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Informal Caregivers' Lived Experiences Caring for a Black Man Receiving Hemodialysis

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Abstract

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MSW, University of South Carolina at Columbia, 2009

BSW, University of North Carolina at Greensboro, 2006

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Numerous quantitative studies have assessed caregiver burden in multiple chronic diseases, but an identified gap and underrepresentation exists in the literature regarding studies using an inductive approach that allow informal caregivers to describe the lived experiences of caring for Black men receiving hemodialysis. The transactional model of stress and coping and the stress process model guided this study. The key research questions centered on the experiences, psychological, physical, and financial limitations associated with caregiving. This phenomenological study used a purposive sample of 15 unpaid primary caregivers over the age of 18 caring for a Black male on hemodialysis from Mecklenburg County. Semi-structured face-to-face interviews were audio-recorded, transcribed, and analyzed for significant themes. The findings indicated majority of the participants experienced psychological reactions, a decline in their physical health, and financial stressors. The participants noticed a change in their loved one and felt caregiving was hard work but found the experience meaningful from a cultural perspective. Although, majority of the participants had family and healthcare providers supported them, they reported the need for additional resources to assist with providing adequate care for their loved one. This study can contribute to social change by providing healthcare professionals with the knowledge to better identify changes in practice necessary to support the needs of informal caregivers. Further research should include implementing informal caregiver support programs, studies addressing the cultural differences and needs of informal caregivers, and the perceptions of Black male patients receiving hemodialysis to address the underrepresentation of Black men in research.

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Dedication

First, I dedicate this dissertation to my Lord and Savior who has been with me every step of this journey. Next, my loving family: my husband, Darrell, and my beautiful daughters, Justice and Lorin, who have supported me throughout these six years and allowed me quality time to complete my “homework” as they call it. It is because of your support and encouragement that I can complete this journey. My days are forever blessed because I have you all as my inspiration. I pray that my studies encourage each of you to have faith that you can achieve whatever you put your mind to.

To my extended family and friends, LaKathy, Marvin, Bernadette, Barbara, Vantisha, and Tish, I thank you for your love and support throughout this journey. Your encouragement, kindness, and prayers supported me through my doctoral journey all the way to the finish line. I hope that I can also support you with your endeavors just as you have supported me.

Finally, to my late mother, Glenda Greene, for instilling the importance of education in me and telling me to never give up on my hopes and dreams. I love you and miss you so much. I hope I have made you proud.

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Chapter 1: Introduction

Introduction

As the U.S. population ages and more individuals are diagnosed with chronic illnesses, the number of caregivers will also continue to rise (Alpert, 2014). Over the years, limited data on the statistics of caregivers has started a growing interest in this population among researchers (Alpert, 2014). The Centers for Disease Control and Prevention (CDC, 2011) reported that 34 million people care for someone over the age of 18 who has an illness or disability. These caregivers can be formal, as in paid, or informal, as in unpaid. Many informal caregivers are family, resulting in informal caregivers providing unpaid care for their loved ones (CDC, 2011). Informal caregivers are present among many domains of chronic illnesses, ranging from Alzheimer's, heart failure, and bipolar disorder; Alzheimer's continues to be the most studied population regarding informal caregiver burden and effects of informal caregiving (Etemadifar et al., 2015; Mioshi et al., 2013; & Perlick et al., 2016).

Informal caregivers are beneficial to the economy and provide social value to their loved ones (Poo & Whitlatch, 2016). Years ago, women were recognized as the informal caregivers due to being unemployed outside the home (Poo & Whitlatch, 2016). However, with the rising number of baby boomers reaching retirement age, over 60% of women work outside the home and continue to resume the role of informal caregiver once they have returned home from work (Poo & Whitlatch, 2016). Today, informal caregivers can be male, female, husband, wife, daughter, son, niece, nephew, or a family friend (Timmerman, 2015). The cost of informal caregiving is estimated to be $450 billion annually (Timmerman, 2015). This amount of economic value continues to be a disadvantage to informal caregivers caring for loved ones in the home (Poo & Whitlatch, 2016).

Informal caregivers are often faced with challenges of financial, psychological, physical, and social strain (Timmerman, 2015). Financially, informal caregivers are presented with the unforeseen costs associated with informal care. Because they are with their loved one most of the time, they must perform the duties of a formal caregiver. This includes spending money to transport their loved one to medical appointments, buying special foods necessary for their loved one’s diet, and taking unexpected time off from work (Jowesy, Strazdins, & Yen, 2016). Psychologically, informal caregivers experience various emotions when caring for a loved one with a chronic illness. Chronic illness can lead to death and informal caregivers are challenged with feelings of fear, grief, worry, stress, and anxiety with having to make major decisions for their loved ones once their end of life nears (Given & Reinhard, 2017).

Psychological stress, which relates to a person’s appraisal system, can lead to physical illness (Gianaros & Wager, 2015). Appraisal systems are encoded and connected to situations and events that an individual find significant (Gianaros & Wager, 2015). Thus, those appraisals that appeared as a threat to one’s physical, social, and personal well-being ignite stress receptors causing increases in blood pressure, which may lead to early onset cardiovascular disease (Gianaros & Wager, 2015). Moreover, when informal caregivers’ health is in jeopardy, their loved one may suffer the consequences as well (Yuda & Lee, 2016). Socially, informal caregivers alter their lifestyles to fit the needs of their loved ones. Often, the informal caregiver must be home with the loved one who needs around-the-clock supervision. All perceived aspects of informal caregiver burden (financial, psychological, and physical) affect informal caregivers' social life (Bakar, Weatherly, Omar, Abdullah, & Aun, 2014). Social isolation and confinement are themes that emerged from a study by Ziegert and Fridlund (2001). When it comes to gender, female informal caregivers express higher burden than men and are in more need of emotional and social support, but male caregivers tend to suppress their feelings of stress due to reluctance to discuss their emotions (Lee et al., 2015; Williams et al., 2016).

Overall, informal caregiver burden is present in all aspects of chronic illness and can affect all involved. In this chapter, I provide a discussion of the background of the research, problem statement, purpose of the research, research questions, theoretical framework for the study, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance. I will include an introduction to the literature review at the end of this chapter.

Background

End-stage renal disease (ESRD) results when the kidneys have reached Stage 5 of chronic kidney disease (CKD; Fresenius Kidney Care, 2016a). At Stage 5, dialysis or a kidney transplant are the only treatment options; individuals who do not choose either of these options could die (Fresenius Kidney Care, 2016a). The two leading causes of ESRD are hypertension and diabetes mellitus (Fresenius Kidney Care, 2016a). Often, these two diseases can be asymptomatic in a patient and the nephrologist diagnoses CKD at a later stage, resulting in ESRD (Fresenius Kidney Care, 2016a). To survive, a patient must initiate hemodialysis treatments, which occur 3 days per week at any given amount of time based on the nephrologist's recommendations (National Kidney Foundation, 2016).

Comorbidities are common in individuals with ESRD, and medical care can be complex and hard to manage (Hain & Sandy, 2013). This often requires informal caregivers to assist with managing medical appointments and providing around-the-clock care (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). The demanding schedule has been identified as a burden because informal caregivers must alter their lifestyle to accommodate the individuals with ESRD (Timmermann, 2015). The informal caregiver may neglect personal needs to ensure the loved one is taken care of, and medical professionals may not be aware of the informal caregiver's feelings or vulnerabilities (Adelman et al., 2014). Once medical professionals recognize that interacting with the informal caregiver is an important aspect of quality of life for both the patient and the informal caregiver, resources can be recommended to ease the impact of the burden for the informal caregiver (Adelman et al., 2014).

Problem Statement

The problem addressed in this study was the limited knowledge of the experiences and perceived burden of informal caregivers who take care of Black male patients receiving in-center hemodialysis. Studies have been conducted assessing caregiver burden for hemodialysis patients, but the underrepresentation of Black men receiving hemodialysis in these studies remains (Chan et al., 2016; Urquhart-Secord et al., 2016). Therefore, the ability to explore racial or ethnic differences for a caregiver caring for a Black man receiving hemodialysis is limited. Black men are faced with various social factors that can become stressful to their livelihood. Black men are more likely to die 7 years earlier than White males and women of all races, and black men are also more likely to be diagnosed with a poorly managed chronic illness (Griffith, Ellis, & Allen, 2013). In addition to a Black man being diagnosed with ESRD, new feelings of fear, sadness, and anger become present with having to depend on a healthcare professional who may not be the same race or gender as them. This could put a great strain on the relationship between the Black man and his caregiver, further affecting both the caregiver and the Black man's quality of life (Norton et al., 2016).

Individuals on hemodialysis report feeling stress, loss of freedom, loss of control, loss of independence, emotional stressors, and physiological factors such as fatigue, muscle cramps, and nausea (Al Nazly et al., 2013). Across populations, informal caregivers of those receiving hemodialysis have reported similar feelings of loss of social life, emotional distress, and physiological stressors (Cantekin, Kavurmaci, & Tan, 2015), but research has yet to capture the experiences specific to caring for Black male patients. Moreover, earlier quantitative studies explored informal caregiver burden, but knowledge of the entirety of the experiences of the caregiver remains limited. Suri et al. (2014) conducted a quantitative survey of the perceptions of hemodialysis patients on the burdens of their informal caregivers and suggested that further research on informal caregiver burden be undertaken. Explorations of informal caregiver burden in informal male caregivers of individuals with ESRD, and of Black female informal caregivers of persons receiving dialysis comprise the limited research on this important subset of informal caregivers (Byers, Wicks, & Beard, 2011; Williams et al., 2016). However, studies remain limited exploring the lived experiences of an informal caregiver solely caring for a Black man receiving hemodialysis.

Purpose

The purpose of this study was to improve the understanding of informal caregiver burden and reveal the lived experiences of informal caregivers caring for a Black man receiving in-center hemodialysis. This research sought to add to the limited knowledge of the lived experiences of individuals caring for a Black man receiving hemodialysis, the effects of informal caregiver burden, and effective interventions to reduce informal caregiver burden and improve an informal caregiver's quality of life. A qualitative, phenomenological design was proper for this study because I ascertained the perceptions of individuals who were informal caregivers of people receiving hemodialysis. I used semi-structured face-to-face interviews that were audio-recorded and transcribed in conjunction with field notes to develop an understanding of the lived experiences of informal caregivers' burden of caring for a Black man receiving in-center hemodialysis.

Research Questions

RQ1: What are the lived experiences of informal caregivers who provide care for a Black man receiving in-center hemodialysis?

RQ2: What are the psychological symptoms that informal caregivers experience providing care for a Black man receiving in-center hemodialysis?

RQ3: What are the physical symptoms that informal caregivers experience providing care for a Black man receiving in-center hemodialysis?

RQ4: What are the financial limitations that informal caregivers experience providing care for a Black man receiving in-center hemodialysis?

Frameworks

The theoretical frameworks for this study was Lazarus and Folkman’s (1984) transactional model of stress and coping (TMSC) and Pearlin et al.’s (1990) stress process model (SPM). This theory is known for evaluating the impact of stressful events on an individual’s coping abilities (Glanz, Rimer, & Viswanath, 2015). TMSC suggests a person and their environment impact their psychological, social, and health well-being (Glanz et al., 2015). There are five concepts of TMSC: (a) primary appraisal, (b) secondary appraisal, (c) coping efforts, (d) outcomes of coping, and (e) dispositional coping styles (Glanz et al., 2015). TMSC will offer guidance on how informal caregivers perceive and cope with stressors in their lives and guide the development of the interview instrument and the analysis of the data.

Pearlin et al. (1990) expanded on Lazarus and Folkman’s (1987) TMSC using SPM. SPM is defined as the different stressors and social factors that impact an informal caregiver’s quality of life over a period (Aneshensel & Avison, 2015). Background and contextual variables, such as age, gender, ethnicity, socioeconomic status, and caregiver history, are recognized as factors that impact a caregiver’s quality of life (Kim et al., 2017; Turner, 2013).

Nature of the Study

The nature of this study was qualitative with a phenomenological approach. I explored the lived experiences of individuals caring for a Black man receiving hemodialysis. To gain an understanding of human behavior, researchers have used the qualitative method to provide a deeper understanding of experiences (Oun & Bach, 2014). The phenomenological approach allowed for an understanding of the meaning of the lived experiences of informal caregivers providing care for Black men receiving in-center hemodialysis (Patton, 2015). I used face-to-face interviews to provide the descriptions of informal caregiver burden through the lived experiences of the informal caregivers. I used the computer software NVivo 12 for inductive data analysis.

Definitions

Caregiving: The humane role of caring for children, the sick, the elderly, the disabled, and the dying (Kleinman, 2015).

Caregiver burden: The response to informal caregiving based on objective burden (time lost, monetary loss) and subjective burden (psychological, social, and physical) (Gater et al., 2014).

End-stage renal disease (ESRD): Determined based on lab values from a nephrologist, the kidney is no longer able to filter toxins out of the body via secretion in urine, so hemodialysis is needed. Other forms of dialysis (peritoneal or home hemodialysis) may be used as well (Fresenius Kidney Care, 2016b).

Formal caregiver: A volunteer or paid individual associated with a formal service provider and has received formal training in caregiving (Family Caregiving Alliance, 2014).

Hemodialysis: The filtering (dialysis) of blood (hemo) outside of the body via an artificial kidney (dialyzer) and then returned to the body (Fresenius Kidney Care, 2016a).

Once the patient has decided to initiate hemodialysis, the patient is connected to the hemodialysis machine via two needles in their access site (arm or leg) or catheter site (upper chest area). Once connected, the tubing from the needles at the access or catheter site connects to a computerized machine that monitors the patient while on treatment based on their prescription. This process is three to four times a week, 3 to 6 hours each time (Fresenius Kidney Care, 2016a).

Informal caregiver: A relative or friend who has a close and personal relationship with a chronically ill or disabled care recipient and aids them (Family Caregiving Alliance, 2014). Informal caregivers do not have formal training.

Patient, loved one, care recipient: An individual who has a chronic illness or disability requiring ongoing assistance daily (Family Caregiver Alliance, 2014). In this study, the patient, loved one, and care recipient is an individual who has a chronic illness and is receiving hemodialysis as a treatment for ESRD.

Physical burden: The change in the health of the informal caregiver. Poor sleep patterns, limited physical function, and impaired mobility are reported by informal caregivers (Yuda & Lee, 2016).

Psychological burden: The perceived effect that informal caregiving has on the informal caregiver. Changes in mood with increased anxiety, worry, and depression are reported by informal caregivers (Given & Reinhard, 2017).

Quality of life: An individual's negative or positive view of their perceived physical and mental health (CDC, 2016).

Social burden: Change in interaction with others outside the home where informal caregivers care for their loved one. Feelings of isolation and confinement are reported by informal caregivers (Bakar et al., 2014).

