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# Burden, Depressive Symptoms, and Perceived Health in Male Caregivers of Persons with End Stage Renal Disease

## Abstract

**Introduction:** Men are increasingly assuming the role of caregiver to individuals with chronic illnesses. The debilitating effects of ESRD cause many of those diagnosed with the disease to require assistance from family caregivers. Caregiver literature well reports that caregivers experience mental and physical health effects related to this role. However, research involving the experiences of male caregivers of individuals with ESRD is understudied. These studies use the background and contextual as well as primary and secondary domains of the Stress Process Model to determine the levels of and explore the experiences associated with caregiver burden, depressive symptoms, and perceived health in two independent samples of male caregivers of persons diagnosed with ESRD.

**Methods:** A series of studies were used to determine the levels of and explore factors associated with caregiver burden, depressive symptoms, and perceived health status. The initial retrospective quantitative study involved completion of questionnaires as measures of objective burden, subjective burden, depressive symptoms, and perceived health status in 29 male caregivers. The second prospective study involved a focus group interview consisting of 6 participants. This study was designed to further explore the experiences contributing to caregiver burden, depressive symptoms, and perceived health. SAS 9.4 and QDA Miner software were used to analyze the quantitative and qualitative data, respectively.

**Results:** Demographic characteristics of caregivers in the retrospective study included a mean age of 57.1 years. The majority of participants were Black, married, unemployed and cared only for the dialysis recipient. Caregivers reported moderate levels of objective and subjective burden, mild depressive symptoms, and good perceived health status. Male caregivers in the prospective study had an average age of 43.7 years. Most participants were Black, employed, and cared for one person. One-half of the caregivers were married. Four themes emerged from the qualitative prospective study, which included care giving experiences, effects of caregiving, and coping strategies.

**Conclusion:** Results of the retrospective study indicated that male caregivers of persons with ESRD experienced significant objective and subjective burden. Overall, caregivers reported mild depressive symptoms, however, one-third reported moderate to severe symptoms. The majority of caregivers in the prospective qualitative study also expressed feeling psychological distress and depression related to the caregiving role. One-third of caregivers in the retrospective study reported their health status as fair or poor, and 14% indicated that their health had worsened since assuming the caregiving role. One-half of caregivers in the prospective study indicated that caregiving responsibilities had negatively affected their physical health. Numerous factors are associated with caregiver burden and depressive symptoms including background and contextual factors such as caregiver age, race, and hours of care. The primary stressor, care recipients' activities of daily living status, was also associated with caregiver objective burden. Caregiver psychiatric morbidity could impede their ability to continue in the caregiving role. Thus, findings from these studies provide support for further research including intervention trials addressing the specific needs of this hidden population of male caregivers.

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**Burden, Depressive Symptoms, and Perceived Health in Male Caregivers of Persons  
with End Stage Renal Disease**

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Presented for  
The Graduate Studies Council  
The University of Tennessee  
Health Science Center

In Partial Fulfillment  
Of the Requirements for the Degree  
Doctor of Philosophy  
From The University of Tennessee

By  
Loretta Alexia Williams  
December 2015

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## **DEDICATION**

This dissertation is dedicated to my husband, Tafari Williams, for his unconditional love and support throughout this challenging endeavor, my sister, Julia A. Barner, for her endless words of encouragement, and most of all to God in heaven who made its completion possible.

I would like to express gratitude to my parents, Lawrence and Mary Smith, my brother Lawrence A. Smith, and my sisters, Rosetta Smith and Marilyn L. Patillo, for their love and support throughout this process. I especially thank my East Shelby church family for their love, support, and unending encouragement. I express my sincerest gratitude to my sister and my friend, Edna M. Smith and my dearest friend, Mrs. Ruth Romona Jackson, for their eternal encouragement, love, and inspiration. I also wish to express my appreciation to my classmates who have inspired and championed me through to the finish line.

Psalm 18:2 “The Lord is my rock and my fortress and my deliverer; My God, my strength, in whom I trust.”

“To God be the glory forever.”

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## ABSTRACT

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**Conclusion:** Results of the quantitative study indicated that male caregivers of persons with ESRD experienced significant objective and subjective burden. Overall, caregivers reported mild depressive symptoms, however, one-third reported moderate to severe symptoms. The majority of caregivers in the qualitative study also expressed feeling psychological distress and depression related to the caregiving role. One-third of caregivers in the quantitative study reported their health status as fair or poor, and 14% indicated that their health had worsened since assuming the caregiving role. One-half of caregivers in the qualitative study indicated that caregiving responsibilities had negatively affected their physical health. Numerous factors are associated with caregiver burden and depressive symptoms including background and contextual factors such as caregiver age, race, and hours of care. The primary stressor, care recipients' activities of daily living status, was also associated with caregiver objective burden. Caregiver psychiatric morbidity could impede their ability to continue in the caregiving role. Thus,



findings from these studies provide support for further research including intervention trials addressing the specific needs of this hidden population of male caregivers.

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## CHAPTER 1. INTRODUCTION

### Overview

The aging United States population of individuals with chronic illnesses has contributed to the rapid rise in the number of informal caregivers (Del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011). Research studies vary regarding the exact number of caregivers in the United States. Estimates indicate that between 44 and 52 million persons provide care to relatives and friends (National Alliance for Caregiving, 2015). The unpaid value of this care is projected at \$375 billion annually (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). The issue of caregiving with its associated costs to society, families, and individuals has become a public health priority of national concern.

Throughout the past three decades many studies have documented the negative outcomes experienced by caregivers of persons with chronic illnesses (Andrén & Elmståhl, 2008; Bolden & Wicks, 2010; Lim & Zebrack, 2004). Findings from these studies indicate that caregivers often experience burden and suffer physical and mental health impairments associated with this role. Researchers report that the negative health experiences of family caregivers are linked to several key variables. These variables include caregiver and care-recipient demographic factors and socioeconomic status, care-recipients' type of illness, number of hours spent providing care, caregiver's health status, and social support system (Robison et al., 2009; Savage & Bailey, 2004; Schoenmakers, Buntinx, & Delepeleire, 2010).

The predominance of caregiving studies has been based upon the experiences of female caregivers providing care for persons with cognitive impairments such as dementia and Alzheimer's disease or chronic mental disorders and physical illnesses (e.g., schizophrenia, cancer, stroke) (Harris, 2003; Kramer & Thompson, 2002; Siefert, Williams, Dowd, Chappel-Aiken, & McCorkle, 2008). Although most caregivers are female, male caregivers comprise a substantial proportion of individuals providing care for family members. Recent studies indicate that approximately 40% of caregivers are males (NAC, 2012). Nevertheless, research involving the caregiving experience of men is scarce. Little is known about the impact that caregiving has on the wellbeing of this population.

Among the illnesses contributing to the increasing need for family caregivers is end stage renal disease (ESRD). End-stage renal disease is a progressive and chronic condition requiring continuing dialysis therapy or kidney transplantation for survival. End stage renal disease is a devastating illness, which has the potential to cause considerable changes in family life. Because of the debilitating effects of the disease, many of these patients require the assistance of caregivers. The prolonged nature of the disease can lead to financial burden and adverse psychological and physical health outcomes for both the caregiver and the patient (Harris, 2003; Wicks, Bolden, Mynatt, Rice, & Acchiardo, 2007; Wilson-Genderson, Pruchno, & Cartwright, 2009). Because

caregiving can result in significant stress and increase caregivers' risk for negative physical and mental health effects, the outcomes related to caregiving of patients with ESRD are of great concern. Not only are caregiver health effects a concern for caregiver and clinician, but also a decline in caregivers' health may result in an inability to continue in the caregiving role. Thus, it is important that their experiences are documented, caregivers at risk for negative outcomes are identified by healthcare providers, and interventions are developed to assist this hidden population of caregivers.

### **Purpose of the Study**

Caregiving research has focused primarily on Caucasian female caregivers of persons with cognitive impairments and other chronic illnesses. These study results are important as there are similarities in caregiving experiences irrespective of patient population. However, because biopsychosocial differences exist between men and women, the findings from these female-oriented caregiver studies cannot indiscriminately be generalized to male caregivers. Some caregiver studies report collectively data analysis involving males and females. However, few studies have explored whether gender differences exist (Houde, 2002). In addition, although caregivers of persons with chronic illnesses share similar negative outcomes associated with burden and depressive symptoms, these results cannot be applied in general to caregivers of the ESRD population. While caregivers share similar experiences across the chronic disease spectrum, there are certain unique factors associated with specific illnesses which result in distinct differences in caregiver experiences (Harris, 2003; Tong, Sainsbury, & Craig, 2008).

Thus, there is a significant gap in the existing body of knowledge associated with the caregiving experience of this population. Because caring for persons with chronic illnesses can result in negative physical and mental health outcomes for the caregiver, assessing these characteristics in male caregivers is essential. Therefore, the purposes of the current quantitative and qualitative studies are the following: (1) determine the levels of and examine the associations among caregiver objective and subjective burden, depressive symptoms, and perceived health status, and (2) identify factors associated with caregiver objective and subjective burden, depressive symptoms, and perceived health in men caring for persons with ESRD, respectively. These goals were accomplished using two samples of male caregivers. First, secondary analysis was conducted using historical data collected from men who participated in a previous study to examine caregiver objective and subjective burden, depressive symptoms, and perceived health status. Second, a current qualitative study including data from focus group interviews was conducted to explore the experiences that contribute to caregiver objective and subjective burden, depressive symptoms, and perceived health in male caregivers of persons with ESRD.



## **Aims and Research Questions**

### **Quantitative Specific Aim One**

This study was guided in part by three quantitative specific aims in addition to one qualitative specific aim. The quantitative specific aims are listed below.

- Quantitative specific aim one was to determine the demographic profile of male informal caregivers of relatives with ESRD, which was determined by asking the question: What is the demographic profile of male informal caregivers of relatives with ESRD?
- Quantitative specific aim two was to determine the levels of subjective and objective caregiver burden, depressive symptoms, and perceived health reported by male informal caregivers of relatives with ESRD, determined by asking the following three questions:
  - What are the levels of subjective and objective caregiver burden reported by male informal caregivers of relatives with ESRD?
  - What are the levels of depressive symptoms reported by male informal caregivers of relatives with ESRD?
  - What is the perceived health status of male caregivers of relatives with ESRD?
- Quantitative specific aim three was to determine the associations among caregiver subjective and objective burden, depressive symptoms, and perceived health in male informal caregivers caring for relatives with ESRD by asking the question: What are the associations among caregiver burden, depressive symptoms, and perceived health in men caring for relatives with ESRD?

### **Qualitative Specific Aim**

The one qualitative specific aim for this study was to explore the experiences that contribute to caregiver subjective and objective burden, depressive symptoms, and perceived health in male informal caregivers of relatives with ESRD by asking the question: What are the experiences of male caregivers caring for relatives with ESRD contributing to caregiver subjective and objective burden, depressive symptoms, and perceived health?

## **Conceptual Framework**

The Stress Process Model (SPM) serves as the theoretical foundation for this study. The SPM is a middle-range theory originally consisting of three primary domains:

stressors, mediating resources, and manifestations of stress (Pearlin, Lieberman, Menaghan, & Mullan, 1981). Stressors are dichotomized into primary and secondary categories (Pearlin, Mullan, Semple, & Skaff, 1990). Primary stressors are those that are likely to occur first in an individual's experiences and include events that are undesired, disruptive, and enduring (i.e., demands of caregiving tasks). Secondary stressors come about as consequences of primary stressors and include role strain and intrapsychic strains. For example, a person may experience role conflict, economic strain, and isolation related to caregiving demands (Harris, 2003; Pearlin et al., 1990).

Mediators of stress are the elements that a person invokes on his or her own behalf as defense against stressors. Mediators consist of social supports which include organizations, groups, and persons that assist in dealing with life's stressors and coping which involves the changes individuals make to their behavioral or psychological state in response to the stressors (Bolden & Wicks, 2010; Pearlin et al., 1981). Manifestations of stress or outcomes include measures of physical and mental wellbeing and the ability to continue in a specified social role (Pearlin et al., 1990).

Although the original model consisted of three domains, the subsequent SPM included background and contextual factors of stress as a fourth domain (Pearlin et al., 1990). The background and contextual factors of stress are subdivided into socioeconomic (SES) characteristics, historical context, family composition, and social network composition. Caregiver background characteristics such as age, gender, SES, and ethnicity significantly may influence caregivers' experiences as these attributes affect the resources that are available to caregivers and are key factors threaded throughout the stress process (Bolden & Wicks, 2008; Pearlin et al., 1990).

To be useful to clinicians in informing interventions leading to positive outcomes for patients and families, theories must be evaluated and their applicability to research and clinical practice established (Bolden & Wicks, 2008). The SPM is a specific and concrete theory that has been successfully used in caregiving research (Kim, Chang, Rose, & Kim, 2012). Moreover, it has been successfully used in research involving caregivers of patients with ESRD.

Pearlin et al. (1990) applied the SPM to caregiving defining stressors as life events, conditions, and experiences that are undesirable and problematic. Thus, caring for chronically ill relatives such as persons with ESRD is an example of a major stressor, which may influence caregiver burden, depressive symptoms, and perceived health status in this population of male caregivers. Primary stressors are related to the demands and needs of the care recipient and include the caregivers' perceived difficulties related to caregiving. Secondary stressors evolve as a result of primary stressors and include caregiver role conflicts and experiences that hinder the caregivers' ability to work and may cause social isolation. The mediators, coping and social support, are used to lessen the effects of the aforementioned caregiving role stressors in the application of the SPM.

Outcomes within the SPM involve the caregivers' wellbeing, physical and mental health, and ability to function in their social roles (Pearlin et al., 1990). Because

caregiving can result in significant stress and increase caregivers' risk for negative physical and mental health effects, these outcomes are of great concern. Not only are negative caregiver health effects a concern for caregiver and clinician, but also a decline in a caregiver's health may result in an inability to continue in the caregiving role. Understanding the constructs of the SPM and how they relate to the caregiving population will be essential to helping healthcare providers identify factors that predict caregiver burden, perceived health status, and depressive symptoms and to developing specific interventions designed for male caregivers of patients with ESRD.

### **Definitions of Major Concepts**

Many theoretical and operational definitions exist in the literature for the concepts explored in this study. Following are the concepts and operational definitions used for the current retrospective and prospective studies.

#### **Burden**

Caregiver burden is defined as caregiver distress as it relates to health, social life, psychological well-being, financial status, and relationship to care-recipients (Del-Pino-Casado et al., 2011). Hoenig and Hamilton (1966) were first to elucidate the concept of burden in the context of caregiving dichotomizing it into subjective and objective dimensions (as cited in Chou, 2000). It was their premise that the activities and specific events in the lives of caregivers should be separate from the feelings, emotions, and attitudes experienced as a byproduct of providing care. In the literature, caregiver burden is described as both predictor and outcome variables. When considering the concept as a manifestation of stress as in the current study, it is described as the negative physical, emotional, psychological, social, and financial effects that caregiving has on the caregiver (Andrén & Elmståhl, 2008).

**Objective burden.** Objective burden is operationally defined in this study as the nature of the caregiving tasks, the amount of time spent performing caregiving duties, and the extent to which these responsibilities change the caregiver's life and household (Brouwer et al., 2004). A 9-item subscale of the Measurement of Burden Scale was used to measure objective burden. The subscale includes nine areas identified in the literature that frequently affect the caregiving experience such as privacy, personal freedom, and energy level (Montgomery, Gonyea, & Hooyman, 1985).

**Subjective burden.** Subjective burden is the emotional responses and mindset of the caregiver toward the caregiving experience (Ampalam, Gunturu, & Padma, 2012). It refers to the way in which the caregiver perceives the effects of objective burden (Brouwer et al., 2004). In this study, subjective burden is operationalized as the negative psychological impact experienced by the caregiver (Glanville & Dixon, 2005). A 13-item

subscale of the Measurement of Burden Scale was used to measure subjective burden. The subscale includes thirteen items focused on how often participants experienced feelings such as usefulness in relationship with the care recipient, fear of future events, and relationship strain (Harris, 2003; Montgomery et al., 1985).

### **Depressive Symptoms**

Depressive symptoms are well documented in caregiver populations with caregivers reporting approximately three times as many depressive symptoms as their non-caregiver counterparts (Adams, 2008; K. R. Chou, 2000; Robison et al., 2009). Depression is consistently associated with being a significant predisposing factor to caregiver burden. It is among the primary psychological problems linked to caregiver burden along with sadness, loneliness, and guilt (Adams, 2008; Robison et al., 2009). The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure depressive symptoms in the current study. Developed by the Center for Epidemiologic Studies, this 20-item self-report instrument is used to measure depressive symptoms in the general population and is the most commonly used instrument in assessment of caregivers' depressive symptoms (Radloff, 1977; Schulz & Sherwood, 2008).

### **Perceived Health**

Perceived health status is well recognized as a valid and reliable predictor of mortality and an important correlate of objective measures of health (Byers, Beard, & Wicks, 2009; S. M. Hunt et al., 1980; Jylha, 2009). In addition, research demonstrates that perceived health is predictive of other factors such as incidence of chronic illnesses, psychological wellbeing, and functional decline even when objective measures of health are considered (Shields & Shooshtari, 2001). For purposes of this study, perceived health is defined as the caregiver's perception of his health status and is operationalized using the self-rated, single-item Caregiver's Perceived Health Form, developed and validated by the National Center for Health Services Research for the Health Insurance Study (Miller, 1990).

## **General Definitions**

### **End-Stage Renal Disease**

End stage renal disease is a progressive condition requiring chronic dialysis treatments or kidney transplantation for survival. Inclusion in this study required that caregivers be the primary care providers for current hemodialysis recipients diagnosed with ESRD. Caregiver report of ESRD diagnosis and current chronic dialysis treatments were used to operationalize ESRD.

## **Caregiver**

Caregiving is a multidimensional activity that involves the act of attending to others or providing a needed service to relatives or friends who are unable to provide for themselves (Eisdorfer, 1991; Pearlin et al., 1990). Caregivers may assume primary, secondary, or tertiary responsibility for the care recipient's needs. Primary caregivers shoulder the bulk of responsibility for the needs of the care recipient and perform most of the caregiving tasks. Secondary caregivers assume caregiving tasks similar to those of the primary caregiver. However, their level of responsibility for the care recipient involves fewer obligations than that of the primary caregiver. Tertiary caregivers assist primary caregivers with caregiving tasks such as grocery shopping and paying bills, but typically have no responsibility regarding care decisions (Dilworth-Anderson, Williams, & Cooper, 1999). In this study, caregiver is defined as an adult male primarily responsible for the care of a relative or loved one diagnosed with ESRD who is identified by the care recipient as their primary caregiver.

## **Caregiver Characteristics**

Caregiver background characteristics such as age, gender, SES, and ethnicity significantly influence caregivers' experiences and outcomes and are key factors threaded throughout the SPM (Pearlin et al., 1990). Caregiver characteristics assessed in this study include age, gender, educational level, SES, caregiver-patient relationship, duration of caregiving role, and hours spent providing care daily. Sociodemographic factors were determined by caregiver self-report in response to items on the Caregiver Demographic Data Form.

## **Concept Relationships**

The domains extrapolated from the SPM, which provide theoretical basis for the conceptual framework in these studies include caregiver background and contextual factors, primary and secondary stressors, and caregiver stress outcomes, measured as objective and subjective burden. The SPM will be used to examine relationships within the model. This theoretical model is useful because it includes multiple factors that account for caregiver burden, depressive symptoms, and caregiver perceived health status, the variables of interest in these studies. Caregiver burden is a multidimensional phenomenon that negatively affects the caregiver's financial, physical, psychological, and social status (Robison et al., 2009). Depressive symptoms and poor caregiver perceived health are strongly associated with burden (Ducharme et al., 2009).

