2017

The Lived Experience of In-Center Hemodialysis Patients Receiving Treatment in DeKalb County, Georgia

Stacey Deniese Cooper
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral dissertation by

Stacey Cooper

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Frazier Beatty, Committee Chairperson, Public Health Faculty
Dr. Kimberly Dixon-Lawson, Committee Member, Public Health Faculty
Dr. Magdeline Aagard, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2017

Abstract

The Lived Experience of In-Center Hemodialysis Patients Receiving Treatment in DeKalb County, Georgia

by

Stacey D. Cooper

MBA, Health Care Management, University of Phoenix, 2009

BSN, Albany State University, 1996

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

August 2017

Abstract

Chronic kidney disease (CKD) is preventable and reversible in the early stages with upstream strategies; however, the number of individuals diagnosed with end-stage renal disease (ESRD) is increasing annually. Although researchers have documented the physiological and psychological stressors associated with hemodialysis (HD), little is known about the effects of in-center HD on the recipients in DeKalb County, Georgia. This study described the experiences of 10 African American HD patients who dialyze in DeKalb County. Using a phenomenological approach, the interviews were transcribed and then analyzed for significant quotes and recurrent themes relevant to receiving HD in DeKalb County. The health belief model was used to identify the perceptions and susceptibilities that formed the lived experiences of the participants. Results showed that 70% of the patients had been diagnosed with hypertension and/or diabetes and that 50% had never heard of ESRD prior to diagnosis. All 10 patients reported never knowing that hypertension and/or diabetes was a major cause of ESRD. The study sought to find common themes related to the perceived threat of ESRD by the participants. This study can be used to implement positive social change by instituting upstream strategies to decrease the prevalence of ESRD or slow the progression of CKD in this population, heightening awareness of this disease in minority communities, and implementing a sustainable health behavior plan to decrease the prevalence of the disease.

The Lived Experience of In-Center Hemodialysis Patients Receiving Treatment in DeKalb County, Georgia

by

Stacey D. Cooper

MBA, Health Care Management, University of Phoenix, 2009

BSN, Albany State University, 1996

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

August 2017

Acknowledgments

I would like to take this opportunity to thank Julia Taylor, regional operations director at Davita, for providing the avenue for me to complete this project. Without her okay, this might not have been possible. I will be forever grateful for your generosity and optimism. Carolyn Mitchell and Tamika Etienne, thank you for your support and allowing me into your facilities to speak to the patients that your care for and protect every day.

I would like to thank my family (Diamond, Emerald, and Melvin) for allowing me to finish this project while I missed family time and put you on the back burner. I appreciate your relentless patience during this critical time. I know that it has not been easy. I would like to thank my parents, Larice and Aniese Cooper, for being my biggest cheerleaders. Also, I thank my brother, Gary, and my sister, Shawnta, for always encouraging me to continue to move forward.

Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Chronic kidney disease (CKD) is unnoticed in the early stages of its development. Because of the lack of early interventions, CKD has grown to epidemic proportions across the globe. According to the Centers for Disease Control and Prevention (CDC, 2007), CKD affected an estimated 16.8% of adults between 1999 and 2004 and increased in prevalence by 104% during that same period. Diabetes and hypertension were the major causes of 60% of those CKD cases. There are 19 million U.S. adults with CKD, and 80,000 are diagnosed with end stage renal disease (ESRD) annually (CDC, 2007). ESRD, known as complete kidney failure or Stage 5 CKD, increases sufferers' morbidity and mortality, and markedly decreases their quality of life (QOL; CDC, 2007). In addition to explaining the functions of the kidneys, this chapter also includes information about the importance of kidney function and the defined stages of CKD, along with a description of the symptoms experienced in each stage.

During digestion, the stomach and intestines remove nutrients from food that the body uses for energy and repair. The remaining contents are sent to the intestines as waste (U.S. Department of Health and Human Services [DHHS], 2013). Expended energy also creates a waste product that must be excreted. If not removed, this waste will accumulate and cause internal damage and possibly death. The kidneys are a major part of this excretory process. As explained by the DHHS (2012), glomerulus located within the nephrons of the kidney is considered the gatekeeper, filtering unwanted waste and excess water while containing normal proteins and cells within the bloodstream.