Assumptions

Assumptions are beliefs that are necessary and are believed to be true but cannot be proven (Simon & Goes, 2013). Exploring perceptions and experiences is essential to understanding the life of an informal caregiver caring for a Black man receiving hemodialysis. The following assumptions guided this study. I assumed that all participants would be truthful, honest, and unbiased to the best of their ability with their responses to the interview questions. I also assumed that a personal relationship existed between the informal caregiver and the care recipient, and informal caregiving resulted in both positive and negative outcomes that impact the informal caregiver and the care recipient.

Scope and Delimitations

The results of this study provided insight into the stress process of the informal caregiver caring for a Black man receiving hemodialysis. The insights gained from this study may assist researchers and healthcare providers in identifying, developing, and implementing resources to assist informal caregivers with managing stress and burden to enhance their quality of life and the quality of life of the Black man receiving hemodialysis. I selected a purposive sample that was delimited to unpaid adult caregivers providing informal care to a Black man receiving hemodialysis within a specific geographic area. Paid formal caregivers were excluded.

Limitations

Limitations are constrictions in a study that may be outside the control of the researcher (Locke, Silverman, & Spirduso, 2007). In qualitative research, the aim is to capture and report a detailed description of the findings (Atieno, 2009). I solely relied on self-reported experiences and perceptions of individuals caring for a Black man receiving hemodialysis. Another limitation of this study is that the findings were limited to the population being sampled and could not be generalized to represent the entire population (Atieno, 2009). I recruited participants through flyers at dialysis clinics, which limited the sample to a specific geographical area.

Significance

This research study provided a greater understanding of the lived experiences of informal caregiver burden for those caring for a Black man receiving in-center hemodialysis. Despite the increased interest in cultural sensitivity and patient-centered care, studies exploring the lived experiences of informal caregivers who care for a Black man receiving in-center hemodialysis remain limited (Brown, Bekker, Davison, Koffman, & Schell, 2016). Researchers have explored informal caregiver burden among informal caregivers of hemodialysis patients outside the United States (Mashayekhi, Pilevarzadeh, & Rafati, 2015). While that research is useful, it does not provide the lived experiences of informal caregivers caring for a Black man receiving in-center hemodialysis.

The incidence of individuals diagnosed with ESRD will continue to rise, and the results from this study will aid in developing culturally based interventions to assist informal caregivers in caring for Black men receiving in-center hemodialysis (Fresenius Kidney Care, 2016a). The positive social benefits of this study will give a voice to this underrepresented population of the hemodialysis community and initiate discussions among healthcare providers about the impact on informal caregivers of caring for a loved one. This study can guide healthcare providers to recognizing caregiver burden in informal caregivers caring for a Black man receiving in-center hemodialysis. I hope that this study will guide healthcare providers with the development of plans of care that include informal caregivers as a part of the treatment plan, referrals to efficient resources, and implementation of effective interventions for informal caregivers to lessen the effects of informal caregiver burden.

Summary

The number of people being diagnosed with CKD and initiating hemodialysis is rising; informal caregivers will be needed to aid their loved ones with navigating the complex healthcare demands associated with ESRD (Kahn et al., 2015; Sajadi, Ebadi, & Moradian, 2017). Hemodialysis patients report feelings of depression, worry, monetary loss, social isolation, and physical limitations (Jonasson & Gustafsson, 2017). These same symptoms are similar in the informal caregiver as well. The life of an informal caregiver is affected due to sudden medical treatments and demanding schedules that interrupt the informal caregiver’s usual lifestyle. Informal caregivers report high social burden when having to care for someone on dialysis (Bayoumi, 2014). They also report feelings of emotional stress and physical symptoms associated with stress (Cantekin et al., 2015; Rutkowski & Rychlik, 2011). However, qualitative studies remain limited on the actual experiences of informal caregiving for Black men receiving hemodialysis. To understand this phenomenon, I performed a study guided by a qualitative phenomenological methodology using TMSC (Lazarus & Folkman, 1984) and Pearlin et al.'s (1990) SPM.

In Chapter 2, I provide a review of the search process for relevant literature on informal caregiver burden in general, social burden, psychological burden, and physical burden on informal caregivers. I present quantitative and qualitative studies on informal caregiver burden in general and in the hemodialysis population. In Chapter 3, I discuss the research methods used in this study to address the research questions to fill the gap in the literature. I also discuss the research design and rationale, role of the researcher, methodology, sample size, instrumentation, selection of participants, data analysis plan, issues of trustworthiness, and ethical procedures. In Chapter 4, I present the specific details of the study including the setting, demographics of the participants, the actual data collected from the interviews, and the results of the study. In Chapter 5, I evaluate the research questions, provide an interpretation of the findings, limitations of the study, implications for social change, and recommendations for future research.

Chapter 2: Literature Review

Introduction

The purpose of this study was to improve the understanding of informal caregiver burden and reveal the lived experiences of informal caregivers caring for a Black man receiving in-center hemodialysis. Despite the increased number of studies related to informal caregivers, studies remained limited regarding specifics on those caring for a Black man on hemodialysis. Studies have found that being an informal caregiver can impose a burden of various emotional, physical, financial, and social stressors (Knowles et al., 2016; Suri et al., 2011; Taylor-Brown, Rosenberg, & McDaniel, 2014). Even though various support services have been identified and implemented across multiple chronic illnesses, specific support services for informal caregivers caring for a Black man receiving hemodialysis remain limited.

Black people continue to have a higher prevalence of developing kidney disease and Black men’s life expectancy was 7 years shorter than women and men of all races, except Native American men (Griffith et al., 2013). Previous studies suggest that further research is needed to address the cultural needs of Black patients as well as their informal caregivers (Cheatham et al., 2008; Griffith et al., 2013). Doing so would allow the effective development of interventions and support programs that would be beneficial and culturally sensitive. Earlier quantitative and qualitative studies explored informal caregiver burden, but knowledge of the entirety of the experiences of the informal caregiver caring for a Black man on hemodialysis remained limited.

Chronic illnesses could occur among any race, age, gender, or socioeconomic status, and they take a toll on the person plagued by the chronic illness. As a result, a chronic illness could hinder the person from being able to perform their activities of daily living, manage medications, and prepare meals (Pearlin et al., 1990). Informal caregivers take on a role they may have little to no experience in to provide the best care possible for their loved one. Researchers have discussed the impact of informal caregivers on the quality of life among hemodialysis patients (Rodrigues de Lima et al., 2017; Shahgholian & Yousefi, 2015; Xie et al., 2016). Caregiving for a loved one on hemodialysis involves transporting the individual to and from dialysis and other doctor appointments, managing medication, preparing meals to ensure that proper diet regimens are being adhered to, and managing medical supplies as needed. An additional task is providing activities of daily living care (Welch et al., 2014). Over the course of time, these tasks can become more demanding and difficult to manage and can result in lifestyle changes for the informal caregiver, including the need to cease employment, and they add the stress of financial burden due to associated expenses.

Literature Search Strategy

I conducted a literature search on informal caregiver burden and chronic illnesses using the multidata base search engine Google Scholar and Thoreau within the Walden University Library website. I used Fresenius Kidney Care’s website, the National Kidney Foundation’s website, and the National Caregiving Alliance’s website as well to seek out relevant literature about informal caregiving and hemodialysis. Key search terms and a Boolean combination of search terms I used were *caregiving, caregiver, caregiver* *burden, chronic disease, hemodialysis, caregiver stress and coping, physical strain, social strain, emotional strain, qualitative and caregiving, phenomenology and caregiving, lived experiences, Black, and Black man.* Using these key terms and a combination of search terms yielded hundreds of articles. I used research studies that met my search criteria and had been published in a peer-reviewed journal between 2008 and 2017.

The inclusion criteria I used to narrow down the literature search included studies written in English, quantitative and qualitative studies published in peer-reviewed journals, studies involving informal caregivers of those with chronic illnesses, and informal caregiver burden of hemodialysis patients. A few studies were conducted outside the United States, but they were included due to meeting the inclusion criteria. There was limited literature on Black patients alone, so I included research focused on various races and ethnicities when reviewing the literature with a focus on whether Black men were participants in the studies. I excluded articles pertained to formal caregiving (e.g., healthcare professionals in a paid setting).

Theoretical Framework

I used Lazarus and Folkman’s (1984) TMSC for this study because this theory has been proven to recognize informal caregiver burden for those providing care for patients on hemodialysis. Stressors can occur when the demands of the individual’s internal or external environment become overwhelming (Lazarus & Folkman, 1984). When an individual is faced with a stressor, the individual will perform primary and secondary appraisals of the stressor. Primary appraisal is when the individual appraises the stressor as harmful, a threat, or a challenge. Secondary appraisal occurs when the individual evaluates if any action could be taken to manage the stressor (Yu, Hu, Efird, & McCoy, 2012). Once a stressor has been identified, the ability to cope with the stressor becomes questioned about how an individual chooses to react (Biggs, Brough, & Drummond, 2017).

Pearlin et al. (1990) expanded on Lazarus and Folkman’s (1987) TMSC using the SPM. SPM suggests that caregiver stress happens over a period, and different social factors can impact the informal caregiver’s quality of life (Aneshensel & Avison, 2015). SPM recognizes background and contextual variables, such as age, gender, ethnicity, socioeconomic status, and caregiver history, as factors that impact a caregiver’s quality of life (Kim et al., 2017; Turner, 2013).

Age. Becoming an informal caregiver can begin at any age. Anderson et al. (2013) found that informal caregivers are more likely to be between the ages of 50 and 64, Black, female, married, and have some college education. Informal caregivers age 65 and older self-report their health as being poorer than informal caregivers age 18–64 (Anderson et al., 2013). Oliveira et al. (2015) found that age played a role in caregiver burden, quality of life, and mental health of informal caregivers. Based on their sample of 300, informal caregivers of children scored higher for depression on the Beck depression inventory, as well as reporting lower caregiver burden than informal caregivers taking care of adults (Oliveira et al., 2015). Informal caregivers of adults had lower scores on their Beck depression inventory but higher scores on caregivers’ burden (Oliveira et al., 2015).

Kim, Spillers, and Hall (2012) investigated background and context variables that impacted an informal caregiver’s quality of life 5 years after the initial diagnosis of cancer for their loved ones. Based on the sample of 1,218 informal caregivers, younger informal caregivers reported a tough time adjusting psychologically compared to older informal caregivers (Kim et al., 2012). Older informal caregivers reported higher physical burden than younger informal caregivers, and income played a role in all age groups (Kim et al., 2012). A similar study conducted by Neri et al. (2012) examined how age and gender affected informal caregivers physically, mentally, and socially. Based on a sample of 176 informal caregivers, those age 65 to 74 years perceived caring for their spouse or loved one stressful, and informal caregivers with lower socioeconomic statuses were more likely to develop depression and experience physical decline and social isolation (Neri et al., 2012). Danilovich et al. (2016) also found that informal caregivers age 50 to 64 years report poorer health than informal caregivers age 18–49. Due to the increasing aging population in general, they also found that informal caregivers lack social support services that help with the physical demands of caregiving (Danilovich et al., 2016).

Gender. Today, there are female and male informal caregivers. Role strain is a secondary stressor that can have a negative impact on how a person performs their informal caregiving duties due to feelings of role overload (Mello, Van Durme, Spruytte, Van Audenhove, & Declercq, 2016). Differences can exist in the way each gender handles caring for a loved one with a chronic illness. For example, Gaunt (2013) examined the role of gender ideologies and how they are judged by men and women in breadwinning and caregiving roles. Based on a sample of 311 (154 men and 157 women), Gaunt found that both men and women used double standards with judging gender role violations. It was those who viewed themselves as egalitarian that had the most difficulty accepting one role is specific to one gender, and traditional individuals felt it was acceptable for women to be the primary caregiver and men to be the breadwinner (Gaunt, 2013). This study shows how stereotypical assumptions should not be made when it comes to caregiving.

Schrank et al. (2016) conducted a study assessing informal caregiver burden of terminally ill cancer patients with a focus on gender differences. Based on the sample of 308 informal caregivers, they found that informal female caregivers experienced emotional burden at a higher rate than informal male caregivers (Schrank et al., 2016). Lim, Ahn, and Ahn (2016) used a multidimensional model to investigate informal caregiver burden of women caring for an older adult with long-term health conditions. Based on 157 women identified as primary informal caregivers, Lim et al. (2016) found that a negative impact was reported the more advanced the needs of the care recipient were and the lower a caregiver’s view of self-efficacy was.

Race and ethnicity. Culture is defined as the traditional behaviors that have been developed by a group of people, race, or given society (Powers & Whitlatch, 2016). There is an underrepresentation of racial and ethnic minorities in research, and such research can help to develop culturally appropriate interventions. Powers and Whitlatch (2016) examined cultural differences and demographics of Black and White caregivers. Based on the sample of 202 informal caregivers, they found both races related their caregiving to religious and spiritual beliefs, but coping patterns were different (Powers &

Whitlatch, 2016). In a similar study, Pharr et al. (2014) examined the cultural perceptions of Asian Americans, Black Americans, Hispanic Americans, and White Americans on caregiving. Based on a sample of 35 informal caregivers, the authors found some commonalities in the perceptions all ethnic groups agreed on with the difficulties of caregiving. However, each ethnic group had distinct cultural norms and beliefs that helped mold their caregiving roles (Pharr et al., 2014).

Siegler et al. (2010) conducted a similar study assessing the psychological responses of caring for loved ones with dementia using the Center for Epidemiological Studies Depression Scale. Based on a sample of 87 (50 White and 37 Black) informal intergenerational caregivers, they found that living arrangements impacted informal caregivers and depressive symptoms (Siegler et al., 2010). Black informal caregivers who lived apart from the care recipient reported fewer depressive symptoms than White informal caregivers, but the findings were reversed when the care recipients lived in the same household as Black informal caregivers (Siegler et al., 2010). Bekhet (2014) conducted a study assessing Black caregivers’ and White caregivers’ psychological and physical well-being related to depression, anxiety, perceived burden, and positive cognitions. Based on a sample of 28 Black and 45 White dementia informal caregivers, Bekhet (2014) found that White caregivers reported higher levels of anxiety, depression, and hostility in comparison to Black caregivers. Black respondents also reported seeing informal caregiving more positively and were more resourceful than White informal caregivers (Bekhet, 2014). Researchers recommend further studies to identify specific factors, such as race, gender, and age, to assess caregiver differences when providing care for a loved one (Bekhet, 2014; Powers & Whitlatch, 2016; Siegler et al., 2010).