The background and contextual domain of the model addresses the setting in which caregiving takes place. Because caregiving does not occur in isolation from an individual's social and experiential past and present, the caregiving process must be considered within these contexts (Raina et al., 2004). Research has shown that caregiver characteristics such as being female, married, and old-aged are predictors of caregiver

depression. Socioeconomic characteristics are of particular importance as they are significant correlates of exposure to care related burden and depression (Grandon, Jenaro, & Lemos, 2008; G. G. Hunt, Ginzler, & Barrett, 2004; Rhee et al., 2008). For example, persons with lower socioeconomic status often have less access to healthcare and community resources, which may result in their experiencing greater caregiver burden. In addition, socioeconomic status is an important factor in the perception of health, and adequate income is a key determinant in helping to alleviate the stress of caregiving (Schulz & Sherwood, 2008; D. R. Williams, Mohammed, Leavell, & Collins, 2010). Insufficient income reduces access to valuable resources that make caregiving more bearable. The stress associated with inadequate income often leads to physical illness, anxiety, and depression and has been identified as a primary indicator of caregiver burden (K. R. Chou, 2000; Pinquart & Sorensen, 2007). While many studies report that caregiver sociodemographic characteristics significantly influence the caregiving experience (Schoenmakers et al., 2010; Siefert et al., 2008), other studies show that factors, such as race and income, have insignificant effects on caregiver burden and depression (Rigby, Gubitz, & Phillips, 2009; I. C. Williams, 2005). The influence of these caregiver characteristics, in some populations, is key to understanding the intensity of stressors and how they are expressed (Pearlin et al., 1990).

Depressive symptoms are extensively documented in caregiving literature. Caregivers report experiencing approximately three times as many depressive symptoms as their non-caregiver counterparts (Adams, 2008; K. R. Chou, 2000; Robison et al., 2009). The most prevalent depressive symptom is depression, which is commonly associated with significant caregiver burden. By some estimates, as many as 50% of caregivers experience symptoms of depression (Clark & Diamond, 2010). Depression is listed among the primary psychological problems experienced by caregivers along with worry, discouragement, anxiety, and guilt (Bolden & Wicks, 2010; Zegwaard, Aartsen, Cuijpers, & Grypdonck, 2011). Men often express depression as anger, hostility, and conflict. Alcohol abuse, suicide, and compulsory detainment may also be associated with depression in men (Branney & White, 2008; Kramer & Thompson, 2002). In addition to contributing to caregiver burden, depressive symptoms may influence caregivers' perceived health status as well as increase the rate at which self-rated health declines over time (Byers et al., 2009; Robison et al., 2009).

### **Significance of Study**

Although the majority of caregivers are females, research shows that male caregivers comprise 40% of those caring for persons aged 18-49 and 33% of individuals caring for persons greater than age 50 (NAC, 2009). The family roles presented by male caregivers vary. These men are fathers caring for children, husbands attending to wives, and sons caring for aging parents. Research shows that male caregivers are not immune to the negative outcomes of caregiving including depression, hostility, grief, and profound isolation (Kramer & Thompson, 2002; Sanders & Power, 2009). When compared to non-caregivers, male caregivers showed higher levels of anxiety and depression, reported more somatic complaints, had difficulty sleeping, and used more



over-the-counter medication (Folkman, Chesney, & Christopher-Richards, 1994; Kramer & Thompson, 2002). Qualitative studies involving male caregivers echoed themes of burden and depression as well. Factors contributing to the sense of male caregiver burden include conflict between caregiving and work, poor caregiver health, and fear of future outcomes for care-recipients (Kramer & Thompson, 2002). Chang and White-Means (1991) found that men in general were healthier, more satisfied with life, and reported less financial and physical stress compared to women. Thus, findings involving male caregivers are inconsistent.

Notwithstanding, research involving the male caregiving experience is scarce. Little is known about the impact that caregiving has on burden, depressive symptoms, and perceived health status in this population. Moreover, the literature addressing the experiences of male caregivers of persons with ESRD is scarce. Consequently, there is little understanding of the ways in which these male caregivers experience and manage the objective and subjective burden that accompanies this role. Like their female counterparts, male caregivers provide significant contributions to their care-recipients, families, and society as a whole (NAC, 2012). Therefore, it is imperative that their unique experiences be explored.

Findings from this research will facilitate dialogue among researchers, clinicians, and health policy makers to help identify factors associated with caregiver burden, depressive symptoms, and poor perceived health status in men caring for individuals with ESRD. In addition, future research will assist healthcare providers in developing interventional programs to address the specific needs of this understudied but important caregiver population.

### **Assumptions**

The following assumptions embedded in the theoretical framework influenced the design of both studies and the interpretation of findings:

- Male caregivers are cognizant of their physical / mental health histories, and are willing and able to self-report information using the selected study instruments.
- Objective and subjective burden are negative outcomes associated with caregiving of chronically ill individuals. Research has shown that stress, which is measured in the current study as burden, is associated with providing care for persons receiving hemodialysis. Thus, male caregivers of persons with ESRD are assumed to experience burden.
- The occurrence of depressive symptoms in caregivers of persons with chronic illness is well documented in the literature. Validity and reliability of the instruments used to measure depressive symptoms in this study have been established in caregivers of patients with ESRD.

- The theoretical framework used in these studies contains concepts applicable to family caregivers of persons with ESRD.
- Caregivers are aware of their health history and are able to provide a subjective health rating using a single-item measure.

### **Limitations**

The following limitations for these studies were identified prior to the conduct of the study:

- Because the sample for both studies was small and involved a cross-sectional design, generalizability and transferability is limited to caregivers who are demographically similar to those who participated in the current studies (Polit & Beck, 2012).
- Caregivers who are severely depressed may not have participated in these studies. Thus, the full range of depression scores possible may not be reflected in the quantitative study sample.
- Missing data is often a problem associated with the use of secondary data sets (Hulley, Cummings, Browner, Grady, & Newman, 2007). Missing data can result in biased or erroneous conclusions.
- The participants in both studies were from the Memphis metropolitan areas. Therefore, the results of these studies may not reflect the experiences of caregivers in rural areas.



## CHAPTER 2. LITERATURE REVIEW

### Introduction

By the close of 2012, over one half million individuals were kidney transplant recipients or being treated with dialysis therapy, an estimated 1,792 cases per million. In addition, 116,946 new cases had been diagnosed. Although the incidence of end stage renal disease (ESRD) among persons younger than 44 years has been stable during the past 20 years, the number of incident cases among those aged 45 and older has continued to rise with a dramatic increase observed in persons aged 65 and older (Saran, Li, & Robinson, 2014). Approximately one-fifth of the ESRD patient population is aged 65-74 years. As the population ages, these numbers are expected to increase (Gayomali, Sutherland, & Finkelstein, 2008).

End-stage renal disease is a progressive and chronic condition requiring continuing dialysis therapy or kidney transplantation for survival. It is a devastating illness, which has the potential to cause considerable changes in family life. The debilitating effects of the disease cause many of these individuals to require assistance from family caregivers with dialysis treatments, medication administration, and activities of daily living. Advances in dialysis treatments and improvements in chronic illness management have had the combined effect of increasing the life span of individuals diagnosed with ESRD. However, persons living with the disease often experience many complications including infection, fatigue, sleep abnormalities, and deterioration of physical health. The detrimental physical effects of the disease are often accompanied by cognitive impairment as well (Walker et al., 2015). Among hemodialysis patients aged 55 years and older, approximately 70% have moderate to severe cognitive impairment (Murray, 2008), which markedly increases caregiver psychological distress. In addition to the physical and cognitive effects associated with the disease, adjusting to a life of continuing dialysis therapy and strict dietary changes also contributes to the negative outcomes experienced by both the care recipient and the caregiver (Gayomali et al., 2008). The burden of ESRD diagnosis is often further complicated by co-morbid conditions such as heart disease, hypertension, and diabetes. Diabetes is the single most common cause of ESRD (Saran et al., 2014). The complications related to diabetes include visual disturbances and difficulty with ambulation, both of which contribute to the care-recipients' functional decline and increase the levels of objective and subjective burden experienced by their caregivers (Gayomali et al., 2008).

Caring for persons with ESRD often necessitates contending with unpredictable and arduous situations, and the prolonged nature of the disease can lead to significant caregiver stress and burden, depressive symptoms, and poor perceived health. The literature amply documents that caregiver burden increases caregivers' risk for compromised mental and physical health (Andrén & Elmståhl, 2008; Cangelosi, 2009; H. Y. Chang, Chiou, & Chen, 2010). In addition to the burden of providing care, caregivers of persons with ESRD are at greater risk of poor health because caregiving responsibilities often leave little time to focus on their health needs (Wilson-Genderson et

al., 2009). Studies show that caregiver burden is strongly associated with poor self-rated health (Belasco, Barbosa, Bettencourt, Diccini, & Sesso, 2006; Wilson-Genderson et al., 2009), which is well recognized as a valid predictor of mortality (Jylha, 2009). According to one study, caregiver burden in older spousal caregivers increased mortality risk greater than 60% during the first 4 years of assuming the caregiving role. Additionally, the emotional strain of caregiving among this group is an independent risk factor for mortality (Schulz & Beach, 1999). Providing care for persons diagnosed with ESRD often contributes to increased burden, chronic stress, and compromised physical and mental health. Thus, these caregivers may also be at increased risk of mortality.

Although ESRD has a devastating impact upon the lives of those affected by it, there is a paucity of research involving the caregiver burden and depressive symptoms associated with caring for persons with the disease. Moreover, the literature is silent regarding the experiences of men who provide care for persons diagnosed with the disorder. Thus, there is a significant gap in the existing body of knowledge associated with the caregiving experience of this male caregiver population. Little is known about the impact that caregiving has on their wellbeing. Because caregiving can result in a precarious state of physical and psychological health for caregivers, it is relevant to nursing. The detrimental effects reported by many women caring for persons with ESRD and other diseases make it imperative that strategies be developed to assist in maintaining the wellbeing of these male caregivers.

## **Method**

A review of literature was conducted using PubMed, CINAHL, Scopus, and Google Scholar databases for the period 1980-2015 using keywords: male caregivers, caregiver health, caregiver burden, depression, caregiver stress, caregiver strain, chronic illness, kidney disease, end stage renal disease, perceived health, self-rated health, and caregiver mortality. Bibliographies of articles were examined also to capture additional references. No studies were found that focused exclusively on male caregivers of persons with ESRD. Thus, information was extrapolated from studies involving mixed caregiver samples and entirely female samples of caregivers of persons diagnosed with chronic illnesses.

## **Male Caregivers in the Literature**

Caregiver literature has focused primarily on caring from the female perspective, chiefly because women constitute the majority of informal caregivers. Additionally, it is socially acceptable in society for women to function in nurturing roles as for centuries, caregiving has been seen as 'women's' work. Men typically were the family 'breadwinners', and for them to cross over this boundary into feminine territory of caregiving was considered deviant. Male stereotyping led to the assumption that men were neither inclined to nor possessed the capability to meet the physical and emotional needs of others (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Kramer &

Thompson, 2002). In fact, Kramer and Thompson state, (2002), “The adjective “male” announces a predisposition to reframe caregiving to something different...generally something less...when the caregivers are men” (p. 21). Nevertheless, smaller family sizes, rising costs of healthcare, and increasing incidence of chronic disease have contributed to the growing number of male caregivers. Between 1984 and 1994, the number of men who reported being primary caregivers increased 50% (Pierce & Steiner, 2004), and a recent national study indicated that approximately 40% of caregivers were males (National Alliance for Caregiving, 2015).

The negative outcomes associated with caring for persons with chronic illness are widely accepted. Findings from the literature indicate that caregivers often experience burden and suffer physical and mental health impairments associated with this role. Negative health experiences of family caregivers are linked to several key variables, including caregiver and care-recipient demographic factors and socioeconomic characteristics, care-recipients’ type of illness and functional status, number of hours spent providing care, caregiver’s health status, and social support system (Robison et al., 2009; Schoenmakers et al., 2010). Gender is also an important variable affecting caregiver outcomes (Lee, DeDios, Fong, Simonette, & Lee, 2013).

Studies suggest that gender differences exist in levels of caregiver burden and depressive symptoms. However, these research findings have been inconsistent across the chronic illnesses. Early studies involving male caregivers reported that men experienced less burden and depressive symptoms than did their female counterparts (Horowitz, 1985; Young & Kahana, 1989). In contrast, some researchers found no significant differences in the levels of burden and depressive symptoms scores between male and female caregivers (Hinrichsen & Niederehe, 1994; Parks & Pilisuk, 1991). Later studies are also inconsistent in these findings (Alexander & Wilz, 2010; Pinquart & Sorensen, 2006). Researchers have suggested many reasons for the conflicting differences in caregiver outcomes, including underrepresentation of men and small sample sizes, fewer stressors, more social resources, and more effective coping strategies in men compared to women (Kramer & Thompson, 2002; Lee et al., 2013; Pinquart & Sorensen, 2006).

Over the past two decades, there has been an increase in the number of studies focused on male caregivers, particularly those caring for persons with cognitive impairment (Fuller-Jonap & Haley, 1995; Geiger, Wilks, Lovelace, Chen, & Spivey, 2015). However, the experiences involving a significant numbers of male caregivers—those caring for persons with chronic physical illnesses—have been largely neglected. While there are studies documenting the collective experiences of both men and women caregivers of persons with chronic illnesses, studies involving both genders often included male caregivers as contrast groups to illustrate the challenges faced by their female counterparts (Kramer & Thompson, 2002). Nevertheless, the extant literature involving caregivers of individuals with chronic illness may offer information that is applicable to men who care for persons with ESRD. Although there are unique factors associated with specific illnesses resulting in distinct differences in caregiver experiences, caregivers of persons with chronic illnesses, such as ESRD, may share similar outcomes.

## **Men's Caregiver Burden**

The concept of caregiver burden has been dichotomized into objective and subjective burden. Objective burden involves the nature of the caregiving tasks, the amount of time spent performing caregiving duties, and the extent to which these responsibilities change the caregiver's life and household. Subjective burden is the emotional response and mindset of the caregiver toward the caregiving experience. It refers to the way in which the caregiver perceives the effects of objective burden (Brouwer et al., 2004). Researchers have found that certain factors significantly increase the levels of burden experienced by caregivers of persons with ESRD. The presence of more patient comorbidities was associated with an increase in caregiver burden. Likewise, caregivers' health condition was inversely associated with burden (Walker et al., 2015; Wilson-Genderson et al., 2009). Additionally, a direct correlation exists between the increasing functional and cognitive impairments, which impede the ESRD patients' ability to care for themselves, and the experience of caregiver burden (Belasco et al., 2006). Burden is further compounded by anxiety, fatigue, deteriorating family relationships, and social isolation (Gayomali et al., 2008). Caregivers also reported that the intense demands and responsibilities of caring for persons diagnosed with ESRD was a tremendous strain, which sometimes caused feelings of resentment (Blogg & Hyde, 2008).

Being male may moderate caregiver burden as men reported experiencing less burden and greater life satisfaction than women in studies that did not focus on ESRD (C. F. Chang & White-Means, 1991; Pinguart & Sorensen, 2006). Different gender coping strategies and response bias were suggested as reasons for male caregivers reporting less burden. Some men cope with caregiver stress by using a managerial approach, which allows them to have a greater sense of control and a feeling of being in charge. They refrain from allowing themselves to become overtaken in the caregiving role by periodically evaluating their ability to meet the needs of the care-recipient. They maintain outside interests, which allows them to reduce the stress of providing care. They also use distraction through sports, hobbies, and substance abuse as methods of coping. Women, on the other hand, use strategies that are emotionally focused such as crying, passivity, and amplified mood changes (Brownhill, Wilhelm, Barclay, & Schmied, 2005; Calasanti & King, 2007). Men are more likely to seek outside support because they are less comfortable in the caregiving role than female caregivers (Pinguart & Sorensen, 2006). In contrast, one qualitative study described male participants as having exposed their feelings of anger, grief, loss of control, fear, and vulnerability. The study also found that men did not use outside resources any more often than did women (Pierce & Steiner, 2004).

Men are less likely to report feelings of psychological distress. They tend to minimize burden when participating in research because they are reluctant to disclose their emotions. Response bias is accentuated with interview and focus group participation as male caregivers may feel particularly compelled to hide their feelings regarding the caregiving situation in these settings (Gallicchio et al., 2002). However, this practice of internalizing feelings may inadvertently place male caregivers at risk for stress-related

disease because studies show that male caregivers experience increased blood pressure, had more negative lipid profiles, higher levels of stress hormone, and lower white blood cell counts when compared to non-caregivers (Kramer & Thompson, 2002).

### **Male Caregivers' Depressive Symptoms**

Depressive symptoms are well documented in caregiver populations of persons with chronic illnesses. When compared to non-caregivers, caregivers experience more adverse mental health effects (e.g., depressive symptoms, burden, stress) (H. Y. Chang et al., 2010; Gayomali et al., 2008; Lee et al., 2013). The causes of depressive symptoms vary and typically include environmental, physical, and emotional stressors, such as strained relationships, chronic stress, and significant life changes. Depression and depressive symptoms are among the primary psychological problems experienced by caregivers along with anger, worry, discouragement, and guilt (Robison et al., 2009). By some estimates, as many as 50% of caregivers experience symptoms of depression (Clark & Diamond, 2010).

The literature is inconsistent regarding the prevalence of depression in male caregivers compared to female caregivers. Some studies report that female caregivers experience depression more frequently than males (Alexander & Wilz, 2010; Pinquart & Sorensen, 2006), while other studies found no differences between depression scores of male and female caregivers (Baker & Robertson, 2008; McConaghy & Caltabiano, 2005). Shanks-McElroy and Strobino (2001) reported moderate to severe depression in male spouse caregivers. In contrast, other studies found that husbands reported fewer depressive symptoms (Anderson et al., 2013; Zarit, Todd, & Zarit, 1986). The studies by Anderson et al. (2013) and Zarit et al. (1986) differed from the aforementioned study in that the husbands in the Shanks-McElroy and Strobino (2001) study were compared to other demographically similar men whereas those in the Anderson et al. (2013) and Zarit et al. (1986) studies were compared to daughters and wives, respectively. Thus, the evidence suggests that when compared to women (regardless of whether they were daughters or wives), men experience less depression. However, compared with male non-caregivers, significantly greater depression occurs in male caregivers.

Despite these inconsistencies, studies involving male caregivers show that they experience many negative outcomes including depression, hostility, grief, and profound isolation. Compared to non-caregivers, male caregivers showed higher levels of anxiety and depression, reported more somatic complaints, difficulty sleeping, and used more over-the-counter medication (Kramer & Thompson, 2002). Qualitative studies involving male caregivers echoed themes of depression as well with contributing factors including conflict between caregiving and work, poor caregiver health, and fear of future outcomes for care-recipients (Kramer & Thompson, 2002; Mays & Lund, 1999; Pierce & Steiner, 2004).

Although, general population literature well supports that women are more apt to *report* feelings of depression than are men, response bias may cause men to minimize or



deny feelings of depression. However, women reporting more depressive symptoms than men does not negate the idea that men may experience depressive symptoms at similar rates (Calasanti & King, 2007), particularly considering that the mortality rate by suicide among men is four times that of women (Hankerson, Suite, & Bailey, 2015). Compared to women, men are thought to have more difficulty expressing their emotions and therefore, are adept at masking depressive symptoms. Behaviors usually attributed to ‘masked depression’ in men include aggressive and self-destructive conduct such as road rage, substance abuse, physical and sexual violence, and gambling (Brownhill et al., 2005). Men suffering from depression also report physiological symptoms, such as insomnia, fatigue, headaches, and generalized pain (Kramer & Thompson, 2002). The relationship of generalized somatic symptoms to physical illness makes diagnosing depression in men more difficult. Depression can be secondary to or a risk factor for stress-related illnesses and is often observed in persons with comorbid diabetes, cardiovascular disease, and substance abuse. Recognizing depressive symptoms in male caregivers of persons with ESRD may be more problematic as this population of caregivers often forego caring for their own health (Gayomali et al., 2008).

Male caregivers of persons with ESRD may be at particular risk for depression. The prolonged nature of ESRD and associated complications create significant caregiver burden. However, caregivers of this population have the added challenge of ensuring transportation for relatives receiving in-center dialysis. Alternatively, caregivers may assume responsibility for transportation, which may cause disruption in paid employment and subsequent financial strain. While home hemodialysis was designed to ease caregiver burden, often caregivers assume total responsibility for ensuring correct technique with increasingly complex dialysis therapy. In addition, the recovery time following dialysis therapy can be lengthy and pose major problems. Coupled with anxiety, fatigue, and social isolation, caregivers of persons with ESRD are especially vulnerable to psychological distress (Gayomali et al., 2008; Tong et al., 2008). It is important that clinicians are aware of the inevitable stress related to caring for persons diagnosed with ESRD and the potential depressive symptoms reported by the men who care for these individuals so that interventions can be designed to improve caregiver outcomes.

