will be destroyed by erasing the tapes.

Field notes, audio-tapes of the interviews, and transcripts of the interviews have only the assigned alphanumeric code. The investigator assigned an alphanumeric code for each participant. For example, the first participant was assigned the alphanumeric code A-1, the second participant was assigned the code B-2, and the third participant was coded C-3. Subsequent participants’ interviews followed a similar alphanumeric pattern.
Data Collection

This study included interviews of individuals who were caregivers for family members dependent upon hemodialysis within a 50 mile radius of a mid-sized city on the Mid-Atlantic coast. The investigator performed all of the interviews. During the interviews, the investigator asked the participants open ended questions in a private setting. The investigator audio-taped the interviews after IRB approval and after obtaining written informed consent from the participant. The interviews were designed to allow the participant to describe the lived experience of caregiving for a family member who is dependent upon hemodialysis to manage ESKD. Interviews took place in a conference room at the hospital at a time negotiated between the participant and the investigator.

Approximately 90 minutes was dedicated to each of the study interviews. The 90 minute time frame included time for the investigator to review the informed consent forms and answer any participant questions. Interviews continued beyond 90 minutes if the participant wanted to continue to explore their lived experience. An additional 15 minutes was allocated for summary transcript review by the participant at a differing point in time after the audio-tapes were transcribed. According to McBrien (2008), the process of summary review increases trustworthiness and credibility in qualitative studies.

The audio-taped interviews were alphanumerically coded and transcribed. To transcribe the audio-tapes, the investigator used a personal computer that had up-to-date security software and was also password protected. Only the investigator had the password to the personal computer.

The investigator asked questions during the interview that pertained to the research question regarding the lived experience of caregivers for family members dependent upon
hemodialysis to manage ESKD. The investigator conducted interviews in an inquisitive and non-threatening manner in a comfortable environment for the participant. The investigator recorded the interviews after informed consent was obtained from the participant. The investigator transcribed the interviews and entered the textual data into QSR NViVO 10® software, a program designed to organize and assist in the analysis of text in qualitative study data.

Instrumentation

This phenomenological study used open-ended interview questions in an attempt to capture the wholeness and essence of the caregiver’s lived experience (Moustakas, 1994). The investigator conducted the interviews and, therefore, was the instrument for this study. The investigator worked to gain the richest data possible by establishing rapport with the participant prior to the interview and used focused questions and prompts to elicit complete descriptions (Giorgi, 2009). The aim of establishing rapport with the participant was to develop trust in the investigator and was essential to a successful interview. Focused open-ended questions and prompts that elicited details of an experience helped the investigator respect the participant and the time limits of the interview and assisted in keeping the conversation on topic (Giorgi, 2009). Audiotaping the interview allowed the participant to engage in a free flow expression of thoughts and sharing of experiences.

The initial questions in this interview format were asked of every participant; however, there was an opportunity for the investigator to follow up to clarify statements and for the participant to provide more details of the experience (Richards, 2009). Some of the interview questions were not needed because the answers to the follow up questions were the result of free-flowing communication through the participant’s thought processes. If the information was not
forthcoming through conversation, the questions ensured the same issues were addressed with every participant. Moustakas (1994) suggested that in a phenomenological study carefully worded questions that make no assumptions about the relationships between the participant and the phenomena under study should be asked.

To answer the research question, what is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD, the following interview questions used in this study included:

- Tell me about your daily life as a caregiver to your family member.
- What are you thinking when providing care to your family member?
- How do you feel when you are providing care to your family member?
- Describe the meaning that your caregiving experience has for you.

Based on participant responses, additional open-ended questions were asked to elicit details of the lived experience of caregiving and aid in descriptive theme identification. Appendix E provides the reader with the Introductory Script and Appendix H details the Interview Schedule detailing interview questions. Additionally, the investigator collected demographic data that assisted in providing context for the experience including caregiver gender, age, employment status, type of relationship, where the family member receives hemodialysis treatments (in the home or at a freestanding center), how many times a week the family member receives the treatment, who provides transportation for the family member if he or she receives treatments at a freestanding center, caregiver self-reported health status, types of duties as a caregiver, presence and type of support system, and years of caregiving. Demographic data provided context for the experience and allowed the investigator to explain the caregiving experience within the context of providing care for a family member who is dependent upon hemodialysis.
**Data Analysis**

In this dissertation study, the family members who served as caregivers of family members receiving hemodialysis described their experiences to the investigator in an audio-taped interview. The investigator asked questions designed to elicit responses that described the lived experience of caregiving (Appendix H details the Interview Schedule). The investigator transcribed the audio-taped interviews using a word processing software package and ensuring that the alphanumeric code was the only participant identifier on the transcription document.

The investigator performed data reduction using descriptive analysis. The Giorgi design for data analysis was chosen for this study because the method welcomes descriptions of a lived experience (Mansour & Porter, 2008). Giorgi (2009) outlined the criteria necessary for a qualitative research study using a phenomenological approach, which included the three intertwining steps of reduction, description, and the search for meanings in the phenomenon under study.

In anticipation of using the Giorgi method of data analysis, the investigator bracketed *a priori* knowledge of the phenomenon of caregiving and was aware of this knowledge throughout the data collection and analysis processes (Ebrahim, Wilhelmson, Moore, & Jakobsson, 2012). Following the process described by Giorgi (2009), the investigator read the interview transcript for a sense of the participant’s whole experience of caregiving without marking on the transcript or taking notes. Secondly, the investigator read the interview transcript again more slowly and marked the document where there were perceived shifts in textual meaning. Giorgi (2009) suggested that investigators break the text content into sections that have the same or similar meaning and terms this as “meaning units” (p. 129). Then, the textual unit sections are grouped together. Each transcript was addressed in the same manner.
In the third step of the process, the investigator examined and appraised the similar elements and determined the psychological implications of the description. The investigator used transcripts from all participants in this phase of the analysis. Using transcripts from all study participants allowed integration of the “meaning units” (p. 129) into a cogent description of the lived experience of providing care for a family member who is dependent upon hemodialysis to manage ESKD. This step was most important as the investigator reflected on the meaning of the content shared through personal storytelling by the caregiver (Wertz, 2008).

Wertz (2008) described a fourth step in the Giorgi process, which occurs when the investigator summarizes the psychological structure of the phenomenon in response to the research question and sub-questions. Aligning the data analysis with the research question and sub-questions reflects the nature of phenomenology, examining the context and meaning of lived experiences of phenomena as perceived by the individual in a given situation (Giorgi, 2009).

Demographic information was collected and used to describe the caregiving experience within the context of caring for a family member who is dependent upon hemodialysis. The demographic data collected included the caregiver’s gender, age and employment status, type of relationship, location of hemodialysis (home or ambulatory center) and frequency of hemodialysis, caregiver’s self-reported health status, support system, if available, caregiver duties, and years of caregiving.

**Trustworthiness and Credibility**

This study employed an audit trail to enhance trustworthiness (Golafshani, 2003). Audit trails involve descriptions written in the field, called field notes (Rodgers & Cowles, 1993). Field notes can supplement the audio-taped interview. Field notes in this study were taken discretely and included the nonverbal responses of the participants, features of the physical space
where the interview was being held, and interruptions during the interview process. The field
notes were alphanumerically coded to ensure confidentiality of the participant. The audit trail
included pre-interview notes such as rationale for the chosen research method, correspondence
with faculty mentors, decision points about meaning units, similarities and dissimilarities, and
thought processes affecting decision-making regarding the study (Rodgers & Cowles, 1993).

suggested that peer debriefing offers an investigator a way to increase credibility and
trustworthiness in a qualitative study. Peer debriefing is a process in which an experienced or
expert colleague blindly reviews the data and follows the same data analysis process as the
investigator (McBrien, 2008). The investigator and colleague expert then compare notes to
determine similarities in the data analysis results. If differences are noted, review of the
transcripts and data with collaborative discussion and shared understanding between the
investigator and colleague expert will occur.

Some scholars argue that an outsider could offer alternative explanations that guard
against the investigator’s familiarity with the topic or could show support for the investigator’s
interpretation of the data (McBrien, 2008). Scholars alternatively argue that the peer colleague is
not familiar with the study or the phenomenon and therefore, cannot be expected to provide an
appropriate analysis of the data (McBrien, 2008). This study used the peer debriefing process to
enhance trustworthiness and credibility. The scholarly colleague performing peer debriefing
had access to the coded, anonymous transcripts. The scholarly colleague did not have access to
un-coded transcripts, audio-taped interview data, participant names, or the results of the study.
The investigator did not give the scholarly colleague information regarding who participated in
the study.
Another way to increase trustworthiness and credibility in qualitative studies is for participants to review a summary of their interviews rather than read the entire transcript (McBrien, 2008). Reviewing the transcript summary is not time intensive and does not offer analysis to the participant for his or her validation of the investigator’s interpretation. In the dissertation study, the investigator gave participants a summary of the transcript of their interview to review and determine if the content was an accurate reflection of the participant’s lived experiences and perceptions (McBrien, 2008). An additional 15 minutes (beyond the interview time of 90 minutes) was allocated for transcript summary review by the participant at a time negotiated between the investigator and participant after the audio-taped interviews were transcribed and checked for accuracy.

A reflexive writing journal was maintained during the study process. As the investigator had experienced the phenomenon of caring for a family member who was dependent upon hemodialysis and, therefore, was interested in the experience of others, the investigator sought means to achieve bracketing the lived experience so as to be open to the experience of others. After each interview, the investigator recorded notes and thoughts of the participants’ statements. The investigator also recorded any assumptions and biases or prejudices noted while analyzing the data. The investigator used the recorded notes as part of the process of achieving and maintaining a non-biased approach to the transcript data analysis and research findings. These measures aided in establishing study trustworthiness and credibility (Golafshani, 2003; McBrien, 2008; Rodgers & Cowles, 1993).

**Summary**

Phenomenology is a descriptive tradition of qualitative inquiry. Seeking to describe and understand human lived experiences and relationships, the investigator of this descriptive
phenomenological study explored the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD, including the possible existence of caregiver burden. The investigator used purposive sampling to identify six family members in local ambulatory hemodialysis centers in the mid-Atlantic region. Using a homogeneous group of individuals experiencing the same phenomenon facilitated the interview process through focused attention on one topic (Richards, 2009).

The investigator took ethical principles of human research into consideration when developing this study. The investigator discussed informed consent procedures in chapter three. Design appropriateness and rationale, sampling strategy, and the data collection and analysis procedures are discussed. In chapter four, the investigator will discuss study results and interpretation of the results.
Chapter 4

Findings

Chapter one explored how medical treatments for a family member, specifically hemodialysis, can create lifestyle changes and interrupt the established flow of life for the family. The problem and purpose statement, nature of the study, definitions, assumptions, limitations and delimitations, and the framework for this study, entitled Structural Model: Predictors and Outcomes of Burden, developed by Savundranayagam et al. (2011) was presented to the reader in chapter one. Chapter two addressed the qualitative and quantitative caregiver literature with a focus on the literature search process and historical perspective of caregiving that assisted the researcher in determining what was known and not known in the literature regarding the research problem. Quantitative studies measuring precursors, characteristics, and outcomes of burden were addressed. Qualitative studies related to the experience of caregiving were discussed.

In chapter three, the investigator discussed informed consent procedures, design appropriateness and rationale, sampling strategy, the process to maintain participant confidentiality and anonymity, and the data collection and analysis procedures. In chapter four, the investigator discusses study results and presents the experience of the participants. Chapter four contains the data collection steps, the interview process, participant demographic information, data analysis steps, and discussion of themes identified in the study.

The purpose of this descriptive, phenomenological study was to explore the lived experience of caregivers providing care to a family member using hemodialysis. The study included a series of six semi-structured interviews that were audio-taped and transcribed. During the interviews, participant caregivers shared their experience expressing their thoughts, feelings,
and the meaning of the caregiving with the investigator. The interviews included questions about the caregiver’s daily routine and care giving activities as well as perceptions about their experiences and relationship with the care receiver, the impact of caregiving on their work or social life, and their emotional or physical health since providing care.

This study allowed caregivers to share their daily lives and experiences. Using a phenomenological approach, this study enhanced current literature by providing experiential knowledge of caregivers who care for a family member using hemodialysis as a treatment for ESKD. For this qualitative study the overall research question was: What is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD? Two sub-questions for this study were:

R – 1: What are the perceptions that caregivers have about the experience of providing care for family members dependent upon hemodialysis as a treatment for ESKD?

R – 2: What is the meaning that caregivers give to the experience of caregiving for family members dependent upon hemodialysis as a treatment for ESKD?

The philosophical orientation for this study was curiosity around the human condition, which Giorgi (2009) described as a universal concept. The phenomena of caregiving is contextual and multidimensional and was studied through the contextual lens of the individual (Giorgi, 2009; Wertz, 2008).

Data Collection Procedures

Sample

The investigator enrolled a purposive sample of six volunteer family members who met the study inclusion criteria and experienced the phenomena of caring for a family member who is dependent upon hemodialysis to manage ESKD. The investigator initially recruited five female

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participants and then added a sixth participant, who was a male, to provide the caregiving experience from a male perspective. Each participant engaged in the interview process to answer the research question and all other pertinent questions arising from the data. The investigator asked the participants open ended questions during a private, audio-taped interview.

**Sampling Strategy**

The investigator acquired Institutional Review Board approvals from University of Phoenix and a Health System in central Virginia on the mid-Atlantic coast. Additionally, the Health System hospital provided approval to conduct research on the premises (refer to Appendix C for the PRN form). With the assistance of the nurse manager who served as the institutional gatekeeper, the investigator located potential participants in a medical renal nursing unit and in-patient hemodialysis unit located in a hospital in a mid-sized city in the mid-Atlantic region. The nurse manager (gatekeeper) did not determine eligibility of participants or obtain informed consent; rather the role of the nurse manager was only to assist the investigator with obtaining access to potential participants.

**Interview Process**

When a caregiver indicated an interest in being a participant in the study, the investigator negotiated a time and place for further review of the informed consent process, signing of the informed consent form, and the formal audio-taped interview. The investigator performed all of the interviews. Interviews took place in a conference room at the hospital at a time negotiated between the participant and the investigator.

Approximately 90 minutes was dedicated to each of the study interviews. The 90 minute time frame included time for the investigator to review the informed consent forms and answer any participant questions. Actual time for the audio-taped interview ranged between 45 and 70
participants were informed of their alphanumeric code at the time of the interview meeting.

The investigator asked open-ended questions during the interview pertaining to the research question regarding the lived experience of caregivers for family members dependent upon hemodialysis to manage ESKD (See Appendix H Interview Schedule). The investigator conducted interviews in an inquisitive and non-threatening manner in a comfortable environment for the participant. The investigator recorded the interviews with participant consent.

The investigator gained the richest data possible by establishing rapport with the participant prior to the interview and used focused open-ended questions and prompts to elicit complete descriptions (Giorgi, 2009). Participants stated they were comfortable in the interview setting and with the investigator prior to starting the interview. Audio-taping the interview allowed the participant to engage in a free flowing expression of thoughts and sharing of experiences.

The initial questions in this interview format were asked of every participant; however, there was an opportunity for the investigator to follow up to clarify statements and for the participant to provide more details of the experience (Richards, 2009). To answer the research question, what is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD, the following interview questions asked in this study included:

- Tell me about your daily life as a caregiver to your family member.
- What are you thinking when providing care to your family member?
- How do you feel when you are providing care to your family member?
- Describe the meaning that your caregiving experience has for you.
Five of the six participants met with the investigator twice during the data collection process. The first meeting was to obtain informed consent and conduct the interview while the purpose of the second meeting was transcript summary review. Both meetings took place in person in a confidential setting at a time negotiated between the investigator and the participant. The investigator was unable to contact one participant for a transcript summary review because her telephone number had been disconnected.

Data Analysis Method

The study used the Giorgi (2009) method of data analysis. The Giorgi design for data analysis was chosen for this study because the method welcomes descriptions of a lived experience (Mansour & Porter, 2008). Giorgi (2009) outlined the criteria necessary for a qualitative research study using a phenomenological approach, which included the three intertwining steps of reduction, description, and the search for meanings in the phenomenon under study.

During the data analysis phase, the investigator set aside, also known as bracketing, a priori knowledge of the phenomenon of caregiving and was aware of this knowledge throughout the data collection and analysis processes, which ensured a focus on the participant experience (Ebrahim et al., 2012). Specifically, the investigator bracketed previous lived experience of caregiving for a family member who was dependent on hemodialysis. The investigator also bracketed the model used as a theoretical framework for this study and other theories of caregiving found during the literature search.

Following the process described by Giorgi (2009), the investigator read the interview transcript for a sense of the participant’s whole experience of caregiving without marking on the transcript or taking notes. Secondly, the investigator read the interview transcript again more
slowly and marked the document where there were perceived shifts in textual meaning. Then, the textual unit sections were grouped together. Each transcript was addressed in the same manner.

After the two steps in the process described by Giorgi (2009), the investigator entered the textual data into QSR NVivo 10® software, a program designed to organize and assist in the analysis of text in qualitative study data. The software program assisted in organizing the data into nodes that allowed the investigator to develop categories and see patterns emerge from the data. The investigator used the categories to develop a frequency table that contributed to the development of themes related to the research question and sub-questions.

In the third step of the process, the investigator examined and appraised the similar elements and determined the psychological implications of the description. The investigator used transcripts from all participants in this phase of the analysis. This step was most important as the investigator reflected on the meaning of the content shared through personal storytelling by the caregiver (Wertz, 2008).

Wertz (2008) described a fourth step in the Giorgi process, which occurs when the investigator summarizes the psychological structure of the phenomenon in response to the research question and sub-questions. Aligning the data analysis with the research question and sub-questions is the fourth step in the process. In this step the investigator reflected upon the nature of the phenomena and examined the context and meaning of lived experiences of being a caregiver for a family member dependent upon hemodialysis as perceived by the individual.