Socioeconomic status. Social determinants of health consist of those conditions that individuals are accustomed to. The World Health Organization (WHO, 2017) defined social determinants of health as “the conditions in which people are born, grow, work, live, and age, and the set of forces and systems shaping the conditions of daily life” (para. 1). In reference to chronic disease, social determinants of health are associated with lifestyle, poverty, living and work situation, and socioeconomic status (Cockerham, Hamby, & Oates, 2017). Socioeconomic status has a greater impact on social determinants of health, in addition to stress, social inequality due to racial discrimination, lack of income, and lack of education (Cockerham et al., 2017). These social factors can have positive and negative effects that can influence the biological outcomes of an individual (Cockerham et al., 2017; Norton et al., 2016).

Income and education can have a major impact on an individual’s quality of life (Adler, Glymour, & Fielding, 2016). In relation to informal caregiving, some informal caregivers view caring for their loved one as a stressful second job with no monetary compensation. This could be due to the healthcare system’s demand to follow the rules and regulations of their payor sources, such as the Centers for Medicare and Medicaid Services (Mair & May 2014; O’Hare et al., 2014). Do et al. (2014) also found that income can affect the outcome of the informal caregiver. Based on a review of the behavioral risk factor surveillance system, with a sample size of 74,135 informal caregivers and 216,652 non-caregivers, Do et al. (2014) found that the health of the informal caregivers was not as good as the noncaregivers in the study. Those who were higher in age, had lower incomes, were of non-White race/ethnicity, and had more than one child reported poorer health (Do et al., 2014).

Caregiver history. The amount of time required for caring for a loved one with a chronic illness can have negative effects on an informal caregiver’s emotional, social, and financial well-being (Taylor-Brown et al., 2014). Ahn et al. (2015) studied a sample of 238 patients who had a diagnosis of stroke and had an informal caregiver from October 2013 to April 2014 and found that caregivers’ health status, income, marital relationship, and duration of hospitalization were the main indicators of caregiver burden. Informal caregivers reported they could cope with the initial onset of the stroke, but as time progressed, they experienced a reduction in financial income. This decreased informal caregivers’ social activities and contributed to poor health (Ahn et al., 2015).

Røthing, Malterud, and Frich (2015) conducted a study examining coping strategies and behavior patterns that informal caregivers use to deal with caring for their family member with Huntington’s disease. Based on a sample of 15 informal caregivers, Røthing et al. (2015) found that, with the progression of the disease, informal caregivers reported social isolation and disregarded their needs and wants to care for their loved one. Figueiredo et al. (2014) examined the impact that caregiving has on informal caregivers caring for a loved one with early advanced chronic obstructive pulmonary disease. Based on a sample of 167, the informal caregivers who had been caring for their loved ones with advanced chronic obstructive pulmonary disease reported increased feelings of depression/anxiety than informal caregivers caring for a newly diagnosed loved one with chronic obstructive pulmonary disease (Figueiredo et al., 2014).

Primary and secondary stressors. Primary stressors are objective and relate to the person providing direct care to their loved one. Informal caregivers are the primary individuals to assist their loved ones with their activities of daily living (Kim et al., 2017). This can produce extreme stress for the informal caregiver. Secondary stressors are reactions to the primary stressors and can affect informal caregivers' emotional, physical, social, and financial well-being (Kim et al., 2017). For example, when a patient has been diagnosed with ESRD, the patient is given the options to start home dialysis or in-center hemodialysis. The burden for the patient who begins hemodialysis in-center is minimal (LeBeau, 2013). The patient has paid caregivers who provide care and bear the burden of care. However, when a patient initiates home dialysis, it is the informal caregiver who must bear that burden of caring for the patient (LeBeau, 2013). Even though the patient and the informal caregiver have control over their lives with home dialysis, the burden of the informal caregiver can begin to take a toll (LeBeau, 2013).

Role strain is common for caregivers caring for a patient with a long-term chronic illness. Capistrant et al. (2014) examined how current and long-term informal caregiving affected spouses' risk of depression. The authors conducted a longitudinal study reviewing data from the Health and Retirement Study on married spouses age 50 and older. Spousal caregivers were found to have elevated risks for depression in their current role as well as over the long term (Capistrant et al., 2014).

Mediators of stress. Coping can have positive effects on a caregiver's health and well-being. Coping involves the actions and perceptions individuals use to lessen the impact of stressors in their lives (Yu, Wang, He, Liang, & Zhou, 2015). Individuals can learn to cope on their own and from others. Ineffective coping can lead to informal caregivers' perceiving their role as frustrating and become unable to utilize the appropriate resources (Grady et al., 2016). Social support from other family members and friends plays a significant role in helping an informal caregiver to cope with their stressors (Anderson & White, 2017). Anderson and White (2017) examined the experience of caregiving from an intergenerational family perspective. Based on a sample of 73, Anderson and White found that even though the families and patients were faced with challenges, the family could put all differences aside and form a cohesive bond.

The functions of social support can vary for the informal caregiver. Examples of social support relationships include religion, family ties, occupation, volunteer groups, and the healthcare system. Yu et al. (2015) found that informal caregivers can perceive social support could be positive and negative. Instrumental and expressive support is central to identifying social support resources. Instrumental support consists of types of physical assistance the informal caregiver may have in their network (Nishio, Kimura, Ogomori, & Ogata, 2017). For example, this could be an individual who comes to the caregiver's home and assists them with household chores. Expressive support can also be viewed as emotional support. Expressive support consists of the informal caregiver having someone they perceived as trustworthy, caring, confident, and uplifting (Nishio et al., 2017). For example, Han et al. (2014) found that positive and affectionate support and interactions reduced emotional burden directly and indirectly (Han et al., 2014). Bakar et al. (2014) also found that informal caregivers need social support to assist with caregiving tasks and responsibilities to reduce the outcomes of stress.

Outcomes of stress. The outcomes of stress can include symptoms of depression, anxiety, and other cognitive and physical disturbances that can impose a challenge on the well-being of the informal caregiver (Gianaros & Wager, 2015). Cognitive appraisal links stress psychologically and physically based on meaning and significance to an individual, and cardiovascular issues may arise (Gianaros & Wager, 2015). Trivedi et al. (2013) reviewed data from the Behavior Risk Factor Surveillance System and found that most of the informal caregivers reported good health, mental health, and social support. In contrast, Do et al. (2015) found that when it comes to gender, daughter, and daughter-in-law, informal caregivers report adverse effects on their health.

Literature Review

Due to the limited literature on informal caregiver burden in caregivers caring for a Black man receiving hemodialysis, it was necessary to research findings of other chronic illnesses that provided a similar overview of informal caregiver burden for those with chronic illnesses like ESRD. Al Nazly and Samara (2014, para. 2) defined caregiver burden as, “a multidimensional bio-psychosocial reaction that results from an imbalance of care demands relative to the caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill.” Researchers have conducted studies on caregiver burden caring for loved ones with various chronic illness including multiple sclerosis, Parkinson disease, mental illness, cancer, and chronic heart failure to name a few (Ebrahimi et al., 2017; Katz et al., 2015; Kent et al., 2016; May et al., 2016; Morley et al., 2012).

However, the most current studies included an overrepresentation of caregiver burden in caregivers of Alzheimer’s patients (Martins de Araujo et al., 2017; Gilden et al., 2014; Goren et al., 2016; Koca, Taskapilioglu, & Bakar, 2017; Lebrec et al., 2016; Monin, Schulz, & Kershaw, 2013). The authors found that the informal caregivers in these studies reported similar feelings of sadness, financial strain, fatigue, social withdrawal, and physical decline (Martins de Araujo et al., 2017; Gilden et al., 2014; Goren et al., 2016; Lebrec et al., 2016; Monin et al., 2013).

Grapsa et al. (2014) examined burden in informal caregivers of patients with various chronic diseases. Based on the sample of 73 caregivers’ (43 men and 30 women) feelings of worry, anxiety, and fear of death were reported (Grapsa et al., 2014). The authors also found that the informal caregivers also felt that their patients needed psychological support from them and preferred psychological support from family members and friends, but often refused to accept help from other medical professionals (Grapsa et al., 2014). Vaingankar et al. (2012) conducted a similar study with a larger sample size on informal caregiver burden. The authors found that feelings of worry and embarrassment were reported by the informal caregivers (Vaingankar et al., 2012).

Bahrami et al. (2014) examined caregiver burden of informal caregivers caring for their loved ones with heart failure. Based on a sample of 18 informal caregivers, four themes emerged. The authors found that the informal caregivers reported feelings of emotional stress, physical stress, lack of social support, and incompetence with taking care of their loved one (Bahrami et al., 2014). However, Covelli et al. (2016) found that even though the sample of 216 informal caregivers reported emotional, financial, and physical symptoms, emotional and physical symptoms decreased over time, and financial burden remained the same (Covelli et al., 2016). Onozawa et al. (2016) assessed the impact that early morning off symptoms (EMO) in Parkinson's disease patients had on their informal caregivers. EMO is the delay of medication effects of an individual with Parkinson's disease usually caused by gastroparesis (Onozawa et al., 2016). Based on the sample of 2,205 surveys, the authors found that age, gender, work situation, living situation, relationship to the patient, sense of burden, the experience of EMO, the frequency of EMO, and problems related to EMO affected the informal caregiver (Onozawa et al., 2016).

Hartnett, Thom, and Kline (2016) examined caregiver burden in informal caregivers of women with ovarian cancer using the Caregiver Reaction Assessment. In contrast to previous articles that found caregiver burden to be emotionally and physically stressful, the informal caregivers felt honored to be caring for their loved one and scored higher on economic and financial burden than mental or physical burden (Harnett, Thom, and Kline 2016). Kim et al. (2015) conducted a quantitative longitudinal study examining early caregiving of informal caregivers caring for patients with cancer and examined the caregiver's development of physical conditions over a six-year time span. The authors surveyed a total of 1,517 caregivers after 2 years with follow-ups five and eight years after post-diagnosis (Kim et al., 2015). Stressed caregivers did experience physical health problems. The stressed caregivers had the possibility of developing heart disease, and spousal caregivers were more likely to develop chronic back pain and arthritis (Kim et al., 2015). The authors recommended that HCPs develop and implement stress management programs for patients and their caregivers (Kim et al., 2015).

There was a limited amount of qualitative literature on informal caregivers caring for Black men receiving hemodialysis that existed. Once a patient has been diagnosed with CKD, the individual may require additional support physically, financially, and mentally. Often, informal caregivers are there to support these patients. Hemodialysis patients (HD) have experienced a significant amount of burden they do not mention to informal caregivers or healthcare professionals (HCP). Informal Caregivers and HCPs have played a significant role in assisting the hemodialysis patient improve their symptoms associated with HD. Al Nazly et al. (2013) conducted a qualitative study examining the stressors and coping strategies Jordanian hemodialysis patients used. The patients reported experiencing social isolation, a restricted lifestyle, and dependence on their caregivers (Al Nazly et al., 2013). The patients reported relying on God to cope with their disability as well as rely on their family for support. Their caregivers played a role in assisting the patients around the home and being a support person for them (Al Nazly et al., 2013).

Even though the literature presented in this dissertation speaks about informal caregiver burden in hemodialysis modalities and other chronic diseases, literature on the lived experiences of caregivers caring for a Black man on hemodialysis remain limited.

Racial and ethnic minorities are presented with higher rates of co-morbidities and social disparities of health. The lack of clinical trials continues to hinder implementation of appropriate interventions based on race and ethnicity (Brown et al., 2012). Blacks report discrimination daily and have found themselves engaging in coping mechanisms that will help reduce the stress that discrimination brings.

Himmelstein et al. (2015) conducted a study examining how Black men and women respond to daily discrimination in the Detroit area. Based on a sample of 221, the authors found that Blacks used vigilance coping to mediate the stress that accompanied discrimination. Women and men both reported their stress increased their depression symptoms with the correlation being higher in women. The authors also found that women reported poorer health than men (Himmelstein et al., 2015). The authors suggested that future studies examining discrimination and health should be conducted among different racial and ethnic groups (Himmelstein et al., 2015).

Men, in general, engage in riskier behaviors, are less likely to practice health-promotion, and are not as motivated to attend the doctor like women (Levant et al., 2014). These behaviors contribute to the lower life expectancy of 5.2 years in comparison to women. The concept of manhood consists of the construction of identity obtained through interpersonal relationships and factors. Factors that have been contributed to the masculinity of men are race, ethnicity, and class. However, these factors have been reported as a hindrance by Black men (Griffith et al., 2015). Black men in the United States are faced with racism, segregation, and economic discrimination which can also affect their health (Griffith et al., 2015). Griffith et al. (2015) conducted a study exploring themes that explained how Black men defined their health and manhood. Based on the sample of 73 males, the authors found that the men felt that independence contributed to being healthy, but not necessarily physical health. The men also included having a stable job, attending church, eating well, fulfilling their responsibilities to their families and communities. The men linked being aware of their bodies helped with defining their manhood (Griffith et al., 2015). Role strain is present in the masculinity of Black men and can cause psychological distress; if unrecognized, role strain can be detrimental to men’s health (Griffith et al., 2015).

James and Harville (2015) examined the barriers and motivators to participating in health research of Black men using mobile devices. Based on a sample of 311 Black men, the authors found that younger males were interested in using a health app on their smartwatch and were motivated by incentives to participate. Older men were more open to being educated about a health topic they were interested in, in contrast to younger men declined to participate if the health topic was not of interest to them (James & Harville, 2015). The older men reported that the lack of minority research is a barrier. This study assisted with the gap in literature about the lack of research on the Black man in general. A later study by Cheatham et al. (2008) examined barriers to health care and health-seeking behaviors in Black men. The authors conducted a literature review and found that socioeconomic status, religious beliefs, racism, masculinity, peer influences, and lack of awareness about the need of primary care were barriers identified (Cheatham et al., 2008).

Stress continues to be a factor for Black men and studies that describe their experiences remain limited (Ellis et al., 2015). Black men are aware of how stress can hinder their independence, but not the physical harm it can cause to their bodies (Griffith et al., 2015). Ellis et al. (2015) conducted a phenomenological study on 150 Black men and 77 Black women examining the perspectives Black men had on stress and coping and the perceptions of Black women who observed how Black men viewed stress. The authors found that the men could identity coping mechanisms when having stressed feelings, but not all stressful situations required coping (Ellis et al., 2015). The women in the study reported having a different perception of the men's coping behaviors, but they both could identify the emotional, physical, and social consequences of stress (Ellis et al., 2015). This study was ideal in identifying the gap in the literature because there continues to be limited literature on the perceptions of Blacks in general and a further gap exists in exploring the lived experiences of caring for a Black man on hemodialysis.