### **Perceived Health of Male Caregivers**

Single-item measures of self-rated health are reliable predictors of mortality and an important correlate of objective measures of health (Christian et al., 2011; Jylha, 2009). Self-rated health is also predictive of other factors, such as incidence of chronic illnesses, psychological wellbeing, and functional decline even when objective measures of health are considered (Shields & Shooshtari, 2001).

Although some researchers argue that the predictive value of self-rated health is related to recent deterioration in health status (Christian et al., 2011), studies indicate that physical health is not the sole factor influencing self-rated health status as many people with no health problems report their health as “good” rather than “excellent” (Shields & Shooshtari, 2001). Additionally, self-rated health has been related to serum inflammatory

markers irrespective of health status, a finding that further dispels the notion that self-rated health is exclusively related to knowledge of objective health diagnoses (Christian et al., 2011). Shields and Shooshtari (2001) found that other factors influencing self-rated health include (a) age; (b) the ability to independently complete activities of daily living (ADLs); (c) pain; (d) familial risk factors; (e) socioeconomic status; (f) lifestyle; and (g) psychological well-being.

In the general population, men reported better self-rated health than did women with a significant difference noted between the ages of 45 to 54. Unsurprisingly, older aged men rated their health as fair or poor. The ability to independently complete ADLs was a powerful determinant of self-rated health, and men with limited function reported their health as fair or poor as well. Socioeconomic status was directly correlated with self-rated health, and men who had more education reported higher self-rated health than those who had less education. Although pain and familial risk factors were significant influences in women's self-rated health, neither of these were influential determinants of self-rated health in men. Healthy lifestyle behaviors positively affected self-rated health. Conversely, unhealthy lifestyle behaviors, such as smoking, substance abuse, and physical inactivity, negatively impacted self-rated health. Interestingly, improving health habits, such as a reduction in cigarette smoking, did not impact self-rated health scores. Emotional well-being also influenced self-rated health. Men with low self-esteem had greater odds of reporting fair or poor health (Shields & Shooshtari, 2001).

The indefinite uncompensated care provided by caregivers of persons with ESRD often compromises the mental health of these individuals, which frequently leads to depressive symptoms (Harris, 2003). Male caregivers of persons with chronic illness not only showed higher levels of anxiety and depression compared to non-caregivers, but also reported more somatic complaints, difficulty sleeping, and used more psychoactive medications (Kramer & Thompson, 2002). Understanding that caregivers of persons with ESRD experience psychological distress and increased physical illnesses is important as these factors affect caregivers' self-rated health (Shields & Shooshtari, 2001).

In addition, caregiver self-rated health is influenced by levels of burden, and caregivers of persons with ESRD often experience significant burden related to the caregiving role (Belasco et al., 2006; Cangelosi, 2009; H. Y. Chang et al., 2010). As noted previously, caregivers of persons with ESRD may experience substantial burden secondary to many factors including patient comorbidities and level of function and caregivers' health status. Thus, they are at risk for increased mortality when compared to non-caregivers. The relationship between burden and self-rated health in caregivers is also influenced by coping strategies. Caregivers' appraisal of their caregiving situation and the ability to cope with the demands of the caregiving role are important factors influencing caregiver well-being (Pinquart & Sorensen, 2006). Although some studies report that male coping strategies are more effective than female coping strategies, the dearth of information involving self-rated health in male caregivers of persons with ESRD limits knowledge of coping techniques in this population.

## **Conclusion**

The purpose of this literature review was to examine the empirical evidence involving burden, depression, and self-rated health in male caregivers of persons with ESRD. Although no studies were found involving this population of caregivers, the information extrapolated from the reviewed studies support findings of male caregiver burden, depressive symptoms, and poor self-rated health. Because caregiving can result in significant stress and increase caregivers' risk for negative physical and mental health effects, the outcomes related to male caregivers of patients diagnosed with ESRD are of great concern. Burden and depressive symptoms are strongly associated with poor self-rated health, which is a valid and reliable indicator of mortality (Christian et al., 2011). Thus, male caregivers of persons with ESRD may be at increased risk of mortality making research involving this population of caregivers highly relevant. Not only are caregiver health effects a concern for caregiver and clinician, but also a decline in caregivers' health may result in an inability to continue in the caregiving role. Thus, it is important that the experiences of male caregivers of persons with ESRD are documented, caregivers at risk for negative outcomes are identified by healthcare providers, and interventions are developed to support the mental health of this hidden population of caregivers.



## **CHAPTER 3. METHODOLOGY**

This chapter addresses the research design used to conduct the two studies. Included are a detailed discussion of the sample and setting, inclusion/exclusion criteria, and instrumentation for each study. Also included are the procedures used to conduct the studies, site preparation, and selection of participants. Finally, this chapter outlines the data analysis techniques and strategies used to protect human subjects.

### **Research Design**

The research design consisted of a series of two independent studies using different approaches. The first study consisted of an historical cross-sectional study of 29 male caregivers of individuals diagnosed with end stage renal disease (ESRD), who participated in a larger quantitative study in 2003. Based on the nature of the data generated, the first study will be hereinafter referred to as the quantitative study of male caregivers. The second study consisted of a current cross-sectional study of six male caregivers of persons with ESRD, who participated in focus group interviews. Similarly, the second study will be called hereinafter the qualitative study of male caregivers. These sequential studies provided descriptive data about both samples of male caregivers as well as insight into the experiences associated with caregiver objective and subjective burden, depressive symptoms, and perceived health status since beginning their caregiving process.

### **Sample and Setting**

Both studies received university Institutional Review Board (IRB) approval and were designed to explore the levels of objective and subjective burden, depressive symptoms, and perceived health status of men caring for individuals with ESRD. The quantitative study involved a secondary analysis of data obtained from a convenience sample of 29 male caregivers who participated in a larger study of family caregivers in 2003. This sample size was deemed sufficient for an exploratory study. The 2003 study examined the predictors of health and burden in 120 informal caregivers of persons diagnosed with ESRD who were receiving in-center hemodialysis or home peritoneal dialysis. The subsample of male caregivers was recruited from three private, physician-owned dialysis centers located in the Memphis metropolitan area.

The qualitative study included a convenience sample of six male caregivers of persons diagnosed with ESRD who were recruited specifically for participation in a focus group. Among persons aged 20-39, Blacks are 3.8 times more likely to have a diagnosis of ESRD than are Whites. In addition, the rates of ESRD are considerably higher for Blacks aged 60 or greater than for their white counterparts (Saran et al., 2014). Thus, the recruitment strategy for the focus group was designed to include a racial distribution similar to the national ESRD population. Because the highest prevalence of ESRD in

Blacks occurs in the southeastern United States (Saran et al., 2014), the study was conducted in a geographical area where ESRD has a significant impact.

### **Inclusion and Exclusion Criteria**

The following criteria were used to select the samples for both the quantitative and qualitative studies. Inclusion criteria were participants (a) resided in the Memphis metropolitan area; (b) were age 18 or older; (c) self-identified as the primary current or previous caregiver of the dialysis recipient; (d) were able to speak, read, and understand English; and (e) were willing to give written and verbal consent. Exclusion criteria were caregivers (a) residing outside the Memphis metropolitan area; (b) providing care for persons receiving dialysis for acute renal failure; and (c) unable to speak, read, and understand English.

### **Instrumentation**

Participants involved in the quantitative study completed questionnaires after receiving verbal instruction from the principal investigator (PI). The subgroup analysis of data from this quantitative study used the Caregiver Demographic Data Form, the Measurement of Burden Scale, the Center for Epidemiological Studies Depression Scale (CES-D), and the Caregivers' Perceived Health Form. The qualitative study consisted of focus group interviews. The interview questions were guided by the Focus Group Interview Guide. Prior to beginning the focus group, participants completed the Male Caregiver Demographic Data Form (**Appendix A**).

### **Quantitative Phase Instruments**

**Caregiver demographic data form.** The Caregiver Demographic Data Form used in the 2003 study was developed by the PI of the 2003 study and is a self-report questionnaire that provides characteristics of the care recipient and the family caregiver. This instrument included the following caregiver demographic variables: age in years, gender, race, marital status, years of education, annual income, and relationship to the patient. Family caregivers also reported on the care recipient's age in years, gender, race, employment status, level of assistance with activities of daily living (ADLs), number of months on dialysis therapy, type of dialysis treatment, and presence or absence of diabetes. In addition, caregivers reported the hours spent per week in caregiving activities, whether or not they resided with the care recipient, level of satisfaction with social support, and whether or not they were providing care for someone other than the dialysis patient. The questionnaire required approximately 5 minutes to complete.

**Caregivers' perceived health form.** Caregivers' perceived health status was measured using the Caregivers' Perceived Health Form. Developed and validated by the National Center for Health Services Research for the Health Insurance Study (Miller, 1990), the form consists of a single self-rated health question devised to evaluate the caregiver's personal assessment of his health status. Responses range from 1 (excellent) to 5 (poor). The questionnaire required less than 1 minute to complete. This instrument is valuable because studies show that self-rated health measures are as good as or better than other measures of physical and mental health. Construct validity of the measure is supported in that self-rated health is a strong correlate with more objectively rated health scales, such as the Sickness Impact Profile and the Perceived Well-Being Scale (S. M. Hunt et al., 1980; Jylha, 2009; Shields & Shooshtari, 2001).

### **Centers for Epidemiological Studies-Depression Scale (CES-D)**

The CES-D was used to assess depressive symptoms. The 20-item self-report instrument was developed by the Center for Epidemiologic Studies and is the most commonly used instrument in assessment of caregivers' depressive symptoms. It is designed to assess factors such as depressed mood, feelings of guilt, energy level, and somatic complaints over the past week. The CES-D scores range from 0 to 3 and are categorized from *rarely* or *none of the time* to *most* or *all of the time*. Higher scores reflect more frequent depressive symptoms. To discourage a response set, questions 4, 8, 12, and 16 are reversed scored and worded positively. The total instrument score ranges from 0 to 60 with a score of 15 or less indicating no depressive symptoms, 16-20 mild distress, 21-30 moderate distress, and greater than 31 indicating severe distress (Zich, Attkisson, & Greenfield, 1990). Items for the CES-D were selected from existing scales, including Beck's Depression Inventory (Beck, Steer, & Carbin, 1988), Zung's Self-rated Depression Scale (Zung, 1965), and Raskin's Depression Scale (Radloff, 1977), which supports the instrument's construct and content validity. The CES-D has high internal consistency and good test-retest reliability. The instrument has been widely used to assess depressive symptoms in caregiving studies including research relative to caregivers of dialysis patients (Arechabala, Catoni, Palma, & Barrios, 2011; Matsuu et al., 2001). A Cronbach's alpha coefficient of .89 was obtained for the sample of male caregivers of dialysis recipients in the current study. The scale required 5-10 minutes to complete.

### **Measurement of Burden Scale (MBS)**

Although many caregiving studies measure burden as a one-dimensional construct, the MBS was chosen because it was designed to measure two dimensions of caregiver burden. Thus, the instrument consists of two subscales: Measurement of Objective Burden (OB) and Measurement of Subjective Burden (SB). Although some researchers contend that progress in caregiver burden research has been hindered by the application of nonspecific measures of burden to different caregiver populations (K. R. Chou, 2000), the non-specific MBS has been used in previous research with caregivers of persons with ESRD (Harris, 2003).

Montgomery, Gonyea, and Hooyman (1985) defined objective and subjective burden as “the extent to which caregiving behaviors disrupted or changed caregivers’ lives and households,” and “attitudes toward or emotional reactions to the caregiving experiences,” respectively. These theoretical definitions of objective and subjective burden are consistent with the definitions in the theoretical framework for the current study.

Objective burden is the degree to which caregiving tasks disrupt and change various aspects of the caregivers’ life. The OB subscale is a 9-item questionnaire in which respondents report the extent to which caregiving tasks have changed areas of their life such as personal time, privacy, and freedom. The 5-point Likert scale ranges from *a lot more* (1) to *a lot less* (5). The scale ranges from 9 to 45 with higher scores indicating greater objective burden. The OB subscale has adequate internal consistency reliability ranging from .70 to .94 (K. R. Chou, Chu, Tseng, & Lu, 2003). Subjective burden involves the emotional responses and mindset of the caregiver toward the caregiving experience. The SB subscale consists of a 13-item, 5-point Likert scale ranging from *rarely or never* (1) to *most of the time* (5). The total score for the scale ranges from 13 to 65 with higher scores indicating greater subjective burden. Internal consistency reliability for the SB subscale ranges from .66 to .86. Construct and content validity of the MBS are supported as items were drawn from the Zarit Burden Inventory (K. R. Chou et al., 2003). The observed Cronbach’s alpha coefficient for this study of male caregivers of persons with ESRD was .77 for both the objective and subjective burden subscales. The MBS required approximately 5 to 10 minutes to complete.

## **Qualitative Study Instruments**

**Male caregiver demographic data form.** Demographic data were obtained from participants in the qualitative study using the Male Caregiver Demographic Data Form, a self-report questionnaire developed by the PI of the current study. The instrument was designed to characterize the sample of male family caregivers of persons diagnosed with ESRD. The demographic variables included the caregiver’s race, marital status, age in years, annual income, highest educational level, and relationship to the care recipient. Care recipient information including the patient’s age in years, gender, and length of illness in years were reported as well. Lastly, personal and family histories of anxiety and depression and alcohol and substance abuse were obtained as these factors may influence depressive symptoms.

**Focus group interview guide.** The IRB-approved Focus Group Interview Guide was designed by the PI to facilitate the focus group. The guide consists of an introduction, which was used to explain the purpose of the study to the participants and a series of questions designed to explore participants’ caregiving experience. The PI developed the questions based upon the study specific aims and findings from the retrospective study.

## **Procedure for the Quantitative Study**

Permission was obtained to conduct the initial *quantitative* study from the university's IRB. Written and verbal approvals to recruit caregivers for the larger study were obtained from the dialysis centers' owners. In addition, the caregivers provided verbal and written informed consent prior to participating in the study (Harris, 2003). Prior to initiation of the analysis of de-identified data for this investigation, the university IRB approved the study protocol and analysis plan.

## **Site Preparation for the Quantitative Study**

In the initial quantitative study, Harris (2003) prepared a letter for the patients and their caregivers, which was given to the dialysis centers' owners and medical directors 3-4 weeks prior to beginning data collection. The letter included the study purpose and an explanation to patients and caregivers that the patient's care would not be affected if they declined to participate in the study. Harris also distributed to potential participants IRB-approved pamphlets, which included a description of the study's purpose. The dialysis centers' registered nurses were prepped for the study 2 weeks prior to beginning data collection. The nurses were educated regarding the purpose of the study and the effect that caregiving has on the mental and physical health of caregivers of person with ESRD.

## **Selection of Participants for the Quantitative Study**

Following IRB approval, participants were recruited for the Harris (2003) study from three dialysis centers in the Memphis metropolitan area. The primary caregiver was selected for participation in the larger study based upon the dialysis patients' responses to the question "If you become unable to care for yourself, who would you ask to take care of you?" The PI for the current quantitative study was given de-identified data with subject numbers for the 29 male caregivers included in the original sample of 120 caregivers. No personal identifiers (e.g. birthdates, social security numbers, etc.) were included in the dataset and no other study documents were provided to the PI for the current study.

## **Data Analysis for the Quantitative Study**

The de-identified data for the retrospective study were maintained in a password protected Microsoft Excel file. The data were analyzed using SAS 9.4 (Cary, NC). The statistical analyses for this study included descriptive statistics (i.e., means, frequencies, standard deviations, percentages), *t*-Tests, and Pearson correlation analyses. Because the study was exploratory and included a small sample, the level of significance was set at 0.10 for each research question.

## **Procedure, Site Preparation, and Selection of Participants for the Qualitative Study**

The university IRB approved this secondary analysis of de-identified data as well as the *qualitative focus-group* prospective study. Recruitment of focus-group participants involved placing flyers and brochures in the community and throughout the university, sending an email blast using the university's email listserv, and advertising in the university newsletter and on local radio stations. In addition, snowball sampling was used as participants identified other caregivers interested in participating in the study. Upon being contacted by potential participants, the PI used an IRB-approved checklist, based upon the inclusion/exclusion criteria, to determine eligibility. After determining eligibility, an IRB-approved script was read to the caregivers. Those who desired to participate were enrolled in the study and informed that they would be contacted by phone once the date, time, and location of the focus group interview were determined. The participants were subsequently contacted by phone and informed when and where the focus group interview would take place. Site preparation for the focus group interview involved selecting a location that was quiet, comfortable, and easily accessible for participants. The qualitative study involved selection of a convenience sample of 6 male caregivers who were self-identified as current or previous primary caregivers of a person diagnosed with ESRD.

Data collection for the prospective study began in July 2014 and continued until May 2015. The PI contacted the male caregivers by telephone to obtain their input regarding the most convenient time for them to participate in the focus group. The focus group interview was held in a conference room in the College of Nursing at the University of Tennessee Health Science Center. The focus group interview began with the PI obtaining written informed consent from each of the participants. The participants were also given an opportunity to complete the Male Caregiver Demographic Data form. Once these items were completed, the audio recorded interview began using the IRB-approved Focus Group Interview Guide. The PI was assisted by a study co-investigator who took notes and provided a summary of major points at the end of the session. Each caregiver received \$50.00 for their participation. In the week following the focus group, letters of appreciation were sent to each of the study participants. QDA Miner (Montreal QC, Canada) was used to analyze and categorize thematic content in the qualitative study.

## **Quantitative Specific Aims**

**Specific aim one.** Specific aim one is to determine the demographic profile of male informal caregivers of relatives with ESRD.

Demographic information was imported from an Excel file into SAS 9.4 to estimate simple descriptive statistics. The UNIVARIATE procedure was used to estimate the measures of central tendency and dispersion, and determine whether assumptions were met regarding normality of the underlying sampling distributions for caregiver and



care recipient characteristics including age, hours of care per week, months on dialysis, and number of years since patients' diabetes diagnosis. The FREQ procedure was used to estimate proportions for variables related to caregiver race, marital and employment status, whether or not the caregiver resided with the care recipient, satisfaction with social support, and whether or not the caregiver cared for someone other than the patient as well as patients' gender, race, employment status, ADL assistance requirement, dialysis type, and presence or absence of diabetes diagnosis.

**Specific aim two.** Specific aim two is to determine the levels of subjective and objective caregiver burden, depressive symptoms, and perceived health reported by male informal caregivers of relatives with ESRD

The levels of objective and subjective burden derived from the MBS subscale scores and the CES-D depressive symptom scores were analyzed using the UNIVARIATE procedure to estimate measures of central tendency and dispersion, and determine whether assumptions were met regarding normality of the underlying sampling distributions. The FREQ procedure was used to obtain frequencies and percentages of caregiver perceived health status as measured by the Caregiver's Perceived Health Form.

**Specific aim three.** Specific aim three is to determine the associations among caregiver subjective and objective burden, depressive symptoms, and perceived health in men caring for relatives with ESRD.

Pearson product moment correlation coefficients were estimated by the CORR procedure to quantify the associations of caregiver objective and subjective burden, depressive symptoms, and perceived health. Because the literature shows that certain caregiver and care recipient characteristics contribute to caregiver burden, depressive symptoms, and perceived health, additional statistical analyses were used to examine the effects of caregiver race (Black, White), caregiver marital status (married, unmarried), caregiver employment status (employed, unemployed), ADL assistance (requires no assistance, requires assistance), and care-recipient presence or absence of diabetes on objective and subjective burden, depressive symptoms, and caregiver perceived health. The independent two sample *t*-Tests based on the T-TEST procedure were used to test hypotheses pertaining to the relationships among these variables.

### **Qualitative Specific Aim**

The qualitative specific aim for this study is to explore the experiences that contribute to caregiver subjective and objective burden, depressive symptoms, and perceived health in male caregivers of relatives with ESRD

The focus group interview was audio-recorded, transcribed *verbatim*, and checked for accuracy by the PI. QDA Miner software was used to analyze and categorize thematic

content. Qualitative analysis began with open coding through a process of line-by-line examining, comparing, conceptualizing, and categorizing (Silverman, 2009) participant descriptions of their caregiving experiences. Textual data were explored inductively using content analysis to generate codes. The codes were merged into categories, and from the categories emerged themes. Some categories were subcategorized and corresponding sections of textual data were designated to individual categories or subcategories.

### **Protection of Human Subjects**

The current studies were approved by the university's Institutional Review Board (IRB). Consideration of human subjects was provided through use of verbal and written informed consent and explanation of risks associated with the study. Verbal consent was obtained from participants prior to completion of the study surveys. Completion of the study surveys constituted written consent for participation in the initial quantitative study. Furthermore, written consent was obtained prior to participation in the focus group.