Normally, there are two kidneys in the human body. Each kidney is approximately the size of a fist, bean shaped, located on both sides of the spine, and vital for human survival (see Appendix A). Kidneys are organs that work 24 hours a day to keep the body clean and chemically balanced (DHHS, 2012). The kidneys have been described as a pump that deciphers how much sodium, potassium, and phosphorus needs to return to the body and how much needs to be excreted (DHHS, 2012). The sodium potassium pump is an amazing phenomenon, but it is not the extent of the kidneys' function. Kidneys also release hormones that are necessary for optimum QOL. For example, erythropoietin, one of those hormones, stimulates the bone marrow to produce red blood cells (DHHS, 2012). Renin, another hormone released by the kidneys, helps to regulate blood pressure (DHHS, 2012). A final crucial hormone regulated by the kidneys is calcitriol, the active form of vitamin D that is responsible for maintaining healthy teeth and bones as well as supporting the body's chemical balance (DHHS, 2012). When kidneys are no longer capable of producing these hormones, it is called a decrease in kidney function and is officially diagnosed as CKD (DHHS, 2012). A slight decrease in conjunction with the aging process is expected, but the progression to CKD is culture specific. The decrease happens progressively, not all at once. ESRD marks the final stage and renal replacement therapy (RRT) is needed to avoid mortality.

According to Collopy, Kivlehan, and Snyder (2013), CKD is categorized into five stages that are defined by a glomerular filtration rate (eGFR).

- Stage 1 – eGFR > 90 ml/m
- Stage 2- eGFR 89-60 ml/m

- Stage 3- eGFR 59- 30 ml/m
- Stage 4- eGFR 29-15 ml/m
- Stage 5- eGFR < 15 ml/m

The stages of CKD have associated signs and symptoms. Hypertension is a symptom experienced in Stage 1. There might be some elevation of waste in the blood, called creatinine or urea. Stage 2 entails a further reduction in kidney function, with more of an increase of urea in the blood. This category, localized to newborn infants and individuals who are elderly, is expected to occur in both populations. Stage 3, on the other hand, has symptoms of anemia and bone disease, both of which occur because the kidneys are incapable of releasing the hormones renin and calcitriol (Collopy et al., 2013). Stage 4 is more aggressive and symptomatic. Individuals experience fatigue and loss of appetite because of the buildup of waste within the body. Fluid retention is usually noticeable in the periorbital area (i.e., around the bottom eyelid) and in the face, hands, and legs, including pitting edema in the legs. Frequent urination at night also occurs at this stage. Stage 5 is considered complete kidney failure, so RRT becomes necessary. The method of and preparation for treatment are discussed in depth with the individuals at Stage 4.

Hypertension and diabetes are the two major contributors to kidney failure. The CDC (2016) consider hypertension as a blood pressure of 140/90 or greater. Practitioners have defined prehypertension as a systolic pressure range of 120 to 139 and a diastolic pressure range of 80 to 89. The CDC described diabetes as the body's inability to produce enough insulin or its failure to use its own insulin. Both scenarios cause a buildup of glucose in the blood. Diabetes is by far the leading cause of ESRD (Collopy et al., 2013). According to the CDC, diabetes was the leading cause of 33% of new ESRD cases in Georgia in 2005, and in 43% of the cases, hypertension was the primary cause of CKD. In addition to diabetes and hypertension, high levels of either protein or albumin are indicative of decreasing kidney function.

Some groups are disproportionately affected by kidney disease. Specifically, African Americans are 3 times more likely than other ethnic groups to develop ESRD (CDC, 2014). Powe (2003) asserted that there is an increased risk of CKD in the minority population, the African American population in particular, that is related to this group's poor access to care, inadequate health behaviors, and poor clinical management. There is a gap in the relationship of CKD and ESRD awareness of the disease among African Americans in DeKalb County, Georgia. I conducted this study to identify an intervention that explored ESRD and its treatment in this population. The prevalence of ESRD has increased to epidemic proportions, and continued growth is expected, mirroring the increased number of cases of diabetes and hypertension in the African American community and the aging population.

There are several options for treating CKD and ESRD, including in-center hemodialysis (ICHD). According to the Southeastern Kidney Council (SKC, 2010), 16,000 people currently are receiving dialysis in Georgia, with a little more than 1,600 of them residing in DeKalb County. Although much is known about kidney disease such as CKD and ESRD, little is known about individuals' experiences and perceptions of treatment options related to dialysis, particularly ICHD. I thought it important to explore and understand the experiences of the individuals who undergo these treatments within this particular setting because the treatment options impact their QOL. According to the CDC (2014), kidney failure can lead to other health problems such as possible pulmonary edema and pericarditis, an infection of the heart; increased levels of potassium and possible death; decreased production of red blood cells and more susceptibility to infections; possible weakening of the immune system and possible depression; and premature death. It was important to understand more clearly how certain treatment options can exacerbate the decreased QOL experienced by individuals diagnosed with kidney disease. The social change implication of this study is to reduce individual suffering and build professional understanding of ICHD to improve patient health and QOL over the course of kidney disease treatment.