Qualitative studies. Welch et al. (2014) conducted a qualitative study on 21 caregivers examining their lived experiences of caring for a loved one on home hemodialysis. The caregivers were given interviews via telephone answering five open-ended questions regarding their experiences and recommendations (Welch et al., 2014). The authors found that the caregivers were well educated by the nursing staff on how to assist their loved one with initiating dialysis in the home, but they felt that the day to day operations of being the primary caregiver were overwhelming for some (Welch et al., 2014). The caregivers could have support services from the staff 24/7 and reported feeling at ease with that available resource. Other types of burden the caregivers mentioned were financial strain, feelings of helplessness, and depression (Welch et al., 2014). A limitation of this research was that the sample size of Black men receiving home dialysis was five compared to 14 White and one Asian. The authors suggested that there is a need to perform more longitudinal and diverse studies to further examine needs and concerns of caregivers of hemodialysis patients (Welch et al., 2014).

O’Hare et al. (2017) conducted a qualitative study examining the lived experiences of informal caregivers caring for patients with CKD. A total of 17 caregivers were interviewed between April 2014 and May 2016. The authors found that three themes emerged from the interviews. The caregivers felt that their role as caregiver was shaped by the patient’s illness and willingness to have them involved in their care, their care was also shaped by the healthcare system needs, and there was increased tension among the patients and the healthcare system (O’Hare et al., 2017). The caregivers felt that the healthcare system would overlook them when it comes to making delicate decisions about their loved ones as well as sometimes feeling forced to convince their loved ones to accept a certain form of treatment (O’Hare et al., 2017).

Feldman et al. (2013) conducted a qualitative study on burdens that HD patients face, how to improve those burdens, HCP attitudes towards palliative care for HD patients, and perceptions of kidney transplant. The authors interviewed 34 HCPs (eight physicians, two nurse practitioners, four social workers, 13 registered nurses, and seven patient care technicians), and 20 caregivers (15 informal and five formal). The study took place in New York City from June to October 2012 in three outpatient HD clinics (Feldman et al., 2013). The authors found that all the participants felt that the HCPs were unaware of the HD patient’s symptoms, HCPs were uncertain of who is to treat the symptoms, and had trouble providing symptom management (Feldman et al., 2013).

Rodrigues de Lima et al. (2017) conducted a qualitative study examining the perceptions of family members taking care of a hemodialysis patient in northwest Brazil. The authors interviewed a total of eight informal caregivers and found that the informal caregivers were knowledgeable on how to care for the patient. They also found that the informal caregivers reported feelings of social, financial, psychological, and health stressors that hindered them from effectively taking care of their loved ones (Rodrigues de Lima et al., 2017). Rabiei et al. (2016) conducted a qualitative study examining the lived experiences of caregivers caring for a patient on HD in Iran. Based on a sample of twenty informal caregivers, the authors found that the informal caregivers reported feelings of uncertainty, frustration, worry, feelings of hopelessness, and social isolation (Rabiei et al., 2016). However, the informal caregivers did report using spirituality to cope with their duties and felt that they "must" adhere to the principles of their Muslim traditions (Rabiei et al., 2016).

Kidney transplantation remains lower among Blacks than Whites, and racial disparities have been documented (Browne et al., 2016; Milgore et al., 2016; Wachterman et al., 2015). Wachterman et al. (2015) suggest that the lack of research on Blacks and kidney transplantation count for the lower number of kidney transplants in the Black community. However, what they found was that Blacks were indeed interested in kidney transplantation, but they had concerns about the process of kidney transplantation, equity organ allocation, and discordance between the patient and the transplant center regarding their status on the transplant list (Wachterman et al., 2015). A similar study by Salter et al. (2015) suggested that Blacks were less likely to be referred for kidney transplants due to time of dialysis initiation. Based on a sample of 36 Black adults, the authors found that females and older males reported better experienced with hemodialysis. Younger males felt social isolation from their family and friends.

Overall, all the participants felt they were treated poorly by the healthcare staff and not educated enough on the kidney transplantation process (Salter et al., 2015).

Surprisingly, Black male hemodialysis patients have a lower mortality rate than White male hemodialysis patients, but there continues to be low representation of Black male patients in health research (Kovesdy et al., 2013).

Quantitative studies. Quantitative studies assessing informal caregiver burden collect data via Likert scales, but the lived experiences or narratives of the informal caregiver remain limited. As mentioned previously, there is an overabundance of quantitative studies that were conducted outside of the United States, but informal caregiver burden did not vary much from the United States. For example, Washio et al. (2012) conducted a quantitative study investigating what factors are identified in informal caregivers of hemodialysis patients in northern Japan. Based on a cross-sectional study on 108 pairs of hemodialysis patients and their informal caregivers, the authors found that informal caregivers who reported heavy burden were often the spouse of the hemodialysis patient, suffered a chronic medical condition, and provided more time physically and financially (Washio et al., 2012).

Avşar et al. (2015) conducted a quantitative study on burden, anxiety, depression, and sleep quality on informal caregivers of hemodialysis patients compared to caring for patients who had renal transplants in Turkey. Based on a sample of 133 informal caregivers (68 for those on HD and 65 for those with renal transplants) the authors found that informal caregivers who cared for patients that received HD had higher rates of depression and anxiety, poor sleep quality, and caregiver burden than caregivers of patients with renal transplants (Avşar et al., 2015). In a similar study, Al Wakeel and Bayoumi (2016) examined caregiver burden between HD and peritoneal dialysis (PD) informal caregivers in Saudi Arabia. Informal caregivers of HD and PD patients were surveyed over the course of one year. The authors found that socio-demographics played an influential role in this study. Female informal caregivers were dominant in HD and PD, the informal caregiver's age played a part in higher caregiver burden in both HD and PD, but overall, caregiver burden for informal caregivers was higher in PD compared to HD (Al Wakeel and Bayoumi, 2016).

Financial burden is another caregiver stressor and has also been reported as a cause of depression in (Sezer et al., 2013). Walker et al. (2016) examined the perspectives of patients and caregivers and economic considerations when choosing a modality for dialysis in New Zealand. The authors gathered patients' and caregivers' perceptions of what financial stressors they experienced with different dialysis modality choices (Walker et al., 2016). Caregivers and patients reported financial losses and gains with choosing a dialysis modality (Walker et al. 2016). The caregivers and patients reported choosing home dialysis due to the flexibility of being able to work, but over time the costs of home dialysis became a burden due to hidden costs. Those who chose in-center hemodialysis were content with not having to pay a higher power bill due to the increased chance of anemia, which makes the patients cold (Walker et al., 2016).

Taylor et al. (2016) felt that a peer support group for CKD patients and their caregivers would be useful, but they were unsure of how patients and caregivers felt about peer support programs. The authors interviewed 26 patients and their caregivers, examining their preferences and expectations of a formal support group (Taylor et al., 2016). The authors found that the patients and caregivers were skeptical of a formal support group due to limited understanding of peer support and lack of emotional readiness (El-Melegy et al., 2016). This study allowed the authors to gain a better insight into what would be useful to patients and caregivers regarding a peer support program (El-Melegy et al., 2016). Ghane et al. (2016) examined the effectiveness of problem-focused coping strategies on caregiver burden with Iranian caregivers. Half of the caregiver participants received the intervention, and half did not (Ghane et al., 2016). The authors introduced the intervention to the participants and found that baseline caregiver burden scores did not differ between the intervention group and the control group (Ghane et al., 2016). However, the authors did find caregiver burden decreased in the group with the intervention and participants ended up having significantly different scores at the end of the study (Ghane et al., 2016).

Jadhav et al. (2017) examined psychiatric morbidity, quality of life, and burden in hemodialysis patients and their caregivers in India. The authors implemented the ZBI to assess the informal caregiver’s burden (Jadhav et al., 2017). An interesting finding in this study was that a high number of male patients were represented in the study. Men allocated to 68% of patients, while women made up 62% of caregivers (Jadhav et al., 2017). Those patients with a psychiatric diagnosis had a lower QOL score, and caregivers reported increased burden in caring for patients with a psychiatric illness (Jadhav et al., 2017). This study also had limitations due to the lack of diversity in the sample size. The authors recommended the development of support groups that benefited both the patient and the caregiver (Jadhav et al., 2017).

Summary

Informal caregivers have played a significant role in the life of individuals with chronic illnesses. However, caring for a loved one with a chronic illness can have adverse effects on the informal caregiver. A review of the literature identified many recurring themes related to informal caregiver burden. The main themes that emerged from this literature review were that informal caregiver burden could cause psychological distress, financial distress, social isolation, and affect physical well-being. The TMSC and SPM were the models of framework used to study the informal caregivers' experience related to background and context, primary and secondary stressors, mediators of stress, and outcomes. Even though the studies from the literature review discovered how informal caregiver burden effects the informal caregiver caring for a loved one with a chronic illness, limited studies were found involving informal caregivers caring for a Black man on hemodialysis independently.

Furthermore, Black men continue to have higher incidences of the two main causes of ESRD which are hypertension and diabetes, and there is limited literature understanding the Black man and health disparities in general (Bruce, Griffith, & Thorpe Jr., 2015; Veenstra, 2013). The ESRD population will continue to grow over the years, and the need for guidance, training, and support for informal caregivers will assist in changing the outcomes of stress (Nobahar & Tamadon, 2016). There seems to be a gap in the literature for qualitative phenomenological research about the lived experiences of caring for Black man on hemodialysis. Quantitative and qualitative studies have been conducted providing very useful information regarding informal caregiving and chronic illness, the need for more studies examining the lived experiences of caring for a Black man on hemodialysis will assist in developing culturally sensitive interventions to assist the informal caregiver caring for a Black man on hemodialysis. Based on the literature review, this research proposed to employ a qualitative method design to address the research questions outlined in Chapter 1. In the next chapter, I will discuss information about the research methods used in this study to address the research questions to fill the gap in the literature.

Chapter 3: Research Method

Introduction

The purpose of this study was to improve the understanding of informal caregiver burden and reveal the lived experiences of caregivers who are caring for a Black man receiving in-center hemodialysis. I explored the background and context variables of primary stressors and secondary stressors that influence informal caregivers emotionally, physically, and financially. I explored the mediators of coping and support, identifying how informal caregivers cope with informal caregiving and their experiences and opinions about their social support network. Lastly, I explored how these background and context variables influenced the informal caregiver’s quality of life emotionally and physically.

In this chapter, I outline and explain the research design, the rationale for the research design, and the research questions. I include the role of the researcher, addressing any personal or professional relationships of the researcher with the participants. I discuss biases and ethical concerns and justifications for the use of incentives. I discuss methodology, the process of recruiting participants, the number of participants, and the relationship between saturation and sample size. I also discuss instrumentation, procedures, data analysis plan, and issues of trustworthiness.

Research Design and Rationale

The following research questions were addressed in this study:

RQ1: What are the lived experiences of caregivers who provide care for a Black man receiving in-center hemodialysis?

RQ2: What are the psychological symptoms caregivers experience providing care for a Black man receiving in-center hemodialysis?

RQ3: What are the physical symptoms caregivers experience providing care for a Black man receiving in-center hemodialysis?

RQ4: What are the financial limitations caregivers experience providing care for a Black man receiving in-center hemodialysis?

Other qualitative approaches that could have been used for this study include a case study approach and an ethnographic approach. Case studies consists of in-depth understandings of individuals, small groups, or organizations over a longer period of time (Creswell, 2013). This was not ideal for this study due to my focus on the lived experiences of caring for a Black man receiving hemodialysis. Ethnography consists of studying a specific culture examining the shared patterns of the group (Creswell, 2013). This was not ideal for this study either because the race, ethnicity, or culture of the volunteer participants were the focus of the study. Phenomenology originated in Germany by philosopher Edmund H. Husserl who wanted to study how individuals described their experiences through their senses (Patton, 2015). He felt that sensory experiences of a phenomenon must be defined, explained, and understood (Patton, 2015). For my study, I chose a phenomenological approach because I wanted to explore the phenomenon subjectively, hearing actual words from the caregivers rather than viewing statistical data in a quantitative design.

Role of the Researcher

My role as the researcher in this qualitative phenomenological study was to reveal the lived experiences of informal caregivers caring for a Black man on hemodialysis. As the primary investigator, I acknowledged that I have been employed in the field of hemodialysis for approximately 6 years. However, the results of this study will not be used for company purposes. I have provided indirect care to in-center hemodialysis patients at various facilities in Mecklenburg County, Alexander County, and Catawba County. I am currently employed by one of the largest dialysis companies in the world as a renal social worker. Although I do not provide direct patient care, I do have frequent interaction with hemodialysis patients.

Nonetheless, I have minimal contact with their caregivers because the patients can speak for themselves and manage their own care. I do not plan to collaborate with the caregivers associated with previous clinics where I have been employed. I am not required to contact a caregiver unless there is concern about the well-being of the patient or if the patient informs me to contact their caregiver to relay information to them. I plan to use my professional experiences to gain an understanding of this population and their experiences. I do not have any personal relationships with the participants in the study. To ensure credibility of this study, I will control biases by being meticulous in my record-keeping and developing an interview protocol that ensures the participants meet the aims of the study (Noble & Smith, 2015; Smith & Noble, 2014).

Participants

The participants being recruited for the study had to be an informal caregiver of a Black man, 18 years or older, receiving in-center hemodialysis. My plan was to gather a purposive sample of 15–20 individuals who self-identify as informal caregivers of a Black man receiving in-center hemodialysis. I determined saturation when the responses of the participants did not add additional data to the study and similar responses were repeatedly seen (Nelson, 2017). Participants were recruited voluntarily via flyers I posted in clinics after I received approval from the medical director and clinical manager of the clinics. The flyer included my phone number to call for more information on the study. The participants had to be a caregiver of a Black man receiving in-center hemodialysis for at least 6months, 18 years of age at the time of the study, and their loved one had to be currently receiving hemodialysis at one of the facilities in Mecklenburg County, North Carolina. Once I made initial contact, I gave potential participants more information about the study and confirmed that they met the eligibility requirements. After their eligibility was confirmed and they agreed to participate in the study, I met the participant in person or mailed out a packet with detailed information of the study to reiterate what was discussed via the phone. I included informed consent in this packet and instructions on how to contact me with any questions. If the participant did not return the informed consent form in person, a self-addressed stamped envelope was included in the packet.

When I received the signed consent forms, I scheduled face-to-face interviews with the participants in a place that ensured privacy and confidentiality. The interviews were recorded via an iPad and tape recorder that only I had access too. Once the interviews were completed, I immediately transcribed the interviews verbatim and included my handwritten notes to ensure that all data were analyzed.

Instrumentation

I conducted face-to-face semi structured in-depth interviews that lasted between 30 and 60 minutes. These semi-structured in-depth interviews were audio recorded and included open-ended questions developed using the literature, experience, and theory that guided this study. The questions allowed for elaboration on the topic, and I adapted and added additional probes to clarify what the participant was saying. All the questions were researcher developed and included limited demographic questions about age, gender, ethnicity, socioeconomic status, and caregiving history.