Participants in both studies were informed that the risk involved in participating in the studies included uncomfortable or troublesome feelings or emotions associated with answering survey questions or questions posed in the focus group interview, identification of potential untreated depression or suicidal ideation, and loss of anonymity or confidentiality. As part of the informed consent process, participants were informed that their participation was voluntary and could be withdrawn at any time without loss or penalty to the dialysis recipient.

To ensure participants' anonymity and confidentiality, appropriate guidelines were followed. The PI for the original quantitative study was responsible for keeping track of participant enrollment in the original quantitative study. The PI for the current qualitative study ensured that all electronic data obtained from the focus group interview were password protected. Upon completion of study instruments, all forms were coded to protect participant identity. Information obtained from study participants was referenced by assigned study numbers and maintained in a locked file cabinet to which only the PI for the current qualitative study had access. Conclusions and results did not disclose specific cases. Results were presented in the form of statistical analysis and de-identified text from the focus group interview. Personal identifiers were destroyed at the conclusion of the study.



## CHAPTER 4. QUANTITATIVE RESULTS

### Introduction

By the close of 2012, over one-half million individuals were kidney transplant recipients or being treated with dialysis therapy, an estimated 1,792 cases per million. In addition, 116,946 new cases of ESRD had been diagnosed (Saran et al., 2014). End-stage renal disease (ESRD) is a progressive and chronic condition requiring continuing dialysis therapy or kidney transplantation for survival. It is a devastating illness, which has the potential to cause considerable changes in family life. The debilitating effects of the disease cause many of these individuals to require assistance from family caregivers, with dialysis treatments, medication administration, and activities of daily living.

Advances in dialysis treatments and improvements in chronic illness management have had the combined effect of increasing the life span of individuals diagnosed with ESRD. However, persons living with the disease often experience many complications including infection, fatigue, sleep abnormalities, and deterioration of physical health. The detrimental physical effects of the disease are often accompanied by cognitive impairment as well (Walker et al., 2015). Among hemodialysis patients aged 55 years and older, approximately 70% have moderate to severe cognitive impairment (Murray, 2008), which markedly increases caregiver psychological distress. In addition to the physical and cognitive effects associated with the disease, adjusting to a life of continuing dialysis therapy and strict dietary changes also contributes to the negative outcomes experienced by both the care recipient and the caregiver (Gayomali et al., 2008). The burden of ESRD diagnosis is often further complicated by co-morbid conditions such as heart disease, hypertension, and diabetes. Diabetes is the single most common cause of ESRD (Saran et al., 2014). The complications related to diabetes include visual disturbances and difficulty with ambulation, both of which contribute to the care-recipients' functional decline and increase the levels of objective and subjective burden experienced by their caregivers (Gayomali et al., 2008).

Caring for persons with ESRD often necessitates contending with unpredictable and arduous situations, and the prolonged nature of the disease can lead to significant caregiver stress and burden, depressive symptoms, and poor perceived health. The literature amply documents that caregiver burden increases caregivers' risk for compromised mental and physical health (Andrén & Elmståhl, 2008; Cangelosi, 2009; H. Y. Chang et al., 2010). In addition to the burden of providing care, caregivers of persons with ESRD are at greater risk of poor health because caregiving responsibilities often leave little time to focus on their health needs (Wilson-Genderson et al., 2009). Caregiver burden is strongly associated with poor self-rated health (Belasco et al., 2006; Wilson-Genderson et al., 2009), which is well recognized as a valid predictor of mortality (Jylha, 2009). Providing care for persons diagnosed with ESRD often contributes to increased burden, chronic stress, and compromised physical and mental health. Thus, these caregivers may also be at increased risk of mortality.

Although ESRD has a devastating impact upon the lives of those affected by it, there is a paucity of research involving the caregiver burden and depressive symptoms associated with caring for persons with the disease. Moreover, the literature is silent regarding the experiences of men who provide care for persons diagnosed with the disorder. Thus, there is a significant gap in the existing body of knowledge associated with the caregiving experience of this male caregiver population. Little is known about the impact that caregiving has on their wellbeing. Because caregiving can result in a precarious state of physical and psychological health for caregivers, it is relevant to the nursing profession. The detrimental effects reported by many women caring for persons with ESRD and other diseases make it imperative that strategies be developed to assist in maintaining the wellbeing of these male caregivers.

## **Background**

Caregiver literature has focused primarily on caring from the female perspective, chiefly because women constitute the majority of informal caregivers. However, smaller family sizes, rising costs of healthcare, and increasing incidence of chronic disease have contributed to the growing number of male caregivers. Between 1984 and 1994, the number of men who reported being primary caregivers increased 50% (Pierce & Steiner, 2004), and a recent national study indicated that approximately 40% of caregivers are males (National Alliance for Caregiving, 2015).

Negative health experiences of family caregivers are linked to several key variables, including caregiver and care-recipient demographic factors and socioeconomic characteristics, care-recipients' type of illness and functional status, number of hours spent providing care, caregiver's health status, and social support system (Robison et al., 2009; Schoenmakers et al., 2010). Gender is also an important variable affecting caregiver outcomes (Lee et al., 2013).

Findings from many studies suggest that gender differences exist in levels of caregiver burden and depressive symptoms. However, these research findings have been inconsistent across chronic illnesses. Researchers have suggested many reasons for the conflicting differences in caregiver outcomes including, underrepresentation of men, small sample sizes, less stressors, more social resources, and more effective coping strategies in men compared to women (Kramer & Thompson, 2002; Lee et al., 2013; Pinquart & Sorensen, 2006).

Over the past two decades, there has been an increase in the number of studies focused on male caregivers, particularly those caring for persons with cognitive impairment (Fuller-Jonap & Haley, 1995; Geiger et al., 2015). However, the experiences involving a substantial proportion of male caregivers—those caring for persons with chronic physical illnesses—have been largely neglected. While there are studies documenting the collective experiences of both men and women caregivers of persons with chronic illnesses, studies involving both genders often included male caregivers as contrast groups to illustrate the challenges faced by their female counterparts (Kramer & Thompson, 2002). Nevertheless, the extant literature involving caregivers of individuals

with chronic illness may offer information that is applicable to men who care for persons with ESRD. Although there are unique factors associated with specific illnesses resulting in distinct differences in caregiver experiences, caregivers of persons with chronic illnesses, such as ESRD, may share similar outcomes.

### **Conceptual Framework**

The Stress Process Model (SPM) served as the theoretical foundation for this study. The SPM is a middle-range theory originally consisting of four primary domains: background and contextual factors, stressors, mediating resources, and manifestations of stress (Pearlin et al., 1981). The background and contextual factors of stress are subdivided into socioeconomic (SES) characteristics, historical context, family composition, and social network composition. Caregiver background characteristics such as age, gender, SES, and ethnicity significantly influence caregivers' experiences and are key factors threaded throughout the stress process (Pearlin et al., 1990).

Stressors are dichotomized into primary and secondary categories. Primary stressors include events that are undesired, disruptive, and enduring (e.g., demands of caregiving tasks). Thus, experiencing the demands of caregiving tasks associated with caring for chronically ill relatives (e.g., persons with ESRD) is an example of a major stressor, which may influence caregiver burden, depressive symptoms, and perceived health in this population of male caregivers. Secondary stressors occur as consequences of primary stressors and include role strain and intrapsychic strains. Secondary stressors for caregivers of individuals with ESRD might include role conflict, financial strain from job loss, and social isolation related to caregiving demands (Pearlin et al., 1990).

Mediators of stress are the elements that a person invokes on their own behalf as defense against stressors. Mediators consist of social supports (e.g., organizations, support groups) and coping, which involves the changes individuals make to their behavioral or psychological state in response to the stressors (Bolden & Wicks, 2010). Manifestations of stress or outcomes include measures of physical and mental wellbeing and the ability to continue in a specified social role (Pearlin et al., 1990). Because caregiving can result in significant stress and increase caregivers' risk for negative physical and mental health effects, these outcomes are of great concern.

The SPM has been successfully used in research involving caregivers of patients with ESRD (Harris, 2003). Not only are caregiver health effects a concern for caregiver and clinician, but also a decline in caregivers' health may result in an inability to continue in the caregiving role. Understanding the constructs of the SPM and how they relate to the caregiving population will be essential to helping healthcare providers identify factors that predict caregiver burden, depressive symptoms, and perceived health status and to developing specific interventions designed for male caregivers of individuals with ESRD.

In the current study, we incorporated factors from two domains described in the SPM that could potentially influence manifestations of caregiver stress, background and

contextual factors and primary and secondary stressors. Mediators were not examined in the current study because the focus involved examining factors contributing to caregiver stress outcomes. Because the literature has shown that patient characteristics are also associated with caregiver burden (Gayomali et al., 2008; Murray, 2008), we added this domain to the model.

## **Methods**

### **Research Design**

This historical cross-sectional study consisted of 29 male caregivers of individuals diagnosed with ESRD, who participated in a larger quantitative study in 2003. The data were examined to provide a demographic description of this sample of male caregivers as well as to explore their levels of caregiver objective and subjective burden, depressive symptoms, and perceived health status.

### **Sample and Procedure**

Following university Institutional Review Board (IRB) approval, a secondary analysis was conducted using data obtained from a convenience sample of 29 male caregivers who participated in a larger study examining predictors of health and burden in 120 informal caregivers of persons diagnosed with ESRD. This sample size was deemed sufficient given the exploratory nature of the current study. This sample of male caregivers was recruited from three private, physician-owned dialysis centers located in the Memphis metropolitan area. Written and verbal approval to recruit caregivers for the larger study was obtained from the dialysis centers' owners. In addition, the caregivers provided verbal and written informed consent prior to participating in the study (Harris, 2003). The letter of approval for this study is provided in the **Appendix B**.

## **Measures**

Participants involved in the Harris (2003) study completed questionnaires after receiving verbal instruction from Dr. Harris. The current cross-sectional study involved analysis of data obtained from the Caregiver Demographic Data Form, the Measurement of Burden Scale, the Centers for Epidemiological Studies Depression Scale (CES-D), and the Caregivers' Perceived Health Form.

## Study Instruments

**Caregiver demographic data form.** The Caregiver Demographic Data Form used in the Harris (2003) study was developed by Dr. Harris and is a self-report questionnaire that provides characteristics of the care recipient and the family caregiver. This instrument included the following caregiver demographic variables: age in years, gender, race, marital status, years of education, annual income, and relationship to the patient. Family caregivers also reported on the care recipient's age in years, gender, race, employment status, level of assistance with activities of daily living (ADLs), number of months on dialysis therapy, type of dialysis treatment, and presence or absence of diabetes. In addition, caregivers reported the hours spent per week in caregiving activities, whether or not they resided with the care recipient, level of satisfaction with social support, and whether or not they were providing care for someone other than the dialysis patient. The questionnaire required approximately 5 minutes to complete.

**Caregivers' perceived health form.** Caregivers' perceived health status was measured using the Caregivers' Perceived Health Form. Developed and validated by the National Center for Health Services Research for the Health Insurance Study (Miller, 1990), the form consists of a single self-rated health question devised to evaluate the caregiver's personal assessment of his health status. Responses range from 1 (excellent) to 5 (poor). The questionnaire required less than 1 minute to complete. This instrument is valuable because studies show that self-rated health measures are as good as or better than other measures of physical and mental health. Construct validity of the measure is supported in that self-rated health is a strong correlate with more objectively rated health scales, such as the Sickness Impact Profile and the Perceived Well-Being Scale (S. M. Hunt et al., 1980; Jylha, 2009; Shields & Shoostari, 2001).

### Center for Epidemiological Studies-Depression Scale (CES-D)

The CES-D was used to assess depressive symptoms. The 20-item self-report instrument was developed by the Center for Epidemiologic Studies and is the most commonly used instrument in assessment of caregivers' depressive symptoms. It is designed to assess factors such as depressed mood, feelings of guilt, energy level, and somatic complaints over the past week. The CES-D scores range from 0 to 3 and are categorized from *rarely* or *none of the time* to *most* or *all of the time*. Higher scores reflect more frequent depressive symptoms. To discourage a response set, questions 4, 8, 12, and 16 are reversed scored and worded positively. The total instrument score ranges from 0 to 60 with a score of 15 or less indicating no depressive symptoms, 16-20 mild distress, 21-30 moderate distress, and greater than 31 indicating severe distress (Zich et al., 1990). Items for the CES-D were selected from existing scales, including Beck's Depression Inventory (Beck et al., 1988), Zung's Self-rated Depression Scale (Zung, 1965), and Raskin's Depression Scale (Radloff, 1977), which supports the instrument's construct and content validity. The CES-D has high internal consistency and good test-

retest reliability. The instrument has been widely used to assess depression in caregiving studies including research involving caregivers of dialysis patients (Arechabala et al., 2011; Matsuu et al., 2001). A Cronbach's alpha coefficient of .89 was obtained for the sample of male caregivers of dialysis recipients in the current study. The scale required 5-10 minutes to complete.

### **Measurement of Burden Scale (MBS)**

Although many caregiving studies measure burden as a one-dimensional construct, the MBS was chosen because it was designed to measure two dimensions of caregiver burden. Thus, the instrument consists of two subscales: Measurement of Subjective Burden (SB) and Measurement of Objective Burden (OB). Although some researchers contend that progress in caregiver burden research has been hindered by the application of nonspecific measures of burden to different caregiver populations (K. R. Chou, 2000), the non-specific MBS, has been used in previous research with caregivers of persons with ESRD (Harris, 2003).

Montgomery, Gonyea, and Hooyman (1985) defined objective and subjective burden as "the extent to which caregiving behaviors disrupted or changed caregivers' lives and households," and "attitudes toward or emotional reactions to the caregiving experiences", respectively. These theoretical definitions of objective and subjective burden are consistent with the definitions in the theoretical framework for the current study.

Objective burden is the degree to which caregiving tasks disrupt and change various aspects of the caregivers' life. The OB subscale is a 9-item questionnaire in which respondents report the extent to which caregiving tasks have changed areas of their life such as personal time, privacy, and freedom. The 5-point Likert scale ranges from *a lot more* (1) to *a lot less* (5). The scale ranges from 9 to 45 with higher scores indicating greater objective burden. The OB subscale has adequate internal consistency reliability ranging from .70 to .94 (K. R. Chou et al., 2003). Construct and content validity of the MBS are supported as items were drawn from the Zarit Burden Inventory (K. R. Chou et al., 2003). Subjective burden involves the emotional responses and mindset of the caregiver toward the caregiving experience. The SB subscale consists of a 13-item, 5-point Likert scale ranging from *rarely or never* (1) to *most of the time* (5). The total score for the scale ranges from 13 to 65 with higher scores indicating greater subjective burden. Internal consistency reliability for the SB subscale ranges from .66 to .86. The observed Cronbach's alpha coefficient for this study of male caregivers of persons with ESRD was .77 for both the objective and subjective burden subscales. The MBS required approximately 5 to 10 minutes to complete.



## **Procedure**

Permission was obtained to conduct the initial *quantitative* study from the university's IRB. Written and verbal approvals to recruit caregivers for the larger study were obtained from the dialysis centers' owners. In addition, the caregivers provided verbal and written informed consent prior to participating in the study (Harris, 2003). Prior to initiation of the analysis of de-identified data for this investigation, the university IRB approved the study protocol and analysis plan.

## **Site Preparation**

In the initial quantitative study, Harris (2003) prepared a letter for the patients and their caregivers, which was given to the dialysis centers' owners and medical directors 3-4 weeks prior to beginning data collection. The letter included the study purpose and an explanation to patients and caregivers that the patient's care would not be affected if they declined to participate in the study. Harris also distributed to potential participants IRB-approved pamphlets, which included a description of the study's purpose. The dialysis centers' registered nurses were prepped for the study 2 weeks prior to beginning data collection. The nurses were educated regarding the purpose of the study and the effect that caregiving has on the mental and physical health of caregivers of person with ESRD.

## **Selection of Participants**

Following IRB approval, participants were recruited for the Harris (2003) study from three dialysis centers in the Memphis metropolitan area. The primary caregiver was selected for participation in the larger study based upon the dialysis patients' responses to the question "If you become unable to care for yourself, who would you ask to take care of you?" The PI for the current quantitative study was given de-identified data with subject numbers for the 29 male caregivers included in the original sample of 120 caregivers. No personal identifiers (e.g. birthdates, social security numbers, etc.) were included in the dataset and no other study documents were provided to the PI for the current study.

## **Data Analysis**

The de-identified data for the quantitative study were maintained in a password protected Microsoft Excel file. The data were analyzed using SAS 9.4 statistical package. The statistical analyses for this study included descriptive statistics (i.e., means, frequencies, standard deviations, percentages), *t*-tests, and Pearson correlation analyses. Because the study was exploratory and included a small sample, the level of significance was set at 0.10 for each research question.

Specific aim one is to determine demographic profile of male informal caregivers of persons with ESRD. Demographic information was imported from an Excel file into SAS 9.4 to estimate simple descriptive statistics. The UNIVARIATE procedure was used to estimate the measures of central tendency and dispersion, and determine whether assumptions were met regarding normality of the underlying sampling distributions for caregiver and care recipient characteristics including age, hours of care per week, months on dialysis, and number of years since patients' diabetes diagnosis. The FREQ procedure was used to estimate proportions for variables related to caregiver race, marital and employment status, whether or not the caregiver resided with the care recipient, satisfaction with social support, and whether or not the caregiver cared for someone other than the patient as well as patients' gender, race, employment status, ADL assistance requirement, dialysis type, and presence or absence of diabetes diagnosis.

Specific aim two is to determine the levels of objective and subjective caregiver burden, depressive symptoms, and perceived health status reported by male informal caregivers of persons with ESRD. The levels of objective and subjective burden derived from the MBS subscale scores and the CES-D depressive symptom scores were analyzed using the UNIVARIATE procedure to estimate measures of central tendency and dispersion, and determine whether assumptions were met regarding normality of the underlying sampling distributions. The FREQ procedure was used to obtain frequencies and percentages of caregiver perceived health status as measured by the Caregiver's Perceived Health Form.

Specific aim three is to determine the associations among objective and subjective burden, depressive symptoms, and perceived health status reported by male informal caregivers of persons with ESRD. Pearson product moment correlation coefficients were estimated by the CORR procedure to quantify the associations of caregiver objective and subjective burden, depressive symptoms, and perceived health. Because the literature shows that certain caregiver and care recipient characteristics contribute to caregiver burden, depressive symptoms, and perceived health, additional statistical analyses were used to examine the effects of caregiver race (Black, White), caregiver marital status (married, unmarried), caregiver employment status (employed, unemployed), ADL assistance (requires no assistance, requires assistance), and care-recipient presence or absence of diabetes on objective and subjective burden, depressive symptoms, and caregiver perceived health. The independent two sample *t*-tests based on the T-TEST procedure were used to test hypotheses pertaining to the relationships among these variables.

## **Results**

### **Male Caregiver and Care Recipient Characteristics**

Specific aim one is to determine the demographic profile of male informal caregivers of persons with ESRD.



A summary of the demographic characteristics of the caregivers is summarized in **Table 4-1**. The majority (79.3%) of the 29 study participants were Black, married (65.5%), and unemployed (51.7%). The average age was  $57.1 \pm 16.4$  years. Three participants were caring for more than one person. Most participants (82.7%) lived in the same residence as the care recipient and provided an average of 20.9 hours of care each week. An overwhelming majority (89.6%) of the sample cared for female patients, a finding consistent with national data reported for persons diagnosed with ESRD (Saran et al., 2014).

The care recipients' mean age was  $63 \pm 11.9$  years. Most (65.5%) did not require assistance with activities of daily living (ADL). The majority of the care recipients (93.1%) received in-center hemodialysis, the most common type of dialysis treatment. Because diabetes is a risk factor for development of ESRD, it is not surprising that more than half (57.1%) of the patients had a diagnosis of diabetes (**Table 4-2**).

### **Objective and Subjective Burden, Depressive Symptoms, and Perceived Health Status Scores**

Specific aim two is to determine the levels of objective and subjective caregiver burden, depressive symptoms, and perceived health status reported by male informal caregivers of persons with ESRD.