**Trustworthiness and Credibility**

The investigator used several means to establish trustworthiness and credibility in this dissertation study. The investigator in this study employed an audit trail to enhance
trustworthiness (Golafshani, 2003). Field notes supplemented the audio-taped interview and were taken discretely. The notes included the nonverbal responses of the participants, features of the physical space where the interview was held, and interruptions during the interview process. The field notes were alphanumerically coded to ensure confidentiality of the participant. The investigator used the field notes to recall the actual interview. Participants’ non-verbal expressions and intonation were important when the investigator recalled the content of the conversation and participant’s responses to interview questions. When reading through the transcripts, the investigator used the field notes to recall participant’s emotions and body language when answering questions during the interview. Using the field notes to recall the actual interview helped the investigator better understand the lived experience of caregiving for a family member who was dependent upon hemodialysis.

Another technique used to increase trustworthiness and credibility for this study was for participants to review a summary of their interviews (McBrien, 2008). An additional 15 minutes was allocated for summary transcript review by the participant at a different point in time after the audio-tapes were transcribed, usually within a week. After the interview, the investigator gave participants a summary of the transcript of their interview to review and determine if the content was an accurate reflection of the participant’s lived experiences and perceptions (McBrien, 2008). One participant was unable to review the transcript summary because her phone number had been disconnected when the investigator attempted to call and arrange a meeting to review the transcript. The investigator had no other contact information for the individual participant. The investigator listened to the tape again and double checked the accuracy of the transcript in relationship to the recording.
This study also used the peer debriefing process to enhance trustworthiness and credibility as described in chapter three. The investigator accepted the invitation of a scholarly colleague (peer reviewer) to assist in the process for ensuring the rigor of the data analysis of the dissertation study, as approved by the two IRBs. The colleague readily agreed to serve in this role to ensure study trustworthiness and credibility. The colleague was a registered nurse with a doctoral degree and previous experience in conducting qualitative research (Seegers, 2005; 2007). The colleague signed a non-disclosure agreement as required by the two IRBs (see Appendix J).

The scholarly colleague performing peer debriefing had access to the coded transcripts used to ensure confidentiality. The scholarly colleague did not have access to un-coded transcripts, audio-taped interview data, or participant names. The investigator did not give the scholarly colleague information regarding the identity of participants in the study.

The peer reviewer and investigator processed and analyzed the data separately using the Giorgi method of data analysis. The investigator contacted the peer reviewer when data analysis was completed to discuss insights and to clarify decisions of the investigator, using the audit trail to recount the investigator’s analysis process. The colleague provided assistance with categorizing data and offered beginning themes for the investigator to consider and compare with her own analysis. The investigator and peer reviewer identified most of the same categories and beginning themes and there were no major discrepancies or differences in data analysis between the investigator and peer reviewer. A minor discrepancy existed with one subtheme in that the peer reviewer offered several different categories that included participant’s emotional responses. The investigator identified the same emotional responses; however, the investigator decided that the emotional responses should not be separated, but rather placed into the one sub-
theme. At the end of the meeting with the peer reviewer, the investigator gathered all notes and copies of the colleague’s coded transcripts. The investigator further reviewed the notes and comments made by the colleague, clarified information with the peer reviewer when appropriate, and assimilated all of the information into the themes identified by the investigator.

A reflexive writing journal was maintained during the study process. Because the investigator had previously experienced the phenomenon of caring for a family member who was dependent upon hemodialysis the investigator sought means to achieve a non-judgmental approach to the data so as to be open to the experience of others. After each interview, the investigator recorded notes and thoughts of the participants’ statements. The investigator also recorded any assumptions, biases, or prejudices noted while interviewing the participant or analyzing the data. The investigator used the recorded notes as part of the process of achieving and maintaining a non-biased approach to the transcript data analysis and research findings. These measures aided in establishing study trustworthiness and credibility (Golafshani, 2003; McBrien, 2008; Rodgers & Cowles, 1993).

Results

A demographic questionnaire was developed by the investigator and used to collect descriptive information about the participant. The investigator used the demographic data to explain the caregiving experience within the context of providing care for a family member who is dependent upon hemodialysis. The demographic data collected included caregiver gender, age, employment status, and the type of relationship with the family member. The data collected also included caregiver self-reported health status, types of duties as a caregiver, presence and type of support system, and length of time as a caregiver. See Table 2 for a summary of the participant’s coded demographic information that includes gender, age, length of time as a
caregiver, and relationship with the family member. Other data collected included the location where the family member received hemodialysis treatments (in the home or at a freestanding center), how many times a week the family member received the treatment, and who provided transportation for the family member if he or she received treatments at a freestanding center (see Table 3).

This study included interviews of six individuals who self-identified as caregivers for family members dependent upon hemodialysis and lived within a 50 mile radius of a mid-sized city on the Mid-Atlantic coast. There were five females in the study who ranged in age from 29 to 56 years old. There was one male participant who was between 25-30 years old. The caregivers’ relationships with the family member included daughter, wife, granddaughter, and son-in-law. Participant A – 1 cared for her maternal grandmother who received hemodialysis. Participants B – 2 and D – 4 were the daughters of mothers on hemodialysis, while Participant C - 3 cared for her father. Participant E – 5 was the wife of the family member on hemodialysis. Participant F – 6 was the son-in-law of his wife’s mother who is on hemodialysis.

The average length of time of caregiving was 3.7 years and ranged from two months to 10 years. Three caregivers had been managing care for the family member for two years, one caregiver managed care for the family member for 10 years, and one caregiver managed care for four years. One caregiver’s family member had been on hemodialysis for two months. See Table 2 for more details.
Table 2: Participant Code and Demographic Information

<table>
<thead>
<tr>
<th>Participant Code</th>
<th>Participant Gender</th>
<th>Participant Age Range</th>
<th>Length of Time as a Caregiver</th>
<th>Relationship with Family Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>A – 1</td>
<td>F</td>
<td>25-30</td>
<td>4 years</td>
<td>Granddaughter of maternal grandmother</td>
</tr>
<tr>
<td>B – 2</td>
<td>F</td>
<td>35-40</td>
<td>10 years</td>
<td>Daughter of mother</td>
</tr>
<tr>
<td>C – 3</td>
<td>F</td>
<td>35-40</td>
<td>2 years</td>
<td>Daughter of father</td>
</tr>
<tr>
<td>D – 4</td>
<td>F</td>
<td>25-30</td>
<td>2 years</td>
<td>Daughter of mother</td>
</tr>
<tr>
<td>E – 5</td>
<td>F</td>
<td>55-60</td>
<td>2 months</td>
<td>Wife</td>
</tr>
<tr>
<td>F – 6</td>
<td>M</td>
<td>25-30</td>
<td>2 years</td>
<td>Son-in-law of wife’s mother</td>
</tr>
</tbody>
</table>
Participant Employment Status

Five participants reported working full-time while caring for their family member. One participant worked part-time while in college full-time. Two of the participants who worked full-time reported that they worked in the healthcare field, one as a certified nursing assistant and the other as a hospice nurse. One participant, who worked full-time, stated she worked in the IT department of a large local healthcare organization. One participant who worked full-time reported that she worked at a local community college as a manager and is in graduate school part-time, working on a master’s degree in accounting. The remaining participant who worked full time is employed in a local factory and works rotating shifts. One participant stated she was a senior student in a baccalaureate nursing program and worked as a pharmacy technician part-time while she was in college (see Table 3 for a summary description of employment status).
<table>
<thead>
<tr>
<th>Participant (Caregiver)</th>
<th>Caregiver Employment Status</th>
<th>Location of Hemodialysis Treatment/ Frequency</th>
<th>Transportation to Hemodialysis, if Ambulatory Center</th>
<th>Caregiver Self-Reported Health Status</th>
<th>Caregiving Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td>A - 1</td>
<td>Part-time employee Full-time Student</td>
<td>Ambulatory Center/3 times a week</td>
<td>Family or Hired Aides</td>
<td>“Average”</td>
<td>Bathing; manage medications; schedule medical appointments; shopping; hair appointments;</td>
</tr>
<tr>
<td>B - 2</td>
<td>Full-time</td>
<td>Ambulatory Center/3 times a week</td>
<td>Medical Transport Company</td>
<td>“Pretty healthy”</td>
<td>Point of contact for medical personnel; grocery shopping; arranging hemodialysis transportation; arrange physical therapy; ordering supplies; manage medications</td>
</tr>
<tr>
<td>C - 3</td>
<td>Full-time</td>
<td>Ambulatory Center/3 times a week</td>
<td>Family or Medical Transport Company</td>
<td>“Poor, very poor”</td>
<td>House cleaning; socializing; manage medications</td>
</tr>
<tr>
<td>D - 4</td>
<td>Full-time</td>
<td>Ambulatory Center/3 times a week</td>
<td>Family or Drives Self</td>
<td>“Pretty good, pregnant with second child”</td>
<td>Manage medications; accompany to medical appointments; medical supplies; insurance company</td>
</tr>
<tr>
<td>E - 5</td>
<td>Full-time</td>
<td>Ambulatory Center/3 times a week</td>
<td>Family</td>
<td>“Excellent”</td>
<td>Bathing; cooking meals; wash clothes; manage medications; medical supplies; accompany to medical appointments; manage finances</td>
</tr>
<tr>
<td>F - 6</td>
<td>Full Time</td>
<td>Ambulatory Center/3 times a week</td>
<td>Family or Drives Self</td>
<td>“Top Notch”</td>
<td>Emotional support for wife; cares for child while wife does things for mother; assists with dietary adherence; attends medical appointments</td>
</tr>
</tbody>
</table>
Presentation of Themes for Sub-Question 1

Data saturation in a phenomenological study necessitates the addition of new participants until a repetition of data is reached (Bowen, 2008). According to Bowen (2008), data saturation ensures replication in categories with thorough explanation of the category. In this study, participants were experts in the phenomenon of caregiving for family members dependent upon hemodialysis and were an appropriate sample. Data saturation was reached with the first five participants and adding the sixth participant demonstrated that the same themes and sub-themes existed within his experience.

For this qualitative study the overall research question was: What is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD? There were three themes and nine sub-themes identified that related to the first sub-question: What are the perceptions that caregivers have about the experience of providing care for family members dependent upon hemodialysis as a treatment for ESKD? The themes are: Caregiving is Hard Work; Caregiving is Stressful, and Caregivers Need a Support System. There are eight sub-themes that directly relate to the experience of caregiving for a family member using hemodialysis. The sub-themes are: Organizing Care Requires Planning, Co-Morbid Conditions Compound Basic Care Needs, A Different Challenge Every Day, Transportation is an Ongoing Challenge, Compromised the Health of Caregiver, An Unbalanced Life, An Indeterminate Timeline, Shared Decision Making, and Sharing the Workload (See Table 4: Frequency Table for Sub-question R-1 Theme and Sub-theme details).
Table 4. Frequency Table for Sub-Question R-1 Themes and Sub-themes

<table>
<thead>
<tr>
<th>Sub-Question R-1: Perceptions of Caregiving</th>
<th>A - 1</th>
<th>B - 2</th>
<th>C - 3</th>
<th>D - 4</th>
<th>E - 5</th>
<th>F - 6</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving Is Hard Work</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>6</td>
</tr>
<tr>
<td>Organizing Care Requires Planning</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>5</td>
</tr>
<tr>
<td>Co-morbid Conditions Compound Basic Care Needs</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>6</td>
</tr>
<tr>
<td>A Different Challenge Every Day</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Transportation is an Ongoing Challenge</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Caregiving is stressful</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Compromised Health of Caregiver</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Changes in Lifestyle</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>An Indeterminate Timeline</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Caregivers Need a Support System</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Shared Decision Making</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Sharing the Workload</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>

**Caregiving Is Hard Work**

Caregivers perceived that their experience of providing care for a family member who is dependent on hemodialysis as hard work. This major theme was found in all of the participant interviews. Caregivers in the study shared that they helped the family member with various aspects of daily personal care, assisted in transportation of the family member to and from the dialysis center or made arrangements for transport, and managed finances. Caregivers also kept a calendar to organize medical appointments and assistive personnel, served as the main contact person for physician and ancillary health care staff, bought groceries and supplies, cooked meals, accompanied family members to medical appointments, cleaned house, and/or managed medications and treatments for other medical conditions. Caregiving duties were carried out in addition to other responsibilities in the caregiver’s life such as caring for children, working full
or part-time, and attending college-level education programs. One participant reflected that she was busy every day, working hard to keep on top of all her life demands. She recalled that she told her sister the following about her struggles, “…doing these things for mom was a full time job and then having a REAL full time job that I have to report to everyday and then have school, too” (B - 2). The participant placed emphasis on the word ‘real’ to differentiate the job of caregiving for her mother from her work in a paid position as a manager. Another participant cared for her grandmother in addition to working part time and going to school full time. She lamented she could not do as much as she wanted for her grandmother, “Before school got so crazy, I would stay with her but right now I can’t do it” (A – 1).

**Sub-theme: organizing care requires planning.**

All six caregivers had siblings or other family members with whom they shared caregiving duties. Coordinating the schedule was felt by caregivers to be the best way to allocate caregiving duties and responsibilities among the other family members and allowed the caregiver some personal time as well. Two caregivers thought that a good way to manage the added responsibilities of caregiving for a family member on hemodialysis was to have a calendar to coordinate the family member’s activities. One participant stated, “There are five children and 14 grandchildren in the family and we take turns doing things for my grandmother, so we have to organize. The calendar is the best way to organize everyone” (A - 1).

The other participants echoed these sentiments and related stories of organizing personal schedules with family member’s routine needs and medical appointment schedules. Participant B – 2 shared, “I have two sisters and we put up a calendar to make sure these are the weekends that we can help out.” Regarding organizing her busy schedule with full-time employment and
transporting her mother to dialysis three times a week, Participant D – 4 stated, “I would have to leave work and take my breaks to take her to the center three times a week.”

For the five caregivers who worked full time, flexibility in their work schedule was very important to them in order to organize and plan the care their family member needed. Four caregivers reported being able to come in late to work, take extended lunch breaks, or leave early to attend to caregiving duties for the family member. The support they received from their supervisor or manager at work to care for their family member helped to decrease stress and served to increase their dedication to the job. Participant E – 5 shared, “My co-workers and my manager give me lots of support. My manager is going through something similar with her sister so she is good to me.” Participant B – 2 related a story of a former employer who admonished her for leaving work to attend to her mother when she was in the hospital shortly after her stroke. She said, “I used to work 60-70 hours a week and had been there for 13 years when mom had the stroke. My supervisor wanted me to stay late to meet with a client who was 45 minutes late for the appointment. I just couldn’t do it. I knew it was time to leave that job.” Now, she works for an employer who allows her flexibility in her daily schedule, “…to have flexibility and leave early, that means the world to me.”

As caregivers move through differing stages of their lives, the ability to organize and plan care that will meet the demands of caring for their family member was questioned. Participant D - 4 was pregnant at the time of the interview and she expressed concerns that her organization and planning would not work as it was currently designed when the baby was born. She shared that when her baby is born she anticipated more conflict in managing and organizing care for her mother as her newborn will take priority for her attention. This participant expressed anguish at the thought of how she will
manage and organize care for her growing family and her mother at the same time, “I just won’t be able to run back and forth like I did…it’s hard to balance,” she continued, “I don’t see her as much as I used to because when you have your own family, your own children take precedence” (D - 4).

Increased stress occurred when one caregiver did not plan or organize care for the family member. Participant C - 3 relied on her brother to give her directions for her contribution to the care of their father. The brother did not keep an organizational calendar and she shared that she does not plan her life, “I just go with the flow; I don’t plan and have to go day by day” (C – 3). She expressed that her practice of non-planning caused increased stress and led her to poor self-care habits such as chain smoking and poor nutritional choices. Participant C – 3 shared, “I drink about a 12 pack of Pepsi® right now…always caffeine and nicotine, that’s how my body is going right now.”

**Sub-theme: co-morbid conditions compound basic care needs.**

All six of the caregivers expressed that their family members needed more assistance because of co-morbid conditions such as stroke, myocardial infarction, amputation of lower extremities, or chronic obstructive pulmonary disease (COPD), conditions that may or may not be unrelated to their dependence on hemodialysis. An activity of daily living such as bathing and dressing was difficult for a family member who had a stroke or difficulty with breathing. Caregivers expressed the need to either provide physical care for the family member or make arrangements for others to provide the care. Participants shared that they hired nursing assistants for daily care or transported the family member to their home several times a week to allow the family member to shower. As Participant A – 1 explained, “My grandmother can’t walk up
stairs anymore and her full bathroom is on the second floor so I bring her to my house several
times a week to shower since I have a one story house.”

This is an area where an organizational calendar and working with other family members
assisted the caregiver in arranging for the family member’s care. For a family member without
other chronic illnesses, hemodialysis treatments did not render them unable to care for
themselves. The family members of several caregivers were able to care for their own basic
needs and did not need assistance. In these situations, caregivers expressed that this was one
aspect of care they were relieved to not need to arrange for the family member. As Participant -
2 expressed, “She needs people with her all the time. I’m just trying to manage the parts and
work full time. Thank goodness we have nursing aides to help her.”

Three participants recalled an old saying, ‘once a man, twice a child’ when referring to
the provision of physical care for their family member. Participants expressed sadness at the
situation in which they found themselves needing to provide physical care for their family
member. One participant, who cared for her husband who had a previous stroke and who had
been recently, diagnosed with multiple myeloma, recounted, “I bathe him. He can do his mouth
care but he can’t comb his hair. I shave him…it’s just not what I envisioned my life being and
excuse me for becoming emotional…it’s kind of like having another child” (E – 5). Regarding
her father who now needed more help with physical care because of recent lower extremity
amputations, Participant C – 3 recounted, “What’s that saying? Once a man and twice a child so
I guess that’s what it is.”