To ensure content validity, I conducted a pilot study asking the questions I planned to ask participants. I used the first two interviewees who met the inclusion criteria as participants for the pilot study. I asked the intended questions and evaluated if the questions were clear, easy to understand, and if the responses were relevant to answer the research questions. Based on the responses, I made revisions as needed. If no changes were suggested, I used the data as part of the study data.

Recruitment Procedures and Data Collection

The data was collected from face-to-face interviews from the participants. Participants were recruited via flyers at three clinics in Mecklenburg County, North Carolina. Depending on the participant’s preference of the location to be interviewed, I ensured that the participants were safe and comfortable. I was the only researcher involved in this study; therefore, I conducted 100% of the interviews. I planned to limit the interviews to thirty minutes to eliminate participant fatigue. I provided the participants with my contact information. The contact information included my email address, phone number, and other ways to contact me cost-free in case they had questions or concerns after the interview. I obtained the contact information of the participants as well to be able to contact if I needed clarification of the data obtained. I also informed the participants that there would be no further contact with them once the data collection period has ended. Due to the study being voluntary, the participants were informed that a $20 gas card would be provided upon completion of the interview due to the participants taking the time to participate in the study.

Data Analysis Plan

After the completion of all interviews, I organized the data by transcribing the interviews and sorting the information into categories (Creswell, 2009). I reviewed the data to gain a general understanding of the data that had been collected. Next, I begun coding the data. Creswell (2009) states, "coding is the process of organizing the material into chunks or segments of text before bringing meaning to information" (p. 186). NVivo is the analytic software to assist in coding the data as well as finding themes.

Issue of Trustworthiness

In qualitative research, validity must be present throughout the study. This includes choosing valid research questions, using the appropriate methodology to answer the research questions, ensuring the research design is valid for the methodology, the use of the appropriate sample and data analysis, and the results are valid for the sample (Leung, 2015). To ensure the credibility of the data, I built the trust of the participants by being open, honest, and non-judgmental when speaking with the participants allowing them to feel comfortable enough to share their individual experiences. I made every attempt to obtain a variety of participants to give a broad picture of the lived experiences of caring for a Black man receiving hemodialysis. Triangulation of different data sources allowed the ability to justify and establish themes from the participants (Creswell, 2009 p. 191). To assure that I understood the answers, I repeated the responses back to the participants for accuracy confirmability.

Ethical Procedures

To conduct this research study, I obtained approval from the Fresenius Kidney Care Institutional Review Board and Walden University's Institutional Review Board (Approval Number 07-18-18-0185858). The participants who volunteered in the study had to be 18 years old at the time of the study. Once those approvals were received, informed consent was obtained from the participants informing them that they could withdraw from the study at any time without penalty. Minimal risk of emotional and mental distress and questions that could be difficult to answer was disclosed to each participant. Confidentiality was maintained by assuring the participants that their actual names would not be used when being audio-recorded. I had the only access to all audio recordings, field notes, and transcriptions. All nonelectronic items were locked in a file cabinet and all computer files were password-protected with additional back-up storage. The data will be destroyed after 5 years.

Summary

This qualitative design used a phenomenological approach to guide the framework for this study allowing this researcher to capture the experiences of the caregiver caring for a Black man receiving hemodialysis, including the possible presence of caregiver burden. This chapter presented the research design and rationale, role of the researcher, sampling and methodology, instrumentation, data collection, and data analysis plan that was conducting the study of the caregivers caring for a Black man receiving hemodialysis. In Chapter 4 I will present the specific details of the study including the setting (s), demographics of the participants, the actual data collected from the interviews, and the results of the study.

Chapter 4: Results

Introduction

The purpose of this study was to improve the understanding of informal caregiver burden and reveal the lived experiences of informal caregivers caring for a Black man receiving in-center hemodialysis. Studies have been conducted assessing caregiver burden for hemodialysis patients, but the underrepresentation of informal caregivers caring for Black men receiving hemodialysis in these studies remain present (Chan et al., 2016; Urquhart-Secord et al., 2016). Therefore, the ability to explore racial or ethnic differences for a caregiver caring for a Black man receiving hemodialysis is needed. In this chapter, I discuss my findings from 15 semi structured interviews with caregivers caring for a Black man on in-center hemodialysis. I used open-ended questions to gather data on the lived experiences and various stressors, such as psychological stressors, physical stressors, and financial stressors. These open-ended questions were developed to draw out answers based on the four research questions that framed this qualitative study. In this chapter, I go into further detail about the demographics of the participants, data collection process, data analysis process, evidence of trustworthiness, and themes identified in the study. The research questions used to guide the study were:

RQ1: What are the lived experiences of informal caregivers who provide care for a Black man receiving incenter hemodialysis?

RQ2: What are the psychological symptoms that informal caregivers experience providing care for a Black man receiving incenter hemodialysis?

RQ3: What are the physical symptoms that informal caregivers experience providing care for a Black man receiving incenter hemodialysis?

RQ4: What are the financial limitations that informal caregivers experience providing care for a Black man receiving incenter hemodialysis?

Pilot Study

After Institutional Review Board approval from Walden and Frenova, I conducted a pilot study and data collection. Pilot studies are conducted on a small number of participants to evaluate a research instrument for validity (Dikko, 2016). A researcher can detect flaws in the research instrument and have an opportunity to adjust (Dikko, 2016). I conducted a pilot study using two participants who were caregivers caring for a Black man receiving incenter hemodialysis. I scheduled interviews according to the availability of each participant. I reviewed the informed consent with the participants and answered any questions before signing the consent form.

Both participants consented to audio recording during their interviews. The pilot allowed me the opportunity to evaluate the reliability and validity of the interview questionnaire. It also allowed the opportunity to assess if the interview questions were in proper alignment with the research questions and determine the need for revisions. The participants did not recommend any revisions after completing the interviews. Because there were no revisions recommended, I included their responses in the analysis and results of the study.

Research Setting

This research study took place in three in-center hemodialysis clinics in Mecklenburg County, North Carolina. I distributed a total of 12 flyers (Appendix A) in the lobby of the three clinics. Potential participants approached me as I posted flyers and canvassed the lobbies to ensure the flyers were visible. I used a prescreening questionnaire to assess eligibility based on questions of age, competence, proficiency in speaking English, their role as the informal caregiver for a Black man on in-center hemodialysis, and their relationship to the Black man. I informed participants that their names would not be used and would be replaced with pseudonyms.

I identified the settings for the study based on the purpose of the study. I looked for dialysis clinics that had a census of over 60 patients. The clinics were in busy areas close to bus lines and light rail. The clinics also allowed for flexibility in conducting the interviews due to the different hours, ranging from 4:30 a.m. until 11:00 p.m. I was able to use multiple rooms in the clinics, ranging from vacant offices and conference rooms. These rooms had comfortable chairs, a table, and a door for privacy. I was able to put a “do not disturb” sign on the door in case staff were not aware that an interview was in process. There were public libraries close to the clinics as well that had more than enough rooms to use that were private and quiet.

Demographics

The study participants consisted of 15 informal caregivers caring for a Black man receiving in-center hemodialysis. I used purposive sampling to select the participants based on their knowledge of the phenomenon. After I identified additional criteria, I developed a demographic questionnaire to collect descriptive information about the participants. The demographic data collected included the caregivers’ age, gender, race, relation to the Black man receiving in-center hemodialysis, marital status, education level, employment status, and annual income (see Table 1). Other self-reported demographic data I collected were inquiries about a decrease in income; self-reported physical health status; chronic illness; length of time as a caregiver; place of residence; social, financial, and emotional support; and inquiry of caregiving to others besides the Black man receiving hemodialysis (see Table 2).

The participants consisted of 14 women with an age range of 24–79. There was one man who was 38 years of age. The participants’ relationships with the Black man receiving in-center hemodialysis consisted of wives, sisters, a niece, a granddaughter, and friends. All participants identified as Black except for two participants, who identified themselves as White and Hispanic. Three participants had a high school ddiploma, two had completed a certificate program, two had completed some college, three completed an associate’s degree, two completed a bachelor’s degree, two had completed a master’s degree, and one had completed a doctoral degree. Ten participants were married.

Ten participants reported a decrease in income due to the participants currently being unemployed. Five participants did not report a decrease in income. Eight participants reported having a chronic illness. Six participants rated their health as excellent, eight rated their health as good, and one rated their health as fair. The average length of time as a caregiver across participants was 11.8 years, ranging from 4 to 24 years. Thirteen participants lived in the same home as their loved one and two did not. Eleven participants cared for someone else, and 11 reported having social support.

Table 1

Demographic Information

Participant	Age	Gender	Race	Relation	Highest education level	Marital status
Mary	70	F	B	Wife	Doctorate	Married
Ann	64	F	W	Wife	Certificate	Married
Sarah	79	F	B	Wife	Associate’s degree	Married
Judy	52	F	B	Friend	Diploma	Single
Bernice	61	F	B	Sister	Associate’s degree	Married
Tara	53	F	B	Wife	Master’s degree	Married
Jean	54	F	B	Friend	Certificate	Single
Lisa	61	F	B	Wife	Associate’s degree	Married
Shonda	39	F	B	Niece	Master’s degree	Single
Tisha	64	F	B	Wife	Diploma	Married
Missy	24	F	B	Granddaughter	Some college	Single
Jose	38	M	H	Friend	Diploma	Single
Veronica	45	F	B	Wife	Bachelor’s degree	Married
Robin	42	F	B	Wife	Bachelor’s degree	Married
Marie	45	F	B	Sister	Some college	Married

Table 2

Additional Demographic Information

Participants	Decrease in income	Physical health rating	Chronic illness	Time as caregiver	Live in the home	Care for another	Social supports
Mary	Y	Good	Y	10	Y	Y	N
Ann	Y	Good	N	9	Y	N	Y
Sarah	Y	Fair	Y	13	Y	N	N
Judy	Y	Good	Y	21	N	Y	Y
Bernice	N	Excellent	Y	20	Y	Y	Y
Tara	N	Excellent	N	10	Y	N	Y
Jean	Y	Excellent	N	21	Y	N	N
Lisa	Y	Excellent	N	20	Y	Y	Y
Shonda	N	Good	N	4	N	Y	Y
Tisha	Y	Good	Y	6	Y	N	Y
Missy	Y	Excellent	N	10	Y	Y	Y
Jose	N	Excellent	N	5	Y	N	N
Veronica	N	Good	Y	13	Y	N	Y
Robin	Y	Good	Y	10	Y	Y	Y
Marie	N	Good	Y	5	Y	Y	Y

Note. Time as caregiver is in years

Data Collection

Sampling Strategy and Sample Size

Before I could engage in the data collection, I obtained Institutional Review Board approvals from Walden University and Fresenius Kidney Care were obtained. Fresenius Kidney Care's Institutional Review Board division named Frenova were the governing body over the approval to post the flyers in the clinics (see Appendix B). Neither clinical managers nor medical directors aided in my recruitment of participants. Their role was to function as points of contact when I needed to use a private office for interviews. The sample included a purposive sample of 15 participants who met the inclusion criteria based on the eligibility prescreening questionnaire (see Appendix C).

Interviews were in private, and participants were asked open-ended questions that were audio recorded.

Interview Process

Once an informal caregiver indicated interest in participating in the study, I discussed a time and place to review the prescreening questionnaire to determine eligibility, review the informed consent, sign the informed consent form, and record the interview. I conducted all the interviews in a private room at the dialysis clinics based on the time negotiated between the participant and me. The maximum time allotted for the interviews was 60 minutes. The 60-minute time frame allowed me the opportunity to review the informed consent forms and answer any questions from the participant. The time for the interviews ranged from 17 to 45 minutes.

During the interviews, I asked the participants open-ended questions pertaining to the research questions. I established rapport with each participant by going over the informed consent in detail, allowing them to ask questions freely, and providing them with a comfortable environment. Once the participants informed me they were comfortable to proceed with being audio recorded, I proceeded with the interviews. All questions in the interview format were asked, and based on the responses from the participants, additional questions were asked for clarification so participants could provide more details of their experiences (see Appendix D). Upon completion of the interview, I thanked participants for sharing their experiences and gave them their $20 Target gift card.

Evidence of Trustworthiness

I established the credibility of this study by audio recording the interviews and using these interviews to transcribe participants’ responses accurately. Clarity was confirmed as needed during the interview, and I reviewed my notes taken during each interview. Transferability of the study was done by providing a detailed outline of the research method, data collection process, and results from the data collected. Dependability was accomplished in the study via the pilot study consisting of two caregivers who reviewed the interview questions and provided feedback. I was able to accomplish confirmability through triangulation and a detailed outline of the research method to reduce bias in this study.

Findings of the Study

The results of the participants’ transcribed interviews are documented in this section. Data saturation was achieved at 13 participants, but I had already scheduled the remaining three interviews. I completed them as well due to the enthusiasm of the participants who wanted to share their experiences. Those two interviews yielded similar responses as the other 13 participants as well. NVivo was used to import, store, and organize the data. I used NVivo to code the data, and eight themes emerged (see Table 3).

Table 3

Emergent Themes Based on Research Questions

Questions	Major themes
RQ1: What are the lived experiences of informal caregivers who provide care for a Black man receiving in-center hemodialysis?	Lack of dialysis knowledge Loss of independence in Black man Good support system Caregiving is hard work
RQ2: What are the psychological symptoms that informal caregivers experience providing care for a Black man receiving in-center hemodialysis?	Feelings of negative emotions Coping comes with the territory
RQ3: What are the physical symptoms that informal caregivers experience providing care for a Black man receiving in-center hemodialysis?	Stress and decline in physical health
RQ4: What are the financial limitations that informal caregivers experience providing care for a Black man receiving in-center hemodialysis?	Decrease in income

Research Question 1

All 15 participants answered RQ1 (What are the lived experiences of informal caregivers who provide care for a Black man receiving in-center hemodialysis?). This question addressed the perceptions of how the participants viewed their lives before and after becoming a caregiver to their loved one. To gather the data for this question, I asked a series of open-ended questions from the interview guide. The themes that emerged from the interview responses were as follows: (a) lack of dialysis knowledge, (b) loss of independence in the Black man, (c) good support system, and (d) caregiving is hard work.

Theme 1: Lack of dialysis knowledge. All 15 participants responded to the questions presented in the interview protocol. The first question asked was, "What did you know about kidney disease?" Eleven of the participants did not know what kidney disease consisted of. Mary said, "Nothing…. when he first started, we were learning about creatine." Judy said, "I didn't know anything about kidney disease until the doctor told me until he got out of prison and told me his kidneys were going bad." Jean said that she had married into the family with kidney disease,

> None of it runs in my family. I basically don't really know a lot of stuff, for what I have learned as far as takeaways in talking to the nurse and his caregivers, as far as his situation of kidney disease, kidney failure.