Objective burden, subjective burden, depressive symptoms, and self-rated health scores are depicted in **Table 4-3**. The range of scores for the 29 participants was 17-39. The average total objective burden score was  $28.8 \pm 4.4$  suggesting that the vast majority of caregivers were experiencing at least moderate objective burden. Only one caregiver had an objective burden score less than 20. Twenty six (89%) of participants' had scores of 21 or greater, and 2 caregivers had scores greater than 32. Thus, 93% of participants reported moderate to high levels of objective burden. Subjective burden scores ranged from 13-65. The average subjective burden score was  $47.7 \pm 9.2$ , indicating that caregivers overall reported moderate levels of subjective burden as well. Ten caregivers (34%) reported moderate subjective burden scores, and 18 caregivers (62%) reported high levels of subjective burden. Montgomery et al., (1985) established no cut-off scores for the MBS subscales. Thus, because the objective and subjective subscale mean scores were greater than the mid-point of possible scores, we determined that the caregivers' mean scores indicated at least moderate burden.

The mean depressive symptoms score for this study sample was relatively low at  $17.0 \pm 7.1$  indicating that on average, caregivers had mild depressive symptoms. Additional examination of the data revealed that 24.1% of caregivers reported mild depressive symptoms, 27.6% reported moderate depressive symptoms, and 6.9% had scores greater than 31 indicating severe depressive symptoms. Thus, more than half (58%) of caregivers reported mild to severe depressive symptoms.

**Table 4-1. Sociodemographic Characteristics of Male Caregivers of Individuals Diagnosed with End-Stage Renal Disease (N=29)**

Characteristics	<i>M ± SD</i>	<i>n (%)</i>
Age (years)	57.1 ± 16.4	
Hours of Care (per week)	20.9 ± 13.9	
Race		
Black		23 (79.3)
White		6 (20.6)
Marital Status		
Single		6 (20.7)
Married		19 (65.5)
Divorced		4 (13.8)
Employment		
Full-time		11 (37.9)
Part-time		3 (10.3)
Unemployed		6 (20.7)
Retired		8 (27.6)
Homemaker		1 (3.5)
Reside with care recipient		
No		5 (17.2)
Yes		24 (82.8)
Social Support		
Very satisfied		12 (41.3)
Satisfied		8 (27.6)
Somewhat satisfied		7 (24.1)
Dissatisfied		2 (6.9)
Caring for More than One Relative		3 (10.3)

**Table 4-2. Sociodemographic Characteristics of Individuals Diagnosed with End-Stage Renal Disease (N=29)**

Characteristics	<i>M ± SD</i>	<i>n (%)</i>
Age (years)	63.0 ± 11.9	
Months on Dialysis	35.8 ± 39.0	
Years Diabetic <sup>a</sup>	18.5 ± 8.4	
Race		
Black		23 (79.3)
White		6 (20.6)
Gender		
Male		3 (10.3)
Female		26 (89.6)
Employment		
Unemployed		10 (34.5)
Retired		15 (51.7)
Homemaker		4 (13.8)
Assistance with ADL		
No assistance		19 (65.5)
Caregiver assistance		8 (27.6)
Assistance from others		2 (6.9)
Dialysis Type		
In-center hemodialysis		27 (93.1)
Continuous ambulatory peritoneal dialysis		2 (6.9)
Diabetic <sup>b</sup>		
No		12 (42.9)
Yes		16 (57.1)

Notes. <sup>a</sup>Variable had 16 responses. <sup>b</sup>Variable had 28 responses.

**Table 4-3. Objective and Subjective Burden, Perceived Health Status, and Depressive Symptoms Scores for a Sample of Male Caregivers of Persons Diagnosed with End-Stage Renal Disease (N=29)**

Instruments	Values	Range of Scores
Measurement of Burden Scale		
Objective Burden		
Total Score, M $\pm$ SD	28.8 $\pm$ 4.4	17-39
Level, n(%)		
High	3 (10)	34-45
Moderate	24 (83)	22-33
Low	2 (7)	9-21
Subjective Burden		
Total Score, M $\pm$ SD	47.7 $\pm$ 9.2	30-62
Level, n(%)		
High	1 (3)	49-65
Moderate	10 (34)	31-48
Low	18 (62)	13-30
Caregiver's Perceived Health Status		
Total Score, M $\pm$ SD	3.0 $\pm$ 1.0	1-5
Centers for Epidemiologic Studies-Depression		
Total Score, M $\pm$ SD	17.0 $\pm$ 7.1	2-56
Level, n(%)		
Severe distress	2 (7)	>31
Moderate distress	8 (26)	21-30
Mild distress	7 (24)	16-20
No depressive symptoms	12 (41)	<15

As shown in **Table 4-4**, caregivers rated their health status as good. However, one-third reported their health status as fair or poor with 14% indicating that their health had worsened since assuming the caregiving role.

### **Relationship among Burden, Depressive Symptoms, and Self-Rated Health**

Specific aim three is to determine the associations among objective and subjective burden, depressive symptoms, and perceived health status reported by male informal caregivers of persons with ESRD.

**Table 4-5** depicts the estimated associations among objective burden, subjective burden, depressive symptoms, and perceived health status. Caregiver objective burden was significantly and positively correlated with caregiver subjective burden,  $r = 0.48$ ;  $p = 0.01$ ; 95% CI [.07, .13]. Weakly positive relationships were noted between caregiver objective burden and depressive symptoms as well as between objective burden and perceived health status. A significantly positive correlation was also observed between caregiver subjective burden and depressive symptoms,  $r = 0.36$ ;  $p = 0.05$ ; 95% CI [.64, .01]. Negligible relationships were detected between subjective burden and perceived health status and depressive symptoms and perceived health status.

### **Additional Quantitative Analysis**

The literature shows that there are some caregiver characteristics and some patient characteristics that appear to influence caregiver outcomes. For continuous attributes, such as age, hours of care, and months on dialysis, Pearson product moment correlation coefficients were estimated to quantify the associations among attributes and outcomes. Other additional analyses were performed to determine whether differences in mean objective and subjective burden and depressive symptoms and perceived health status were observed in this sample based on caregiver race (Black, White), marital status (married, unmarried), employment status (employed, unemployed), care recipient's ADL assistance needs (requires assistance, does not require assistance), and presence or absence of diabetes diagnosis.

Estimated Pearson product moment correlation coefficients among caregiver age, patient age, hours of care per week, months on dialysis, and objective burden and depressive symptoms are depicted in **Table 4-6**. Older caregivers, caregivers who cared for older patients, and caregivers who provided more hours of care reported higher levels of objective burden. Caregivers who provided more hours of care and whose care recipient had been receiving dialysis longer reported more depressive symptoms. **Table 4-7** depicts associations between caregiver and care recipient characteristics and objective and subjective burden, depressive symptoms, and perceived health scores. Significantly higher levels of objective burden were detected in caregivers who were White and whose care recipient required assistance with ADLs.

**Table 4-4. Perceived Health Status Scores in Male Caregivers of Relatives Diagnosed with End-Stage Renal Disease (N=29)**

Self-Rated Health	<i>n</i> (%)
Excellent	2 (6.9)
Very Good	7 (24.1)
Good	11 (37.9)
Fair	7 (24.1)
Poor	2 (6.9)

**Table 4-5. Estimated Pearson Correlations among Objective Burden, Subjective Burden, Depressive Symptoms, and Perceived Health Status (N=29)**

Measures of Burden, Depressive Symptoms and Perceived Health	Patient Characteristics	Sample Correlation	95% CI		
			<i>LL</i>	<i>UL</i>	<i>p</i> Value
Objective Burden	Subjective Burden	0.48	0.71	0.13	0.01
	Depressive Symptoms	0.26	0.12	0.57	0.01
	Perceived Health	0.28	0.10	0.58	0.14
Subjective Burden	Depressive Symptoms	0.36	0.64	0.01	0.01
	Perceived Health	0.16	0.22	0.49	0.43
Depressive Symptoms	Perceived Health	0.10	0.28	0.45	0.60

*Notes.* CI = confidence interval; *LL* = lower limit; *UL* = upper limit.

**Table 4-6. Estimated Pearson Correlations among Patient Characteristics, Objective Burden, and Depressive Symptoms (N=29)**

Measures of Caregiver Burden and Depressive Symptoms	Patient Characteristics	Sample Correlation	95% CI		p Value
			<i>LL</i>	<i>UL</i>	
Objective Burden	Caregiver Age	0.35	0.03	0.63	0.07
	Patient Age	0.42	0.06	0.68	0.02
	Hours of Care	0.36	0.02	0.64	0.06
Depressive Symptoms	Hours of Care	0.32	0.06	0.61	0.09
	Months on Dialysis	0.38	0.00	0.65	0.04

*Notes.* CI = confidence interval; *LL* = lower limit; *UL* = upper limit.



**Table 4-7. Sample Descriptives Using *t*-Tests for Equality of Means**

Variables	Sample Size n	Objective Burden			Subjective Burden			Depressive Symptoms			Perceived Health		
		M	SD	<i>p</i> (DF)	M	SD	<i>p</i> (DF)	M	SD	<i>p</i> (DF)	M	SD	<i>p</i> (DF)
Caregiver Race													
Black	23	27.9	4.0	0.03 (27)	48.2	9.0	0.53 (27)	18.1	11.0	0.80 (27)	3.0	1.0	1.00 (27)
White	6	32.3	4.6		45.5	10.3		19.3	6.3		3.0	1.4	
Marital Status													
Unmarried	10	28.4	2.7	0.66 (27)	46.9	10.9	0.75 (27)	17.0	6.1	0.53 (27)	3.0	1.1	1.00 (27)
Married	19	29.1	5.1		48.0	8.4		19.1	11.7		3.0	1.1	
Caregiver Employment Status													
Employed	14	28.4	4.5	0.65 (27)	47.4	11.0	0.90 (27)	18.6	12.1	0.92 (27)	2.8	1.0	0.29 (27)
Unemployed	15	29.2	4.4		47.9	7.5		18.2	8.2		3.2	1.1	
Activities of Daily Living													
No Assistance	19	27.7	4.4	0.07 (27)	47.4	9.9	0.85 (27)	16.3	5.9	0.24 (10)	2.8	1.1	0.27 (27)
Assistance	10	30.9	3.8		48.1	8.2		22.4	14.8		3.3	0.9	
Diabetes <sup>a</sup> Diagnosis													
No	12	29.9	3.0	0.19 (26)	45.4	8.1	0.30 (26)	20.8	12.2	0.21 (17)	3.1	0.9	0.61 (26)
Yes	16	27.7	5.0		49.2	10.1		15.6	7.3		2.9	1.1	

Note. <sup>a</sup>*n* = 28.

## Discussion

This study sought to examine levels of and associations among caregiver objective and subjective burden, depressive symptoms, and perceived health status in an understudied population of male caregivers of persons diagnosed with ESRD. Few studies have focused on caregivers of persons with ESRD (Arechabala et al., 2011; Saeed, Ahmad, Shakoor, Ghafoor, & Kanwal, 2012) and no studies were found, which focused solely on male caregivers of persons with ESRD. Thus, this study adds to the limited body of knowledge involving this population of caregivers.

The predominance of study participants (79.3%) were Black, a finding consistent with previous research indicating that Blacks are at markedly higher risk for developing ESRD compared to Whites (Grams, Chow, Segev, & Coresh, 2013). Overall caregivers were middle aged (57.1 years) and lived in the same residence as the patient (82.7%). The majority (89.6%) cared for female dialysis recipients and were unemployed (51.7%). On average, caregivers provided 20.9 hours of care each week, and only three provided care for someone other than the individual diagnosed with ESRD. These findings are similar to results of caregiver research in which the average age of caregivers was 49.2 years, 82% cared for one person, and spent on average 20.4 hours per week providing care (National Alliance for Caregiving, 2015).

We also found similarities among demographic characteristics of care recipients to nationally published data. In the current study, care recipients' average age was 63 years, 79.3% were Black, 89.6% were female, 57% were diabetic, and the majority (93.1%) received in-center hemodialysis. According to the United States Renal Data System, the average age for individuals with ESRD is 62.5 years, 36.8% were Black, 40.5% were female, 44.6% were diabetic, and the majority (64%) receive in-center hemodialysis. Thus, individuals in the current study were demographically similar to national averages, except for race and gender (Saran et al., 2014).

Caregivers experienced moderate levels of objective and subjective burden. This finding is not surprising because research shows that certain factors including care recipient comorbidities and caregivers' health substantially increased burden in this population of caregivers (Walker et al., 2015; Wilson-Genderson et al., 2009). Other studies involving caregivers of persons with ESRD (Cohen & Germain, 2014; Wilson-Genderson et al., 2009) as well as other chronic illness such as Alzheimer's disease (Andr n & Elmst hl, 2008) and amyotrophic lateral sclerosis (Pagnini et al., 2010) have found that caregivers experience mild to moderate levels of burden as well. Although many caregiving studies do not differentiate between objective and subjective burden, Chou, Fu, Lin and Lee (2011) found that objective and subjective burden were primarily related to similar factors such as ADLs, caregivers' age, and caregiver's health status in female caregivers of persons with intellectual disability. In the current study, subjective burden was not correlated with similar variables, however, ADL status and caregiver age were significantly correlated with objective burden.

Researchers report that negative health experiences of family caregivers are linked to several key variables including caregiver age, care recipients' type of illness, and number of hours spent providing care (Kim et al., 2012; Robison et al., 2009; Schoenmakers et al., 2010). In the current study, we found that higher levels of objective burden were associated with older caregivers, patient age, and greater hours of care. We also found that depressive symptoms were associated with increased hours of care and more months on dialysis indicating that caregivers who spend more hours immersed in the caregiving role and those who have been providing care for longer lengths of time are more prone to psychological distress. Subjective burden involves the emotional responses and mindset of the caregiver toward the caregiving experience (Brouwer et al., 2004). Caregivers' average subjective burden scores reflected at least moderate levels of burden, an expected finding as studies well indicate that caregivers of persons with ESRD experience significant levels of burden (Belasco et al., 2006; Gayomali et al., 2008).

Many risk factors have been identified in the literature that are positively associated with depression including initial depressive symptoms, poor perceived health status, and White race (Joling et al., 2012). In the current study, increased hours of care and more months on dialysis were positive associative factors. Caregivers who were White also experienced higher levels of depressive symptoms. Care recipients' decrease in functional independence markedly increase caregivers' objective burden (Gayomali et al., 2008), which may increase depressive symptoms. Care recipients requiring assistance with ADLs was associated with increased depressive symptoms in caregivers. Studies involving depressive symptoms in male caregivers are inconsistent. Some studies report that male caregivers experience less depression than female caregivers (Alexander & Wilz, 2010) and others report no differences in levels of depression between genders (Baker & Robertson, 2008). Our study results indicate that more than half (58%) of caregivers reported mild to severe depressive symptoms suggesting that depressive symptoms were a problem for this sample of male caregivers of persons with ESRD.

Overall, caregivers in the current study rated their health status as *good*. However, one-third of caregivers reported their health status as fair or poor, and 14% indicated that their health had worsened since assuming the caregiving role. Shields and Shoostari (2001) reported that men between ages 45 to 54 reported significantly better self-rated health than did women and that the ability of care recipients to independently complete ADLs was a powerful determinant of self-rated health. In the current study, the average age for caregivers was 57 years, and most care recipients independently performed ADLs. These factors may help to explain the overall *good* perceived health status rating of this sample of male caregivers. However, caregiver self-rated health is also influenced by levels of burden, and caregivers of persons with chronic illness experience significant burden related to the caregiving role (Cangelosi, 2009; H. Y. Chang et al., 2010). Our study participants reported moderate levels of objective and subjective burden, which may account for the fair and poor health status ratings reported by one-third of the caregivers. In addition, 13% of caregivers indicated that their health had worsened since beginning the caregiving role as reported on the MBS. Although the relationships in our study among perceived health with burden and perceived health with depressive symptoms were weak or negligible, there is indication that at least for some of these

caregivers, physical health is associated with care-related stressors. Thus, for some caregivers, health is an issue as with other larger caregiver studies, health is an issue.

### **Limitations and Strengths**

There are several limitations to this study. The study involved analysis of secondary data from an existing data set, which can cause threats to internal and external validity. Analyzing secondary data also limited us to use of the variables that were chosen for the primary study. Use of the cross-sectional design was a limitation because this type of research design only reveals associations found at a specific point in time as opposed to presenting differences in findings over time. Thus, causality cannot be inferred from the current study results. In addition, because the study involved a cross-sectional design and a small sample size, generalizability is limited to caregivers who are demographically similar to those who participated in the current study. A further limitation involved self-selection bias, which also limits generalizability. Caregivers who volunteered to participate in the study, may have been less stressed than those who did not respond. A final limitation may involve 'response bias'. All study participants were male, and the majority of participants were black. Research suggests that response bias may be among the reasons for male caregivers reporting less burden and depression than female caregivers. Additionally, previous research has shown that Blacks may be better able to cope with psychological distress than Whites (Friedemann, Buckwalter, Newman, & Mauro, 2013; Sleath, Thorpe, Landerman, Doyle, & Clipp, 2005).

Despite the limitations, this study is innovative in that it is the first to highlight the impact of burden, depressive symptoms, and perceived health status in men caring for individuals diagnosed with ESRD. A second strength of this study is that participants were male and the majority were Black. This is significant because until now, research has primarily focused on caregiving from the White female perspective, and no studies were found, which focused on the experiences of this population of male caregivers. Third, few studies have used a multidimensional approach to examining caregiver burden. Most previous studies have examined only one aspect of caregiver burden. A fourth study strength involves use of standardized scales to measure burden, depressive symptoms, and perceived health status, which allowed for comparison with studies examining similar variables in other caregiver populations. Fifth, variables such as caregiver age, hours of care per week, and months on dialysis were similar to those reported in nationally published studies. Lastly, because the data were collected from three dialysis centers, the study included participants from all socio-economic levels, thereby, increasing the external validity of findings. Although our study is descriptive and limited in scope, our findings in such a small sample are important and promising. Male caregivers of persons with ESRD experience burden, depressive symptoms, and changes to their health. Thus, it is important that their experiences are documented, caregivers at risk for negative outcomes are identified by healthcare providers, and interventions are developed to assist this hidden population of caregivers.

## Practice and Policy Implications

Results of this study suggest that male caregivers of persons with ESRD may be at risk of psychiatric morbidity. Thus there are important implications for practice and policy. Clinicians must target at-risk male caregivers early in the caregiving process before they suffer negative outcomes. To this end, healthcare providers of persons with ESRD must determine who assists these individuals with their caregiving needs and make early and ongoing communication with male caregivers a priority. Caring for persons with ESRD can result in mental and physical deterioration and have a devastating impact on the lives of the caregiver and care recipient. Thus, early intervention is key. Dialysis clinics are perhaps among the best places to initiate caregiver education about the disease, introduce networks of support for male caregivers, and provide practical assistance for anticipated needs. For example, because caring for persons with ESRD often causes financial burden, practitioners who staff dialysis centers and nephrology clinics may need to assist caregivers with accessing resources to help alleviate financial strain.

A growing trend suggests that ESRD patients have better outcomes when dialyzed more frequently at home when compared to the three times per week therapy that is quite common. However, Cohen and Germain (2014) found that caregivers who assisted with home dialysis trended toward higher levels of burden than did those whose care recipients received in-center hemodialysis. Burden in caregivers who provide home dialysis has not been well studied. Researchers suggests that because home hemodialysis relies heavily on informal caregivers, exposing the burden that these caregivers experience may be controversial (Cohen & Germain, 2014). Nevertheless, as more men take on the caregiving role and perhaps assist with home dialysis treatments, more research must be done to determine how these changes impact male caregivers.

Implications for policy include development of specific resources and increased access to social support services, which might help to decrease the levels of burden and depressive symptoms in this population of male caregivers. Caregiver employment was significantly correlated with objective burden in the current study. Employers are often not understanding to caregivers who are frequently absent due to caregiving responsibilities (Chen, 2014). This may be especially true of caregivers of persons with ESRD as the dialysis recipient is dialyzed most often three times each week. Thus, it is imperative that caregivers who have Family Medical Leave Act (FMLA) benefits understand and exercise their rights as employees to use these benefits as this may assist with decreasing their levels of burden and depressive symptoms. Gender-specific health promotion strategies are also important to assist male caregivers with managing the psychological distress associated with caregiving. Early promotion of interventional programs designed to assist male caregivers during the initial phase of the caregiving process may be beneficial to managing burden and depressive symptoms throughout their caregiving careers.