There are three options available in the treatment of ESRD: transplantation, peritoneal dialysis (PD), or HD. Of these three options, the Centers for Medicaid and Medicare (CMS) prefer transplantation because it more closely mimics the normal functions of the kidneys and offers a better QOL (as cited in Bostock et al., 2013). Although this treatment might be the most effective for ESRD, kidney transplant is not available for many patients (Collopy et al., 2013). Collopy et al. (2013) noted that more than 95,000 individuals currently are waiting for kidney transplants. Some patients might die while waiting, and others might receive dialysis as an alternative treatment. According to Bostock et al. (2013), even though there has been a decrease in the mortality rate of dialysis patients, approximately 15% to 20% continue to die each year, a situation that emphasizes the importance of early transplantation.

In addition to being the most effective, transplantation is the most cost efficient of the three treatment options. Patients incur a single expense for the transplantation surgery and maintain much more manageable costs for antirejection medications. In comparison, HD requires continuous treatment and payment until the patient either dies or receives a transplant. The positive impact of a kidney transplant on morbidity, mortality, QOL, and medical expenses is undeniable (Bostock et al., 2013).

Lindqvist, Carlsson, and Sjoden (2000) compared the QOL and clinical outcomes of patients undergoing HD and PD. Results demonstrated that patients undergoing both treatments have stressors. PD requires placement of a catheter in the peritoneal cavity during the treatment process. The catheter has an external port that is visible outside the abdomen. This port is the reason a number of patients choose HD over PD; they sometimes perceive the port as distorting and negatively affecting their body image. A licensed and trained nurse provides in-center education to patients on how to perform treatments. According to Harwood and Clark (2011), a liquid solution is infused into the body by way of the external port (see Appendix B). The solution remains in the peritoneal cavity to allow the removal of toxins by osmosis and diffusion. Toxins cross over to an area of higher concentration, which is the dextrose in the solution, and then drain from the body by way of the external port. This option is less traumatic to the body, and after a sufficient level of supervised training, patients can self-administer this treatment in the comfort of their own homes (Harwood & Clark, 2011). Patients also can use HD at home, but it requires a different access type and equipment (see Appendix C).

According to Collopy et al. (2013), there are three different access types known to HD therapy. A catheter is used temporarily to allow for emergency dialysis, permanent access placement, and maturation; however, patients are more susceptible to infections with this access type. A fistula is the preferred access type, but it requires surgical placement and maturation time. The graft is preferred second to the fistula, but it also requires surgical placement and maturation time. PD uses the peritoneum as a semipermeable membrane, whereas HD uses an artificial kidney called a dialyzer as the semipermeable membrane. The access mechanism is used to move blood from the body to the machine and the artificial kidney. Excess fluid, toxins, and some electrolytes are removed (Collopy et al., 2013). HD has an adverse effect on sufferers' QOL because of related fatigue, blood pressure complications during treatment, access complications, and acquired infections. The time spent traveling to and from dialysis, as well as the time spent receiving treatments, are other drawbacks to HD (Seccareccia & Downar, 2012).

When HD is performed in the comfort of the patient's home, the process is called home hemodialysis (HHD). My study focused on ICHD. The CMS have specific guidelines known as the conditions for coverage to ensure the safety of HD patients (Bednar & Latham, 2014). HD employees must know these guidelines and follow them on a daily basis. Mark, Molzahn, Berry-Hauf, Hutchings, and Hughes (2014) suggested that patients have died in dialysis facilities resulting from the neglect or failure by staff to follow rules and regulations.

Much progress has been made over the years to ensure safety after an unrecognized risk has taken place (Bednar & Latham, 2014). It is understood that patients' lives are in the hands of caregivers each time patients enter the facility. Consistency and retention with regard to staff provide a sense of security and continuity of care for ICHD patients (Lee, Gudex, Polvlsen, Bonnevie, & Nielsen, 2008), yet there is a high turnover rate in dialysis treatment facilities, so maintaining competent employees also has presented a challenge for the facilities (Longo & Hain, 2014). These occurrences have been known to create anxiety and apprehension for ICHD patients (Longo & Hain, 2014).