Missy said,

> When he first started, actually I didn't really know what it was. It was just like, I know he goes to this place all day, and they say they take all of his blood out and put it back in.

The other six participants were aware of kidney disease.

A follow-up question was, "What other options were discussed about hemodialysis?" Eight participants said that they were not informed of the other forms of dialysis. Mary said, "No. We were told nothing until after we came here to Fresenius and then we were told options that he could be put on the kidney transplant list." Ann said, "Down the road. Not then though." Sarah said, "They didn't give us any options, number one. Number two, when they put that shunt in him, they said they had to put it in him." Judy said, "They didn't tell me nothing about all that, they just told me about another fistula that he had to get in his chest if he keeps continue doing drugs." Missy said, "Actually, I wasn't. That was more my grandma who handled that. But as far as day to day, I didn't know there was anything else that would help." The other seven participants were not informed of other options by a healthcare provider. Instead, they were informed by personal experience from other family members and friends.

Theme 2: Loss of independence in the black man. All 15 participants responded to the question, "In regard to culture since you are caring for a Black man, what differences if any, have you noticed since caring for him?" Mary said, "A constant reminder of his pills, his medicines. Um…. It's so hard for him to take his baths. He can't bathe. He can't hold certain silverware if it's too long or too heavy. He can't cut meats." Ann said, "He's not able to accept the fact that he is no longer able to do the things he once was able to do and that frustrates him sometimes." Sarah said,

> He had his own anger, so it was…because of the fact that he was down here, and you know he was blinded with the cataract surgery, so that added to his despair. So now him being immobile, as far as he's concerned, he had to get over that loss, you know, he had to grieve that, and grieving is different for each and every person.

Judy said, "Yeah, he's angry at his self, and he's angry with because he's on dialysis. Not in control." Bernice said, "He's got a little mean streak in him. It's just that he don't like for nobody to tell him what to do. That's all." Tara said, "I do know there are times that he doesn't want to share how he feels about things. He doesn't want to appear weak. So, you know he doesn't want to share his emotions on how he's feelings."

Jean said, “It feels very secure. He tells me and opened up. Men don’t talk a whole lot about private things. Other things, he may get a little teary eyed. He don’t cry, cry.” Lisa said, “He’s moody.” Tisha said, “He’s crazy and cranky.” Missy said, “He’s very demanding and entitled.” Robin said, “Dialysis patients are some of the worst patients to have because they are angry. They’re angry and depressed.” Marie said,

> His attitude, because his dependence is kind of, because he’s gotten a lot meaner because it’s like he’s lost that sense of dependence that he had because he’s had to depend on other people where he hadn’t had to depend on nobody before he was, he’s gotten sick.

Shonda did not have a direct response on the changes noted with her uncle, be she did say,” I think when it comes to an African American man, and you have to start helping them, it messes with their pride a little bit. They try not to show it, but you can tell.” Jose noticed a different change in his loved one; he said that he noticed that they had a difference of opinions when it comes to personal and political issues. Veronica did not focus on her loved one. Instead, she voiced her concern about her husband being denied a kidney transplant and how Whites get kidney transplants before Blacks.

Theme 3: Good support system. All 15 participants responded to the following questions presented in the interview protocol. The questions asked were, “In regard to time off, who helps you the most? Who helps you the least?” Mary said, “I have a wonderful social worker that I talk too. She also said that her son would assist her if she needed time off but her daughter would not help her at all. Ann said that she used to have her son to help her, but his schedule has changed. Therefore, he is not able to help as much. She did say she had church members that have offered to help. Sarah said, “We have the family. The family is intact.” She did not want to go any further when inquired about who helps the most or least. Judy said, “I call his brother sometimes, and he will help, but his sisters, they always talk, but they never do nothing.” Bernice said, “My neighbor and my husband help me. My sister helps the least.” Tara said, “I have my mom and girlfriend to help me.” Lisa said, “My daughter helps me a lot, and my granddaughter will even come and watch over him.”

Shonda said, “I have a cousin like on a Saturday, she will relieve me of that.” She also said that she was the relief for her mother when her mother needs a break from her father. Tisha said, “My children are here to support me when I need it.” Missy said, “My grandmother helps the most, and my brother helps the least.” Jose said, “I got a really good support system.” Veronica said,

> I have a lot of family here. My sister, she’s probably like seven minutes away. My daughter is fine with him, my niece is fine with him. Everybody is in our circle. That’s a good thing because everybody can respond.

Marie said, “My sister is my support person. Two of the participants did not have a good support system, or they chose not to use their supports outside of their loved one. Jean said she did not have a support system, but her loved one had one child that came to visit him only but did not communicate with her. Robin said, “No. I do it all.”

All 15 participants responded to the question presented in the interview protocol about support from their healthcare providers. The question asked was, “What are your feelings regarding healthcare providers?” Eleven of the participants reported having good support from their healthcare providers. Ann said, “I feel that it’s been good. We’ve been fortunate that we’ve been placed in the care of those that seem to take his well-being you know, seriously.” Judy said, “I think they are excellent. The ones that I’ve met so far and the ones that try to help me, they’re helping me. I mean, all of them are nice.” Lisa said, “Oh, I love his doctors. Each time he’s gone into the hospital, they have been more than helpful keeping everything, keeping me informed. Everybody that I’ve had to come in contact with, love ‘em.” Missy said, “I wish there were more so they could actually spend time. I do think that they do well for the time they have.” Veronica said, “They are great. I really like his providers. One of the doctors is really good. We speak together. They’re very concerned.” Robin said, “Well, he just has primary care provider right now that we’re pleased with and he is actually going to a pain clinic, I want to say tomorrow.”

Four participants did not have good experiences with the healthcare providers/staff. Mary said, “It’s truly amazing how you are judged because of a different race. It really is.” Jean said, “I think he—even the primary care, she does what she can, but when we’re there, we sit in the room for a long time. I’ll be like, where’s she at?” She also discussed a time when her loved one started a new medicine, and it caused him to have loose bowels. She said that the doctor never called her back about the side effects. Instead, the dietician called her to inform her of the possible symptoms of the new medicine. Tisha said that she had some previous issues with the healthcare staff at the clinic, so she continues to re-evaluate the staff. Jose does not sit in the room when his loved one attends his medical appointments, so he could not give an opinion.

All 15 participants expressed their need for caregiver support resources. The question asked was, “What type of resources would you like to see developed to support caregivers as well as hemodialysis patients with ethnic backgrounds?” Ann said, “I’d really like to see more attention given to the caregiver to let them know that this is going to be an ongoing thing and that when you get into it, it’s not going to be easy. Prepare the caregivers.” Tara said, “It’s really difficult to find any type of group, a support group for caregivers that would allow the caregivers to get to know each other.” Shonda said, “Maybe some classes or more understanding of like, being told what he can or cannot eat and everything but making sure we totally understand how to care for somebody on dialysis. If somebody needs to come in the house just to check on them once a month to follow through to make sure they’re understanding.” Sara and Jean recommended personal care services in the home to assist with their loved ones.

Veronica said, “Reading materials. More information. How about classes? Classes would be great especially with the spouses and everything. A support team.” Three participants recommended monetary compensation. Judy said, “Let’s see what they can give a person to help a person.” Bernice said, “Financial well-being. Put some money in my pocket.” Three participants did not recommend any resources. Mary said, “Even with resources, you don’t even know if they are going to be implemented. Tisha said, “I don’t need nothing from them. I’m good where I’m at.”

Theme 4: Caregiving is hard work. All 15 participants responded to the question presented in the interview protocol. The question asked was, “What does your role of primary informal caregiver mean to you?” Majority of the participants mentioned certain tasks associated with being a primary informal caregiver. Mary said, “It’s so hard. I gotta watch him as far as his walking. Constant reminder of his pills, his medicines. He can’t bathe, he can’t hold his silverware. There’s so much, it’s overwhelming at times.” Sarah said, “It’s not a negative role. We do what we do. We do home care for him 24/7.” Bernice said,

> It tires you out. It’s a life change because what you were used to doing, now you have to consider you’re caring for someone else, and it’s almost like you’re caring for a child. You have to do everything and assist with medicines.

Tara said,

> I think it’s more of emotional support for him. Just being there for him, understanding what he’s going through, how he’s feeling, keeping his spirits up. Making sure he has transportation to dialysis and stay on top of his doctor’s appointments.

Lisa said, “It’s a challenge. I want to be good at it. I want to understand his needs.” Shonda said, “Well, to me I just feel like it’s basically taking care of the patient thoroughly, you know. Making sure they don’t have an appointment, make sure medicine is being administered, making sure they are properly taking their sugar and everything lining up. Blood pressure, all that.”

Missy said, “That I have to make sure he eats. His bathroom’s clean. And just handling small day to day things for him. Veronica said,

> It’s taking care of the loved one that you love, making sure that he goes to his dialysis, make sure that he goes to his doctor’s appointments, make sure that he’s

> healthy. You make sure that he’s eating properly, taking medication. It’s a lot. It’s something you cannot half do. You have to make sure it’s done properly. And advocate so your loved one can continue to live and be healthy and stay out of the hospital.

Research Question 2

All participants responded to the research question, “What are the psychological symptoms that informal caregivers experience having to provide care for a Black man receiving in-center hemodialysis? The themes that emerged were (a) feelings of negative emotions, and (b) coping comes with the territory. The following interview questions and follow-up question were asked to collect the data: How did you cope with the news that your loved one would have to start hemodialysis? Since caring for your loved one, what changes have you noticed in your mental health if any? Who are you able to talk to if you have feelings of sadness or anger?

Theme 5: Feelings of negative emotions. The question, “How did you cope with the news that your loved one would have to start hemodialysis,” brought up feelings that were fresh in their minds. Most of the participants felt some form of emotion when finding out the news. Mary said, “I cried just like everybody else and just like him. We cried because we didn’t know what dialysis is.” Ann said, “It’s a twofold thing cause he came out of one situation which was very dire, that being one kidney being cancerous and still be able to live life via dialysis, that’s how I cope with that.” Bernice said, “I hated it. I did, because I know being on dialysis, that’s going to take over your life.” Tisha said, “I didn’t really cope with it that good. I tried my best; I was in denial about it.” Missy said, "I was kinda nervous at first." Robin said, "I was devastated, and I felt it was my fault." Tara, Marie, and Shonda reported feelings of shock. Three participants were prepared already. Jean said, "We knew it was coming. They had a couple of years before had said it would eventually come to this; they just prolonged it." Jose said, "My mom was on dialysis, so I already knew what comes with it."

Most participants continued to report negative emotions when answering the follow-up question, "Since caring for your loved one, what changes have you noticed in your mental health if any?" Mary said, "It has taken my quality of life away, and it bothers me. It makes me cry all the time because so many people die from it and I don't know when his day is gonna come." Judy said, "I notice I haven't been sleeping too good and I noticed my attitude change. I noticed I have been in peace since he been away from me, but I'm still worried about him." Tara said, "I'd say maybe—especially in the earlier years, feeling anxious a lot." Shonda and Missy started seeing a therapist to help cope with their emotions. Five participants did not report any changes in their mental health.

Thirteen participants had other people outside of their loved ones that they could talk to when responding to the second follow-up question, "Who are you able to talk to if you have feelings of sadness and anger?" Mary said, "My momma and my brother." Ann said, "I have a close friend." Sarah said, "I have my children that are grown." Judy said, "If I don't talk to my psychiatrist, I can go talk to my cousin." Bernice said, "My neighbor and my husband." Tara said, "My mom and my girlfriend." Lisa said, "My daughter and I have two best friends." Jose said, "My family and friends." Veronica said, "My husband." Robin said, "My friends. Friends and family." Two participants reported they were able to speak to their brother for support. Three participants said they did not have anyone they could talk too.

Theme 6: Coping comes with the territory. All 15 participants responded to the interview question, “How has your ethnic background influenced the way you cope with caring for your loved one?” Majority of the participants mentioned their culture and family dynamics as an influence with coping. Ann said, “Our ethnic background dictates that this is what you do. Your loved one needs care; then you’re the one that’s supposed to do it.” Sarah said,

> The fact that we’re caring people, we’re nurturing people, we have always had to hit the floor running and do what we got to do, handle our business. We had to take care of our own, and that’s what we do to the best of our ability.”

Lisa said, “Well, we as Black women are the nurturing type, no matter who it is, that’s just us. We are nurturers by nature.” Marie said, “Well, strong. Had to be strong, and that’s kind of where I am. That’s how black women are. We’ve had to be strong most of our lives.” Others reported having to care for other loved ones that were ill. Tara said, “I believe definitely that I learned how to cope a lot since I was young. I guess from my mom. My father ended up being really sickly in life, and she was his primary caregiver.”

Research Question 3

Research question three asked, “What are the physical symptoms that informal caregivers experience having to provide care for a Black man receiving in-center hemodialysis?” The theme that emerged was (a) stress and decline in physical health. The following interview questions and sub-questions were asked to collect the data: Since caring for your loved one, what changes were noticed in your physical health? Can you provide examples of how you care for yourself since becoming the primary informal caregiver?

Theme 7: Stress and decline in physical health. All 15 participants responded to the interview question, “Since caring for your loved one, what changes have you noticed in your physical health if any?” The majority did experience some form of physical change and all. Several participants reported poor sleeping habits. Mary said, “Oh yes, I do not sleep at all period!” Judy said, “I notice I haven’t been sleeping too good, and I noticed my attitude changed.” Other participants mentioned stress related weight gain. Jean said, “I’ve gained weight. I don’t get enough sleep because I’m constantly telling him to put his leg down or get up at night and giving him some medications. It’s a lot of stress being up day and night.”

Lisa said, “Stress. In August, I had to go because of my heart.” Four participants reported their chronic conditions getting worse. Tisha said, “I have COPD, and with him, it doesn’t bother my health.” Veronica said, “I am a diabetic myself, and it’s not helping me any because I’m trying to make sure he’s okay versus myself.” Marie said, “Stress. I have to watch that blood pressure because that can really affect that.” Ann said, “Tiredness or not enough time. I had a mini stroke. That’s why we’re here in Charlotte.” Four participants said they had not noticed any changes in their physical health.

All 15 participants responded to the follow-up question, “Can you provide examples of how you care for yourself since becoming the primary informal caregiver? Thirteen participants reported that they did start paying more attention to their health and two reported they had already been proactive in managing their chronic conditions. Four participants reported adopting a healthier diet. Mary said, “I watch more. I watch more as far as salt and sugar. I watch what I eat. I watch what I drink.” Tara said, “I am trying to make sure I eat right, you know, lose weight. Make sure I have a yearly physical and make sure I follow-up with the doctor if I am not feeling well.”