In addition, the significant financial contribution that informal caregivers make to society must be acknowledged and valued. In one state alone, unpaid care is valued at \$10 billion per year (Kelly, 2015). A decline in caregivers' physical or mental health

could mean additional costs for the healthcare system. Additionally, without informal caregivers, the outcomes for many ESRD patients would perhaps be vastly different. Thus, it is important that policy be developed to support informal caregivers through various means such as paid leave for caregivers who are not employed where FMLA benefits are offered, funding for dialysis centers to offer support programs for caregivers, and research funding to study various forms of caregiver needs.

### **Theoretical Implications**

Findings from this study provide partial support for the SPM. Caregiver background characteristics such as age, gender, socioeconomic status, and race significantly influence caregivers' experiences as these attributes affect the resources that are available to caregivers and are key factors threaded throughout the stress process (Bolden & Wicks, 2008; Pearlin et al., 1990). Among the caregiver background and contextual variables, caregiver age, patient age, and being of White race were significantly correlated with objective burden. Primary stressors are those that are likely to occur first in an individual's experiences and include events that are undesired, disruptive, and enduring (i.e., demands of caregiving tasks) (Pearlin et al., 1990). Depressive symptoms scores were correlated with the primary stressors hours of care and months on dialysis. Secondary stressors were not measured in the current study. The cross sectional descriptive design of this study and use of secondary data analysis techniques limited examination of the associations among study variables. Nevertheless, significant correlations found among study variables in this small sample underscores the need for continued research in this population of male caregivers.

### **Future Research**

Findings from this study point to implications for future research. Studies are inconsistent regarding the levels of burden and depression experienced by male caregivers. Some studies report minimal burden and depression levels in male caregivers, while others report levels that are equal to those experienced by female caregivers. These distinct differences between findings suggests the need for more rigorous research involving male caregivers including longitudinal designs, which provide for greater understanding of men's experience of the caregiving trajectory. To date, most studies have employed cross-sectional designs, which only provide a description of the caregiving experience at a given moment in time. In addition, use of larger sample sizes and probability sampling to address methodological issues associated with male caregiver research is important.

Although the measures used in the current study involved standardized scales to measure burden, depressive symptoms, and perceived health status, researchers are challenged to develop objective measures of these outcome variables based solely on male caregivers. Many of the instruments in use today were developed based upon the female caregiver norm. Thus, efforts should focus on developing instruments that are



sensitive to the male caregiving role, which will allow researchers to better capture the experiences of caregiving from the male perspective (Gant, Steffen, & Lauderdale, 2007). Development of gender-sensitive measures may assist with advancing gender-specific interventions to address male caregiver objective and subjective burden, depressive symptoms, and perceived health status. In addition, researchers must be cognizant of gender sensitive language when designing intervention programs for male caregivers as men are likely to respond more readily to wording such as ‘informational seminar’ as opposed to ‘support group’ (Yee & Schulz, 2000). In addition, it is important that researchers involve male caregivers in the design of interventions using community-engaged models.

Finally, caregivers of person with ESRD experience unique situations, which may cause increased levels of burden, depressive symptoms, and poor perceived health status. While intervention studies have been designed to address the needs of female caregivers of persons with ESRD (Wicks et al., 2007), no such studies exist for these male caregivers. Thus, research must focus on developing and testing interventions addressing the specific needs of male caregivers of persons with ESRD. Additionally, because Blacks are at greater risk of developing ESRD, intervention studies addressing the specific needs of this ethnic subpopulation of male caregivers is also warranted.

## **Conclusion**

This study adds to our understanding of objective and subjective burden, depressive symptoms, and perceived health status in informal male caregivers of persons with ESRD. Results demonstrate that caregiver and care recipient characteristics are important factors that increase the risk of caregiver objective burden and depressive symptoms. Generally, the findings of the current study were similar to those of other caregiver populations, which used similar self-reporting questionnaires suggesting that these assessment tools may be helpful in providing important perspectives involving burden, depressive symptoms, and perceived health status in male caregivers of persons with ESRD. In addition, these findings increase the likelihood that previously tested interventions will be relevant to this population. However, additional research is needed to better understand how to support this population of male caregivers.

## **CHAPTER 5. QUALITATIVE RESULTS**

### **Introduction**

Chronic illness, advances in medical technology, and the rising costs of healthcare have led to an increased need for family caregivers. Although the majority of caregiver research focuses on the experience of caring from the female perspective, males constitute approximately 40% of the 43.5 million caregivers in the United States (National Alliance for Caregiving, 2015). During the past 20 years, there has been an increase in the number of studies involving male caregivers. However, these studies have focused primarily on male caregivers of persons with cognitive impairment, such as Alzheimer's disease and dementia (Fuller-Jonap & Haley, 1995; Geiger et al., 2015). There is a paucity of research involving the experiences of men caring for persons with chronic illnesses among which is end stage renal disease.

Individuals with end-stage renal disease (ESRD) are among the chronically ill population often requiring assistance from family caregivers. ESRD is a deteriorating and chronic condition requiring long-term dialysis treatments and frequent health monitoring. It is a devastating illness, which has the potential to cause considerable changes in family life (Del-Pino-Casado et al., 2011). The disease is often secondary to other disorders namely diabetes, heart failure, and hypertension. The individual often experiences shortness of breath, fatigue, cognitive disturbances, and insomnia. Adjusting to the strict dietary controls and fluid and electrolyte restrictions can be difficult and tedious (Walker et al., 2015). The chronic effects and prolonged nature of ESRD necessitate long-term adjustment not only for the patient but also for the caregiver.

Caregivers of persons with chronic illnesses are at risk for negative mental and physical health outcomes (Cangelosi, 2009; H. Y. Chang et al., 2010). Studies have found that caring for persons with ESRD is associated with significant levels of burden (Belasco et al., 2006; Belasco & Sesso, 2002). Factors contributing to caregiver burden in this population include the added responsibilities of complex home dialysis therapy or transportation for care recipients to dialysis clinics for treatment, adhering to the strict dietary requirements, and coping with care recipient comorbidities and cognitive changes (Tong et al., 2008). The increasing levels of burden related to caring for persons with ESRD may lead to depressive symptoms. Wilson-Genderson, Pruchno, and Cartwright (2009) also found that caring for persons with ESRD placed caregivers at increased risk of poor physical health. Caregivers often have difficulty balancing between caring for the patient and attending to their own wellbeing. Thus, their healthcare needs are frequently neglected. While there are studies documenting the collective experiences of both men and women caregivers of persons with chronic illnesses, studies involving both genders often included male caregivers as contrast groups to illustrate the challenges faced by their female counterparts (Kramer & Thompson, 2002). Thus, the current qualitative study was designed to use focus group interviews to explore the experiences associated with objective and subjective burden, depressive symptoms, and perceived health in a sample of informal male caregivers of persons with ESRD.



## Conceptual Framework

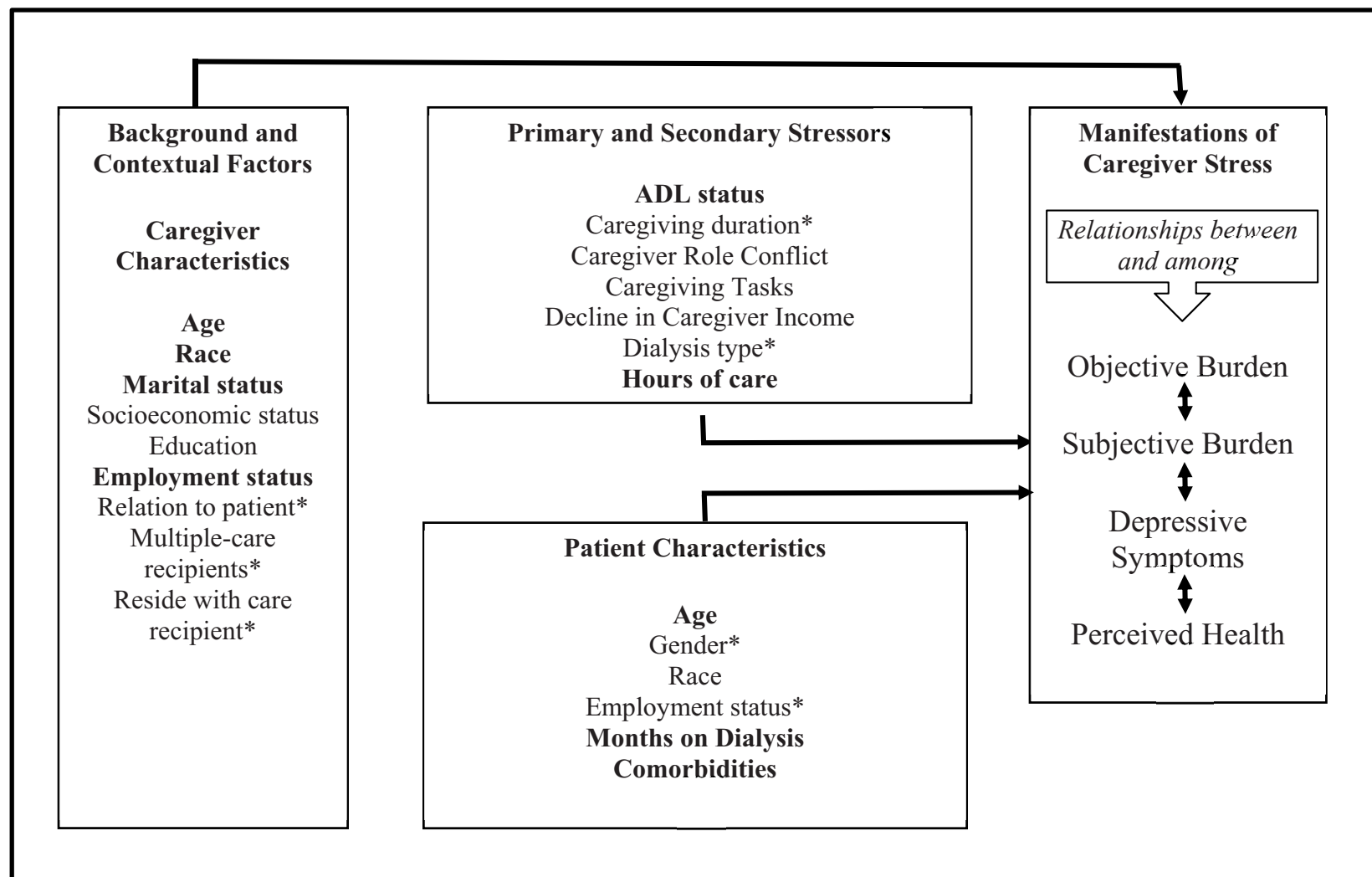
The Stress Process Model (SPM) serves as the theoretical foundation for this study as it provides the primary paradigm for understanding the relationship between stress and health (Pioli, 2010). The SPM is a middle-range theory consisting of four primary domains: background and contextual, stressors, mediating resources, and manifestations of stress (Pearlin et al., 1981). Caregiver background characteristics such as age, gender, SES, and ethnicity significantly influence caregivers' experiences as these attributes affect the resources that are available to caregivers and are key factors threaded throughout the stress process (Bolden & Wicks, 2008; Pearlin et al., 1990). Stressors are dichotomized into primary and secondary categories (Pearlin et al., 1990). Primary stressors are those that are likely to occur first in an individual's experiences and include events that are undesired, disruptive, and enduring (i.e., demands of caregiving tasks). Secondary stressors come about as consequences of primary stressors and include role strain and intrapsychic strains. For example, a person may experience role conflict, economic strain, and isolation related to caregiving demands (Harris, 2003; Pearlin et al., 1990). Mediating resources are the elements that a person invokes on their own behalf as defense against stressors such as social supports and various coping strategies. Manifestations of stress or outcomes include measures of physical and mental wellbeing and the ability to continue in a specified social role (Pearlin et al., 1990).

This model has been successfully used in the previous retrospective study found in chapter four of this dissertation as well as in the original Harris (2003) study examining health and burden in caregivers of persons with ESRD. Thus, we found it useful for the current study. Pearlin et al. (1990) affirmed that the effects of sociodemographic characteristics including age, ethnicity, gender, and socioeconomic status are likely threaded throughout the stress process. In the current study, sociodemographic factors were used to characterize the sample of male caregivers. In addition, the SPM was used in the current study to explore the experiences associated with manifestations of caregiver stress including objective and subjective burden, depressive symptoms, and perceived health. (**Figure 5-1**)

## Methods

### Sample

The aim of the current study was to describe the experiences of male caregivers of individuals diagnosed with ESRD associated with objective and subjective burden, depressive symptoms, and perceived health. The study, which used a qualitative approach, included a convenience sample of six male caregivers who were self-identified as being current or previous primary caregivers of individuals diagnosed with ESRD and recruited specifically for participation in a focus group interview. Among persons aged



**Figure 5-1. Conceptual Framework of Caregiver Stress**

20-39, Blacks are 3.8 times more likely to have a diagnosis of ESRD than Whites. In addition, the rates of ESRD are considerably higher for Blacks aged 60 or greater than for their white counterparts (Saran et al., 2014). Thus, the recruitment strategy for the focus group was designed to include a racial distribution similar to the national ESRD population. Because the highest prevalence of ESRD in Blacks occurs in the southeastern United States (Saran et al., 2014), the study was conducted in a geographical area where ESRD has a significant impact. The IRB letter of approval for this study is provided in **Appendix C**.

## **Data Collection**

An IRB-approved Focus Group Interview Guide was designed by the principal investigator (PI) and used to facilitate the focus group interview (**Figure 5-2**). The guide consists of an introduction, which was used to explain the purpose of the study to the participants and a series of questions designed to explore participants' caregiving experience. The PI developed the questions based upon the study specific aim and findings from the previous quantitative retrospective study conducted by the PI in chapter four of this dissertation. The Focus Group Interview Guide was used to follow predetermined topics as opposed to rigidly adhering to a fixed set of questions. Where necessary, the PI used probes and prompts as appropriate for facilitating the discussion, which is consistent with recommendations for conducting focus groups (Morgan, 1997). Site preparation for this semi-structured focus group interview involved choosing a location that was quiet, comfortable, and easily accessible for participants.

Recruitment for the study began in July 2014 and continued until May 2015. The PI contacted the male caregivers by telephone to obtain their input regarding the most convenient time for them to participate in the focus group interview. Prior to initiating the focus group interview, the PI obtained written informed consent and each participant completed the Male Caregiver Demographic Data form. Once these items were completed, the audio recorded interview began using the IRB-approved Focus Group Interview Guide. The PI was assisted by a study co-investigator who took notes and provided a summary of major points at the end of the session. Each caregiver received \$50.00 for their participation. In the week following the focus group, letters of appreciation were sent to each of the study participants. In addition, the PI received IRB approval to again contact the study participants to ask additional questions.

## **Data Analysis**

The focus group interview was audio-recorded, transcribed verbatim, and checked for accuracy by the PI. QDA Miner (Montreal, QC, Canada) software was used to analyze and categorize thematic content. Qualitative analysis began with open coding through a process of line-by-line examining, comparing, conceptualizing, and categorizing (Silverman, 2009) participant descriptions of their caregiving experiences.

Primary Questions

1. How would you describe your caregiving experience?
2. How has caregiving affected your ability to work?
3. How has caregiving affected your ability to participate in recreational activities?
4. How has caregiving affected your ability to care for your physical health?
5. How has caregiving affected your mental health?

Ancillary Questions

1. What made you decide to participate in this study?
2. Have you thought of anything else that you would like to share since that time?
3. Have you followed through in meeting with any other participants since leaving the focus group?

**Figure 5-2. Interview Guide for Male Caregivers of Persons with ESRD**

Textual data were explored inductively using content analysis to generate codes. The codes were merged into categories, and from the categories emerged themes. Some categories were subcategorized and corresponding sections of textual data were designated to individual categories or subcategories.

## Results

### Qualitative Specific Aim

Explore the experiences that contribute to caregiver objective and subjective burden, depressive symptoms, and perceived health status in male informal caregivers of persons with ESRD

To provide an in-depth analysis of the experiences of male caregivers of individuals diagnosed with ESRD, we conducted a focus group consisting of 6 participants. **Tables 5-1** and **5-2** describe the demographic characteristics of the caregivers and their care recipients, respectively. The qualitative analysis provided greater detail than our previous quantitative study about the participants' experiences contributing to objective and subjective burden, depressive symptoms, and perceived health. Although an interview guide was used to conduct the discussion, the PI also asked questions, which followed the natural course of participants' conversation. Thus, the interview guide was used to introduce topics that were not spontaneously initiated by participants.

Following extensive analysis of the transcript, 3 overarching themes emerged, *care giving experiences*, *effects of caregiving*, and *coping strategies*. Each of the 3 themes were subdivided into categories and subcategories, which are depicted in **Figure 5-3**. The themes, categories, and selected subcategories are presented. Words in italics are directly quoted from participants' statements.

### Care Giving Experience

The theme *care giving experience* was derived in response to the question, '*How would you describe your caregiving experience?*' Caregivers identified a range of thoughts and feelings, which influenced their perspectives on the caregiving experience. Their perspectives were both positive and negative based upon a number of factors. In addition, their perspectives were influenced by indirect factors including caregiver and care recipient characteristics, relationship dynamics between the caregiver and the care recipient, and the presence or absence of social support. From the caregivers' statements, three primary categories were derived for this theme, *positive caregiver perspectives*, *negative caregiver perspectives*, and *indirect influences on caregiver perspectives*.

**Table 5-1. Caregiver Demographic Data**

Participant	Age	Race	Marital Status	Relationship	Education	Annual Income \$	Employment	Decrease Income	Hours of Care per week	Years of Care	Total Cared For
01	30	Black	Single	Son	Graduate	26-51,999	Fulltime	Yes	50 or more	10 or more	2
02	45	Black	Single	Son	Some college	0-25,999	Fulltime	No	1-10	10 or more	2
03	45	White	Married	Father	Undergraduate	26-51,999	Fulltime	No	41-50	1-4	1
04	61	Black	Married	Spouse	Some college	26-51,999	Retired	No	11-20	10 or more	1
05	30	Black	Single	Son	Graduate	52-74,999	Fulltime	No	11-20	5-9	1
06	51	Black	Married	Spouse	Some college	52-74,999	Fulltime	Yes	41-50	5-9	2

Notes. Relationship = Relationship of caregiver to care-recipient. Total Cared For = Total number of individuals receiving care from the caregiver.

**Table 5-2. Care-Recipient Demographic Data**

Participant	Age of Patient	Gender	Employment	Dialysis Years	Resides	Diabetic	Care Assistant	Assistant
01	66	Male	Retired	>5	With CG	Yes	Yes	Family
02	66	Male	Retired	>5	Home alone	Yes	Yes	Family/PA
03	3	Female	Unemployed	3-5	With CG	No	Yes	Family/PA
04	62	Female	Retired	3-5	With CG	Yes	Yes	Family
05	62	Male	Fulltime	3-5	Home with others	No	No	
06	46	Female	Unemployed	>5	With CG	No	No	

Notes. CG = Caregiver. PA = Paid assistance.

<u>Care Giving Experience</u>	<u>Effects of Caregiving</u>	<u>Coping Strategies</u>
<p><b>Positive Caregiver Perspectives</b></p> <ul style="list-style-type: none"> <li>• Commitment</li> <li>• Emotional gratification</li> <li>• Reciprocity</li> </ul> <p><b>Negative Caregiver Perspectives</b></p> <ul style="list-style-type: none"> <li>• Difficult</li> <li>• Disappointment</li> <li>• Fear</li> <li>• Inconvenient</li> <li>• Obligation</li> <li>• Overwhelming</li> </ul> <p><b>Indirect Influences on Caregiver Perspectives</b></p> <ul style="list-style-type: none"> <li>• Caregiver Characteristics</li> <li>• Care Recipient Characteristics</li> <li>• Relationship Dynamics</li> <li>• Social Support</li> <li>• Formal</li> <li>• Informal</li> </ul>	<p><b>Recreational Activities</b></p> <p><b>Self-care/Physical Health</b></p> <p><b>Work/School</b></p> <p><b>Mental Health:</b></p> <ul style="list-style-type: none"> <li>• Objective Burden</li> <li>• Subjective Burden</li> <li>• Depressive symptoms</li> </ul>	<p><b>Adaptive</b></p> <ul style="list-style-type: none"> <li>• Exercise</li> <li>• Meditation</li> <li>• Reading</li> <li>• Religiosity</li> <li>• Solitary activities</li> <li>• Personal behavior change</li> </ul> <p><b>Maladaptive</b></p> <ul style="list-style-type: none"> <li>• Avoidance</li> <li>• Change care recipient behavior</li> <li>• Excessive exercise</li> <li>• Masking feelings</li> <li>• Withdrawal</li> </ul>

**Figure 5-3. Themes, Categories, and Subcategories**



**Positive caregiver perspectives.** Positive caregiver perspectives included commitment to the relationship with the care recipient, emotional gratification, and feelings of reciprocity. Caring was coupled with feeling a sense of pride and satisfaction in the care that was being provided to the care recipient. Spousal caregivers particularly spoke of caregiving as a commitment to their relationship based upon love or responsibility. One husband, describing his commitment to caregiving out of love for his wife states, *“But you know I look at the word “caregiver” itself though, you know, you’ve got to have some love to do it. Everybody can’t be no caregiver. Yeah, you got to care. The word speaks for itself”* (Participant 04). Another husband expressed such commitment and responsibility to his relationship with his wife that he refused help from anyone, including his wife’s relatives, *“If I wasn’t there, I believe they would step in. But, because of the way that I am, I just think that that’s my job you know, and I prefer to do it. So, I believe I would have some support if I allow them to do it but I prefer to do it because that’s my wife. My sister-in-law and I, we have this little heated discussion. She was my sister before she was your wife. Whatever the case maybe, she’s my wife. I can handle it. I’ve got it”* (Participant 06).