Statement of the Problem

There are approximately 884,000 Georgians living with CKD in Stages 1 to 4, according to the Georgia Department of Public Health (GDPH, 2006). According to the CDC (2012), RRT accounts for more than 6% of the Medicare budget. Atkins (2005) suggested that the number of people being diagnosed with kidney failure is expected to increase, mirroring the increase in obesity, diabetes, and hypertension. According to the GDPH (2006), kidney disease is a severe and costly chronic disease in Georgia as well as throughout the United States. Total Medicare expenditures for ESRD reached $33 billion nationally in 2010; Medicare costs for ESRD totaled $75,000 per patient per year (CDC, 2012). GDPH described ESRD as the ninth leading cause of death in Georgia, accounting for 1,475 deaths in 2003, equivalent to 4 deaths every day in 1 year.

According to the SKC (2012), this costly disease affects men more often than women and African Americans more than any other ethnic group. The literature has long documented that ESRD affects African Americans at a higher rate than other races (SKC, 2012). In Network 6 of the SKC, approximately 26% of the general population is African

American and 65% European American, but approximately 60% of the ESRD population is African American and 35% European American (SKC, 2012). There were 9,919,945 people residing in Georgia in 2012. Of that number, approximately 16,943 were receiving RRT. In that same year, the prevalence of ESRD per million was 1,708. DeKalb County, Georgia, has more than 1,400 dialysis patients.

Kidney transplant, the more certain treatment for ESRD, is not available for most patients (Collopy et al., 2013). Therefore, these patients are left to decide whether to receive treatment by ICHD or HHD. The daily process of managing a chronic disease involves illness management and role management. Illness management varies between very complex and technical works (e.g., doing dialysis at home) to quite simple tasks, such as taking a pill (Audulv, 2013). Dialysis patients must commit to treatment therapy three times per week if they are ICHD patients and as much as six times per week if they are self-treating in the comfort of their own homes.

Researchers have evaluated the infection rates within dialysis facilities, clinical outcomes of dialysis patients, and the use of PD versus ICHD. However, there has not been any research evaluating the lived experiences of ICHD patients within DeKalb County. A study of this nature could help to promote patient compliance, change government and company policies, and give ICHD patients a voice to help to improve the QOL of those receiving ICHD by addressing opportunities for a better experience.

Examining individuals' experiences during ICHD is of extreme importance to improving QOL in DeKalb County, given the increasing incidence of comorbidities that can lead to CKD and ESRD. Obesity is a major challenge in DeKalb County.

Approximately 30% of adults and 13% of high school students in the county are obese. If there are no upstream measures to reduce the progression of the number of people developing CKD, the Medicare budget will burst. Most ICHD patients are unable to work, causing an economic deficit in the workforce and labor. DeKalb County, Georgia, could experience an economic decline if CKD continues to mirror the increase in obesity, hypertension, and diabetes.

Research Questions

My study was guided by three research questions (RQs):

RQ1: What are the lived experiences of the African Americans in the DeKalb County area who undergo ICHD treatments?

RQ2: What are the common themes related to the perceived threat (perceived susceptibility and perceived severity) of ESRD in African Americans participating in ICHD?

RQ3: What are the perceived barriers that led to the decision to use ICHD instead of HHD or PD?

Purpose of the Study

The purpose of this study was to give a voice to this population. I evaluated ICHD patients and their experiences within the facility, giving rise to common themes that might support a sustainable intervention and be the foundation to implement social change. Describing this experience is important to help interdisciplinary teams of nephrologists, nurses, dietitians, and social workers to develop plans of action that will meet the specific needs of African Americans, thus increasing compliance, improving

QOL, and ensuring more positive clinical outcomes. Knowing the perceived susceptibilities and perceived severity of this population will help to create a plan of awareness for the community. I provide information that might encourage prevention and early treatment, thus reducing the prevalence of this debilitating disease in high-risk groups.

Theoretical Framework

The health belief model (HBM) is a health behavior application used as a predictor of health behaviors. The model was developed in 1950 by psychologists Rosenstock, Hochbaum, Keegles, and Leventhal to explain why people would or would not use available health services such as chest X-rays and vaccinations, to name a few (McKenzie, Neiger, & Thackeray, 2009). DHHS (2007) noted that the initial HBM was based on six constructs: perceived susceptibility, perceived severity, perceived threat, perceived barriers, perceived benefits, and cues to action. In other words, individuals would have to feel vulnerable to a condition, believe that the condition was serious enough to invoke change, and believe that changing would benefit them in order for action or behavior change to take place. Self-efficacy was added later to the model (Abood, Black, & Ferral, 2003).