Other participants expressed similar sentiments when providing physical care for family
members. Watching a family member transition from being independent to being dependent for
care needs was difficult for caregivers. Participants felt that they experienced role reversal as
their aging parents needed more assistance. They saw this transition as abnormal and it made them sad. “It’s hard to be the caregiver for someone who took care of you for so long, it’s hard to see her like this. That’s the biggest transition” (B – 2). Participant D – 4 shared, “I feel sad at times because I know it’s the end.” In one case, the caregiver expressed frustration because she felt she was in the “sandwich generation,” caring for her young family and mother. Participant D – 4 stated, “I’m in the sandwich generation, taking care of my mom and my children.” Several caregivers expressed difficulty accepting their aging parents becoming dependent and acknowledged that the transition was difficult for the family member as well. “It’s hard to see my dad be dependent,” one participant explained, “I know it’s hard on him, too” (C – 3).

**Sub-theme: a different challenge every day.**

Instrumental activities of daily living (IADL) such as managing dietary restrictions, medication management, and dealing with the insurance and durable medical equipment companies are concerns for caregivers of family members using hemodialysis as a treatment for ESKD. All six participants reported concerns with IADL. Participants reported that they engaged in daily conversations either on the phone or in person with their family member. The conversations were catalysts for a daily “To Do” list for the care of the family member. Participant B – 2 shared that she starts her mornings with a phone call to her mother to ensure the morning nursing assistant had arrived. She then followed up with a report on her mother’s vital signs, blood glucose level, and checking her mother’s calendar. “What’s coming up? Like any doctor appointments and who will take her. What supplies or medications does she need? That’s the day to day stuff” (B – 2). Several participants work nearby where the family member has dialysis treatments and often visited with them during lunch or after work before going home.
for the evening. Participant D – 4 stated, “She lives close to where I work but I live in Southside so we don’t see her in the evenings.”

Daily challenges that some caregivers experienced included managing medications and meal planning and preparation for family members. Other day-to-day challenges involved managing different aspects of the family member’s care like transportation, calling the pharmacy for medication refills, making doctor appointments, ensuring nursing assistant coverage, hospitalization, and managing finances. Participants recalled feeling overwhelmed at times in trying to keep focused on their jobs and own lives while managing differing aspects of the family member’s life. As Participant D – 4 shared, “It’s been very hard to put as much energy into things. Before I could focus more energy on her but now sometimes I feel burdened.” Participant C – 3 recalled, “I have a daughter who has health issues right now, too…I’m getting overwhelmed.”

Some caregivers went grocery shopping for the family member in addition to meal planning based on the dietary restrictions that must be followed by individuals who are dependent on hemodialysis. Other caregivers cleaned the family member’s house at some point during the week. These additional duties resulted in the caregiver feeling pulled in different directions and not fully satisfied with the job they were doing. As one participant explained, “I do the best I can” (D – 4). Participant C – 3 shared, “My stress is trying to maintain work life and home life.”

Sometimes these daily responsibilities result in added stress for the caregiver. One caregiver recounted that she needed to call the insurance company because they did not authorize delivery of oxygen for her mother who has COPD in addition to being on hemodialysis. “She has to have oxygen; she wears it all the time” (D - 4). She expressed frustration at having to call
the insurance company again after all arrangements had been made previously. The time it took away from her workday to focus on this issue was stressful.

Another challenging aspect of care for a hemodialysis patient is dietary restrictions. Two caregivers discussed this as a major issue in caregiving. Only certain amounts of protein, minerals, and fluids are allowed as part of the diet. This can make meal planning and preparation difficult. As an example, individuals who are dependent on hemodialysis must have fresh meats and vegetables. Processed foods like canned vegetables and sausage have increased amounts of sodium that are disallowed on the hemodialysis diet. Caregivers need to be vigilant about the diet of their family member if the family member is not able to do that for themselves. Dietary restrictions can result in difficulty figuring out what foods to prepare for the family member. Participant A – 1 shared a story about making meals for her grandmother that were according to her dietary guidelines. She stated, “Over the summer I was buying groceries for her using the dialysis diet guidelines and foods to keep her healthy. Her fluid restriction is pretty well controlled.” She continued, “My other family members didn’t pay attention to the guidelines.”

Two caregivers shared that sometimes the inability to manage a challenge can result in stress for the caregiver. One participant recalled that because the other family members were busy with their own lives, they bought soup and processed foods for the nursing assistants to prepare for the family member. This caused stress in the participant because she knew that these foods were on the restricted list. When she prepared the meals for her family member, she was diligent to include foods the family member could have. She confronted the other family members about their non-adherence to the approved dietary plan. She recalled, “They would buy
her frozen dinners and canned vegetables. I was like, ‘This isn’t right, buy frozen vegetables instead because they are healthier than canned’ and still easy to fix’ (A - 1).

Another caregiver expressed the same frustration; however, it was directed at his mother-in-law who fixes her own meals. The caregiver reported that his mother-in-law does not adhere to dietary guidelines. When they go out to eat as a family unit or when he and his wife have her over for dinner, he discusses her dietary restrictions and choices with her. He reported trying to appeal to her softer side, stating, “I told her to take care of herself because your daughter is pregnant and I want my children to have their grandmother” (F - 6).

One caregiver reported that managing the finances for the family member can be tricky and stressful. Ensuring that the money for care of the family member is available is important to caregivers. When the cost of care, for example medications, exceeded the financial capacity of the family member, one caregiver felt the need to supplement with her own money. This caused added stress and challenged the ability of the caregiver to manage her own finances. She stated, “I used to pay for her medications, about $400 a month. But now I have a child in daycare and can’t do it. I know she doesn’t buy all of her medications now because of the cost. I can’t help that and just have to let it go” (D - 4). Even though she no longer pays for her mother’s medications, this participant expressed frustration that her mother is not taking care of herself, which leads her to becoming unhealthier with increased visits to the hospital.

Frequent hospitalization of the family member is another challenge that three caregivers in this study experienced. Most of the family members had co-morbid conditions in addition to requiring the use of hemodialysis to manage ESKD. Caregivers expressed that the hospitalizations disrupted their weekly routines and caused added stress and worry about the family member’s condition. Participants recalled having to stop by the hospital before going to
work, home for the night, or at lunchtime. For caregivers with children, this meant prolonged day care for the child. Participant D - 4 recalled that when she visited her hospitalized mother, her daughter was in daycare until eight o’clock in the evening. She had to pay extra money for this service and it upset her that she missed valuable time with her young daughter. Participant D – 4 expressed, “When my mom was in the hospital and my daughter was in daycare, I was upset that the daycare had to take over…I was more concerned about them having to take care of my child.”

Many times caregivers spent time trying to reach physicians and other health care providers to discuss the family member’s care, which led to added frustration and worry. Three caregivers expressed the need to follow up with physicians or the dialysis clinic regarding the family member’s condition. Participant E – 5 shared, “It gives me some relief that he’s in the hospital now; when doctors know you are a nurse they put off your need to explore aggressive treatment.”

One caregiver reported that when they were out of town, his wife attempted to call her hospitalized mother multiple times, to no avail. His wife became frazzled and he offered to drive her home, a 600 mile journey. Participant F – 6 recalled, “My wife just lost it. I held her as she cried. I told her that if we have to leave and drive 600 miles home, that’s fine, we’ll do it.”

Sub-theme: transportation is an ongoing challenge.

All participants reported that their family member received hemodialysis at a freestanding hemodialysis center. The family member arrived at the center at a regularly scheduled time, received dialysis, and waited until their blood pressure stabilized before leaving the center. The participants recounted that the entire time at the dialysis center averaged
approximately four to five hours a day, three days a week, usually every other day except Sunday.

Arranging transportation was challenging for the six caregivers in this study especially when they were responsible for transporting the family member. As most of the caregivers worked full time, they needed the support of their supervisor or manager at work in addition to co-workers to schedule time for transporting the family member during the work week. One caregiver expressed that shuttling her family member back and forth to dialysis was “burdensome.” Participant D – 4 shared, “At first I used to drive mother there three times a week…I would have to leave work and take my breaks to take her to the center and it becomes burdensome after a period of time doing that.” She shared that her mother recognized the issues her daughter was having with transporting her and bought a car. She now drives herself to and from dialysis. Regarding the new situation, Participant D – 4 said, “…that’s a blessing because it was a burden, it really was.”

Another family member had made a tentative schedule with her son to transport her husband but sometimes that arrangement fell through. She then had to scramble to make other arrangements by calling on other family members or friends. This caused added stress and worry that her husband would not get to the dialysis appointment on time and she did not like imposing on others for assistance. On the days her husband has dialysis, Participant E – 5 shared, “…my son takes him. If he can’t then we ask a friend and if he can’t do it then I have to adjust my schedule to take him. Ninety seven percent of the time I pick him up.”

Caregivers who hired others to transport the family member expressed astonishment with the costs of medical transportation. One caregiver hired a retired person to transport her mother but found this too expensive so she arranged for a medical transport company that accepted
Medicare payments. She lamented, “Paying for medical transport isn’t cheap” (B - 2). The added financial burden left the caregiver wondering how she would manage the payments.

Medical transport companies offer door to door service, which means that the drivers do not get out of the van to assist the individual they are transporting nor do they wait past the appointed pickup time before moving on to the next stop. When a family member has special needs, getting to the van can be a challenge. Recent bilateral lower extremity amputations in one family member necessitated the caregiver travel to the family member’s house three times a week and get him ready and to the curb for pick up by the van at the appointed time. Participant C – 3 reported, “The issue was that transport would not get him because he couldn’t get to the van so the family had to provide transportation. Now he has a ramp and can get to the curb.” This added responsibility produced feelings of frustration in the caregiver as she tried to manage the extra care and get to work on time. The caregiver had been out of work for a year and was recently employed.

**Caregiving Is Stressful**

Exploring the nature of caring for family members using hemodialysis as a treatment for ESKD and episodes of declining caregiver health represented an essential part of this experience. Five of the six participants reported working full time and one participant worked part-time while attending college full time in addition to the caregiving responsibilities. One participant was in a graduate degree program as well.

All participants reported stress and anxiety in their lives related to the caregiving experience. The stress and anxiety experienced by the caregivers manifested physical as well as emotional complaints and was often reported as a decline in caregiver health status. Participants expressed that managing a full time workload while caring for children as well as the family
member could lead to feelings of being overwhelmed at times. As Participant C – 3 shared, “I think that he realizes I’m getting overwhelmed with my daughter and he’s not pushing me so much to do for him.” Participant D – 4 stated, “Taking care of an older individual is not a walk in the park when they have so many medical conditions. I do the best I can.”

Caregivers reported experiencing anger and frustration with their situation. For some caregivers the anger is directed toward the family member for not following physician orders when they were younger in order to be healthier when older. Trying to not let the family member know the caregiver is angry adds to the perceived stress. One participant, whose mother was hospitalized, expressed anger that her mother didn’t follow physician orders and was in the hospital. She reported, “I really try hard to not let her know that I am angry” (D - 4). Lamenting her family’s situation, one participant expressed anger and recognized that she had feelings of self-pity, “…sometimes I have a moment when I’m thinking ‘poor me’ or ‘poor him’ and that hurts” (E – 5).

Multiple sources of stress can lead to poor coping mechanisms. One participant (C – 3) admitted that she was a chain smoker, drank a lot of soda, and did not eat very much at all. She served as a caregiver for her father as well as her teenage daughter who was experiencing medical issues at the same time as her father’s issues. Participant C – 3 reflected, “The stress is trying to maintain work life and home life. I have a daughter with health issues right now. I don’t have a support system.” When asked what this participant did to relax she replied, “I smoke, I’m like a chain smoker right now. I feel that the cigarette is my best friend.” This caregiver also experienced guilt when not knowing which family member to focus on at any given time. The caregiver felt like the guilt was another source of stress for her. Knowing she was making poor choices, like smoking and eating junk food, was a cause of stress, too. She
could not identify any positive coping mechanisms that she could use to manage her stress. The participant reported, “My health is poor because of the stress level. I’m so stressed that I think my body would go into shock if I relaxed.”

As the caregiver experiences life changes, such as the birth of a child, coping mechanisms can be affected. For one participant, the impending birth of a new daughter presented added stress. Rather than enjoying her pregnancy and looking forward to the birth of a second daughter, she often feels conflicted between caring for her mother and young family. She expressed that she is not sure how she will manage. She admitted that she is frequently tired and frustrated with her responsibility of caring for her mother. Participant D – 4 reported, “Sometimes I can’t go home from work because I have to take care of her. She’ll throw a guilt trip on me like, ‘Can’t I be first?’ So we go through fights about that.”

**Sub-theme: caregiving can compromise health of caregiver.**

All six participants recognized stress as part of the caregiving experience and how it contributed as a factor in their own health status. Participants rated their health as ranging from “Excellent” to “Poor, very poor.” A summary description of caregiver self-reported health status is located in Table 3.

Three participants admitted they were overweight and did not eat a balanced diet. These individuals felt that when things were calmer in their lives they made better food choices. Eating unbalanced meals and smoking seemed to be a source of added stress for these caregivers, knowing they were making poor choices. One participant was pregnant at the time of the interview and attributed weight gain to the pregnancy (D – 4). Even though some caregivers did not practice healthy dietary habits, they denied risk factors for chronic diseases. The caregivers seemed to take refuge in the fact that they did not have the risk factors for kidney disease such as
diabetes and hypertension. Participant F – 6 reported, “I’m not diabetic and was never on dialysis. I don’t want to be diabetic but I did have hypertension. Now I take care of myself and don’t have it anymore.” Participant B – 2 shared, “Considering the risks for dialysis, I’m pretty healthy.”

Five caregivers recognized that they did not follow a routine plan of exercise when caring for a family member, which they identified as likely to be helpful to them in managing stress. One caregiver lamented the fact that she couldn’t get on a routine at the gym because of the different daily needs of her mother. “There’s just not enough hours in the day,” she reported (B – 2).

Two participants exercised regularly, which they say helped them stay in good physical shape and manage stress and the frustration of the situation. Participant E - 5 admitted that she ate a good diet including lots of fruits and vegetables. Regarding her exercise routine, she reported, “I kick box for one thing…hitting and kicking something as hard as you can helps a whole lot to deal with the frustration.” Participant F – 6 reported that he went to the gym and runs on the treadmill for exercise and stress reduction, “Now I get on the treadmill and run for 25-30 minutes. It feels great.”

**Sub-theme: changes in lifestyle.**

A change in lifestyle, social routines, and the ability to participate in recreational activities is associated with the caregiving role. Two caregivers reported that they used to take vacations with their family member but the hemodialysis treatments make it difficult to arrange. According to the caregivers, the social worker at the dialysis center can assist with making arrangements for dialysis to occur at a vacation destination. However, caregivers also recognized there was a negative impact that hemodialysis treatments had while traveling with
their family member. Regardless of the location, hemodialysis takes time away from recreational activities and causes concerns for the family member because the staff at the new center does not know the family member. Unfamiliar staff and physicians can make some caregivers leery of traveling in case of a family member emergency. This causes some caregivers to feel sad and reminisce about the times they traveled together. As one participant explained, “We were always very active, and travelling ….now he can’t go and sometimes I have to go alone” (E - 5).

Another participant characterized her mother as a travel partner and “best friend” (D - 4). She grieves that her mother can’t travel anymore and called dialysis “the beginning of the end” for her mother. Participant D – 4 stated, “I felt that with all of her health conditions and I didn’t have a family of my own and I wanted that…it was the beginning of life for me and the end of life for her.” Three caregivers shared that when they travel with the family member, they now go on day trips on non-dialysis days if the family member feels good enough to take an outing. “We go to Williamsburg shopping,” reported Participant B – 2 when asked about day trips with her mother.

Sub-theme: an indeterminate timeline.

Five participants acknowledged that when the kidneys fail, hemodialysis gives the recipient an extension of his or her life. They know that hemodialysis replaces kidney organ function; however, many patients on hemodialysis experience complications such as stroke and myocardial infarction. Caregivers often wondered for what length of time they will have with their family member. Some participants are concerned about the financial aspects of dialysis treatments and medications. “There’s nothing miraculous that’s going to happen, we will never get away from dialysis,” conveyed one caregiver (D - 4). Some caregivers discussed the issue of
end of life wishes with the family member to determine their perspective and desires. Participant B – 2 shared that she was approached by a physician and asked if she wanted to stop her mother’s dialysis treatments. She reported, “I was blown away, I wasn’t expecting to hear something like that. There is nothing that she has said to indicate she doesn’t want to be here anymore.” Participant A – 1 shared that her family member wanted “everything” done about a year ago. She wasn’t sure if the other family members who have power of attorney privileges would uphold this request. “I don’t know if the family will keep her on dialysis. So they had a family meeting and brought my grandmother in and she wanted to keep going to dialysis.”

Five caregivers expressed being concerned about not knowing what the future holds. Being able to plan for the future is important to caregivers. One participant expressed wondering what would happen to her family member if something happened to her and she could no longer care for him. Participant E – 5 explained, “I don’t know what to expect. I think down the line what will happen? How would I adjust my life to make sure that he’s taken care of?” This sentiment was echoed in other comments made by caregivers. “That’s the hardest part, how to plan for the future,” one participant answered Participant B - 2. She continued, “Caring for someone who has cared for you, that’s the biggest transition.”

Caregivers recognize the cycle of life as the winding down of one life and the gearing up of another. This is especially evident in the parent-child dyads. When he was first diagnosed with kidney disease, Participant C - 3 expressed the desire to donate a kidney to give her father “more time on earth.” She continued, “I told him, ‘Let’s go to the doctor and see if I am a match.’ I think he would do it if it was the other way around, too.” Another caregiver expressed that she did not want to give her mother a kidney because she felt that she had not yet started her life while her mother had lived a full life. Participant D – 4 shared, “I knew I was not going to
donate a kidney to her, you can call that selfish, that’s fine…I felt that with all of her other health conditions …I felt like I deserved my own chance at a family.”