Most caregivers agreed that they received emotional gratification from their role as caregivers. Participant 06 expressed emotional benefit from just being *“able to help them”* and Participant 04 felt strengthened in the thought that he would receive help in the event that he one day needed a caregiver, *“Get strength... You know, like, I spoke on the Lord, you know. It’s what goes around, comes around.”* One participant who described his experience as *“great”* and appeared to feel a sense of heroism with being the sole caregiver for his father expressed his feelings of gratification related to caring in this manner, *“It’s more on self-preservation as far as looking at it, and me, it’s...okay as far as a benefit, I see my father. My father gets to see his grandson. My father asked bring my grandson, let him spend the night with me. To see the joy on his face and then to see the joy of him having his grandkid there, he can see his grandkid. That gives me a world of joy”* (Participant 05).

Some caregivers expressed the concept of reciprocity in that they were giving back to the person who had cared for them or providing care with the hope that they would be helped in a similar manner if necessary. As one caregiver explained, *“At first, I was uneasy about it, but then at the same time this is my father. This is my life. If it wasn’t for him I wouldn’t be here. So, I was like if I got to do it, I got to do it and no questions asked”* (Participant 05).

Another caregiver added, *“I’m doing this for my wife. Even if I did it for somebody else. Still, you know, I’m going to get old one day and need some help so, hopefully, somebody, you know, will look out for me”* (Participant 04).

**Negative caregiver perspectives.** Despite stating positive feelings about their caregiving role, the overwhelming majority of participants described the difficulties associated with providing care to this patient population. Caregivers felt disappointment,

obligated to provide care, and fearful of future outcomes for the care recipient. They also described caregiving as inconvenient and overwhelming.

During the course of the discussion, caregivers described a range of circumstances that influenced their negative feelings about the caregiving experience. They explained in detail the undesirable changes made in their lives due to their role as caregivers, some making more radical changes than others. The degree to which caregiving changed their lives, from living arrangements and strenuous physical exertion to anxiety and fear of the unknown, in part, contributed to the negative feelings expressed about the caregiving process. Caregiving was described as ‘hard’, ‘challenging’, inconvenient, and ‘overwhelming’. Participant 01 explained, *“I would go drive from campus to their home, get in their truck, take him to the clinic, take their truck back, get in my car, and drive back to campus. So, I was driving 100 miles a day.”* This participant eventually moved in with his parents to help care for them both.

Expressing the physical exertion of carrying the 20-pound dialysis therapy boxes, increased responsibility of being the financial provider and father, and the overwhelming difficulty of it all, Participant 06 stated, *“So, a lot of times when the truck would bring it in (the boxes), they are going to stack them in front of your garage or at your door. I had to carry all this stuff inside, then I had to go to work, and I had to take care of my daughter as well because she’s doing what she has to do to take care of herself. So, it was hard. It was hard.”*

The unpredictability of the ESRD illness trajectory and caregiver knowledge deficit of the disorder led to fear of future outcomes for the care recipients, which also impacted caregivers’ feelings. Dialysis recipients must have vascular access to be dialyzed. For the lay person who is not familiar with ESRD, this can cause anxiety. Expounding further upon the negative experiences, which helped to shape his feelings, Participant 06, after observing the vascular access in his wife’s “neck”, voiced his fear of not knowing whether his wife would live or die, *“They had to put the tube here (pointing to his neck) and for me to see that, it was bothering me. Not knowing what the outcome might be (Participant 06). [Moderator: When you said that it was bothering you, were you concerned that she would not live?], “Yes, because I didn’t know the full extent of what was actually going on. I knew she was having issues with the infection there, the pain and everything. Also, she had it on one side, her exit site, but then they had to switch and put it on the other side. So, I’m not knowing what’s going on. So, when I go to work this stuff...this is affecting me.”*

Each of the caregivers also reported that caregiving was an inconvenience, unexpectedly intruding into their personal, social, and financial lives. One son described, *“Well, like on my lunch break, I might go and run some errands for him and some things that I may have to do, which it cuts into my time”* (Participant 02). Describing how caregiving interfered with family vacations, Participant 06 explained that once his wife began home dialysis, *“taking a cruise, something of that nature, made me work a whole lot more because now I got to carry these boxes.”* [Participant 04 chimed in, *“That’s a heavy box.”*] *“Make sure I got the right amount of boxes for the right amount of days that*

*we had. It was kind of tearing me down.” He further explained that the disorder “interfered with everything. With mine before the transplant, it interfered with everything. It was a lot of work. Like I was saying, I used to love to go to the beach. Me and my children will be on the beach enjoying ourselves but my wife, like I said, she would either be in a hotel sick or she would be at my grandmother's house sick. So, that just interferes with everything you know” (Participant 06).*

## **Indirect Influences on Caregiver Perspectives**

Caregivers under similar circumstances develop contrasting viewpoints about their experiences. In this study, we found that characteristics of both caregiver and care recipient, the relationship dynamics between caregiver and care recipient, and presence or absence of social support indirectly influenced participants’ perspectives about their experiences.

**Caregiver characteristics.** To some extent, the variability among caregivers’ perspectives is related to individual attributes. In this study, caregiver attributes that influenced their perspective included loyalty to the care recipient, suppression of their own emotions, and use of an analytical approach to caregiver related issues.

One caregiver feeling a deep sense of responsibility and as if “*everything rests on my shoulders*” suppressed his emotions. “*It affected everything and it used to actually bother me in my mindset. But what I did was I just kind of push that over to the side like you said and just did what I had to do*” (Participant 06). In contrast, another caregiver, whose experience was exceedingly difficult, shared a different view towards the circumstances of caregiving, “*I've always tried to make anything negative to positive. So, what I did was, instead of pushing it to the side, I put it to the forefront, put it right in front of me. I said how I can pick this apart. So, I just started picking it apart by doing the same thing that I have been doing now*” (Participant 01).

**Care recipient characteristics.** Additionally, caregivers described various care recipient attributes, which negatively or positively influenced the caregivers’ feelings about providing care. Few caregivers described positive aspects of care recipients’ personality. However, one caregiver stated, “*He [his father] was like I need you to have a life, too. Don't let me deter you from what you're doing with my treatments. So, we're going to find a way to work this out where you can save my life and you can have your own life*” (Participant 05). The caregiver explained that his father’s attitude helped to make his caregiving experience more positive.

On the contrary, care recipients described as ‘*stubborn*’, ‘*strong-willed*’, or lacking motivation negatively affected caregivers’ experiences. While none of the caregivers verbalized feelings of resentment toward taking on this role, their nonverbal communication (e.g., sighing, agreement with telling comments, facial expressions)

indicated frustration. *“He's very stubborn. I mean I'm just telling you the truth. He doesn't exercise. He doesn't do what he is told. He still eats the same way. So that's the challenge (Participant 01). The caregiving parent stated, “It's our little girl. She's just turning three and it's definitely hard. She is strong-willed. I mean good grief! (Participant 03).*

Care recipients with multiple medical problems also influenced caregivers' viewpoints. Although Participant 01 employed positive coping strategies, he readily expressed that his father had multiple medical issues, including diabetes and obesity, which made caring for him quite difficult. *“I would literally drive over and get in a bigger vehicle with my Dad who was over 300 pounds and over six foot tall and he can't walk. He hasn't driven for over 13 or 14 years. He's very permanently disabled outside the dialysis or kidney failure. I would go drive from campus to their home, get in their truck, take him to the clinic, take their truck back, get in my car, and drive back to campus. So, I was driving 100 miles a day (Participant 01).*

**Relationship dynamics.** For some participants, the relationship between caregiver and care recipient played a significant role in caregiver stress and, subsequently, helped to determine their perspective of the experience. Husband caregivers did not readily discuss negative aspects of their marital relationship. However, participants who were sons freely described various aspect of the relationship shared with their fathers, which had a positive or negative effect on their perspectives. Having cared for his father the past 11 years, Participant 01 spoke liberally about their relationship and his resulting feelings of anger and frustration. He expressed that his emotions spanned the gamut of those experienced by parents rearing children, *“Sometimes it just comes to the point that I want my Dad to sit down and be quiet. I've always seen my parents being almost as if I am raising two...specifically my father. If I put an age around them mentally --- I would put his age --- he acts sort of mentally like a 13 year old boy. It's like when you raise any child. I get those same emotions. Sometimes it's great and sometimes it's not great. I just try to manage that” (Participant 01).*

Relationship dynamics also involved shifting family roles as caregivers assumed roles previously held by other family members and additional responsibilities. One husband, who was also a father, began shouldering the ‘mother’ role. Because his wife could no longer work, he maintained two jobs, cared for their young daughter, and functioned as caregiver, all of which was mentally and physically taxing. As previously noted, one caregiver spoke of assuming parenting-type responsibilities for both of his parents. Despite having mothers and adult siblings, two sons assumed primary responsibility of caring for their fathers. The stress of these changing roles and additional responsibilities were, for some men, overwhelming at times.

**Social support.** Each of the caregivers had access to or received formal and/or informal social support, which they all felt was important to relieving some of the pressure of providing care. Formal support included visiting healthcare personnel or transportation assistance to and from the dialysis center. Informal support was from

relatives and friends and included activities from assisting with personal tasks to companionship and emotional encouragement. Most caregivers felt that familial support was particularly important to a positive experience, *“Everybody don’t have what it takes but at the same time I think everybody should try. If we four were brothers and our parent is ill with this situation, it’ll make everything even more easier if say you take Monday, Tuesday and Wednesday, and Thursday. That takes pressure off of one person”* (Participant 06).

However, not all caregivers felt that their social support was adequate. In response to the question, *“How satisfied are you all with the support that you are receiving or have received?”* the lack of familial support from his siblings was troubling for one caregiver, particularly. He indicated that his experience would have been better if he had received assistance from his siblings, *“My older brother is 7 years and my sister is almost 10 years older than me and I’ve always been the barer of my parents. But like you said, it would be nice if --- like my brother, he comes home just to have fun, come in and out just to “hey, Dad, how are you doing,” smile, hey --- but he don’t see the real movie, so to speak. He sees it but he doesn’t want to deal with it. My sister is even worse than that, honestly speaking. So, it’s all me”* (Participant 01).

## Effects of Caregiving

**Recreational activities.** To examine the effects of caregiving in this sample of caregivers, we asked how caregiving had affected four areas of their lives: recreational activities, self-care/physical health, work or school, and their mental health. The majority of caregivers felt that their social lives were greatly limited because of caregiving responsibilities. One caregiver affirmed that he really did not want a busy social life. *“Well, it’s [caregiving] made me become kind of reclusive because after dealing with people’s problems all day at work and then having to go and deal with my Dad, I just tend to want to cut off and just go into my cave”* (Participant 02). Another caregiver explained why he and his wife had minimal social interactions with friends, *“Yeah. It’s funny. Our friends ask us all the time why can’t you do this or that. Well, because we have to be home by 7 o’clock so we can get her [their daughter] on her dialysis. If we don’t get her before, especially if she has something going on like she has to go to the doctor the next day, we’ve got to get her on at a certain time. If we don’t, she gone go past that time. We won’t have enough time to get her off her dialysis. And of course, she has to have time to recuperate from that. Yeah, we have several friends we can’t do anything because you’ve got to keep doing this”* (Participant 03).

**Self-care/physical health.** All caregivers agreed that lack of “sleep” and feeling “tired” were primary issues when asked, *“How has caregiving affected your ability to care for yourself?”* One caregiver recalled, *“I almost had an accident you know, driving off the road because I was working so much, sleeping 3 hours a night”* (Participant 01). Weight gain was also an issue because caregivers who were used to



being active and exercising were limited in the amount of time they could dedicate to these activities because of caregiving responsibilities. *"I was very active, playing basketball, went to the gym. So, then I started doing that [home dialysis with his father]. It was like whoa, I'm tired. Let me get me a quick nap before I have to get up and take him off the machine. Then, I ended up gaining 40 pounds"* (Participant 05). Three caregivers reported developing high blood pressure after beginning their caregiving career. *"You know, everybody usually get what 7/8 hours of sleep. I was looking at the trend what 4 or 5 hours of sleep. It affected me. My high blood pressure, it came along"* (Participant 04). Self-neglect was also a common topic threaded throughout the discussion. *"I'm sitting here just listening, and I'm seeing myself in that, you know, trying to take care of everything and make sure everything is okay but at the same time I'm neglecting myself"* (Participant 06).

**Work/school.** Caregiving responsibilities affected work and/or school aspects of caregivers' lives. Caregivers spoke of transferring to a different university, retiring from a job, leaving work often to provide care, and feeling much *"heartache"* because of job-related issues. *"I would have to leave my job and go to the house and assist her. A couple of times, she had to get the ambulance. So, it affected my work. So, I just went on and retired from my job"* (Participant 04). Another caregiver continued, *It was a lot for me because uh, the type of job that I have. I have plenty of time where I could take FMLA. But my job was giving me a hassle with that because I was needed, and so it was causing me a lot of heartache. Like I said, as I sit back and just think about it while I was going through it, dealing with my supervisor because they're not gone really just believe that you to take off all the time* (Participant 06).

**Mental health.** During the discussion, participants often used words and phrases, which provided insight into their frame of mind at various times throughout their caregiving careers. They felt *"affected"*, mentally tired, and bothered *"on the mental side because I couldn't really just understand what was going on"* (Participant 06). Participants commented that the experience was *"messing with my mindset"* (Participant 06) and it was *"playing a toll on me because it was to the point where I felt like I didn't have a life"* (Participant 05). Caregivers described feeling overwhelmed, *"But like I said, sometimes you get to that point of that you just want to scream"* (Participant 03) and mentally exhausted, *"It was messing with my mindset because now I'm trying to take care of myself. Got a new baby, trying to take care of my child. Then, I'm trying take care of her and all of this was coming on me and trying to work at the same time. It was a lot. It had me real extremely tired. But in doing what you have to do, somewhere along the way you're going to stop and you're going to sit down and your body is going to be tired, uh, your mind is going to be tired..."* (Participant 06).

While the majority of participants refrained from using *"depression"* or its derivatives, two caregivers admitted to having feelings of depression. *"This is therapeutic for me because not until now that I realize I actually could be considered as being depressed sometimes"* (Participant 06). Participant 05, who indicated early during

the focus group interview that his caregiver experience had been positive, later stated the following, *I knew I was depressed. I didn't want anybody around me. I didn't want to talk to anybody or anything like that because I'm a very social person. So, with that, it never played a factor as far as depression. It's just I got to the point where I questioned myself what if I wasn't doing this, where would I be or what would I be doing* (Participant 05). Having made this statement, however, he immediately retracted it and moderated having feelings of depression.

Three caregivers, two husbands and one son, seemed particularly troubled by the experience. The son of the dialysis patient stated that on a conscious level, he did not feel depressed. However, he further clarified the thought stating, *"Subconsciously, you can be depressed and/or stressed, you can gain weight or it can cause other problems. So, consciously, I don't believe it's affecting me negatively"* (Participant 01).

Although only two caregivers expressly affirmed feelings of depression, other participants spoke freely about feeling angry. One caregiver indicated several times that he was angry with the care recipient because he refused to recognize that he was being injurious to himself. Recalling an incident in which a negative event triggered an angry outburst, another participant spoke of lashing out at hospital staff who administered medication to his wife although they were aware of her allergy to the medication. This disclosure was provided within the context of his going through *"stressful times"* dealing with his wife's illness. *"But, you know, as far as anger, I did lash out real bad you know, with that but you know, during my time with my wife during all her illness, it is stressful at times"* (Participant 04). He seemed to recognize and acknowledge that his outburst was related to the caregiving process as opposed to a single event.

Caregivers expressed frustration related to ensuring that the care recipient was transported to dialysis three times per week, adhering to medication regimens and dietary changes, and keeping the many physicians' appointments. Participants who assisted with home dialysis shared equal levels of frustration as the responsibility of this mode of dialysis often involved strenuous physical exertion, *"Like you've got the 3 different uh... You've got your red solution that she had to use to pull off the weights or she had the green or she had the yellow. She couldn't carry this stuff and if it was down in our basement, I had to bring it to upstairs. Now, keep in mind, I still got to go to work so it kind of had me tired --- not kind of tired but I was tired a lot. Yeah, I was tired. Those boxes --- it had four bags in them and weighed about 20 pounds up and down the stairs, up and down the stairs"* (Participant 06). *"I remember those days,"* recalled Participant 04.

Not only did caregivers manage daily caregiving tasks, dialysis therapy is time consuming. In addition, the dialysis recipient requires recovery time following each treatment. Among the issues that proved to be most troubling and anxiety producing for caregivers was the infections that the patients experienced. Five of the caregivers described the emotional difficulty associated with seeing their loved ones suffer with the infections. *"My wife had it twice, the infection, uh and it's a lot of pain. When you see them going through it, it bothers you extremely bad"* (Participant 06).

**Coping strategies.** The final theme, *coping strategies*, consists of two primary categories, *adaptive* and *maladaptive*. *Adaptive coping strategies* are described as healthy ways of dealing with stress, which involve being aware of stressors and making attempts to reduce their negative outcomes. Adaptive coping strategies used by the participants include exercise, meditation, reading, religiosity, solitary activities, and personal behavior change. *Maladaptive coping strategies* are unhealthy ways of dealing with stress in which an individual seeks to ignore or deny that stressors exist. Caregivers also used maladaptive ways of coping with the stressors of caregiving including avoidance, attempts to change the care recipient, excessive exercise, masking their feelings, and withdrawal. Select subcategories are discussed.

**Adaptive coping strategies.** Caregivers stated use of a variety of adaptive coping strategies when asked, *“What do you do when you're angry, frustrated, tired?”* Meditation and exercise were used as coping strategies. *“Meditating a lot helped me to take a part the negatives and see the positives in it.”* *“That was my mental way of when I see him [his father] go get this Big Mac or a Whopper with fries. First thing, I was like I want to go get a salad and I wanted to go running”* (Participant 01). Another participant found that engaging in solitary activities helped him to cope with the stress of providing care to his three-year old daughter. *“I design websites, design webpages, work on computers, and yes, that is a solitary activity, just like working out is -- it does give me that creative time and that's probably where I do a lot of my better work”* (Participant 03). The two older men in this study, who were both caring for their wives, spoke freely about their use of religion to cope with the stressors and challenges of caregiving. Faith in God strengthened them to meet the demands and difficulties of providing care. *“But, uh, I think my biggest help comes from the Lord though”* (Participant 04). *“I work through it --- through the power of God”* (Participant 06).

**Maladaptive coping strategies.** Caregivers also used maladaptive coping strategies to escape from the frustrations of providing care including *attempts to change the care recipient, masking feelings, and withdrawal*. Participant 01, explaining his desperate attempts to change his father's behavior, humorously stated, *“I can only counsel him so much. You can only take a horse to the water but you can't make it drink. So, I've drug him to the water. I drug him to the lake, the river, the ocean, the Atlantic, and the Pacific, but that man just won't drink.”*

Another participant who was particularly affected emotionally by caregiving circumstances, yet convinced that he must stay strong for the sake of his wife, masked his own feelings, *“It was affecting me extremely bad because I was like, man I don't know how I'm going to deal with this, but I kept going on because I wanted her to see that I was okay and I was strong with it but at the same time when she is away from me, it was messing with my mindset”* (Participant 06).