Creswell (2009) described the conceptual framework as the theoretical lens that becomes an advocacy perspective that shapes the types of questions asked, informs how data are collected and analyzed, and provides a call for action or change. I used the HBM because it was the most appropriate theoretical lens for this study. The HBM has been used to explore and predict health behavioral changes and health decision making with proven success. The constructs of the HBM pinpointed the perceptions that formed the lived experiences of ICHD patients.

Nature of the Study

I employed a qualitative design with a phenomenological approach that allowed me to explore the general occurrences that this group experiences under this particular phenomenon. The prevalence of CKD has increased globally, but more specifically within the DeKalb County area. Allowing these patients to have a voice could possibly generate social change.

The CMS surveillance database reports the incidence rate (IR) of ESRD. In addition, the CMS and SKC databases present and evaluate the number of facilities and the number of patients whom those facilities service. The facilities report how many treatments are performed each month for each patient. What remains unknown is the impact that these in-center treatments have on the lived experiences of the African American community of DeKalb County. A phenomenological approach served as the platform that allowed me to explore this experience and grasp the nature of the entire scenario.

Operational Definitions

Artificial kidney (dialyzer): An apparatus with hollow fibers used to clean the blood during HD treatments.

Catheter: A tube inserted into a large vein in the neck or chest and placed directly into the heart.

Fistula: An organic structure created by direct connection of an artery and vein in the arm.

Graft: A connection of a vein and an artery using plastic tubing.

Hemodialysis (HD): The process of using a machine to ultrafilter fluid and waste products from the blood by way of a catheter, fistula, or graft.

Home hemodialysis (HHD): Dialysis treatments for patients administered in the home setting.

In-center hemodialysis (ICHD): A facility that provides dialysis treatments.

Kidney failure: The inability of the kidneys to remove waste products and excess water.

Peritoneal dialysis (PD): The process of removing waste products and water from the blood by using the peritoneal cavity as a semipermeable membrane.

Renal replacement therapy (RRT): A type of therapy required when the kidneys are unable to remove waste products and excess fluids; the therapies include HD, PD, and transplantation.

Semipermeable membrane: A sort of barrier that allows certain particulars to pass through.

U.S. Renal Data System (USRDS): A national system that collects, analyzes, and distributes data related to the ESRD program.

Assumptions, Limitations, Scope, and Delimitations

1. ICHD patients are easy to locate because they must regularly visit health care centers for dialysis; however, finding patients who were willing to participate in the study could have posed a challenge.
2. The data collected during the interview sessions was subjective. The patients might not have been open and honest for different reasons related to bias typically encountered during research and/or personal preferences to limit the type of information disclosed.
3. The research was specific to African Americans in DeKalb County, Georgia, who are undergoing ICHD treatments. The results are not generalizable to other target populations.
4. The research design followed a phenomenological approach, which was specific to my interpretation.

Significance of the Study

The SKC (2012) has reported that treatment noncompliance is higher among African American dialysis patients than any other ethnic group. Noncompliance can mean a 30% to 50% higher risk of dying and a 13% higher risk of being hospitalized (SKC, 2012). J. Wells (2011) linked noncompliance to a lack of knowledge, a lack of resources, and a lack of motivation to adhere to the treatment regime. Evaluating the lived experiences of this group might invoke governmental policy changes or facility changes that could lead to greater knowledge and resources for African American dialysis patients, which could then greatly decrease their potential of noncompliance.

The dynamics of an ICHD unit are multidimensional and multifaceted. The consumers of ICHD facilities also have complex issues. Therefore, the results of this study might provide more insight into the experiences of African Americans receiving ICHD treatments as well as undiscovered issues and coping strategies that impact the overall HD experience for in-center patients. The insight gained about perceived severity and perceived susceptibility could form the basis for behavioral interventions that could increase compliance and improve QOL. Having a better understanding of the lived experiences of African American ICHD patients could lead to physical, emotional, mental, and financial benefits at the individual and societal levels.