Withholding or withdrawing hemodialysis from the family member is a topic that had been broached by physicians. Two caregivers were distressed at the thought of withdrawing hemodialysis because they knew that the death of the family member would ensue. Several caregivers were appointed medical durable power of attorney for their family member but have not made life changing decisions regarding hemodialysis for their family member. Caregivers expressed that they felt like as long as the family member wanted to continue with hemodialysis treatments they would support the decision. One participant was “blown away” by the physician suggestion that they stop treatments. She recounted, “I’m not denying her medical issues but that’s like letting her go home to die. We are blessed she is here and as long as she wants to be here, we will follow her wishes” (B - 2).

Caregivers Need a Support System

Six participants reported relying on family and friends to support them in their caregiving efforts. Different types of support were needed by caregivers and offered by others. Caregivers appreciated when family and friends offered emotional support and were non-judgmental listeners. Some caregivers had co-workers who were experiencing similar situations with their family members. Caregivers felt they and their co-workers could offer each other an informal network of support and empathetic presence allowing them to “vent to another person who knows what it is like” (B – 2). These co-workers were felt to make a difference in the lives of the caregiver and these conversations were considered invaluable to the caregivers. “It’s helpful to have people to talk to because they are an objective ear and can tell me to ‘Breathe’ and that’s helpful” (B – 2). Participant E – 5 shared that to have someone to talk with, “…means
everything. If I couldn’t tell somebody what I was feeling, the true feelings, the ugly feelings…UGH.”

All six caregivers appreciated the physical support offered by others in managing care responsibilities for the family member. Sharing transportation, childcare, and visiting with the family member were examples of what others did to assist caregivers. Some caregivers reported that others in the family took the lead in organizing care. Being able to receive directions and accomplish the allocated duty was less stressful to some caregivers than managing the entirety of caregiving duties for the family member. Participant C – 3 recalled, “My brother and his wife are taking care of most of it for my dad right now because of my daughter’s issues.”

Sub-theme: shared decision making.

The six caregivers who participated in this study had siblings and other family members with whom they shared caregiving responsibilities. These other family members also offered emotional and decisional support to one another that reportedly decreased stress in the caregivers. Caregivers often reported sharing in the decision making process along with their family member to determine the best way to manage care. Being able to share in the decision making process alleviated stress for the caregiver and provided alternate viewpoints when weighing options for care. One caregiver stated, “It just seemed like after talking with my sisters, my mother, and the doctor…it seemed like a good combination of all of us deciding,” (B - 2) when discussing moving her mother to a different hemodialysis location that was closer to the caregiver. Having someone with whom to share the decision making responsibilities seemed to be a relief for most of the caregivers in this study.
Sub-theme: sharing the workload.

Six caregivers in the study shared not only decision making responsibilities but also shared the workload of caring for the family member. When families worked together to provide care for the family member on hemodialysis, there was a feeling that sharing the workload decreased overall stress in the caregiver. Participant B – 2 shared, “My aunt is helpful…the people at work are supportive, too. It’s been helpful to have those people to spread out the workload.” Some caregivers used hired nursing assistants to provide daily physical care such as bathing, dressing, and meal preparation. This helped caregivers focus on other things or just relieved caregivers from the added duty of this aspect of care. Participant A – 1 reported that her grandmother needs 24 hour a day care because she is impulsive and at risk for falling. “She lives at her house but needs help all the time because she thinks she can just get up and go.”

Five caregivers reported having extended family members or friends upon whom they could call to help out as needed with various aspects of caregiving, such as transport to the dialysis center or visiting with the family member while the caregiver ran errands or went to work. Participant E – 5 reported, “When my son can’t take him [husband] to dialysis then I call a friend.” According to Participant B – 2, “My aunt, her sister, is helpful. So if she [mother] needs to go to a doctor’s appointment or the hospital, she helps.” When the extended family members or friends provided companionship to the family member, this was considered valuable to the caregiver.

One caregiver’s son and grandson lived with the caregiver and family member, her husband. The caregiver felt that she shared in the work of raising her grandson and her son shared in the work of caring for his father. This living situation brought the caregiver pleasure and she was glad that they had this reciprocal arrangement. Participant E – 5 said, “My son and
his son live with us. Multiple times we’ve thought about kicking him out but I am glad we didn’t because I knew that somewhere down the line we would need each other.” Asking for outside help was difficult for this participant who did not want to “burden other people with our issues” (E - 5). The aforementioned calendars helped to keep the caregivers and the family member organized and showed the allocation of caregiving responsibilities.

When caregivers perceive they do not have others with whom to share workload of caregiving they can experience negative emotions. Participant D - 4 was an only child and she relied on heavily on her husband for support. She acknowledged that when she was with her mother, her husband provided care for their young daughter when he was not at work. His efforts gave her some relief from the stress of worrying about managing presumably juxtaposing priorities. She felt she did not have extended family to assist her in a tangible way even though her mother lived with her aunt. She related that the aunt was 85 years old and provided mainly companionship for the family member, her sister. This caregiver expressed anger and remorse because she felt she had no one to share the responsibilities of caring for her mother, even though her husband was supportive and helped as he could. She explained that she felt angry because “a lot of the time that the burden falls on me because I have no other siblings” (D - 4). Out loud she wished she had someone with whom to share the responsibility and emphasized that she will have more than one child to avoid burdening an only child who may be caring for her in the future. “That’s how I feel, that’s why my husband and I have to have more than one child. It’s a big burden to put on one person” (D – 4).
Presentation of Themes for Sub-Question 2

In this phenomenological study of the lived experience of caregivers of family members on hemodialysis, data saturation was reached with the first five participants. Adding the sixth participant demonstrated that the same themes and sub-themes existed within his experience. Participants reported that caring for their family member who is dependent on hemodialysis is meaningful to them. There were three themes and three sub-themes identified that related to the second sub-question: What is the meaning that caregivers give to the experience of caregiving for family members dependent upon hemodialysis as a treatment for ESKD? The themes are: \textit{Caregiving is Reciprocal, Quality of Life Changes, and Emotional Responses to Caregiving.}

The sub-themes are: \textit{Being an Advocate, Family Member’s Life Changes, and Caregiver’s Life Changes.} (See Table 5: Frequency Table for Sub-question R-2 Theme and Sub-theme details).

Table 5: Frequency Table for Sub-question R-2 Themes and Sub-themes

<table>
<thead>
<tr>
<th>Sub-Question R-2: Meaning of Caregiving</th>
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<th>B - 2</th>
<th>C - 3</th>
<th>D - 4</th>
<th>E - 5</th>
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</table>
Caregiving is Reciprocal

All six caregivers in this study held the belief and expectation that family members care for one another in times of need. These caregivers considered caring for a family member an example of their allegiance to the family unit. The participants admitted that caring for a family member dependent on hemodialysis was difficult and challenging; however, they did not regret the experience and could not imagine not providing care for their family member. The caregivers felt satisfied with their contribution to the health and well-being of their family member and said that the caregiving experience was meaningful to them. As participant A – 1 shared, “I’m grateful for the opportunity to take care of my grandmother. It means a lot to me and I will never regret it.” Four of the participants were caregivers for a parent or grandparent. These caregivers shared that they felt as if they owed the family member back for taking care of them as children. One caregiver summed up her experience of caring for her mother by saying, “She cared for me and you are supposed to do this for your parents” (D - 4). Participant B - 2 also shared this sentiment, “I can’t imagine not being there for my mother. I mean she took care of us and to me, it’s just the way things are done.”

Sub-theme: being an advocate.

Five participants in this study reported that they were the first point of contact for the family member’s medical care needs. Participants reported they needed to advocate for their family member to get required medical treatment, medications, durable medical equipment, and meet other health care needs. Participants used whatever resources they had to help them serve as effective advocates for their family member. For one caregiver, this meant asking her best friend, who was a nurse, for advice and suggestions on questions to ask the health care providers. Participant B – 2 explained, “My best
friend is a nurse here at the hospital so that’s helpful. By working in the hospital she can explain things so I understand better about how to get things done and who I need to talk to.” Caregivers described advocating for resources to help family members experience an improved life. These resources encompassed physical therapy and durable medical equipment such as a walker or home oxygen. Participant D – 4 elaborated, “Today I had to call the insurance company to get the oxygen. She has to have it and they didn’t deliver it.”

Advocating with the physician for increased medical surveillance was also discussed by caregivers. Three caregivers related that they had to advocate for the family member’s health care needs with physicians, including hospitalization to determine causes of acute illness or a decline in the family member’s condition. In one case the caregiver argued with a physician who felt that, as a nurse, she should manage the family member’s acute illness at home. She recalled, “I knew something was wrong with my husband and the doctor said something about people abusing the emergency rooms. I brought him in anyhow. It was a good thing I did because his hemoglobin level was five” (E - 5).

Quality of Life/Lifestyle Changes

Five caregivers recognized that they and their family members experienced changes in quality of life when the family member started on hemodialysis. Participant A – 1 shared, “My grandmother doesn’t get out much, not only because of the dialysis but because it’s a chore for some of the family members to get her in and out of the car.” The feeling that these changes led to a decreased quality of life in the family member was pervasive throughout the interviews. Some caregivers thought that even with the decline in physical status and a decreased quality of
life, the family member was happy they were alive. Participant B – 2 said, “Since the stroke she is considerably weaker and…can’t do all the things she used to but she can do some things. There’s nothing, she has not indicated …she doesn’t want to be here anymore.” Caregivers also expressed they were happy the family member was alive and able to do things with the caregiver. “I just want to get as much enjoyment as I can and as many memories as I can with her,” explained Participant A – 1 when discussing her grandmother. “We go out to eat and shopping,” she continued.

The changes in lifestyle and quality of life were often associated with the schedule and timing of hemodialysis. “We could still go places after he had the stroke but with the dialysis, it’s limiting,” explained Participant E – 5. Changes were also associated with dietary restrictions, medical procedures, dealing with unexpected issues, physical decline, and limitations on travel. “I took my grandmother to my sister’s baby shower. I got a friend from school help me maneuver the wheelchair. It is a lot to take her and a chore to get her in and out of the car,” reported Participant A – 1.

**Subtheme: family member’s life changes.**

Participants acknowledged that the quality of life for their family member was different now that the family member was on hemodialysis. In some cases, caregivers thought the quality of life for their family member was less than it had been previously yet they acknowledged that the family member seemed happy. Caregivers expressed relief that the family member was happy at this point in their lives. Participant B – 2 shared, “Since the stroke she can’t do the same things. Her quality of life has changed but for her, she’s happy.”

Participants reported making efforts to normalize activities to improve the family member’s quality of life as much as possible and create memories. Some of the activities
caregivers and their family members participated in together included eating meals out at restaurants. This could be complicated sometimes, given the dietary restrictions of the family member. Picking the right restaurant and the right meal took planning. The caregivers felt that they were responsible for encouraging the family member to stick to the dietary restrictions when they were out. One participant shared that he felt he needed to remind his family member to adhere to the dietary restrictions so that she wouldn’t suffer complications with hemodialysis. Participant F – 6 shared, “I told her, ‘You can’t have chili. Eat salads with light dressing and protein like chicken.’ And she needs to cut down on sweets because she is diabetic.”

Women caregivers interviewed shared that their outings also included going to the hair salon or nail salon with the female family member. These outings helped to create normalcy and a bond between the women that allowed them to forget about dialysis and other restrictions for a while. Participant A – 1 shared the following, “I take her to get her hair colored. She does not like her gray showing! We get our nails done, that’s a real treat for her.”

Day trips were another way that caregivers helped the family member have an improved quality of life. Three caregivers expressed that these day trips were a source of enjoyment for both the caregiver and family member. These experiences helped create good memories that the caregivers could recall in the future when feeling sad. Participant A – 1 expressed excitement when she took her grandmother to her pregnant sister’s ultrasound appointment. “It was the gender reveal appointment. It was a girl and my grandmother just lost it, she was laughing and so excited!”

When the health of the family member did not allow for activities such as these to occur, it caused the caregiver emotional distress. One participant became emotional when thinking about her father’s distress at not being able to do the things he liked to do. She recalled, “…he’s
gone gloomy. He can’t do the things he used to do” (C - 3). Thinking about her father’s declining health made her very sad and tearful during the interview.

**Sub-theme: caregiver’s life changes.**

Caregivers acknowledge that their lives are different and more stressful with the added responsibilities of caring for their family member. Participants lamented the fact that they had not been able to take a vacation or get away for any length of time because they were beholden to the care of the family member. Several caregivers reminisced about family vacations, which they are not able to take while caring for their family member. Participant D – 4 shared this about vacationing with her mother, “We can never take vacations again. I used to take her to Vegas and I can’t do that now because we have to make appointments.” Participant B – 2 lamented, “I haven’t had a vacation in two years, since my mom had the stroke.”

The caregivers in this study related that they tried to do things that helped them feel better and shift focus from the family member to themselves. These activities included going to lunch with friends, getting a massage, and taking in a movie. Participant B - 2 shared that on some weekends she goes out with friends to “decompress.”

When caregivers were unable to do special things for themselves, it added to the feeling of being overwhelmed. Participant D - 4 described her life as a caregiver as, “living the mundane” and moving from day to day. Being overwhelmed left the caregiver feeling that there was no relief from the caregiving responsibilities. Participant D – 4 shared, “I get tired of seeing her fight through this and I get tired myself. I feel like it’s a losing battle.”

**Emotional Responses to Caregiving**

Six caregivers expressed feelings of anger, frustration, and sadness during the interviews. These feelings were attributed to the relationship the caregiver had with the
family member and decline in the family member’s health. “I know she does not buy all
of her medication because of the cost and I just can’t help that. I have to let it go,”
lamented Participant D – 4. Participant C – 3 shared, “Since he’s been home he’s been
slow, sluggish. Like he’s trying to get us to accept the fact… I think he’s going downhill
fast.” When the family member experienced a sudden decline in health, caregivers
reported feeling sad and depressed. Participant E – 5 reported that her husband is newly
diagnosed with multiple myeloma in addition to having had a stroke and being on
dialysis. She expressed sadness about the situation because, “I don’t like the decline in
him. I don’t like him having to be dependent.”

Four participants acknowledged that hemodialysis was keeping their family
member alive and the treatments sometimes caused pain for the family member. Seeing
their family member in pain was distressing to the caregivers interviewed for this study.
For one participant, the thought that her mother was suffering was so distressing she felt
that death would be a relief for her mother. Participant D - 4 recounted, “I would almost
be relieved if she died that she is no longer suffering.”

Three caregivers reported feeling angry and frustrated with the situation, rather
than the family member themselves. Participants acknowledged that they could not
identify anyone to blame specifically for the situation they were in; however, they still
felt angry. Participant E – 5 explained, “Sometimes I’m angry, to be honest. I don’t
know who I am angry at but I’m angry that this has happened not only to him but to us, to
me, to our family.” One caregiver did express frustration with family members for not
adhering to medical and dietary protocols, which hastened physical decline and
sometimes resulted in hospitalization. “I get frustrated because she doesn’t follow the
doctor’s instructions about her diet. It makes angry because I think ‘this is unnecessary’ because she knows better” (F – 6).

Three caregivers felt sad when seeing their family member struggle with a decline in their physical status. Watching the family member become more introverted and less participative in outings and activities they used to take enjoyment in was difficult for caregivers. Participant C - 3 shared that she observed her father’s behavior after bilateral lower extremity amputations. He became less communicative with her and other family members after the surgery. She recounted, “I don’t like it. I feel sad because he’s not going to the grocery store or anything” (C – 3).

One caregiver reported that she treasured the time she spent participating in social activities with her family member. When discussing spending time with her grandmother, Participant A – 1 said, “I treasure those moments, I just want to get as much enjoyment as I can and make as many memories as I can with her.” She continued, “I talk to her about my grandfather who died when I was in fourth grade… I ask her about my favorite recipes she used to make for me.” Another participant also expressed pleasure that the family member was happy with her quality of life. Regarding her mother, Participant B – 2 reported, “She’s always upbeat and expecting a great-grandchild…she’s happy and I am grateful.”

All six caregivers expressed they were aware of changes in their emotional status and the feelings created by the caregiving experience. Five caregivers felt that they used positive coping mechanisms to help manage the emotional responses to caring for a family member. The most common activities noted by caregivers in this study to manage these feelings were exercise and prayer. Participant D - 4 noted that she relies on her new
found faith to get her through the tougher times, “I don’t know what it is, but I know God has a plan.” Participant E – 5 shared, “For the last few years I’ve been nursing for 24 hours. I pray a lot. I swim and kick box and take pictures…hiding behind the lens is a good place to hide sometimes, I become invisible.”

Summary of Findings

There are six major themes identified in this study. The themes are: Caregiving is Hard Work; Caregiving is Stressful, Caregivers Need a Support System, Caregiving is Reciprocal, Quality of Life Changes, and Emotional Responses to Caregiving. There are 12 sub-themes that directly relate to the experience of caregiving for a family member using hemodialysis. The sub-themes are: Organizing Care Requires Planning, Co-Morbid Conditions Compound Basic Care Needs, A Different Challenge Every Day, Transportation is an Ongoing Challenge, Compromised the Health of Caregiver, An Unbalanced Life, An Indeterminate Timeline, Shared Decision Making, Sharing the Workload, Being an Advocate, Family Member’s Life Changes, and Caregiver’s Life Changes.

Caregivers perceived that caring for a family member dependent on hemodialysis is stressful and hard work. During the interviews, caregivers shared stories of trying to balance multiple priorities in their lives while organizing and arranging for care or directly caring for the family member. They acknowledged that having others to share the decisions and workload with helps to decrease the stress of the caregiving role. Participants revealed that stress and anxiety played a part in their caregiving experience with varying effects on their self-reported health status, lifestyle, and social activities.