In addition, caregivers described becoming reclusive and feeling somewhat compelled to withdraw from their social lives because of the demands of caregiving. The



doctor's appointments, dialysis treatments, and surgeries as well as other caregiving responsibilities were tiring and mentally taxing, *"Well, it makes you withdraw because you be tired, you've got other things on your mind. You're thinking about doctor's appointment that you may have to go through or like I said I was going through it when she was having a lot of surgery. That was dealing with my mindset, concerned about her not knowing what the outcome was going to be"* (Participant 06).

## Discussion

The purpose of this study was to use focus group interviews to explore the experiences associated with objective and subjective burden, depressive symptoms, and perceived health in a sample of male caregivers of persons diagnosed with ESRD. The data in previous studies involving caregivers of this population were derived from quantitative measures. This is the first study, to our knowledge, exploring factors contributing to burden, depressive symptoms, and perceived health in male caregivers of individuals with ESRD.

Given what is known about caregiver burden and depressive symptoms in the literature, our findings suggests that the men in this group shared comparable experiences to other caregivers of persons with ESRD. Similar to findings from our previous quantitative study, results of the current study revealed that male caregivers in this population experience significantly increased levels of objective and subjective burden. *Objective burden* defined is the nature of the caregiving tasks, the amount of time spent performing caregiving duties, and the extent to which these responsibilities change the caregiver's life and household. *Subjective burden* involves the emotional responses and mindset of the caregiver toward the caregiving experience. Although the participants did not expressly state that they experienced *burden*, both objective and subjective burden were pervasive throughout the focus group interview. This finding is consistent with research suggesting that men are less likely to report feelings of psychological distress and more likely to imply emotion (Ridge, Emslie, & White, 2011). Each of the caregivers reported some degree of emotional distress related to the caregiving situation, an expected finding as studies well indicate that caregivers experience lower levels of subjective wellbeing and higher levels of stress than non-caregivers (Del-Pino-Casado et al., 2011; Losada et al., 2010). The literature involving caregivers of persons with ESRD reports that this population of caregivers experience a variety of emotional difficulties including anxiety, negative perceived health, and depression (Gayomali et al., 2008).

Caregivers in the current study spoke at length about the effect that caregiving had on their mental state. We found that several factors were associated with caregiver objective and subjective burden and depressive symptoms. Caregivers indicated that physical (e.g., *"...a lot of strain on your body"*) and psychological distress (e.g., *"It was messing with my mindset."*), which we identified in this study as objective and subjective burden, respectively, were directly related to the caregiving role. They further identified factors contributing to their distress including the arduous tasks of home dialysis therapy, debilitating effects of the disease on the care recipient, time consuming in-center and

home dialysis treatments, physicians' visits, and strict medication regimens. Caregivers of persons with comorbid diabetes complications were further burdened by the demands of caregiving, an unsurprising finding because research shows that care recipient comorbidities substantially increased burden in this population of caregivers (Walker et al., 2015). In addition, the unpredictable complications of ESRD such as infections and surgeries were profoundly worrisome for some caregivers.

Although only two caregivers expressly affirmed feelings of depression, other participants spoke freely about feeling anger, which is associated with depression in men (Martin, Neighbors, & Griffith, 2013). In general, caregivers who expressed the greatest physical and psychological distress were also the men who described feeling "*depressed*" or "*angry*". An exception involved the caregiver who described his experience as "*great*", yet later revealed that he too experienced a period of depression.

In general, caregivers expressing the highest burden and depressive symptoms were also the participants who stated that they had experienced a change in their health since beginning the caregiving role. This finding is not surprising as research shows that caregiver burden increases caregivers' risk for compromised mental and physical health (H. Y. Chang et al., 2010). However, it is important to note that demographic factors may also have contributed to changed health status in these caregivers as they were both spousal caregivers and older than other caregivers in the group, a finding consistent with other research indicating that older spousal caregivers perceive worse physical health (Pinquart & Sorensen, 2011).

Research findings suggest that caregivers with positive perspectives about life's circumstances were better able to cope with the challenges and demands of caregiving. Certain personality characteristics including resilience, commitment, and optimism diminish the impact of negative experiences and the harmful effects of stress (Stajduhar, Martin, Barwich, & Fyles, 2008). We too found that caregiver characteristics influenced their perspective on caregiving and affected their psychological wellbeing. The mean age of this sample of caregivers was 43 years. Thus, most of them began caregiving as young adults, a time when life expectations and ambitions are high. Husbands are not expecting to become caregivers for their wives, to assume the maternal role in their child's life, or to lose one-half of their household income. Sons are not anticipating becoming primary caregivers to their parents. These unanticipated life events can make disappointment with the caregiving experience inevitable. However, some caregiver characteristics tend to buffer the negative feelings. One caregiver whose situation was exceedingly difficult commented that he always tried to "*turn negatives into positives*". Thus, although he was unsure about whether he was depressed and admitted to feeling anger and discontent, he used positive coping strategies to overcome the negative feelings. In addition, caregivers who were willing to accept formal or informal assistance fared somewhat better than those who felt they had to take full responsibility for care of the dialysis recipient and refused help from others. Similarly, Chang, Chiou, and Chen (2010) found that social support may buffer the negative effects of caregiving.

Care recipient behavior and caregiver-care recipient relationship also contributed to caregiver burden. Caregivers whose relatives were concerned about their own health as well as the wellbeing of the caregiver reported more positive caregiving experiences. Participants who reported gratifying relationships with the care recipient were also those who implied less burden and depressive symptoms. On the contrary, caregivers whose relationship with the dialysis recipient was somewhat contentious, voiced feelings of greater distress. Those caring for individuals who behaved in unhealthy and detrimental ways expressed greater frustration and used more coping strategies than the aforementioned caregivers. One caregiver repeatedly expressed feeling angry with his father because of his persistent noncompliance with the treatment regimen and childlike behavior. These findings support previous research suggesting that behavioral and psychological behavior of care recipients influenced caregiver burden (Gayomali et al., 2008) and depression (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014)

Other factors cited by caregivers as significant disruptive influences in their social, personal, and financial lives further contributing to their distress included minimal social activities, significantly decreased self-care, early retirement, and financial loss. They also described job difficulties related to supervisors who lacked understanding of the nature of ESRD and the subsequent amount of time needed away from the job to perform caregiving duties.

Previously reported literature indicates that caregivers use both adaptive and maladaptive strategies to cope with chronically stressful situations (Wrosch, Amir, & Miller, 2011). Participants in the current study discussed using coping strategies consistent with these categories. When asked how they coped with the stress associated with caregiving, the majority indicated using adaptive coping strategies such as exercise, meditation, and religiosity. Through the course of the discussion, the PI surmised that some caregivers used maladaptive coping strategies such as avoidance, excessive exercise, and masking their feelings. Only one caregiver reluctantly admitted to becoming angry such that he felt badly about his behavior. Caregivers were unwilling to admit to using less socially acceptable maladaptive coping strategies including the self-destructive behaviors often displayed in men who are depressed (Martin et al., 2013).

### **Limitations and Strengths**

Generalizability of this study is limited because the findings reflect the views of a small group of male caregivers of persons with ESRD. The study is also limited in that the participants are not a homogenous group. The sample consists of caregivers who are husbands, sons, and a father, each of which have differing roles and responsibilities in their relationship to the care recipient. Self-selection bias may also be a limitation. Male caregivers who volunteer for research participation may represent men who are comfortable seeking formal assistance or those who are experiencing severe burden prompting them to seek help. Less represented may be men who do not seek community assistance or those who are not comfortable sharing their emotional distress with others. Thus, generalizing research findings is again limited. Another limitation of the study may

involve social desirability response bias in which participants responded to questions in a socially acceptable way as opposed to with complete honesty. In addition, male caregivers may feel uncomfortable discussing their feelings with a relative stranger, particularly an investigator of the opposite sex. Thus, they tend to underreport psychological distress as may have been the case in this study. Lastly, recruitment of minority male participants for this study was significantly challenging.

Despite limitations, this study has several strengths. This study is innovative because it is the first qualitative study to explore experiences associated with burden, depressive symptoms, and perceived health in men caring for individuals diagnosed with ESRD. A second strength of this study is that it highlights the similarities of comments in this small sample of male caregivers to findings previously published in caregiving literature. Lastly, because this population of male caregivers is understudied, findings from this study provide significant insight into their experiences.

### **Practice Implications**

Study results suggests that male caregivers of persons with ESRD are at risk of negative mental health outcomes. Thus, there are important implications for practice. Practitioners must understand that caregivers are at greater risk of psychiatric morbidity and negative perceived health, which allows for aggressive screening and early identification of these at-risk caregivers. Nurses employed in dialysis clinics and nephrology practices are often the initial point of contact into the healthcare system for ESRD patients and their caregivers. Thus, they may be in the best position to identify at-risk male caregivers and provide practical assistance for anticipated needs. Practitioners must not only recognize this vulnerable population of caregivers early in their caregiving careers, but they must also educate and act as advocates for these men. Caregivers must be educated about ESRD, its complications, and treatments. They must also be provided with educational materials regarding self-care, access to social support networks, and resources for formal assistance.

### **Conclusion**

Despite limitations, our findings, though preliminary, show promising evidence of the importance of exploring burden, depressive symptoms, and perceived health in male caregivers of persons with ESRD. Findings suggests that male caregivers of persons with ESRD experience significant burden, depressive symptoms, and changes in their physical health related to the caregiving role. Our findings also indicate that there is a link between sociodemographic characteristics, caregiver and care recipient attributes, and caregiver-care recipient relationship and caregivers' experience of burden and depressive symptoms. Recognizing that male caregivers of persons with ESRD experience burden and depressive symptoms, suggests the need for further research, including intervention trials to help maintain the health and wellbeing of this hidden population of caregivers.

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## APPENDIX A. MALE CAREGIVER DEMOGRAPHIC FORM



### Mental Health in Male Caregivers of Persons with ESRD

Code: \_\_\_\_\_

#### Male Caregiver Demographic Data Form

**Directions:** Please answer each question by filling in the blank or placing an **X** in the box.

1. What is your age in years? \_\_\_\_\_
2. What is your race/ethnicity?
  - ☐ African American/Black
  - ☐ Caucasian/White
3. What is your marital status?
  - ☐ single, never married
  - ☐ married
  - ☐ divorced
  - ☐ separated
  - ☐ widowed
4. I am the \_\_\_\_\_ of the dialysis recipient.
  - ☐ spouse
  - ☐ father
  - ☐ brother
  - ☐ parent
  - ☐ child
  - ☐ other
5. What is your highest educational level?
  - ☐ less than high school
  - ☐ high school
  - ☐ some college
  - ☐ undergraduate degree
  - ☐ some graduate school
  - ☐ graduate degree



- 6. What is your annual household income?**
- ☐ \$0-25,999
  - ☐ \$26,000-51,999
  - ☐ \$52,000-74,999
  - ☐ more than \$75,000
- 7. What is your current employment status?**
- ☐ full-time
  - ☐ part-time
  - ☐ retired
  - ☐ unemployed
- 8. Has your income decreased since you began providing care?**
- ☐ yes
  - ☐ no
- 9. What is the age of the dialysis recipient? \_\_\_\_\_**
- 10. What is the gender of the dialysis recipient?**
- ☐ male
  - ☐ female
- 11. What is the employment status of the dialysis recipient?**
- ☐ full-time
  - ☐ part-time
  - ☐ retired
  - ☐ unemployed
  - ☐ retired
- 12. How long has the dialysis recipient been receiving dialysis treatment?**
- ☐ less than 1 year
  - ☐ 1 - 3 years
  - ☐ 3 - 5 years
  - ☐ greater than 5 years
- 13. How many hours of care do you provide per week?**
- ☐ 1-10
  - ☐ 11-20
  - ☐ 21-30
  - ☐ 31-40
  - ☐ 41-50
  - ☐ 50 or more



- 14. How long have you been providing care for the dialysis recipient?**
- ☐ less than 1 year
  - ☐ 1 - 4 years
  - ☐ 5 - 9 years
  - ☐ 10 years or more
- 15. How many people do you care for including the dialysis recipient?**
- ☐ 1
  - ☐ 2
  - ☐ 3
- 16. Where does the dialysis recipient live?**
- ☐ with you
  - ☐ at their house alone
  - ☐ at their house with other people
  - ☐ with another family member
- 17. If you do not live with the dialysis recipient, how far do you live from the dialysis recipient?**
- ☐ 1-5 miles
  - ☐ 6-10 miles
  - ☐ 11-15 miles
  - ☐ 16-20 miles
  - ☐ 21 miles or more
- 18. Do you have assistance with caring for the dialysis recipient?**
- ☐ yes
  - ☐ no
- 19. If you have assistance with caring for the dialysis recipient, in what form is this help?**
- ☐ family
  - ☐ friends
  - ☐ paid help
  - ☐ other
- 20. Do you have a history of depression or anxiety?**
- ☐ yes
  - ☐ no

**21. Does someone in your immediate family have a history of depression or anxiety?**

- ☐ yes
- ☐ no

**22. Do you have a history of problem drinking?**

- ☐ yes
- ☐ no

**23. Does someone in your immediate family have a history of problem drinking?**

- ☐ yes
- ☐ no

**24. Do you have a history of drug use?**

- ☐ yes
- ☐ no

**25. Does someone in your immediate family have a history of drug use?**

- ☐ yes
- ☐ no

**26. Have you had any losses over the past year?**

- ☐ death of a loved one
  - ☐ job loss
  - ☐ loss of an important relationship
  - ☐ other (please describe)\_\_\_\_\_
- 

**27. During the past month have you often been bothered by feeling down, depressed, or hopeless?**

- ☐ yes
- ☐ no

**28. During the past month have you often been bothered by little interest or pleasure in doing things?**

- ☐ yes
- ☐ no

**29. Please list any medical problems that you are currently experiencing:**

**30. Please list the medications that you are currently taking:**

**31. Contact person other than someone living with you:**

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

**Please be sure that you have completed all questions on the survey.**



IRB NUMBER: 14-03145-XP  
IRB APPROVAL DATE: 08/11/2014

**APPENDIX B. INSTITUTIONAL REVIEW BOARD APPROVAL FOR  
PILOT STUDY**

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THE UNIVERSITY OF TENNESSEE  
Health Science Center

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Institutional Review Board  
910 Madison Avenue, Suite 600  
Memphis, TN 38163  
Tel: (901) 448-482

March 07, 2015

Loretta Alexia Williams, BSN, RN  
UTHSC - CON - Nursing- Academic Programs  
920 Madison Building

**Re: 15-03732-XM**

**Study Title:** A Pilot Study of Mental Health in Male Caregivers of Persons with End Stage Renal Disease

Dear Ms. Williams:

The Administrative Section of the UTHSC Institutional Review Board (IRB) has received your written acceptance of and/or response dated March 6, 2015 to the provisos outlined in our correspondence of March 3, 2015 concerning the application for the above referenced project.

The IRB determined that your application is eligible for **exempt** review under 45CFR46.102 (f) in that it does not involve 'human subjects' as defined therein. In accord with 45 CFR 46.116(d), informed consent is waived. Your application has been determined to comply with proper consideration for the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects. Therefore, this letter constitutes full approval of your application (version 1.0) for the above referenced study.

In the event that volunteers are to be recruited using solicitation materials, such as brochures, posters, webbased advertisements, etc., these materials must receive prior approval of the IRB.

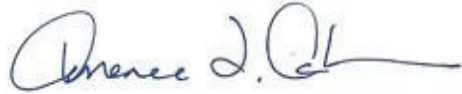
Any alterations (**revisions**) in the protocol must be promptly submitted to and approved by the UTHSC Institutional Review Board prior to implementation of these revisions. In addition, you are responsible for reporting any unanticipated serious adverse events or

other problems involving risks to subjects or others in the manner required by the local IRB policy.

Sincerely,

A handwritten signature in black ink that reads "Donna Stallings". The script is cursive and fluid.

Signature applied by Donna L Stallings on 03/07/2015 03:28:02 PM CST

A handwritten signature in blue ink that reads "Terrence F. Ackerman". The script is cursive and fluid.

Signature applied by Terrence F Ackerman on 03/07/2015 03:29:13 PM CST

Donna Stallings, CIM  
IRB Administrator  
UTHSC IRB

Terrence F. Ackerman, Ph.D.  
Chairman  
UTHSC IRB

**APPENDIX C. INSTITUTIONAL REVIEW BOARD APPROVAL FOR  
MENTAL HEALTH IN MALE CAREGIVERS WITH END STAGE RENAL  
DISEASE**

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THE UNIVERSITY OF TENNESSEE  
Health Science Center

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Institutional Review Board  
910 Madison Avenue, Suite 600  
Memphis, TN 38163  
Tel: (901) 448-4824

April 29, 2015

Loretta Alexia Williams, BSN, RN  
UTHSC - CON - Nursing- Academic Programs  
920 Madison Building

**Re: 14-03145-XP**

**Study Title:** Mental Health in Male Caregivers of Persons with End Stage Renal Disease  
[Award #A141309-001]

Dear Dr. Williams:

The IRB has received your written acceptance of and/or response dated April 20, 2015 to the provisos outlined in our correspondence of April 20, 2015 concerning **revisions** to your previously approved project, referenced above.

The Administrative Section of the IRB determined that your application is eligible for **expedited** review under 45 CFR 46.110(b) (2). The IRB has reviewed these materials and determined that they do comply with proper consideration for the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects. Therefore, this letter constitutes approval of the attached revisions. Approval does not alter the expiration date of this project, which is March 18, 2016.

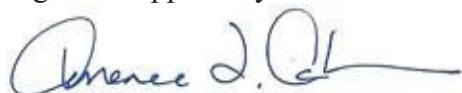
In the event that subjects are to be recruited using solicitation materials, such as brochures, posters, webbased advertisements, etc., these materials must receive prior approval of the IRB. Any revisions in the approved application must also be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subject or others in the manner required by the local IRB policy.

Finally, **re-approval** of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written approval of the IRB.

Sincerely,



Signature applied by Donna L Stallings on 04/29/2015 11:26:12 AM CDT



Signature applied by Terrence F Ackerman on 04/29/2015 11:27:02 AM CDT

Donna Stallings, CIM  
IRB Administrator  
UTHSC IRB

Terrence F. Ackerman, Ph.D.  
Chairman  
UTHSC IRB

Attachment: Revisions

Loretta Alexia Williams, BSN, RN  
Re: 14-03145-XP  
April 29, 2015

1. The study application was updated to version 1.16 to (a) update funding/contract source; (b) update study procedures; (c) update study site to include subject's choice and (d) minor verbiage changes.
2. The inclusion of a newly created consent cover statement for the focus group dated April 20, 2015 [stamped approved by the IRB on April 29, 2015]. **The UTHSC IRB stamped-approved consent cover statement must be used to enroll prospective subjects in the study.**
3. An Inclusion/Exclusion Verification Form, Version 1.0 dated April 6, 2015 and an Interview Guide for Focus Group, Version 1.0 dated April 6, 2015 were attached to this submission [stamped approved by the IRB on April 29, 2015].



## VITA

Loretta Alexia Williams was born in Memphis, Tennessee in 1966. She received her Associate Degree in Nursing from Shelby State Community College in Memphis, Tennessee in 1994. She received her Bachelor of Science in Nursing from Union University in Germantown, Tennessee in 2002. She entered the Ph.D. program at the University of Tennessee Health Science Center in Fall 2011. She has over 21 years of experience in multiple facets of the nursing profession including neurosurgical/surgical intensive care, medical/surgical, psychiatric, and nursing education. She has held various roles within these settings, which include staff nurse, charge nurse, assistant nurse manager, and nursing instructor.

She presented a poster for abstract presentation at the annual Southern Nursing Research Society conference in 2013. She also presented the Keynote Address at the Sigma Theta Tau International Honor Society Induction. She co-authored a book chapter, which was published by Springer Publishing in 2015. She has been a member of Sigma Theta Tau since 2010. In addition to being a Jonas Scholar, she is also a member of the American Nurses Association, the Tennessee Nurses Association, and the Southern Nursing Research Society.

Loretta Alexia Williams received a Doctor of Philosophy in Nursing Science degree from the University of Tennessee Health Science Center in December 2015. Her dissertation research focused on burden, depressive symptoms, and perceived health in male caregivers of persons with end stage renal disease. Currently, she is an instructor at the University of Tennessee Health Science Center in the BSN Nursing program.