Summary

The functions of a healthy kidney are vital to an optimal QOL. Once the kidneys are incapable of performing efficiently, a spiral decline in health is inevitable. The stages of kidney failure and the signs and symptoms that follow are known to practitioners, but upstream strategies to prevent the underlining causes are deficient. The two major causes of CKD are hypertension and diabetes, both of which are preventable conditions. Because there is an absence of upstream strategies to address those two comorbidities, the number of people diagnosed with CKD is expected to continue. There has been a plethora of research on CKD, ESRD, and the different modalities of treatment, but there has been no research on the effect of ICHD on the DeKalb County treatment sufferers. The key to improvement lies in understanding the lived phenomena of ICHD patients. Results will help to illuminate the complex experience of being diagnosed with kidney failure and then needing and deciding on RRT (PD, HHD, or ICHD). Chapter 2 reviews the literature relevant to CKD, ESRD, and their treatment options, with the emphasis on ICHD.

Chapter 2: Review of the Literature

Introduction

Quality health care services are not always easily accessible to African American communities. Therefore, more often than not, the diagnosis of CKD is in the late stages and is a complete surprise to the individual. Individuals diagnosed with ESRD in this manner must try to comprehend what ESRD means and then make lifestyle changes and choices. The first choice starts with deciding which treatment modality will work with the patient's lifestyle, if given the option to choose. A number of African Americans do not have information-seeking skills or sufficient patient-physician communication to make informed decisions. There are five treatment options to choose from, but African Americans are more likely to be presented with ICHD. Research has shown that ICHD reimbursements became more beneficial than home treatment options to practitioners and company owners. Because there was greater reimbursement for ICHD, home therapies were seldom offered to African American patients with CKD. Research has shown that there are a number of disparities in health care; as a result, African Americans are disproportionately affected by chronic disease.

The first dialysis treatment was performed at the University of Washington Hospital in 1960 to extend the life of a man who was experiencing renal failure (Blagg, 2011). Fifty-four years have passed since the first HD treatment, and exploration is still needed into chronic renal failure and those who experience renal failure. Interestingly, home therapy (i.e., dialysis at home) was initiated shortly after HD in 1966 (Blagg, 2011). The home program was started because the advantages were clear, particularly the opportunity for rehabilitation and the lower ongoing costs after training, which were less than half the costs of ICHD (Blagg, 2011).

There are two options of PD home therapy available to patients: continuous ambulatory peritoneal dialysis (CAPD) and continuous cycling peritoneal dialysis (CCPD). With CAPD, patients perform fluid exchanges at least four times per day. CCPD allows the machine to conduct the exchanges at night while patients sleep (Baillie, Lankshear, & Featherstone, 2011). The difference is that CAPD is conducted manually during the day and CCPD is conducted by a device at night, both with the same results. However, if there is a power outage, patients will have to conduct manual exchanges. Lindqvist et al. (2000) explicitly showed that no matter the treatment option, patients suffer physiological and psychological stressors. However, of the three options of dialysis, namely, CAPD, CCPD, and HD, patients who undergo HD experience the greatest decline in QOL (Lindqvist et al., 2000).

The option most preferred by nephrologists in past years has been HD. The main reason ICHD has been preferred by this group is because it allows a large number of patients to be treated at one time (McIntyre, 2010). According to Collopy et al. (2013), placing patients on dialysis fundamentally changes their lives and marks the transition from a regular and constant body cleansing of toxins to a lifestyle where there is a recurrent buildup of toxins followed by rapid removal. The result has significant effects on nearly every organ system of the body. HD treatment requires a catheter, fistula, or graft to gain access to the blood. The catheter, considered dangerous because of the possibility of recurrent infections in the receiver’s body, is placed for quick access to allow permanent access to mature. Fistulas and grafts require invasive placement procedures and a waiting period after surgery for maturation. After maturation, blood is accessed through 15-, 16-, or 17-gauge needles at each treatment. Once there is access to the patients’ blood, they are connected to a dialysis machine for a prescribed number of hours. Seccareccia and Downar (2012) demonstrated that although dialysis can extend a life, there also is substantial mortality associated with it. HD can negatively affect QOL by causing fatigue, fluctuations in blood pressure, problems with vascular access, and infection, to name a few (Seccareccia & Downar, 2012).

Research Strategy

I used several different strategies to find support in the research literature for this project. The Walden University database was accessed using such broad search terms such as *kidney disease* and *CKD*. More specific to the study, search words *renal disease, renal failure*, *renal replacement therapy*, and *renal insufficiency* were used to locate pertinent literature. The reference lists of the articles ascertained through the research database yielded yet another avenue to retrieve resources. Walden Online Library and Goggle Scholar were the two online databases that I employed to retrieve articles and books of reference. A host of articles related to CKD and ESRD were in the online databases. A number of articles discussed living with renal failure and RRT. Articles specific to African Americans were found in the review, but there was no research specific to the DeKalb County area.