Caregivers found meaning in the act of caring for a family member dependent on hemodialysis. Participants expressed feeling loyal to their family member and accepted the
responsibility of caregiver as part and parcel of their role in the family. Even though the responsibility was sometimes daunting, the caregivers expressed no regrets about their role in the family member’s life. At times, caregivers felt conflicting emotions including anger and frustration when providing care for their family member who is dependent on hemodialysis. Sometimes these emotions were directed at the family member. Other times the anger and frustration were directed at no one in particular. Caregivers expressed satisfaction when serving as an advocate, knowing they were doing the best they could to ensure positive outcomes for their family member.

**Conclusion**

In chapter four, the investigator discussed the study results and presented themes and sub-themes resulting from data analysis. Chapter four contained all of the data collection steps, the interview process, participant demographic information, data analysis steps, and discussion of themes and sub-themes identified in the study. Chapter five focuses on interpretation of the study findings, recommendations for further research, and conclusions.
Chapter 5

Interpretation of Findings, Recommendations, and Conclusions

In chapter one the investigator explored how hemodialysis treatments created lifestyle changes and interrupted the flow of life the patient and his or her family members had established. The investigator presented to the reader in the first chapter the problem and purpose statement, nature of the study, definitions, assumptions, limitations and delimitations, and the framework for this dissertation study. The Structural Model: Predictors and Outcomes of Burden, developed by Savundranayagam et al. (2011) served as the framework for this dissertation study.

In chapter two the investigator conducted a literature search and presented current quantitative and qualitative research. Chapter two focused on the literature search process and historical perspective of caregiving. The literature review assisted the researcher in determining the breadth and depth of literature regarding the experiences of caregivers. Quantitative studies measuring precursors, characteristics, and outcomes of burden were presented, as well as qualitative studies that related to the experience of caregiving.

In chapter three, the investigator discussed informed consent procedures, design appropriateness and rationale, the sampling strategy, the process to maintain participant confidentiality and anonymity, and the data collection and analysis procedures. In chapter four, the investigator discussed study results and presented the experience of the participants by discussing themes and sub-themes resulting from data analysis. Chapter four addressed the data collection steps, the interview process, participant demographic information, data analysis steps, and the themes and sub-themes identified in the study. Chapter five focuses on conclusions, implications, and recommendations based on the study findings.
The purpose of this descriptive, phenomenological study was to explore the lived experience of caregivers providing care to a family member dependent upon hemodialysis. The study included a series of six semi-structured interviews with male and female caregivers of a family member dependent upon hemodialysis. The investigator conducted and audio-taped the interviews as approved by two IRBs (University of Phoenix and the local Richmond Health System) and after receiving informed consent from the participants. The investigator transcribed the audio-tapes. During the interviews, participant caregivers shared their experience of caregiving for a family member dependent upon hemodialysis, expressing their thoughts, feelings, and the meaning of caregiving with the investigator. The interviews included questions about the caregiver’s daily routine and care giving activities as well as perceptions about their experiences and relationship with the care receiver, the impact of caregiving on their work and social life, and their emotional or physical health since providing care.

**Interpretation of Findings**

For this qualitative study the overall research question was: What is the lived experience of caregivers who provide care to a family member dependent upon hemodialysis as a treatment for ESKD? Two sub-questions for this study were:

R – 1: What are the perceptions that caregivers have about the experience of providing care for family members dependent upon hemodialysis as a treatment for ESKD?

R – 2: What is the meaning that caregivers give to the experience of caregiving for family members dependent upon hemodialysis as a treatment for ESKD?

Six major themes and 12 sub-themes were identified in this dissertation study. Three major themes in this study related to sub-question R – 1, what are the perceptions that caregivers have about the experience of providing care for family members dependent upon hemodialysis as
a treatment for ESKD? These themes were: Caregiving is Hard Work; Caregiving is Stressful, and Caregivers Need a Support System. The nine sub-themes that directly related to sub-question R – 1 were: Organizing Care Requires Planning, Co-Morbid Conditions Compound Basic Care Needs, A Different Challenge Every Day, Transportation is an Ongoing Challenge, Compromised the Health of Caregiver, An Unbalanced Life, An Indeterminate Timeline, Shared Decision Making, and Sharing the Workload.

Three major themes emerged in this study related to sub-question R – 2, what is the meaning that caregivers give to the experience of caregiving for family members dependent upon hemodialysis as a treatment for ESKD? These themes were: Caregiving is Reciprocal, Quality of Life Changes, and Emotional Responses to Caregiving. The three sub-themes that directly related to sub-question R – 2 were: Being an Advocate, Family Member’s Life Changes, and Caregiver’s Life Changes.

**Caregiving is Hard Work**

All caregivers in this dissertation study perceived that caring for a family member dependent on hemodialysis was hard work. The theme of Caregiving is Hard Work emerged from the participants’ discussions about how they tried to manage and organize daily activities for the family member in addition to themselves and their families. In some cases the caregivers identified that the hard work was not physical work but rather the mental work of trying to balance multiple priorities at the same time. Schumacher, Beck, and Marren (2006) called the mental work of caregiving, “invisible work” (p. 44). For caregivers, some of the priorities for the family member paralleled their own life priorities. Some examples of these types of priorities were buying groceries, preparing meals, cleaning the house, and attending appointments. These priorities were managed for both the caregiver and his or her immediate
family as well as for the family member dependent upon hemodialysis. Some of the mental, or invisible, work also included monitoring the family member for changes in their physical or mental condition and alerting the proper health care provider. With limited medical knowledge or education, assessing a family member was potentially difficult for the caregiver.

In several cases the hard work was physical care of the family member in addition to the mental work of balancing multiple priorities and monitoring the family member’s health. One participant cared for her husband and assisted him with ADLs. Because he had a stroke and was debilitated and weak, he depended on her for physical care in addition to managing the other priorities. Providing physical care for her husband took time and effort for this caregiver who also worked full time. Another caregiver brought her grandmother to her house to shower several times a week. Because her grandmother had difficulty walking and getting into and out of a car, this took much effort on the participant caregiver’s part.

Objective burden in the Structural Model, which served as the framework for the dissertation study, reflected caregiving tasks, duties, or activities (Savundranayagam et al., 2011). The experience of caregivers identified in the Structural Model regarding hours on care tasks was reflective of physical assistance the caregiver needed to provide help to the family member with activities of daily living (bathing, dressing, toileting, etc.). Poulshock and Deimling (1984) found that a patient’s requirements for assistance in ADLs were independent from the presence of cognitive impairment. The findings in this dissertation study were similar to those of Poulshock and Deimling as none of the family members in this dissertation study experienced dementia even though they had co-morbid conditions that rendered them unable to perform some, if not all, of their ADLs.
Three caregivers in this dissertation study made arrangements with outside agencies and hired nursing assistants to help manage the family member’s personal care needs and activities of daily living (Participants A – 1; B – 2; C – 3). Two caregivers reported that the family member received 24-hour a day care by paid nursing assistants (Participants A – 1; B – 2). One caregiver reported that the family member received paid assistance for eight hours a day (Participant C – 3). The hired nursing assistant caregivers provided physical care in the family member’s home. Even with hired nursing assistants to provide most care with the family member’s ADLs, the participant caregivers who used hired assistance still provided some basic care to their family member. The participants who provided more care around ADLs more often expressed that their caregiving experience was harder and more difficult. This is similar to the idea of objective burden in the model. However, only one participant actually referred to her caregiving as being a burden.

Archbold, et al. (1990) identified preparedness as one variable that could influence a family member’s ability to manage the challenges and responsibilities of caregiving. The findings from the study by Archbold et al. showed that the better a caregiver is prepared to manage a patient’s needs in the home, the less the caregiver perceived being strained with the added responsibilities of caring. The concept of preparedness, as discussed by Archbold et al., was directed at determining competence or a specific skillset required for caregiving duties. In this dissertation study, the caregivers did not identify a direct skillset or level of competence that they needed to achieve in order to assume the role. Participants in this study did not specifically address their preparation for the role of caregiver for the family member who was dependent upon hemodialysis. However, the caregivers in this study did seek out others who they perceived were able to assist them; the caregivers used identified resources to facilitate the
development of their competence. For example, one participant took comfort in discussing her mother’s care needs with a friend who was a nurse. The participant (B – 2) believed that having a friend to provide information on how the health care system worked and to whom she should direct her questions helped her be in a better position to advocate for her mother. Contrary to what would be expected, being a nurse or health care provider did not necessarily make caregiving easier. Participant E – 5 was a nurse and, although she felt prepared to provide physical care for her husband, she lamented the fact that she provided nursing care for patients in her work as a hospice nurse and at home for her family member and never really got a break from caregiving.

Preparedness for caregiving was not clearly identified as a theme or sub-theme in this study. Perhaps the reason that preparedness was absent as a strong theme or sub-theme was because some caregivers in this study had health care skills or knew others who were health care providers. The health care skills of caregivers included being a nursing assistant, nurse, and nursing student who also worked as a pharmacy tech part-time. As stated previously, several caregivers hired nursing assistants to help the family member who needed assistance and the remaining family members were able to manage their own ADLs without assistance. As a family members’ health declines over time and for families without some healthcare experience, perhaps preparedness would emerge as a stronger element for caregivers.

Raina et al. (2004) reported that with many familial caregiving situations, the caregiver may not have chosen or planned to assume the caregiver role and they typically did not receive payment or days off from caregiving responsibilities. Schumacher et al. (2006) identified that within families of patients with chronic illness, caregivers served as primary or secondary caregivers. Primary caregivers were the day-to-day providers while the secondary caregivers
helped with intermittent activities (Schumacher, Beck, & Marren, 2006). The caregivers in this study who had siblings did not express how they were chosen as a caregiver to a family member on hemodialysis (as opposed to, or in addition to, someone else in the family). One participant was an only child. She indicated that she became the caregiver by default since she had no siblings with whom to discuss or share the matter of caregiving, although her husband was supportive and participated in care of the children and sometimes the care of his mother-in-law. Several of the caregivers in this study expressed that they were the primary caregiver and other caregivers reported that they provided intermittent care; however, this intermittent care was frequent (several times a week).

Schumacher et al. (2006) reported that the average caregiver of a family member is a 46 year old female caring for a mother. Wives and daughters were the most likely to be a caregiver although sons, sons-in-law, and others in the family were also identified as caregivers (Schumacher et al., 2006). In this study, five participants were female and one was a male with the average age of 36 years old. The family members receiving care included one father, one husband, one grandmother, and three mothers (including one mother-in-law).

The duties of caregivers in this dissertation study did not include management of the technical aspects of hemodialysis or other technical duties for which they needed extensive education. However, the duties did include assistance with management of dietary restrictions, medications, and organizing schedules for dialysis and medical appointments. Caregivers in this study acknowledged the difficulties they experienced with managing dietary restrictions of the family member, dialysis transportation schedules, and organizing their daily work responsibilities and social life with the family member’s daily life activities. While these activities did not require specialized education per se, an innate sense of organization and
planning helped some caregivers stay on top of the myriad of activities. One caregiver did not have this innate sense, which made organizing activities difficult for the caregiver.

According to Schumacher et al. (2006) some caregiving activities are not as apparent as others. While physical care is visible, some care provided by caregivers is not. In this study caregivers reported performing activities such as checking up on the family member, making sure the nursing assistant had arrived, and setting up appointments. Schumacher et al. call these activities “invisible work” (p.44), which the investigator considered part of the mental work of caregiving.

The perception that caregiving was hard work was based on the “invisible work” done by the caregiver (Schumacher et al., 2006, p. 44). The invisible work included the caregiver’s organizing his or her own busy life as a parent and employee as well as managing the family member’s schedule. Trying to stay on top of everything was challenging for some caregivers in this study. The caregivers in this study did not discuss days off or payment for their duties as a caregiver.

The investigator could not conclusively say that caregivers perceived that caregiving was hard work because they were not adequately prepared to manage the additional responsibilities of caring for their family member or because they did not receive days off from the responsibilities of caregiving. According to Beanlands, Horsburgh, Fox, Howe, Locking-Cusolito et al. (2005), the activities of caregiving are learned over time through lived experiences of trial and error. The major theme of hard work in this study stemmed from the caregiver trying to manage multiple priorities on a daily or weekly basis for different individuals (self, family member, child, etc.) and providing some physical care for the family member as well. The fundamental nature of caregiving was related to the lived experience of providing care to the
family member. In order to fully understand and appreciate the essence and meaning of the experience of caring for a family member dependent upon hemodialysis, caregivers must live through the experience. This is consistent with the findings by Beanlands et al. who used a qualitative, descriptive study using grounded theory to examine caregiving of patients who are dependent upon hemodialysis.

**Caregiving Is Stressful**

Participants in this dissertation study revealed that the stress and anxiety played a part in their caregiving experience with varying effects on their self-reported health status, lifestyle, and social activities. Caregivers experienced chronic stress when caring for a family member dependent upon hemodialysis. In previous studies, caregivers reported feeling overwhelmed with the responsibilities associated with caregiving (Belasco & Sesso, 2002; Burns et al., 1993; Cangelosi, 2009; Savundranayagam et al., 2011). When caregivers experienced these overwhelming feelings they reported anxiety, emotional stress, fatigue, and relationship changes between the caregiver and the family member (Savundranayagam et al., 2011; Schneider, 2004).

The theme of *Caregiving is Stressful* emerged from the caregiver’s perceptions of their experiences of providing care to the family member using hemodialysis. Caregivers in this study felt chronically stressed and one participant admittedly felt burdened with the duties and responsibilities of caring for a family member dependent upon hemodialysis. Another caregiver felt overwhelmed with the experience of caregiving. Caregivers in this study understood their experience of caregiving for a family member based on their perceptions of how they tolerated the stress of caregiving.

Schumacher et al. (2006) reported that caregiver’s perceptions of the experience of caregiving for a family member could influence their perception of the experience as positive or
negative. The caregiver’s perception of the experience leads to increased or decreased stress levels. Participants in this study felt stressed; however, several caregivers perceived and gave meaning to the experience of caregiving as positive while two caregivers perceived and understood the meaning of the experience of caregiving as negative.

Acknowledging that caring for a family member was stressful, one participant (Participant B – 2) shared that she was glad to be able to help her mother. This caregiver felt good about helping her mother and perceived her experience as a caregiver as a positive experience. Participant D – 4’s experienced frustration and felt burdened with the caregiving experience and taking care of her mother. During the interview the participant seemed somewhat resentful of her role as a caregiver for her mother even though she felt she did a good job. Therefore, Participant D – 4 perceived her experience as a caregiver as both a positive and a negative experience.

Schneider (2004) explored fatigue as a factor contributing to and an outcome of caregiver burden. In a study of 80 subjects who were caregivers for patients on hemodialysis, Schneider showed that physical fatigue may be experienced more than mental fatigue in those providing care for family members using hemodialysis. Schneider did not explore the reason the caregivers were physically fatigued but rather included it as part of the multidimensional construct of caregiving. The study by Schneider did not include length of time in caregiving, which could have affected the study findings.

Most caregivers in this study did not express feeling physically fatigued as a result of caregiving duties; however, one caregiver did express physical fatigue but stated this was a result of being pregnant at the time of the interview. While some participants described unhealthy practices caring for themselves, most of the participants relayed that they were experiencing
good health without risk factors for kidney disease. Because of this relative good health, issues with physical fatigue did not emerge from the descriptions of the caregiver’s experiences as has been noted in the published literature.

Previous research on the informal caregiver’s responses to stress inducing factors related to caregiving included declining health status (Hirano et al., 2011; King et al., 2002). Declining caregiver health status during caregiving activities was well documented in the hemodialysis caregiver literature (Belasco & Sesso, 2002; Nguyen, 2009; Schneider, 2003; Schneider, 2004). In this study, five caregivers were reportedly in good health although four of them admitted they would like to start exercising and lose some weight. One caregiver described a declining health status due to feelings of being overwhelmed, which led her to make poor dietary choices and chain smoking cigarettes. The investigator concluded that the self-health status reports of participants in this study did not coincide with what was previously published in the literature (Hirano et al., 2011; King et al., 2002).

In a 2011 randomized controlled study, Hirano et al. (2011) explored the effects of regular exercise on subjects’ sense of burden. The subjects in the Hirano et al. study were caregivers of patients with dementia. Hirano et al. found that subjects who participated in moderate exercise three times a week reported better sleep and decreased fatigue than those who were in a control group. The subjects in Hirano et al. study also had statistically significant decreases in the Zarit Caregiver Burden Interview scores. Two of the participants in this dissertation study stated they exercised on a regular basis and both stated that they felt it helped them manage the stress and decreased feelings of burden. One of the participants (E – 5) used a swimming and kickboxing routine to help defuse feelings of stress and frustration and admitted that these activities helped her stay in good health. Another participant (F – 6) used running as a
stress release and to stay in good health. Other participants who did not exercise recognized the need to exercise. At the time of the interview; however, they used other strategies to decrease stress and feelings of burden. The other strategies included talking with friends and co-workers and going to the movies or out with friends for the evening. Findings from caregivers in this study who participated in a regular exercise program were consistent with the Hirano, et al. study results albeit in a different patient population.

One of the five dimensions of caregiving measured in the Caregiver Burden Inventory is length of time the family member is dependent on the caregiver for care (Caserta et al., 1996). According to Caserta et al. (1996), time dependence included restrictions on the caregiver’s time, both daily and over time. These restrictions on the caregiver’s time affected the perception of burden in a caregiver.

Caregivers in this dissertation study wondered out loud about the length of time they would be required to provide care for their family member. None of the caregivers in this study mentioned switching the responsibilities with another person even though they admitted that having other people to share the workload helped to decrease the perceived stress of the situation. One caregiver in this study had been a caregiver for approximately 10 years (Participant B – 2). During the interview she mentioned that planning for the future was difficult because of the unknown length of time she would be in the caregiver role. According to the published literature, caregiver burden increases as the length of time in caregiving increases (Caserta et al., 1996). For Participant B – 2, this was not entirely consistent because although she admitted it was difficult to be a caregiver, she did not feel it was a burden. Other caregivers in this dissertation study experienced burden with less time of caregiving. This was the case in
Participant D – 4 who had been a caregiver for two years and Participant E – 5 who was a caregiver for two months.