Shonda said, “I’m more conscious as far as what I eat. I’m actually getting ready to start working out.” Missy said, “I eat vegetables, make sure I’m active at least 30 minutes a day. I’ve cut down on a lot of fried things.” Two participants reported exercising more. Lisa said, “I’ve started going back to the gym because that was something I really enjoyed doing when I was going to work.” Veronica said, “I exercise more. I have lost a lot of weight. I take my medicine like I’m supposed to.” Two participants did not report any examples.

Research Question 4

Research question four asked, “What are the financial limitations that informal caregivers experience having to provide care for a Black man receiving in-center hemodialysis?” The theme that emerged was financial strain. The following interview question and sub-questions were asked to collect the data: What financial limitations, if any, are present and how have you dealt with the limitation? How has hemodialysis affected your loved one’s finances?

Theme 8: Decrease in income: All 15 participants responded to the follow-up question, “What financial limitations, if any, are present and how have you dealt with the limitation? Mary said, “Oh yes. We couldn’t pay the rent, our lights were behind, and our water was behind. I had to make minimum payments. We did use Crisis a couple of times for the power." Sarah said, "Financially, my overall income is cut down to less than a third of my income. But, it is what it is." Judy said, "Yeah, I paid money out of pocket for him to go to the doctor and before he could get sliding scale. He gets social security now, but it still wasn't enough because he has to pay child support." Bernice said, "We can tell a difference because, you know, when he came, it was just me and my husband. So, it's like almost everything doubled. We use the money that we would have saved up."

Jean said, "It just stopped. I was trying to do part-time work, but it' so stressful because he has good nights and bad nights of sleeping. We applied for the LEAP program." Lisa said, "Financially, it's rough." Tisha said, "Let's say the tax bill is due, and if my tax bill's $125, my two kids are gonna make sure the balance is paid." Missy said, "I just know I have to make sure I have to put more toward my grocery budget 'cause he do eat." Robin said, "Because he is not able to work. So that's why I have all of these part-time jobs to compensate for this because he gets SSI." Marie said, "Sometimes I have to take time off work to take him to the appointments and things. So sometimes that cuts my time at work." Five participants reported no limitations.

All 15 participants reported a decrease in their loved one's income based on the follow-up question, "How has hemodialysis affected your loved one's finances?" Mary said, "It was horrible. It was really bad because he was getting disability, but that really wasn't much because it was based on my income." Sarah said,

> He worked until he was past 65, about 67. This is not a person that sat down at home. My retirement became secondary to him actually being sick. I didn't retire just to retire. So, it was to take care of him.

Bernice said, "When he came on dialysis, he was receiving his sick pay, so it didn't really affect him that much, maybe a little bit, but not much." Jean said, "His financial income is maybe 50, not over 100, over the limitations for Medicaid."

Lisa said, "I actually went into retirement to be able to take care of him. I used some of my 401(k) to make sure bills, and things were taken care of because he does get disability, but that didn't work." Tisha said, "Well, at first, he was the provider when he was working. Now he gets Social Security, and it's a major cut, but we deal with it." Missy said, "He stopped working. We get food stamps and we have family members that help us with bills and things like that." Veronica said, "It put a strain in us financially. So that means I am the breadwinner. I work a lot, and that's my choice to make sure we keep the lifestyle that we had before he got ill." Robin said,

> I have four jobs. My job is a ten-month job, so it's extra hard because I don't work during the summer. I have to find my own money in the summer. He does not even get full disability, so his funding is very limited.

Marie said, "With him being sick an all, he's had to go on Social Security." Four participants reported no change in finances.

Summary

The purpose of this study was to explore the lived experiences of informal caregivers caring for a Black man receiving in-center hemodialysis. In addition to exploring the lived experiences, psychological, physical, and financial stressors were explored as well. Data saturation was believed to be achieved based on the similarity of responses in later interviews. During the coding process, eight themes emerged to support the four research questions. These results revealed important insight about the lived experiences of the caregivers, their stressors, their coping strategies, and resources needed to help caregivers in this specific population. In Chapter 5 I will evaluate the research questions, provide an interpretation of the study’s findings, limitations of the study, implications for social change, and recommendations for future research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological study was to improve the understanding of informal caregiver burden and reveal the lived experiences of informal caregivers' caring for a Black man receiving in-center hemodialysis. Even though there is increasing literature on ESRD, few studies focus on Black men. This study was conducted to improve the understanding of informal caregiver burden and to address the gap in the literature that exists when it comes to caring for a Black man receiving in-center hemodialysis. Another gap in literature is the lack of qualitative studies conducted that explored the lived experiences of informal caregivers. A sample of 15 informal caregivers were interviewed as part of this research. TMSC and SPM (Lazarus & Folkman, 1984 & Pearlin et al., 1990) provided the theoretical framework for this study. Both frameworks helped in the recognition of informal caregiver burden for those caring for patients on hemodialysis. In this chapter, I provide a detailed discussion of the interpretation of the findings, the study's limitations, recommendations for leaders and future leaders, and implications for social change.

Interpretation of the Findings

The findings from this research study may help with improving caregiver resources and support for informal caregivers caring for a Black man receiving in-center hemodialysis. The findings from this research study revealed important perceptions of informal caregivers' lived experiences, psychological stressors, physical stressors, and financial stressors associated with caring for a Black man receiving in-center hemodialysis. In the literature review in Chapter 2, I mentioned the limited number of studies focused on those caring for a Black man receiving in-center hemodialysis. Studies have found that being an informal caregiver can impose a burden of various emotional, physical, financial, and social stressors (Knowles et al., 2016; Suri et al., 2011; Taylor-Brown et al., 2014). This correlates with the findings in the study that participants did experience emotional, physical, financial, and social stressors when discussing their lived experiences.

There was a total of eight themes that emerged from the research questions, and they were consistent with the findings from the existing literature. These themes include (a) lack of dialysis knowledge, (b) loss of independence in the Black man, (c) good support system, (d) caregiving is hard work, (f) negative emotions, (h) coping comes with the territory, (i) stress and decline in physical health, and (j) decrease in income.

Theme 1: Lack of Dialysis Knowledge

ESRD is diagnosed at Stage 5 and the initiation of renal therapy is started. In most cases, the diagnoses were a shock to the Black men and their caregivers due to their lack of knowledge and preparation about kidney disease in general. Nine participants and their loved ones were not aware of what kidney disease was, and six participants and their loved ones were knowledgeable about kidney disease. Their responses ranged from not knowing about kidney disease at all, not wanting to know anything about kidney disease, denial, and already knowing about kidney disease due to their profession. This supports similar findings by Kazley et al. (2014) who found that Black hemodialysis patients were less informed about the causes of kidney disease and the types of treatments for kidney disease. Lissanu et al. (2019) found that even though the participants had not reached Stage 5 yet in CKD, they were unaware of the severity of their CKD.

Theme 2: Loss of Independence in the Black Man

The study findings revealed that the participants noticed a change in their loved one since he had started hemodialysis. The participants had to take on the role of the primary informal caregiver and ensure that their loved one was cared for properly. Most of the participants described that they had noticed the change due to role strain. All of the participants were female except one, and their new role of becoming the primary informal caregiver was not received well by their loved one. The responses ranged from their loved one not being able to accept that he was not as independent as he once was, he had become angry and cranky due to a loss of control, and he did not want to share his feelings. These findings support the study conducted by Griffith et al. (2015) that Black men were more likely to correlate independence to being healthy, but not necessarily physical health. The authors further explained that Black men felt that being able to support their family defined their manhood (Griffith et al., 2015). Levant et al. (2014) also found a strong correlation between manhood and independence.

Theme 3: Good Support System

A compelling argument exists that social support improves the outcomes for informal caregivers. A social support system could consist of relationship ties with a religious community, family ties, volunteer groups, and the healthcare system. According to Yu et al. (2015), caregivers can view social support as positive or negative. Most of the participants perceived their social supports in a positive light and expressed that their social supports have helped reduce the stress that caregiving brings. Three participants viewed their social supports in a negative light. One participant in this study admitted that her loved one had siblings who call to check on him, but when she would reach out to them for assistance with sitting with him in the home for a few hours while she goes out in the community or getting him to medical appointments, they would not return her call. Another participant in this study noted that she did not have anyone she could call for support, and it had started to take a toll on her mentally and physically.

Caregivers also viewed healthcare providers as a form of support to ease the burden of caring for their loved one receiving hemodialysis. The participants in this study expressed that their loved one’s healthcare providers were supportive and included them when discussing medical information about their loved ones. These study findings do not agree with findings by O’Hare et al. (2017) who noted that the caregivers in their study felt that support from healthcare providers was tense and their feelings were disregarded when making delicate decisions about their loved ones. Another study conducted by Feldman et al. (2013) did not agree with these findings either. The caregivers in that study felt that the hemodialysis staff were not caring and did not acknowledge their concerns about their loved ones. These findings add to the absent literature on informal primary informal caregivers caring for a Black man receiving in-center hemodialysis as well as primary informal caregivers caring for an in-center hemodialysis patient in general.

Most of the participants mentioned the need for resources to support them. During the interviews, the participants recommended several ideas that healthcare providers could consider when developing programs. An example of a recommendation was having caregiver classes that assist with caring for their loved one on hemodialysis. Another example was to have the healthcare providers come to the home and check on them monthly to ensure they are doing well. Other participants mentioned financial incentives for caring for their loved ones because they have experienced a decrease in their overall income. These findings add to the absent literature on informal caregivers caring for a Black man receiving in-center hemodialysis as well as informal caregivers caring for an in-center hemodialysis patient in general. Informal caregivers assisting their loved one with home hemodialysis already had this type of support according to a study conducted by Welch et al. (2014). Ghane et al. (2016) found that the implementation of problem-focused coping strategies was beneficial to both the informal caregiver and the patient.

Theme 4: Caregiving is Hard Work

All of the participants perceived that caring for a Black man receiving in-center hemodialysis was arduous work. This theme emerged from the participants' discussions about how they viewed their role as primary informal caregiver. Most of the participants reported that they had to manage and organize daily activities, such as giving medications, travel to medical appointments, and meal preparation for their loved one and for themselves. Two participants described that their hard work was not physical work, but more mental work with making sure they balance work life, family life, and leisure time. These findings support findings by Rodrigues de Lima et al. (2017) who found that caregiving for a loved one on hemodialysis involved transporting them to and from dialysis appointments and other medical appointments, medication management, and meal preparation.

Theme 5: Feelings of Negative Emotions

According to the theoretical framework of Lazarus and Folkman's (1984) TMSC, there are primary and secondary stressors. Informal caregivers have the greatest responsibility providing direct care for their loved ones, which in return, can cause secondary stressors that affect the emotional, physical, social, and financial well-being of the caregiver (Kim et al., 2017). The sample in this research study consisted of 14 women and one man. Do et al.'s (2015) research correlates with this study's findings; they found that these outcomes of stress are more present in female informal caregivers. When the participants were introduced to their new role of becoming the primary informal caregiver, it became stressful, and they expressed conflicting emotions.

This theme emerged through varied emotions the participants expressed verbally during their interviews. The participants expressed feelings of sadness, depression, anger, guilt, denial, and shock. The findings were consistent with the literature about primary informal caregivers experiencing secondary stressors. Avşar et al. (2015) found that the outcomes of stress can impose a challenge on the psychological well-being of the primary informal caregiver. They found that primary informal caregivers caring for loved ones receiving hemodialysis had a higher rate of depression and anxiety than those caring for a loved one who had a renal transplant (Avşar et al., 2015).

Theme 6: Coping Comes With the Territory

According to Yu et al. (2015), coping can have positive effects on a caregivers' health and well-being. Most of the participants reported that their ethnic background did influence how they coped and cared for their loved one. Powers and Whitlatch (2016) defined culture as traditional behaviors that have been developed by a group of people, race, or given society. Thirteen of the participants in this study identified as Black, one identified as White, and one identified as Mexican. Powers and Whitlatch (2016) found that Black and White informal caregivers had similar views on using religion and spirituality to care for their loved one, but they had different coping patterns. A similar study conducted by Pharr et al. (2014) found that Asian Americans, Black Americans, Hispanic Americans, and White Americans had similar views on the difficulties of caregiving, but each racial group had distinct cultural beliefs that molded their role in caregiving.

All the participants correlated caring for their loved one as an intergenerational task and something they were taught to do. Research conducted by Anderson and White (2017) on the experiences of caregiving from an intergenerational family perspective confirms this point. Even though the diagnosis of ESRD could be challenging for patients and caregivers, the families were able to put those challenges aside and take care of their loved ones. Research has shown that Black people view informal caregiving in a more positive light than White people do (Bekhet, 2014).

Theme 7: Stress and Decline in Physical Health

Informal caregiver burden can hinder a caregivers’ physical well-being as well. The majority of the participants reported physical changes since becoming the primary informal caregiver to their loved one. Caregiver history played a role in the well-being of the informal caregiver. The participants’ caregiver history ranged from five years to 21 years. The participants that had over ten years of caregiver history reported the highest amount of physical changes including; exhaustion, lack of sleep, hypertension, and diabetes. These findings provided evidence to support the research showing a connection between caregiver history and poorer health (Ahn et al., 2015). Kim et al. (2015) study also supported the findings of this study. They found that the longer an individual remains the primary informal caregiver, they experienced physical health problems.

Caregiver interaction with healthcare providers concerning their decline in physical health did not agree with previous research by Grapsa et al. (2014). Grapsa et al.’s study reported no positive interactions with healthcare providers regarding the physical health of the informal caregivers nor their loved ones. In contrast, the participants in this study were proactive with speaking to their healthcare providers to prevent further physical health decline. They continued to report positive relationships not only with their own healthcare providers, but with their loved ones’ health providers as well.

Theme 8: Decrease in Income

Financial strain is the most mentioned form of burden that an informal caregiver experiences when caring for a person with a chronic illness. Socioeconomic status can have a major impact on the well-being of a caregiver. In this study, the participants expressed their dislike of their decrease in income when their loved one became ill and wished that there was some form of monetary compensation for becoming the primary informal caregiver. They also expressed becoming stressed due to the rising cost of medications that their loved one was prescribed. Figueiredo et al. (2014) found comparable results where the participants expressed their dislike of the rising cost of medications and the decrease in their overall household income. A similar study conducted by Ebrahimi et al. (2017) support the findings as well. They authors found that once the caregivers loved one had to stop working, the caregivers had difficulty purchasing items needed to adequately care for their loved one.