Review of Literature

Although other studies have employed a qualitative approach to explore the subjective experiences of individuals who have undergone dialysis treatments, the purpose of this study was to explore the perceptions and lived experiences of ICHD patients as well as their perceived susceptibility to ESRD and the severity of the disease prior to ICHD. A second aim of the study was to formulate an understanding of the barriers to home therapies among African Americans. Numerous studies have been conducted to compare PD to HD. For instance, Choi et al. (2013) conducted a comparison study of 1,060 Korean participants. This prospective, observational cohort study found that PD yielded a far better survival rate than HD in the early years of treatment. Heaf and Wehberg (2014) examined the relative survival rate of HD patients to PD patients in Denmark. According to Heaf and Wehberg, there has been a significant increase of ESRD survival over the past 20 years across both modalities; however, nonacute and early referrals played a significant part in the increased survival rate.

The clinical outcomes of PD and HD, along with their impact on QOL, have been explored. Quantitative and qualitative approaches have been used to collect data about patients' PD and HD experiences. Research to date has identified the need to emphasize that appropriate primary care and early referrals can make a significant difference in patients' modality choice and overall survival rates. Clarkson and Robinson (2010) reported that the patients in their study expressed the inability to maintain religious and cultural customs resulting from fatigue, leg cramps, headaches, and lack of energy. The malaise effects that started after dialysis treatments and continued into the next day caused an inability to complete chores and maintain employment, stimulating feelings of depression.

In addition, ICHD patients expressed the inability to be intimate with their spouses or significant others (Nazly, Ahmad, Musil, & Nabolsi, 2013). Polaschek (2003) was able to demonstrate through a qualitative approach how renal failure and the treatments created enormous physiological and psychosocial issues for patients undergoing dialysis treatments. Practitioners and immediate staff played significant roles in patients' abilities to cope. Maintaining constant communication and keeping patients informed also have been important positive factors for patients, along with empathy for their situations (Bass et al., 1999). Lindqvist et al. (2000) illustrated how renal failure and treatments can affect QOL regardless of treatment modality. Results of their study suggested that HD patients appeared to encounter the largest decrease in QOL; however, many remained hopeful.

Primary Care

ESRD is a debilitating disease that is associated with a decrease in the QOL of those it affects (Clarkson & Robinson, 2010). It can decrease economic growth and development while steadily increasing morbidity and mortality (Atkins, 2005). Early intervention, starting with primary physicians, is key to changing the poor outcomes of patients with ESRD (Amedia & Perazella, 2006; Atkins, 2005; Fortin et al., 2013; Powe, 2003; Schoolwert et al., 2006; Stevens & Levin, 2013). Monitoring GFR and albuminuria (increased albumin in urine), especially in patients already diagnosed with hypertension and diabetes, is a key factor in diagnosing developing renal insufficiency that can indicate

CKD. Primary physicians recognizing these important factors can provide early referrals to nephrologists.

Atkins (2005) attempted to show the patterns surrounding CKD in the cross-sectional Australian diabetes kidney study. From April 1999 to December 2000, the study, conducted in an Australian community, monitored the albuminuria levels, serum creatinine levels, fasting glucose levels, glucose tolerance levels, blood pressure, and hematuria of 11,247 adults over the age of 25 years. As a result, the study associated microalbuminuria with glucose intolerance and hypertension. Atkins was able to show a parallel relationship between diabetes and albuminuria, thus exposing an important risk factor to the development of CKD. By using data from the USRDS, Atkins showed how diabetes had increased as the major cause of CKD and, ultimately, RRT. Atkins suggested the development of detection and prevention programs to eradicate or decrease the prevalence of diabetes, hypertension, and CKD with a concerted effort from global institutions, governmental entities, health care providers, and practitioners. He also suggested lifestyle modifications and increases in education in communities of high prevalence.

Nephrologists are able to provide their patients with education to manage hypertension and glucose levels to support the delay of CKD and prevent the progression to ESRD (Stevens & Levin, 2013). They also provide angiotensin-converting enzymes inhibitors (ACEIs) to support blood pressure control and angiotensin II receptor blockers (ARBs) to aid in glucose control, both of which have proven effective in delaying the progression to ESRD (Stevens & Levin, 2013). Unfortunately, primary physicians usually do not recognize the changes in the eGFR and albumin levels, causing late referrals (Amedia & Perazella, 2006; Clarkson & Robinson, 2010). A study conducted by Schievink et al. (2015) illustrated just how effective the rennin-angiotensin system is if used early enough in delaying ESRD.