The indefinite nature of hemodialysis was essential to the experience for caregivers in this study. Caregivers in this study acknowledged the gift of life that hemodialysis brought to their family member. The caregivers recognized and acknowledged that without hemodialysis their family member would die, which was a profound realization that was part of the essence of the hemodialysis caregiving experience. Caregivers were grateful the family member had and took the opportunity for an extended life by using hemodialysis even though the treatment schedules, medications, and dietary restrictions created other problems in the life of the caregiver. The caregivers weighed the two alternatives, dependence on hemodialysis or death, and knew that the choice of hemodialysis was the right one for their family even though there was no predictable timeline for the extension of the family member’s life. The knowledge that hemodialysis provided the family member with prolonged life was seemingly a constant in the caregiver’s thoughts and influenced their feelings, perceptions, and the meaning of the caregiving experience. The experience of caring for a family member who was dependent upon the technology of hemodialysis seemed to heighten the caregiver’s awareness of the line between life and death.

Several caregivers in this study reportedly had end-of-life decision making conversations with the family member and the health care provider. The caregivers in this study found it difficult to discuss withdrawing hemodialysis from the family member. When the health care provider broached the option of discontinuing hemodialysis, the caregivers seemed to become upset and sad, knowing that stopping the hemodialysis would result in death of the family member. Caregivers in this study did not want to stop hemodialysis without the family member
experiencing a severe co-morbid condition because they wanted the family member to live; however, the never ending nature of hemodialysis treatments created weariness in caregivers.

The participants appreciated the paradox concerning their own feelings and understood that stopping the dialysis was a life altering decision not only for their family member, but for themselves as well. The caregivers did not want to have to make the determination to stop treatment unless there was a serious medical issue for the family member. The investigator could not locate studies in the published literature that mention the issue of the feelings associated with discontinuing hemodialysis in an otherwise healthy family member.

**Caregivers Need a Support System**

According to the published literature, challenges for a caregiver included adequate and appropriate social support systems (Belasco & Sesso, 2002; Nguyen, 2009). Part of an appropriate social support system included having another person to share the workload with or at least listen to the caregiver in a nonjudgmental manner. This support was reported in the literature to reduce the caregiver’s feelings of situational stress (White, Richter, Koeckeritz, Munch et al., 2004).

The social support also included other family members who helped the primary caregiver care for the family member dependent upon hemodialysis. Schumacher et al. (2006) called the other family members “secondary caregivers” (p. 44) because they provided intermittent care for the family member on hemodialysis and, therefore, supported the primary caregiver through their efforts. Caregivers in this study perceived that the creation of a network of support around the family member dependent upon hemodialysis improved the caregiver’s feelings of situational stress. The *Caregivers Need a Support System* theme emerged from caregivers’ experiences and perceptions of the helpfulness of others as they provided care to a family member who was
dependent upon hemodialysis. From the participant descriptions the two major themes of *Caregiving is Stressful* and *Caregivers Need a Support System* were intertwined, but separate.

White, Richter, Koeckeritz, Munch et al. (2004) explored family resiliency and found that social support, in the form of close friends and family members, improves family resiliency. According to White et al., not having another person to share the workload increased the caregiver’s feelings of stress and burden and resulted in poor family dynamics and decreased family resiliency. Sometimes simply having other family members to share the workload was not enough to result in decreased caregiver stress. One participant was an only child and reported feeling burdened with the caregiving responsibilities of her mother. She did have a husband who helped care for her young daughter; however, the participant did not identify him as someone who shared the workload of caregiving for her mother. One caregiver in this study admitted that even though she had other members in the family who helped care for the family member dependent on hemodialysis, the demeanor and activities of others’ caring were sometimes at odds with her caring activities. An example was when the participant caregiver purchased fresh fruits and vegetables to prepare for her grandmother while her other family members bought canned vegetables and soup for the grandmother. Paradoxical behavior of the different family members, providing care as they saw fit, disrupted the family dynamic because it resulted in fighting amongst the family members, increasing the stress level of the participant caregiver.

Caregivers reported that co-workers often provided an informal network of emotional support, which helped reduce the feelings of stress. The experience of the caregivers in this dissertation study coincided with the findings in the literature that report the caregiver experienced less stress with a support network of other people (Schumacher et al., 2006; White,
Richter, Koeckeritz, Munch et al., 2004). The lived experience of the participants included that appropriate and adequate social support networks, for the most part, helped caregivers in this study feel less stressed and better able to manage the responsibilities of caring for their family member who is dependent upon hemodialysis.

**Caregiving is Reciprocal**

Schumacher et al. (2006) found that caring for a family member can be a source of personal satisfaction and pride. Caregiving was discussed as a way for the caregiver to express love for the family member receiving care (Schumacher et al., 2006). In their article, Schumacher et al. found that caregivers reported personal satisfaction with their caregiving efforts and for keeping their family member free of complications related to the chronic disease process.

The major theme of *Caregiving is Reciprocal* emerged from the manner in which the participant caregivers relayed information about their lived experience of providing care for their family member. In this study, the lived experiences of caregivers were varied; however, the caregivers consistently felt they needed to care for their family member as an extension and show of their love and respect for the family member. The caregivers in this study perceived a sense of duty to care for a family member needing care, especially a husband, parent, or grandparent. One caregiver (Participant F – 6) felt it was his duty to care for his wife, which included caring for his mother-in-law. However, he did not feel a sense of duty to care for his mother-in-law in absence of his wife.

All caregivers in this study felt satisfied with the job they were doing in taking care of their family member. Caregivers expressed satisfaction with their job as a caregiver especially when they served as an advocate and ensured positive outcomes for their family member. The
field notes revealed that participants smiled and exhibited facial expressions congruent with satisfaction when expressing their thoughts and feelings about the job they felt they were doing as caregivers for their family member.

Montgomery and Kosloski (2009) identified that role reversal occurs in the caregiver-care receiver dyads as caregivers took on more of the physical and emotional responsibilities for the family member who needed care. Role reversal is often an insidious process leading to frustration and loss of role identity in the relationship for the caregiver and the family member (Montgomery & Kosloski, 2009). According to Montgomery and Kosloski, loss of role identity refers to the role transition caregivers can go through as a result of the caregiving experience. An example of this would be when a wife becomes a caregiver for her husband. According to Montgomery and Kosloski, role reversal and loss of role identity is a gradual process as the caregiver takes on more responsibility for the care of the family member. Embedded in the concept of loss of role identity, as the wife makes the transition, her role functions change such that she becomes less of a wife and more of a caretaker to her husband, so much that she may cease to see herself as a wife and only see herself as a caretaker.

Three of the caregivers in this study mentioned that it was difficult caring for their family member and that seeing him or her be dependent on others, including the caregiver, for care was emotionally hard on the caregiver. Three caregivers referred to a saying about a “second childhood” when discussing the family member’s need for physical care. One caregiver, a wife (Participant E – 5), shared her experience of caring for her husband. The participant described taking care of her husband’s basic needs and ensuring his safety. This participant’s interview responses revealed the complex nature of caring for a spouse. Several participants described events where they felt a reversal in roles was occurring with their family member; however, none
described losing their identity in the relationship. From the participant’s descriptions it became clear that the caregiver’s decision to provide care for a family member can be chosen because of a sense of duty and reciprocity in the relationship. The caregivers in this study did not perceive that they lost their role identity because most of them lived independently from the family member and engaged in activities to preserve their own identities such as working, going to school, and engaging with friends as a form of social support. One caregiver lived with the family member who was dependent upon hemodialysis; however, she did not express loss of role identity during her interview.

Quality of Life Changes

Quality of life refers to self-identified level of satisfaction with personal living conditions (Schneider, 2004). There has been some quantitative investigation into the caregiver’s perceptions of quality of life while caregiving for their family member (Fan et al., 2008; Ferri & Pruchno, 2009; Wicks et al., 1997). The investigator believed it was essential to explore caregiver’s perceptions of their own quality of life when serving as a caregiver for their family member dependent on hemodialysis.

In this dissertation study, the investigator inquired about the caregiver’s quality of life. Interestingly, while discussing their own quality of life, the caregiver also described the family member’s quality of life. The investigator discerned from the descriptions that the concept of quality of life for the caregiver and family member were intertwined for participants in this dissertation study. The caregiver described different activities that were felt to improve the caregiver’s quality of life as well as the family member’s quality of life. An example of this was when caregivers described taking the family member out to dinner and to the nail or hair salon. Other examples included taking day trips out of town on non-dialysis days. These activities and

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short day trips served as a source of relationship building, memory-making, and quality time spent together for the dyad.

Several published studies show an inverse relationship between quality of life and caregiver burden (Belasco, Barbosa et al., 2006; Belasco & Sesso, 2002; Wicks et al., 1997). The studies showed that as the responsibilities and duties associated with caregiving increased the caregiver’s quality of life decreased. One caregiver in this dissertation study expressed feeling burdened with the care she provided to her mother and stated that her life was “mundane” (Participant D – 4). This statement provided some support for previous studies that show an inverse relationship.

The caregivers in this study recognized that hemodialysis had introduced a different pattern in their lives and their family member’s lives. The caregivers acknowledged to the investigator that their quality of life had changed and for some, had diminished greatly. The participants in this study conceded that the family member’s quality of life had changed as well. The caregivers felt that the family member seemed to be happy with life despite the lifestyle change that was brought on by hemodialysis. The caregivers described that it was important for the caregiver, as well as, the family member dependent upon hemodialysis to have a positive quality of life.

**Emotional Responses to Caregiving**

At times, caregivers felt conflicting emotions when providing care for their family member who is dependent on hemodialysis. The theme *Emotional Responses to Caregiving* emerged through the varied emotions caregivers expressed verbally and through the non-verbal communication noted by the investigator during the interviews and recorded in the field notes. The emotional responses of caregivers in this study to caregiving ranged from “glad I can help”
to frustration and anger. The caregivers reported that the emotional responses to caregiving were different depending on the day and the type of caregiving activity in which the caregiver participated. Part of the essence of caregiving is the range of human emotions that come with providing care to the family member dependent upon hemodialysis.

Even though the responsibility was sometimes daunting, the caregivers in this study did not express regrets about their role as a caregiver in the family member’s life. Montgomery and Kosloski (2009) reported that some caregivers felt frustrated as they took on more of the responsibilities of caring for a family member. Cangelosi (2009) reported that the frustration could be borne from being ill prepared to assume the duties of caregiving. Archbold et al. (1990) discussed that a caregiver’s educational preparation for the caregiving role contributed to the feeling of caregiver burden if not competent or skilled to perform the duties of caregiving.

Caregivers in this dissertation study experienced frustration with the family member, the situation in general, and the health care system, specifically the medical doctors who cared for the family member. None of the caregivers in this study expressed frustration with being ill prepared to assume the duties of caregiving for the family member. The findings in the published literature are not represented in this study (Archbold et al., 1990; Cangelosi, 2009).

There were no published studies found that explored the positive feelings associated with caregiving for family members dependent upon hemodialysis. However, in a study focused on family resiliency, White, Richter, Koeckeritz, Munch et al. (2004) described the power of positive relationships and family integrity as essential to the development of positive coping mechanisms when faced with difficult circumstances such as a family member who has a chronic illness. Much of the caregiver literature was focused on quantifying the stress and burden associated with caregiving for a family member. Even though the caregivers in this study
expressed some frustration and anger, they also expressed feeling grateful that they could give
back to and care for their family member.

Caregivers conveyed satisfaction when serving as an advocate, knowing they were doing
the best they could to ensure positive outcomes for their family member. The caregivers in this
study also felt joy and happiness when participating in social activities with the family member.
When recalling situations that evoked positive emotions, the investigator noted that the
caregivers’ faces shined with memories. The participant descriptions and investigator field notes
provided support that the positive emotions of joy and happiness outweighed the anger and
frustration the caregivers experienced in the caregiving situation. The investigator considered
that the positive perceptions of the caregiving experience outweighs the negative perceptions an
important insight that could perhaps be explored in future research.

**Structural Model: Predictors and Outcomes of Burden**

The framework that informed this study was the model by Savundranayagam et al. (2011)
entitled *Structural Model: Predictors and Outcomes of Burden*. The model provided a beginning
appreciation of caregiver burden and identified connections between essential concepts. The
model was based on the experiences of patients with Alzheimer’s disease and their caregivers
and incorporated existing research on predictors of caregiver burden and outcomes of caregiving
burden (M. Savundranayagam, personal communication, February, 14, 2013). The model was
chosen for this study because it provided a multidimensional perspective on the nature of
informal family caregiving and some initial information about the experience of caregiver
burden. However, the goal of this study was to provide a complete description from caregivers
through their personal stories and experiences of the phenomenon of providing care to a different
population, which included their perceptions and feelings.
While the model provided some understanding, phenomenological exploration using an inductive approach focused on the lived experience of the caregivers (Giorgi, 2009). While conducting the study, the investigator bracketed the model (set aside pre-suppositions) and examined the participant’s experience. The investigator used field notes to aid in data analysis of the interview transcripts. Following the inductive analysis of the interviews that generated themes and subthemes, the investigator then considered what was learned through the participant’s shared experience with what was already known about caregiving burden.

**Application of model to a new population.**

A question prior to the study existed regarding the transferability of the model to the hemodialysis caregiver population. During model development, Savundranayagam et al. examined caregivers of patients with Alzheimer’s disease and non-specified dementia. It was unclear if the experience of caregiving for family members with Alzheimer’s disease and dementia represented the essence of the experience for caregivers of other patient populations such as hemodialysis patients. However, because caregiver groups are not homogeneous, Savundranayagam et al. stressed the importance of exploring caregiver burden in different populations to examine relationships between predictors and outcomes of caregiver burden that are potentially related to ethnicity, socioeconomic status, and the care receiver’s medical diagnosis. The purpose of this descriptive, phenomenological study was to explore the lived experience of caregivers providing care to a family member using hemodialysis. Data analysis of interview conversations with six participants revealed several links to the model by Savundranayagam et al., as well as differences.

Several assumptions predicated the development of the *Structural Model: Predictors and Outcomes of Burden* (Savundranayagam et al., 2011). One assumption was that the caregiver-
care receiver dyads shared an interpersonal relationship prior to the event requiring a change to
the caregiver-care receiver relationship. Caregivers in this study had an interpersonal
relationship with the family member that included daughter (Participants B – 2; C – 3; D – 4),
wife (Participant E – 5), granddaughter (Participant A – 1), and son-in-law (Participant F – 6)
prior to the family member starting hemodialysis treatments. In this study the caregivers and
family members were not necessarily dyads, but rather part of a family caregiving experience.
This may account for some differences in the experiences of the caregivers.

White, Richter, Koeckeritz, Munch et al. (2004) described the power of positive family
relationships as integral to the development of positive coping mechanisms when a family is
faced with difficult circumstances. In this dissertation study, five participants described positive
relationships with the family member. One participant described interpersonal conflict with the
family member, her mother. This participant (D – 4) experienced self-reported caregiver burden
because she was frequently conflicted between caring for her young daughter and her mother.
Thus, the quality of the relationship was important to explore in this study.

The second assumption stated by Savundranayagam et al. (2011) is that the activities of
caring for another person negatively affected other aspects of the life of a caregiver. An example
of the second assumption is that caregiving may require an employment change or interfere with
social activities or other interpersonal relationships. Caregivers in this study acknowledged that
their daily lives and lifestyle had changed as a result of caregiving for a family member who is
dependent upon dialysis. One of the caregivers expressed that she changed jobs while in the
caregiving role, which was predicated by a change in her family member’s health status
(Participant B – 2). Moulton (2008) also addressed social isolation, which can be the result of
loss of leisure time because of caregiving responsibilities affecting lifestyle or changes in non-
familial interpersonal relationships. In this study, one caregiver expressed that since the initiation of dialysis, she and her family member (her husband) could no longer participate in the same social activities as prior to the initiation of hemodialysis and she felt alone and sad when she had to go to social events without him (Participant E – 5).

The third assumption of the model was that emotional stress often accompanied caregiving responsibilities (Savundranayagam et al., 2011). Caregivers in this dissertation study perceived that the experience of caregiving for a family member dependent upon hemodialysis was stressful and hard work. Caregivers acknowledged negative emotions such as anger and frustration associated with the caregiving experience. In the model, stress burden only addressed the perceived negative emotional effects of caregiving on the caregiver. Worry, anxiety, and feelings of hopelessness were included in the dimension of stress burden (Savundranayagam et al., 2011). In this dissertation study, caregivers also expressed gratefulness and happiness that they could provide care for the family member. The identification of positive emotions was not represented in the model. The positive emotions were associated with social activities that the caregiver and care receiver engaged in together such as going to the nail salon or shopping (Participants A – 1; B – 2). These social activities served to strengthen the bond between the caregiver and family member and helped build the relationship as noted by White, Richter, Koeckeritz, Munch et al. (2004).

Social support, in the form of close friends and family members, was shown in the literature to be an important aspect of caregiving (White, Richter, Koeckeritz, Munch, et al., 2004). Sezer, Eren, Ozcankaya, Civi, Erturk et al. (2003) suggested that characteristics of the family may affect social support systems. The characteristics noted by Sezer et al. (2003) included socioeconomic status and garnering of resources. According to Sezer et al., caregivers
who were on the lower end of the socioeconomic strata experienced more challenges with coping as they cared for a family member. The investigator did not inquire about the socioeconomic status of participants in this dissertation study, only whether they were currently employed. Perhaps this element, the effects of socioeconomic status and coping, could be explored in future studies.