Limitations of the Study

The findings are limited to primary informal caregivers over the age of 18 years caring for a Black man receiving in-center hemodialysis in Mecklenburg County, North Carolina. The findings are reflective of those primary informal caregivers caring for a Black man receiving incenter hemodialysis who volunteered to take part in this study. The number of participants in the study created some limitations. The sample size of 15 made it difficult to recruit and the interviews were difficult to schedule due to the participants having other obligations that interfered with scheduling their interviews at times. The small sample size does not reflect the entire population of primary informal caregivers caring for a Black man receiving incenter hemodialysis. The interview questions were pilot tested with primary informal caregivers who represented the study population.

Although I worked in a similar setting where the primary informal caregivers visited with their loved ones, I conducted the participant interview process without preconceived ideas or personal biases. I conducted each interview with genuine interest and made sure I used the interview questions as a guide and not to lead the participant in any way. Whenever I was unclear about a response, I asked for clarification to ensure accuracy for these one-time interviews.

Significance of the Findings and Social Change Implications

This qualitative study examined the lived experiences of primary informal caregivers caring for a Black man receiving incenter hemodialysis. The Transactional Model of Stress and Coping and the Stress Process Model were used to formulate questions to explore primary informal caregivers' perceptions and beliefs about their role as primary informal caregiver. I recorded the participants' responses to understand their lived experiences. The core themes from the findings helped answer the research questions. The research that addressed the lived experiences of primary informal caregivers caring for a Black man receiving incenter hemodialysis was limited. The findings of this study contributed to the literature by increasing the body of knowledge for the primary informal caregiver caring for a Black man receiving hemodialysis, healthcare professionals, and other public health leaders with a better understanding of the needs and perceptions of primary informal caregivers caring for a Black man receiving incenter hemodialysis.

The study results may promote social change by providing healthcare professionals and other public health leaders with a clearer understanding of how primary informal caregivers cope with having to care for their loved one receiving incenter hemodialysis. The information can be used to provide healthcare providers the knowledge to implement programs that support primary informal caregivers of incenter hemodialysis patients of in general. Also, several of the participants expressed that they were not aware how rigorous the process was for caring for their loved one on hemodialysis. This makes education to the patient and the primary informal caregiver imperative. Healthcare providers need to start educating the patients and their primary informal caregivers at stage four of CKD about the upcoming responsibilities on both parts.

Many of the participants described the mental health and physical health changes they have endured since becoming the primary informal caregiver to their loved one. Some of the participants decided to seek mental health therapy and become proactive in taking charge of their physical health challenges. Therefore, resources specific to caregivers from the healthcare professionals at the clinic level would assist with addressing any mental health or physical health concerns.

A majority of the participants describe their financial limitations that came with caring for their loved one receiving incenter hemodialysis. When a family becomes accustomed to a two-income household and abruptly drops down to one, the financial stress alone can cause emotional distress and physical distress over periods of time. Healthcare professionals are key when assisting primary informal caregivers finding financial resources to help with finances.

Recommendations for Future Research

A qualitative phenomenological study was chosen because there was a gap in the literature addressing the lived experiences of primary informal caregivers caring for a Black man receiving incenter hemodialysis. The findings of this study have begun to fill the gap and provide a basis for proposing recommendations. However, due to limitations, some questions were unanswered, but present opportunities for new questions. The following are recommendations for future research studies.

First this study was conducted on primary informal caregivers caring for Black man receiving incenter hemodialysis only. The participants' attitudes, beliefs, coping mechanisms, and support systems were for the present time and not over a period of time. Conducting a similar study with primary informal caregivers at the beginning of their role with caring for a Black man receiving incenter hemodialysis over a period of three years may reap new into what immediate needs could be addressed to assist with role strain. A qualitative study implementing an informal caregiver support program could provide added information about how primary informal caregivers cope with ESRD long-term when they have resources to support them.

Several of the participants discussed a loss of independence in their loved one once they started incenter hemodialysis. A qualitative study about the lived experiences of Black men receiving incenter hemodialysis could provide new information about the diverse ways Black men cope with their diagnosis of ESRD. This study could also address the gap in literature when it comes to Blacks taking part in research studies.

Recommendations for Practice and Policy

Hospitals, nephrology offices, and hemodialysis clinics are critical community partners. These entities interact with CKD patients, ESRD patients, and primary informal caregivers regularly, with allows them the opportunity to develop, implement, and provide resources to assist patients and primary informal caregivers cope with the diagnosis of ESRD. Furthermore, with the lack of research on Black men with ESRD and Black men having an increased risk of developing ESRD, cultural sensitivity training should be provided to all healthcare professionals with an emphasis on providing adequate care for the Black receiving incenter hemodialysis.

Several participants expressed the need for monetary compensation to aid with the needs of their loved ones receiving incenter hemodialysis. Many of the participants loved ones did qualify for Medicare but did not qualify for Medicaid due to income restrictions. Although the participants expressed a decrease in their loved one’s income, they continued to be ineligible for Medicaid. Medicare does not pay for personal care services in the home and this responsibility falls on the participants. Some of the participants described having to aid their loved ones with activities of daily living and transportation to and from hemodialysis treatments and other medical appointments. Based on these findings, I recommend the caregivers advocate for Medicare to include personal care services for those specifically in the ESRD community. In addition, a policy should be created to appoint funds to that target personal care services or monetary aid for primary informal caregivers caring for ESRD patients.

Dissemination of Research Finding

The results of my study may help provide insight into the lived experiences of primary informal caregivers caring for a Black man receiving incenter hemodialysis and how they cope with caregiver burden. This study findings will be disseminated locally, statewide, nationally, and globally. I plan to conduct presentations of the findings to the healthcare staff of the clinics included in this study as well as present to Frenova Institutional Review Board committee per their request upon completion of the study. Also, I plan to share the findings with other healthcare professionals in the community with an emphasis on the National Kidney Foundation, Family Caregiver Alliance, and the CDC through oral presentation. In addition, the research will be submitted for publication in research journals including the *American Journal of Kidney Disease, American Journal of Public Health, Health Promotion Practice, Journal of Chronic Diseases, and Chronic Illness.*

Conclusion

This study allowed me to see the impact of caring for a Black man receiving incenter hemodialysis through the eyes of 15 primary informal caregivers. During this process I realized that more supports are needed to address this specific population. When a patient with ESRD initiates treatment in the clinic, it is assumed that their primary informal caregivers can provide adequate care. This is not the case. Majority of the participants were not aware of the added responsibilities that came with caring for their loved one on hemodialysis. Most did not know what to expect when they were informed that their loved one had to start hemodialysis to survive. As a result, the participants experienced financial stressors, psychological stressors, and physical heath stressors. Secondly, challenges of the Black man receiving incenter hemodialysis were highlighted guiding the need for future research about the lived experiences of a Black man receiving incenter hemodialysis.

The study also revealed that the participants felt they needed. They did express that their role was exhausting yet rewarding. They also expressed that based on their upbringing, caring for their loved one is the right thing to do. Majority of the participants did have a support system they could rely on in time of need, but they expressed the need for resources to assist them with coping. The participants focus was to make sure that their loved one was well-taken care of and survived a long time on hemodialysis. I supplied several ideas for future studies focusing on primary informal caregiver burden as well as future studies focusing on the Black man hemodialysis patient. By disseminating this research to learned forums, this study will add to the existing literature by increasing the body of knowledge for the primary informal caregiver caring for a Black man receiving hemodialysis, healthcare providers, and others for a better understanding of the lived experiences of primary informal caregivers caring for a Black man receiving incenter hemodialysis.

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Appendix A: Letter of Cooperation from Research Partner

Study Permission

Erica J Trembath <Erica.Trembath@frenovarenalresearch.com>

Wed 9/19/2018 12:05 PM
To: Clara L Gray <Clara.Gray@fmc-na.com>; ghart@metrolinanephrology.com <ghart@metrolinanephrology.com>; Marcus Botts <Marcus.Botts@fmc-na.com>; Karmen Strickland <Karmen.Strickland@fmc-na.com>; bhippen@metrolinanephrology.com <bhippen@metrolinanephrology.com>; Michael R Waltz <Michael.Waltz@fmc-na.com>; dtierney@metrolinanephrology.com <dtierney@metrolinanephrology.com>
Cc: Tanikka Greene <tanikka.greene@waldenu.edu>; Tanikka J Greene-Akrie <Tanikka.Greene-Akrie@fmc-na.com>

Dear All—

Tanikka Green is permitted to conduct the study, “The lived experiences for caring for a black male receiving HD,” in the following dialysis facilities:

- West Charlotte (1146)
- Charlotte (1328)
- N Charlotte (1325)

A study summary is attached.

Objectives:

- The purpose of this study is to improve the understanding of unpaid primary caregiver burden and reveal the lived experiences of caregivers who are caring for a Black man receiving in-center hemodialysis.

Note to Clinic Manager:

- Copies of the informed consent forms must be placed in the medical records by the research staff.
- If a study subject is hospitalized, please notify the principal investigator as soon as possible.
- The original, completed Governing Body Meeting Minutes Memo must be placed in the Governing Body Binder. In the event an audit occurs, it is important (and your responsibility) to ensure that this documentation of study permissions is in place.

Note to PI/Research Coordinator:

- Provide the clinic manager a three-ring binder labeled with the study protocol number (if applicable) and title.
- The binder must contain:
  - Copy of protocol
  - Blank copy of informed consent form
  - List of participating patients

  - Contact information for PI and study coordinator
  - Frenova contact information
  - Completed Governing Body Meeting Minutes Memo

Permission Terms to Conduct Research in a Fresenius Facility

Frenova Renal Research Study Number	031-2018 Greene
Study Title	
The lived experiences for caring for a black man receiving HD	
Principal Investigator	Tanikka Greene
Principal Investigator’s Institution	Walden
Principles	**Explanation**
Date PRC Permission Granted	19SEPT2018
Specific Permission Terms/Conditions (if applicable)	• PI will post study information for recruitment • PI will attend a clinic staff meeting to inform staff about the study • Participants will receive $20 gift card after study completion
Length of Study (Per Subject)	Approximately 60 minutes
Institution Review Board (IRB) Expiration Date	17JUL2019
Clinics Permitted to Host Research	• West Charlotte (1146) • Charlotte (1328) • N Charlotte (1325)
Anticipated Number Subjects	15-20 participants
Trial Activities to be Completed by Fresenius Facility Staff	• There are no activities for the clinic staff.
Documents to be used by Study Staff	• Informed Consent Form • Demographic Information • Interview Protocol • Questionnaires
Study Staff Members	• Tanikka Green
PI and Study Staff Responsibilities	• Contact CM to schedule study in service • All study activities
Trial Contact Information	• 252-367-0492

Thank you for your support of research in your dialysis clinic.

Please contact me with any questions or concerns.

Best,

ERICATREMBATH
Clinical Manager, Investigator Initiated and Administered Studies

PHONE 844.CKD.ESRD
(844.253.3773)
DIRECT 612.248.9403

Frenova
Renal Research

FrenovaRenalResearch.com

Appendix B: Interview Protocol

Interview Protocol

Special consideration will be noted in the event the participant has to leave in the middle of the interview to care for their loved one. The researcher will offer the option for the participant to complete the interview at another agreed mutually time. The interview can be completed via telephone or a neutral location (i.e., the public library). The interview can also be completed at the dialysis clinic with the coordination of the clinical manager to prevent conflicts in the daily routines of the clinic (conference room or other private room).

Questions with Probes (if needed):

1. Tell me about your life before you became a caregiver to your loved one? What did you know about kidney disease? If currently employed, what financial limitations, if any, are present and how have you dealt with this limitation? What services have you used to assist with your financial stressors? How has hemodialysis affected your loved one's finances?
2. How has your life been affected since becoming the primary informal caregiver for your loved one on hemodialysis? What does your role of primary informal caregiver mean to you? What does the term, "quality of life" mean to you?
3. How did you cope with the news that your loved one would have to start hemodialysis? What other options were discussed about hemodialysis? How has your loved one's kidney disease affected you? Since caring for your loved one, what changes in your physical health or mental health if any??

4. How has being a caregiver to your loved one help you view your health? Can you provide examples of how you care for yourself has changed since becoming the primary informal caregiver?
5. Let’s talk about the social supports (clarify what it means) you have? In regard to time off, who helps you if you need some assistance? How do they assist in helping you? Who helps you the most? Who helps the least? Who are you able to talk to if you have feelings of sadness or anger?
6. Since you are caring for a Black man, what differences if any, have you noticed since caring for him? Did your loved one attend routine medical appointments before his diagnosis? What are your feelings regarding healthcare providers? How has your ethnic background influenced the way you care for your loved one? What about how has your ethnic background influenced the way you cope with caring for your loved one? What type of resources would you like to see developed to support caregivers as well as hemodialysis patients with different ethnic backgrounds?
7. What other limitations or unexpected barriers limit your ability to provide adequate care to your loved one? How have you expressed this to the medical staff at the clinic or other healthcare providers that you attend personally? Have you ever mentioned these limitations or barriers to your loved one? How did they respond?

Wrap up question: Are there any final thoughts related to your life experiences with caring for you loved one that you would like to share with me at this time?

Thank you for your time.

Appendix C: Recruitment Flyer

Please Reply By: 10/31/2019

CAREGIVER RESEARCH PARTICIPANTS NEEDED

Are you an unpaid primary caregiver for a loved one on dialysis?
AND
Are you caring for a black male receiving hemodialysis?

You may be eligible to participate in a research study I am conducting for my dissertation at Walden University to have your opinions heard about being a caregiver to a Black male on hemodialysis.

Additional Eligibility Requirements:

- 18 years of age or older
- Must be the unpaid primary caregiver (e. g. not working for a company or receiving compensation for care)
- Speak English fluently

Interview Requirements

- The interview location for the participants will be at their personal discretion (public library or clinic conference room).
- All interview sessions will be between 30 minutes to an hour.

Participants will receive a $20 gift card upon completion of the interview.

Please contact Tanikka Greene at [redacted] or [redacted]

Appendix D: Prescreening Questionnaire

Unpaid Primary Caregiver Pre-Screening Research Participant Form

This pre-screening questionnaire is being conducted by a researcher named Tanikka J. Greene who is a doctoral student at Walden University. Please understand that as a volunteer taking part in this research study, you do not have to answer any question or questions due to personal reasons. Please note any unanswered question will exclude you from the screening process to participate in the study.

Date: ______________________________ Time: _____________

Are you at least 18 years of age? _____________

Do you feel competent enough to understand the reasons for this research study? __Yes __No

Are you proficient in English? __Yes __No

Are you an unpaid primary caregiver for a Black male receiving in-center hemodialysis? __Yes __No

What is your relationship to the Black male on dialysis?
__ Husband
__ Son/Son-in-Law
__ Brother/Brother-in-Law
__ Other Relative, Specify: _____________
__ Friend
__ Neighbor
__ Other not stated, Specify: ____________