Poor or inadequate social support systems were identified in the literature as presenting a challenge for caregivers who experienced an increase in caregiver burden (Belasco & Sesso, 2002; Nguyen, 2009). Lack of a support system has been shown in the literature to increase stress as well (Burns et al., 1993; Savundranayagam et al., 2011). Caregivers in this dissertation study expressed they had an informal support system. When caregivers felt they had other family and friends to share in caregiving duties, the caregivers expressed that having another person to share the workload of caregiving was helpful and reduced stress levels (Participants A – 1; B – 2; E – 5). Caregivers perceived that having a support system was essential to reduce stress and anxiety of the daily responsibilities of caregiving. The support system for the six caregivers in this study was an informal structure and consisted of other family members, friends, or co-workers.

The structural model did not include or address the component of support systems for caregivers. If a support system structural component were added to the model, the investigator suggested it be added within the stress burden construct. The construct of stress burden addressed the emotional effects of caregiving on the caregiver. The emotional effects included worry, anxiety, and feelings of hopelessness (Savundranayagam et al., 2011).

The investigator believed that the support system element fits best with the stress burden construct in identifying the challenges associated with caregiving for a family member dependent
upon hemodialysis, because social support seems to lessen the stress burden. The theme
*Caregiving is Stressful* emerged from the caregivers’ perception of stress in the experience of
caregiving. The caregivers identified that a support system was an essential element in the
experience of caregiving and helped to decrease the feelings of anxiety and stress associated with
the lived experience. There were no studies identified in the literature that focused specifically
on informal support systems for caregivers for comparison. However, White, Richter,
Koeckeritz, Munch et al. (2004) found that informal support systems were essential to improve
family resiliency.

In the literature, formal support systems included dialysis nurses and social workers who
served as advocates for caregivers and their family members (White, Richter, Koeckeritz,
Munch, et al., 2004). Montgomery and Kosloski (2009) also addressed formal support systems
as parts of a change in social policies that gave benefits to caregivers of family members. The
changes in social policies included laws and changes in Medicare policies. Also included were
increased sources for private and governmental funding for the care of the family member
(Montgomery & Kosloski, 2009). One caregiver in this dissertation study discussed that she
called her organization’s human resources department to get information on federal laws that
protected her rights as an employee when she cared for her mother who had a stroke while on
dialysis. She was able to use federally approved leave time from work so she could focus on her
mother. In this study, some participants looked for formal support systems to aid in their
caregiving while other participants maintained informal support systems.

**Caregiver duties and responsibilities.**

*Relationship burden* as a concept in the theoretical model used to inform this study was
revealed in the relationship between the caregiver and receiver with a focus on family member
behaviors (manipulative or demanding) that induce stress and strain the caregiver-care receiver relationship. In this study, the family members of several participants exhibited manipulative behaviors that created disruption in the relationship, thereby resulting in relationship burden. Encouraging compliance with medication regimens or dietary restrictions with an uncooperative care receiver may also change the way a caregiver behaves toward the family member. Two of the caregivers in this study experienced relationship burden when ensuring dietary restriction compliance with the family member (Participant A – 1; F – 6). One caregiver experienced this with the family member directly (Participant F – 6). The caregiver expressed frustration with his mother-in-law when she would not comply with dietary restrictions, which occurred frequently and often resulted in hospitalization. The second caregiver experienced frustration with other family members who bought groceries for the family member dependent upon dialysis (Participant A – 1). White, Richter, Koeckeritz, Munch et al. (2004) reported that some female spouses felt like a “warden” (p.368) when addressing their husbands’ dietary restrictions.

Caregivers in this study did not express this sentiment explicitly; however, the topic of dietary restrictions was discussed frequently and at length. Participant F – 6 frequently made comments and exhibited facial expressions of frustration when sharing conversational threads regarding food choices with his mother-in-law.

White, Richter, Koeckeritz, Munch et al. (2004) described the power of positive relationships and family integrity as essential to the development of positive coping mechanisms under adverse conditions such as chronic kidney disease. One participant experienced relationship burden in caring for her mother. As an only child, Participant D – 4 felt she had no one to help her manage the care for her mother. The participant had a young daughter and was pregnant with a second child at the time of the interview. For many years, the participant and her
mother spent much time together and now that the participant was a newlywed with a young family and with the family changes, the caregiver struggled to find time for everyone. The participant reported that her mother tried to make her feel guilty for going home to take care of her young daughter rather than doing things for her mother. The pair engaged in frequent arguments about the issue, which strained their relationship and left the caregiver feeling angry, frustrated, and burdened. The caregiver perceived the situation as mentally and emotionally distressing.

Another participant, C – 3, shared that she and her father were alike in that they wanted things done their own way. The participant reported that after about an hour of visiting and trying to help her father, he would become frustrated and tell her that she was “too bossy.” She reported that they would argue, which strained their relationship. The investigator concluded that the ongoing frustrations experienced by the caregivers regarding dietary management and time spent with the family member strained the relationship and contributed to relationship burden in the caregivers in this dissertation study.

According to the model by Savundranayagam et al. (2011), the levels of perceived stress burden and relationship burden were significantly predictive of the outcomes of caregiver self-rated health and intent to place the care receiver in a skilled nursing care facility. Declining caregiver health status during caregiving activities is well documented in the hemodialysis caregiver literature (Belasco & Sesso, 2002; Nguyen, 2009; Schneider, 2003; Schneider, 2004). In this study, three of six caregivers reported a decline in their own physical health status since being in the role of caregiver for the family member (Participants A – 1; B – 2; C – 3). Two caregivers relied on exercise as a way to reduce the stress and anxiety of caregiving
responsibilities and reported their health status as “excellent” (Participant E – 5) and “top notch” (Participant F – 6).

Hirano et al. (2011) showed that a moderate intensity program of exercise in caregivers who cared for a family member with dementia resulted in better sleep quality and improved quality of life for the caregiver. The two caregivers in this dissertation study who reportedly exercised regularly espoused the finding by Hirano et al. The investigator believed the caregivers in this study found exercise to be helpful with not only weight control but also helped them cope better and reduced situational stress.

One of the caregivers in this study discussed intention to place the family member in a skilled nursing facility (Participant B – 2). The family member of this participant received hired assistance from nursing aides 24 hours a day because she had a debilitating stroke two years ago. The participant discussed that the reason for considering placement was because the family member needed constant supervision for safety reasons because of the stroke, not because of demanding or manipulative behaviors as suggested by the model. Hemodialysis does not, in and of itself, cause cognitive issues; however, the associated vascular changes may cause cognitive decline. The investigator was not able to locate published literature on patients receiving hemodialysis being placed in skilled nursing facility as a result of end stage kidney disease or being on hemodialysis. The investigator concluded that caregivers in this study made every effort to keep their family member in the family member’s own home for as long as possible. The caregivers perceived the decision to keep family members intact in their own home as respect for the family member’s membership as part of the family.

The structural model provided a foundation for this dissertation study. Some aspects of the model were paralleled in the study’s findings. The investigator concluded that the model
elements of relationship burden and stress burden, as well as, objective burden were paralleled in the dissertation study findings. Placing the family member in a skilled nursing facility was not perceived by the caregivers to be essential to the experience of caring for a family member dependent upon hemodialysis.

What makes caring for a family member dependent upon hemodialysis is the life-giving nature and indeterminate timeline of the use of the hemodialysis technology. Some health care providers have broached the subject of withdrawing hemodialysis from the family member with the caregivers, thereby raising the question of intentionally causing the death of the family member. Caregivers in this study experienced emotional difficulty when confronted with the potential death of the family member due to an executed decision to withdraw hemodialysis support. Death of the family member due to other causes did not weigh as heavy on the consciousness of the caregiver like this decision would. This aspect of caregiving was not recognized as a component in the model.

Much of the caregiver literature is focused on caregivers of family members with Alzheimer’s disease and other dementia. Behaviors in these patient populations are different from behaviors in patients with other chronic diseases. When examining and comparing caregiver populations across the board, it is essential the investigator takes the behavioral differences into consideration before making global statements regarding the essence of caregiving.

**Recommendations for Action**

Nurses, Nurse Practitioners, Nephrologists, Social Workers or Case Managers, and other health care professionals who work with caregivers of family members dependent upon hemodialysis should be interested in the results of this dissertation study. The health care
professionals who work directly with caregivers of family members dependent upon hemodialysis can use the results of this study to explore the lives of caregivers with whom they work. Recognizing the same or similar issues in the caregiver’s lives, the health care professional can identify and garner resources for the caregiver. The resources could include formal or informal support groups and licensed counselors to address the caregiver’s feelings of stress and anxiety. Another resource that health care professionals could explore is the development of an exercise program for the caregiver. Regular exercise would allow the caregiver to decrease stress and improve physical self-health. Perhaps the health care professionals could explore discount memberships to local gyms for caregivers or initiate an exercise group for caregivers only. A caregiver-only exercise group would establish an informal network of support while improving the caregiver’s health and decrease the caregiver’s stress levels.

In this study, caregivers identified they felt a need to advocate for their family member because the family member did not have the promised resources. When caregivers feel the need to serve as advocates for the family member, another layer of stress is created for the caregiver, especially when the caregiver does not fully trust the health care providers’ care. Health care providers and other members of the health care team should recognize that caregivers’ stress levels would decrease with patient and family centered care programs. Understanding and respecting the lived experiences of caregivers of family members dependent upon hemodialysis should make the health care professionals more sensitive and in-tuned to the needs of the caregiver and family member. Thus, the health care system will be transformed in favor of the family unit. Table 6 summarizes the recommendations for action as noted in the study.

Table 6. Summary of Recommendations for Action
<table>
<thead>
<tr>
<th>Recommendations for Action</th>
<th>Rationale</th>
</tr>
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<tbody>
<tr>
<td>Formal Support Groups</td>
<td>Identify and garner additional resources for caregivers (including financial aspects of caregiving)</td>
</tr>
<tr>
<td>Licensed Counselors</td>
<td>Assist caregivers in managing stress and anxiety</td>
</tr>
<tr>
<td>Exercise Programs</td>
<td>Assist in decreasing stress and improve caregiver health</td>
</tr>
<tr>
<td>Patient and family centered programs</td>
<td>Assist the caregiver with an advocate for family member to decrease added stress</td>
</tr>
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</table>

Support for the primary and secondary caregivers is very important. When discussing the withdrawal of hemodialysis treatment with a caregiver, the health care team members need to be sensitive to the emotional impact of the decision on the caregiver. Health care providers should provide information regarding withdrawal of treatment with sensitivity and tact, knowing that a decision to withdraw treatment will result in the death of the family member. Resources such as a hospice nurse, a grief counselor, and a spiritual counselor, if the caregiver has one, should be employed to assist the caregiver in the aftermath of a decision to withdraw hemodialysis treatment from the family member.

Caregivers of family members who are dependent upon hemodialysis should be interested in the results of this study. Caregivers can self-identify with the caregivers who participated in the study and recognize some or all of the same experiences, feelings, and work associated with the caregiving role. Recognition of similar experiences and situations could serve as the impetus for the caregiver to explore sharing the workload with other family members and establish support systems. Caregivers can also recognize the importance of self-care and develop an exercise routine to decrease stress and improve their own physical and mental health. If caregivers recognize they need more formalized support, the caregivers can then self-refer to a health care professional for assistance in managing varying aspects of the role.
of caregiver to their family member. Caregivers could also seek out support from a spiritual advisor, if they have one.

The results of this dissertation study are best disseminated through publication of the dissertation through peer-reviewed journals. Another important way to disseminate the results of this study is to share the study and results at appropriate professional health care conferences. The results of this study will be shared with the Nursing Research Council and during Nursing Grand Rounds at the Health System Medical Center, from where the sample was recruited. The investigator will also present the research findings at the College of Nursing to faculty members and the Dean of the nursing program during the faculty development meeting. Nursing students in the nursing research course in the nursing program would benefit from hearing about the research process and study findings.

**Limitations of the Study**

This dissertation study has several limitations. The investigator experienced difficulty recruiting participants and was able to recruit only one male participant and five female participants. The experience of female caregivers may be different than the experience of male caregivers and having only one man in the study does not ensure that the male perspective is provided.

The sample size is small due to the purposive sampling and difficulty with recruitment; however the investigator believed data saturation was reached because no new information was forthcoming after the fifth interview. The investigator conducted interviews of the participants for the study, which was a snapshot in time for the six participant caregivers. The caregiver’s role may change over time and may depend on the acuity of the family member’s chronic illness or the addition of an acute illness. Other changes in the lives of the caregivers may affect their
ability to provide care. Therefore, the study findings may not represent the entirety of the lived experience of the participant caregivers. To gain full perspective of the lived experience of a caregiver for a family member dependent upon hemodialysis, it may be essential to study the caregiving experience with this same population at differing points in time while they remain a caregiver.

Culture and ethnicity are important factors in determining the way family members interact together. The caregivers in this dissertation study all spoke, read, and wrote in the English language. As this study sample consisted of homogeneous participant caregivers, the perceptions and meaning of the caregiving experience may be different for non-English speaking caregivers and those from other cultures.

**Recommendation for Further Study**

The consensus in the literature was that caregiver burden is a multi-dimensional concept (Caserta et al., 1996; Honea et al., 2008; Novak & Guest, 1989; Poulshock & Deimling, 1984; Savundranayagam et al., 2011). Savundranayagam et al. (2011) stressed the importance of exploring caregiver burden in different populations to examine relationships between predictors and outcomes of caregiver burden that are potentially related to ethnicity, socioeconomic status, and the care receiver’s medical diagnosis. The investigator supports this suggestion by Savundranayagam et al. and has contributed to the body of caregiver literature by conducting this dissertation study. Further research needs to be done with caregivers of family members with other chronic illnesses. Future investigators can use the *Structural Model* designed by Savundranayagam et al. as a framework to determine the usefulness of the model in caregiver populations other than Alzheimer’s disease and other dementias and ESKD.
Two of the caregivers in this study identified exercise as a means to reduce stress and anxiety levels. Hirano et al. (2011) conducted a randomized controlled trial comparing moderate exercise versus no exercise in caregivers of family members with dementia. Other studies exploring exercise included King et al. (2002) who conducted a randomized control trial evaluating the effects of moderate intensity exercise on physiological, emotional, and behavioral responses to family caregiving. The King et al. study was conducted in female caregivers of dementia patients. The gap is that there were no studies exploring the effects of exercise on caregivers of family members dependent upon hemodialysis. The investigator suggests future research that explores the impact of exercise on the caregiver’s self-reported health status and stress levels in caregivers of family members dependent upon hemodialysis.

Two participants identified that when experiencing difficult days in performing caregiving duties they relied on their faith system beliefs to help them manage. There were no studies found in the literature that explored spirituality or the role of faith beliefs and religion in caregivers of hemodialysis patients. The investigator suggests future research that explores the role of spirituality, faith beliefs, and religion in caregivers of family members dependent upon hemodialysis.

This dissertation study was a snapshot in time for the participant caregivers. The investigator believes a study that examines the long term effects of caregiving in the population would be appropriate. The investigator also suggests that another interview study at a later date in time and using the same participants could provide information regarding the changes in perceptions and meaning of the caregiver role as time progresses for the caregiver.

The investigator believes that more caregivers of each type of relationship as were the participants’ in the dissertation study should be interviewed to assess transferability of study
findings to other caregivers of family members dependent upon hemodialysis. The investigator believes that the inclusion of male caregivers as participants in any future study is essential to ascertain the male perspective of caregiving for a family member.

Caregiver research based on ethnicity and culture could not be located in the literature. Ethnicity and culture constitutes a large part of an individual and family identity. As such, the investigator also recommends exploration of the caregiving experience for caregivers who do not speak the English language or are from different cultures.

This dissertation study was delimited to a small geographical area on the mid-Atlantic coast of the United States. Further studies that explore the lived experience of caregivers of family members who are dependent upon hemodialysis in different geographical regions should be conducted. There may be important differences in perceptions and meaning of the caregiving experience for those caregivers who live in rural or large urban areas. Additional studies in a variety of geographical regions will aid in determining transferability and generalizability of the results of this dissertation study.

**Summary**

The investigator designed this dissertation study as a result of an identified gap in the literature regarding studies that used an inductive approach in which caregivers specifically described the lived experience of providing care for family members dependent upon hemodialysis as a treatment for managing ESKD. Through face-to-face interviews, the investigator was able to listen to the participants share their stories, feelings, thoughts, and perceptions of their experiences as a caregiver.

The perceptions of caregivers who provide care for a family member dependent upon hemodialysis are that caregiving is hard work and stressful; however, the caregivers found the
experience to be meaningful. Caregivers felt that they needed a support system and developed relationships to secure an informal network of support for themselves. Acknowledging that the length of time for caregiving is indeterminate, the caregivers in this study felt they did the best they could with what resources they had and sought out other resources as they deemed necessary. Caregivers in this study experienced an emotional struggle with the suggestions of health care professionals to withdraw hemodialysis treatments. Caregivers acknowledged that hemodialysis treatments were life-giving and without hemodialysis, the family member would die. When the withdrawal of the family member’s hemodialysis treatments was discussed by health care providers, caregivers experienced difficulty in confronting this complex topic.

The caregivers in this study found meaning in their efforts as a caregiver to a family member dependent upon hemodialysis. Although they acknowledged that being a caregiver was tough, caregivers expressed no regrets in assuming the role of caregiver for their family member. Caregivers reflected on the importance of hemodialysis as a technology that extended the life of the family member. Caregivers made efforts to improve the quality of life for both the family member and the caregiver. The caregivers’ efforts to improve the family member’s quality of life were meaningful for caregivers.

The findings of this dissertation study showed consistency with some previous research findings that quantified the caregiver’s experience. The findings in this dissertation study that were consistent with the current literature were that exercise helped caregivers manage stress (Hirano et al., 2011). Other findings in this dissertation study showed that sharing the workload and having a support system reduced perception of stress and burden in caregivers (White, Richter, Koeckeritz, Munch et al., 2004; White, Richter, Koeckeritz, Lee et al., 2002).
The findings in this dissertation study were not consistent with some of the findings in other types of studies. Caserta et al. (1996) proposed that the longer a person was in the caregiver role, the more caregiver burden was experienced. Individual caregivers in this study experienced differing levels of caregiver burden based on the circumstances of their own situation. Several caregivers who had been in the caregiver role for shorter lengths of time experienced caregiver burden more so than the participant who had been a caregiver for 10 years. The investigator found that, in this dissertation study, the concept of preparedness for the caregiver to assume the role and responsibilities had limited similarity with published research findings (Archbold et al., 1990), because the caregivers did not identify a direct skillset or level of competence that they needed to achieve in order to assume the role.

Some of the dissertation study’s findings were the antithesis of what was previously published. Schneider (2004) focused on caregiver fatigue as an outcome of caregiver burden. The investigator did not recognize physical fatigue as an essential part of the experience in this study’s findings as in Schneider’s study; however, mental fatigue was inferred in the theme Caregiving is Stressful. Previous studies by Savundranayagam et al. (2011) showed that caregivers experienced loss of role identity as part of the caregiving experience. The majority of participants in this study did not experience loss of role identity; however, the theme Caregiving is Reciprocal addressed the issue of role reversal and loss of role identity in this dissertation study.

Archbold et al. (1990) and Cangelosi (2009) reported that caregiver’s preparedness for the role of caregiver was important and instrumental in determining burden. Participants in this dissertation study did not address preparedness for the caregiver role and responsibilities and felt that they were doing the best they could without specialized training or education. However,
several of the caregivers in this study had some background in healthcare, which may account for the difference. The findings in this study did not support the published literature.

One outcome of the theoretical model identified in the first chapter, intent to place (the care receiver in a skilled nursing facility), did not emerge from the interviews in this study. Only one of the participants reported thoughts or plans to place their family member in a skilled nursing facility and not for the same reasons noted in the model, but for safety reasons. The remaining participants in this study realized their family member needed some assistance; however, this assistance was provided to the family member at home either by other family members or with paid caregivers (nursing assistants). As time progresses, the family member may become physically or cognitively less able to function. At that point in the future, the participants may need to consider moving the family member to a skilled nursing facility.

A second outcome of the theoretical model, caregiver self-reported health status, was somewhat reflected in the interview data collected in this study. Four of the six participants reported a decline in health status since becoming a caregiver for the family member dependent on hemodialysis. Two caregivers reported they used exercise as a stress reduction strategy and were in “excellent” (Participant E – 5) and “top notch” (Participant F – 6) health.

Conclusion

End stage kidney disease is a progressive decline in the kidney function that results in toxin build up in the bloodstream of the body. Hemodialysis is one option for successful long-term management of ESKD and prolongs life. Many patients who use hemodialysis have co-morbid conditions that also require monitoring and treatment. These co-morbid conditions include heart disease, stroke, COPD, and diabetes mellitus. Family members often serve as
caregivers to the patients and help them manage treatments, medications, dietary restrictions, and a myriad of other aspects of their family members’ lives.

The numbers of individuals who serve as a caregiver for a chronically ill family member is increasing (Barry, 2010; Belasco & Sesso, 2002; Nguyen, 2009). Investigators have primarily studied caregivers of patients affected by Alzheimer’s disease and non-specified dementia and less was known about caregiving for patients with other chronic conditions (Montgomery & Kosloski, 2009; Savundranayagam et al., 2011). The consensus in the literature was that caregiver burden is a multi-dimensional concept requiring the subjective input of the caregiver to comprehend fully the experience of caregiving (Caserta et al., 1996; Honea et al., 2008; Novak & Guest, 1989; Poulshock & Deimling, 1984; Savundranayagam et al., 2011).

The dissertation study framework, the structural model, came from research with caregivers for patients with Alzheimer’s disease. The model encompassed elements essential to the experiences of other patient and caregiver populations, including caregivers of family members using hemodialysis as a treatment for ESKD (Savundranayagam et al., 2011). Savundranayagam et al. stressed the importance of exploring caregiver burden in different populations to examine relationships between predictors and outcomes of caregiver burden that were potentially related to the care receiver’s medical diagnosis. This study examined the contextual experience of the phenomenon of caregiving for a specific population, caregivers of family members dependent on hemodialysis, through an inductive approach. This dissertation study contributed to the body of caregiver literature by exploring the lived experience of caregivers of family members who are dependent upon hemodialysis as a treatment for ESKD through an inductive, phenomenological approach.
References


Barry, G. M. (2010, June). Caregiver stress: It's real, and its impact can be severe; how to avoid the epidemic. *Health & Elder Care, Business West.com.*


Appendix A: Letter of Permission from Author
Doctoral Student Requesting Copyright Permission

CHRISTINE TURNER

Dr. Savundranayagam. I am a doctoral student at the University of Phoenix wor...
Appendix B: Letter of Copyright Permission from Publisher

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Appendix C: Signed PRN Form from Health System

University of Phoenix

PREMISES, RECRUITMENT AND NAME (PRN) USE PERMISSION

Memorial Regional Medical Center

Please complete the following by check marking any permission listed here that you approve, and please provide your signature, title, date, and organizational information below. If you have any questions or concerns about this research study, please contact the University of Phoenix Institutional Review Board via email at IRB@phoenix.edu.

x I hereby authorize Christine Turner, a student of University of Phoenix, to use the premises (facility identified below) to conduct a study entitled "The Lived Experience of Being a Caregiver for a Family Member Dependent Upon Hemodialysis."

x I hereby authorize Christine Turner, a student of University of Phoenix, to recruit subjects for participation in a study entitled "The Lived Experience of Being a Caregiver for a Family Member Dependent Upon Hemodialysis."

D I hereby authorize , a student of University of Phoenix, to use the name of the facility, organization, university, institution, or association identified above when publishing results from the study entitled (insert title of research study or a brief description of research study).

5/16/15

Date

Jill Kennedy
Chief Nursing Executive
Vice President, Patient Care Services

Memorial Regional Medical Center
8260 Atlee Road, Mechanicsville, VA 23116

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Appendix D: Recruitment Brochure

SHARE YOUR STORY
Sharing your story will help nurses and care managers to identify resources that may help caregivers in the future who share similar experiences.

Please contact the Principle Investigator Christine Turner for details and to see if you qualify for participation.
Christine_Turner@bhsu.org
Phone: 804-314-0728

IRB Approvals Pending:
Bon Secours Health Care System, INC
University of Phoenix

ARE YOU A CAREGIVER TO A FAMILY MEMBER WHO IS DEPENDENT UPON HEMODIALYSIS?
This study explores the lived experiences of caring for a family member who is dependent upon hemodialysis to manage end-stage kidney disease.
Appendix E: Introductory Script

Introductory Script

The purpose of our meeting today is for you to share your story of caring for a family member who is dependent upon hemodialysis with me so I can understand your experience. You have identified that you are a caregiver for a family member who is dependent upon hemodialysis and I’d like to explore that with you today. I will review the informed consent form with you now so you will understand your rights as a participant in this study.

Thank you for agreeing to participate in this study. I would like you to share your feelings, perceptions, stresses, and insights regarding your experiences when caring for your family member. There is no right or wrong answer, only what you experience, think, and feel. I am going to show you the questions that I will ask you so you will have some idea of what I will ask you to describe. I may ask a few questions so you can provide more description of a particular experience.

Sometimes people can become upset when discussing their life stresses. If you become upset or need to take a break during the interview, please let me know. I have tissues here for you to use if you need them and we can get a beverage for you if you desire. I need for you to be honest in your responses so I can truly understand what you are going through. Are you ready to begin the interview?
Appendix F: Letter of Support from Health System Chief Nurse Executive and Nurse Manager

To Whom It May Concern,

I am the Chief Nursing Executive and Vice President for Patient Care Services at Memorial Regional Medical Center, located in Richmond, Virginia. I am writing this letter to express my support of Christine Turner’s dissertation study entitled, "The Lived Experience of Being a Caregiver for a Family Member Dependent Upon Hemodialysis."

I am aware that she will be working with the nurse manager of the renal unit to identify potential participants for this study.

I think that this dissertation study will provide a unique opportunity for caregivers to describe their experiences with caregiving for a family member who is dependent upon hemodialysis. This information is important for nurses as they provide care for patients and family members of patients using hemodialysis to manage ESKD.

Jill Kennedy

Chief Nursing Executive
Vice President, Patient Care Services
Memorial Regional Medical Center
To Whom It May Concern,

I am writing this letter to express my support of Christine Turner's dissertation study entitled, ""The Lived Experience of Being a Caregiver for a Family Member Dependent Upon Hemodialysis."

I am the nurse manager of the Medical Care Center/Renal Unit at Memorial Regional Medical Center, located in Richmond, Virginia. On this unit, nursing care is provided for patients who have complications of end stage kidney disease and who are receiving hemodialysis. We have the opportunity to work with the family members and care providers of these patients. These units will provide a purposive sample from which to recruit participants in the proposed dissertation study.

I will work with Christine to identify potential participants to begin the recruitment process for the study. I agree to sign a Non-Disclosure Agreement per University of Phoenix IRB protocols.

I think that this study will provide a unique opportunity for caregivers to describe their experiences with providing care for a family member who is dependent upon hemodialysis. This information is important for nurses as they provide care for patients and family members of patients using hemodialysis to manage end stage kidney disease.

Mary Freedlander, RN, MHSA
Nurse Manager, Medical Care Center/Renal Unit
Dear Participant,

My name is Christine Turner. I am a student at the University of Phoenix working on a doctoral degree. I am carrying out a research study entitled “The Lived Experience of Caregivers Who Provide Care to a Family Member Dependent upon Hemodialysis.” The reason I am doing this study is to find out more about the lives of people who serve as a caregiver for a family member who is dependent on hemodialysis to treat end stage kidney disease.

This is an interview study. You have been selected as a possible participant because you shared with me that you are a caregiver for a family member who is dependent upon hemodialysis.

This research will involve an interview in which I will ask you questions about your life and experiences as a caregiver related to taking care of your family member. I will audio-tape the interview. I will ask you to describe your experiences of taking care of your family member. I will also take some notes during the audio-taped interview. The interview will last approximately one and one half hours. The date and time of day for the interview will be set at an agreed upon time between you and me. After the audio-tape is transcribed into a written summary, I will need an additional 15 minutes of your time. This extra time is so that you can review a summary of the transcript to make sure I described your experience correctly.

I expect to interview up to 10 other participants. You can decide to be a part of this study or not. I do not have a relationship with the health care professionals that provide care to your
family member. The health care that your family member receives will not be affected by your
decision to be in this study. I will not share any information from the interview with your family
member’s health care professionals or with your family member. If you decide to be in the
study, I will not share your decision with your family member or the health care professionals. If
you decide to not be in the study, I will not share your decision with your family member or the
health care professionals.

At the time of the interview I will assign you a code letter and number. Because I will
give you a code, no one will be able to identify you as taking part in the study. This code will
keep your name confidential so no one will know you participated in this research except me. I
will not tell your name to anyone outside of the research project (you and me). The transcripts of
your interview will be combined with the transcripts of other participants’ interviews. The results
of the study will be presented as a whole. I may publish the results of the study or present them
to other nurses or health care providers.

Investigators can offer a symbolic gesture of compensation to the participant for the time
devoted to the research study. After the interview you will receive a $10 gas station gift card.
This gift card is to thank you for your time and contribution to the study. This gift card can be
used for gas required to travel to the hospital for the interview or the purchase of snacks.

In this research study, there are no predictable risks to you. You may become upset or sad
when you talk about your experiences of being a caregiver for your family member. You may
take a break from the interview if you wish to gather your thoughts and emotions. There may be
no direct benefit to you, but your participation in this study may help me find out more about the
experience, uncertainties, and stressors related to being a caregiver of a family member who is
dependent upon hemodialysis. Understanding what life is like for you can help me better appreciate your experience. It can also potentially help us to develop resources to help others in the future.

If at any time you decide that do not want to be in the study, please tell me in writing. You can simply write a note that says you want to stop being in the study and sign your name. I will honor this request and reply to you in writing. I will keep a paper copy of your request in the study files. If you decide to stop being in the study after the interview, the information you provided will be destroyed by erasing audio-tapes and shredding any written information including the transcripts. I will use your assigned code to find your specific information.

If you have any questions about the research study, please call me, Christine Turner, at the number provided or you may reach me via email. For questions about your rights as a study participant, or any concerns or complaints, please contact the University of Phoenix Institutional Review Board via email at IRB@phoenix.edu.

You may also contact Bon Secours Institutional Review Board for questions or concerns regarding this study: Bon Secours Richmond Health System Institutional Review Board at 8580 Magellan Parkway, Richmond, VA 23227 (804) 627-5157

As a participant in this study, you should understand the following:

1. You may decide not to be part of this study or you may want to withdraw from the study some time before, during or after the study. If you want to withdraw, you can do so without any problems. You will need to notify me and tell me you want withdraw in writing.
2. I will assign you a letter and number code to use instead of your name. Your identity will be kept confidential.

3. I will interview you and audiotape the interview. You must give permission for me to audiotape the interview in order to participate in the study. You understand that the information from the audiotaped interview will be transcribed in writing. Your interview and the written transcripts of the interview will be coded with a letter and a number to ensure confidentiality.

4. Information from the interview (interview audiotapes, transcripts of the interview, and notes) will be kept in a secure and locked area. The transcripts and notes will be kept for three years and then destroyed by shredding. The audiotapes will be erased after transcription is completed and the transcripts are checked for correctness.

5. The results of this study will be used in a dissertation and may be published. The researcher may present the study results at a conference.

6. I have explained the nature of the research study and have answered your questions.

   “By signing this form, you agree that I have explained that the study involves a 90 minute audio- taped interview in which you will share your experiences of being a caregiver for a family member who is dependent upon hemodialysis. I will take notes during the interview. I have told you about the possible risks to you as a participant. I have told you how your identity will be kept confidential. You also agree to meet with me for 15 minutes at a later time and date to review a summary of the transcript of the interview. When you sign this form, this means that you are 21 years old or older and that you give your permission to volunteer as a participant in the study that is described here.”
(□) I accept the above terms.  (□) I do not accept the above terms.
Signature of the Participant ____________________________ Date ______

Signature of the Researcher _____________________________ Date ______
Appendix H: Interview Schedule

Questions:

1. Tell me about your daily life as a caregiver to your family member.

2. What are you thinking when providing care to your family member?

3. How do you feel when you are providing care to your family member?

4. Describe the meaning that your caregiving experience has for you.

Possible Probes

• Tell me more about what you were thinking when (a particular) experience occurred.

• Describe what you were feeling when (a particular) experience occurred.

• How did you manage during the time when (the particular experience) occurred in your life?
Appendix I: Flesch Kincaid Reading Level for informed consent
Non-Disclosure Agreement

Debra Seegers acknowledges that in order to provide the services to Christine Turner (hereinafter “Researcher”) who is a researcher in a confidential study with the University of Phoenix, Inc., Debra Seegers must agree to keep the information obtained as part of its services (as more fully described below) confidential. Therefore the parties agree as follows:

1. The information to be disclosed under this Non-disclosure Agreement (“Agreement”) is described as follows and shall be considered “Confidential Information”: categorization of blinded, coded transcripts using Giorgi method. All information shall remain the property of Researcher.

2. Debra Seegers agrees to keep in confidence and to use the Confidential Information for categorization of blinded, coded transcriptions only and for no other purposes.

3. Debra Seegers further agrees to keep in confidence and not disclose any Confidential Information to a third party or parties for a period of five (5) years from the date of such disclosure. All oral disclosures of Confidential Information as well as written disclosures of the Confidential Information are covered by this Agreement.

4. Debra Seegers shall upon Researcher’s request either destroy or return the Confidential Information upon termination of this Agreement.

5. Any obligation of Debra Seegers under this Agreement shall not apply to Confidential Information that:
   a) Is or becomes a part of the public knowledge through no fault of Debra Seegers
   b) Debra Seegers can demonstrate was rightfully in its possession before disclosure by Researcher/research subjects; or
   c) Debra Seegers can demonstrate was rightfully received from a third party who was not Researcher/research subjects and was not under confidentiality restriction on disclosure and without breach of any nondisclosure obligation.

6. Debra Seegers agrees to obligate its employees or agents, if any, who have access to any portion of Confidential Information to protect the confidential nature of the Confidential Information as set forth herein.

7. Debra Seegers shall defend, indemnify and hold the Researcher and the University of Phoenix harmless against any third party claims of damage or injury of any kind resulting from Debra Seegers use of the Confidential Information, or any violation of by Debra Seegers of the terms of this Agreement.

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8. In the event Debra Seegers receives a subpoena and believes it has a legal obligation to disclose Confidential Information, Debra Seegers will notify Researcher as soon as possible, and in any event at least five (5) business days prior to the proposed release. If Researcher objects to the release of such Confidential Information, Debra Seegers will allow Researcher to exercise any legal rights or remedies regarding the release and protection of the Confidential Information.

9. Debra Seegers expressly acknowledges and agrees that the breach, or threatened breach, by it through a disclosure of Confidential Information may cause irreparable harm and that Researcher may not have an adequate remedy at law. Therefore, Debra Seegers agrees that upon such breach, or threatened breach, Researcher will be entitled to seek injunctive relief to prevent Debra Seegers from commencing or continuing any action constituting such breach without showing or providing evidence of actual damage.

10. The interpretation and validity of this Agreement and the rights of the parties shall be governed by the laws of the State of Virginia.

11. The parties to this Agreement agree that a copy of the original signature (including an electronic copy) may be used for any and all purposes for which the original signature may have been used. The parties further waive any right to challenge the admissibility or authenticity of this document in a court of law based solely on the absence of an original signature.

IN WITNESS WHEREOF, each of the undersigned has caused this Agreement to be duly executed in its name and on its behalf:

Printed Name of Third Party/Vendor: Debra Seegers
Signature: 
Address: 
Date: 5/18/18

Printed Name of Researcher: Christine Turner
Signature: 
Address: 49
Date: 5/18/2018