Poor health care is directly related to disparities not solely due to individuals' behavior, both of which are a catalyst for chronic disease development, morbidity, and mortality (Fortin et al., 2013; Gallegos, 2007; Kim, Kumanyika, & Kim, 2010). Logan, Guo, Dodd, Muller, and Riley (2013), as well as Kim et al. (2010), cited the following as a common misconception: Individuals are responsible for their own health and well-being; thus, disparities in health care are not a societal problem, but one of individual choice. However, Schneider (2010) pointed out that the social environment can influence and have profound effects on health behaviors if there is an unhealthy culture; as a result, chronic disease develops. Schoolwert et al. conducted a study in 2006 that identified the criteria for a disease to be considered a public health issue: level of burden caused by the disease, disproportionate distribution of the disease, known methods of prevention, and evidence showing that prevention methods are not in place. CKD meets the criteria to be labeled a public health issue, so it should receive public health attention and prevention efforts, according to Schoolwert et al.

Schoolwert et al. (2006) defined a public health issue as an economic burden that continues to grow, disproportionately affects ethnic groups, and is preventable with upstream strategies in place. Schoolwert et al. used a case study approach to present known strategies to prevent CKD development, such as early identification of those at risk and close monitoring. Individuals at risk had two major health issues, namely, hypertension and diabetes. Schoolwert et al. conducted a comparison, starting with statistical analysis from the USRDS. According to the researchers, there were approximately 14,500 ESRD patients in 1978, a number that increased to approximately 100,359 in 2002. There also was an increase of people using dialysis and transplantation from 42,000 to 431,000, respectively, in those same years. This burden decreased productivity and economic growth, as asserted by Atkins (2005). The death rate due to ESRD was approximately 71,000 in 2000, but it is expected to reach 352,000 by 2030.

In 2001, national health care expenditures were more than $22 billion, 64% of which went to Medicare costs. There were more than 385,000 people in the United States with ESRD receiving RRT (Schoolwert et al., 2006). Schoolwert et al. (2006) identified a parallel between the increase in CKD and how it met the first criterion of a public health issue, that is, how CKD affects African Americans at a greater rate than any other ethnic group. Schoolwert et al. estimated that 2% of European American men, 1.7% of European American women, 5.5% of African American men, and 6.3% of African American women developed ESRD between 1993 and 1995. There was a significant increase in a 5-year time frame of 2.5%, 1.8%, 7.3%, and 7.8%, respectively (Schoolwert et al., 2006).

Schoolwert et al. (2006) presented known strategies to prevent CKD development, such as early identification of those at risk and close monitoring. Performing annual urine testing could detect proteinuria or microalbuminuria for early interventions and referrals. They also proposed maintaining strict blood pressure and blood sugar control, prescribing ACEIs and ARBs as helpful early intervention strategies, strategies that Atkins (2005) also advocated. Education that includes lifestyle and dietary changes for those at risk would support management of the precursors to CKD development.

Schoolwert et al. (2006) established that for this population, such strategies were not in place, as evidenced by late referrals, suboptimal care, and undiagnosed and untreated CKD. ESRD surveillance was active and monitoring ESRD patients; however, no tracking mechanism was in place for patients in the early stages of CKD. Therefore, interventions were not timely enough to implement primary and secondary prevention methods to decrease mortality and morbidity and to improve patient outcomes.

The statistical data in this study gave credence to the research. The data also helped to build the position of poor accessibility to quality health care and primary interventions for African American communities. This study expressed the impact of poor care management and the negative results.

Amedia and Perazella (2006) determined that CKD and ESRD were manageable diseases, but they emphasized that disease management (DM) begins with primary care. DM has been described as a coordinated effort between and among clinicians to provide education, screenings, and early diagnoses and referrals. Gallegos (2007) showed that minority populations are the most in need of quality of health care services, including screenings, medication, education and prevention, and life-saving technology. However, these services are usually inaccessible and unaffordable for most minorities, which results in health care disparities that are ecological in nature, meaning that they are prevalent in the social, economic, physical, and environmental conditions of minority groups (Atkins, 2005; Fortin et al., 2013; Nelson, 2002; Sorensen et al., 2011).

Gallegos (2007) also emphasized that DM is an exchange of patient information between insurance providers and health care providers. Increasing funds for an increase in nephrology presence and rapid consults could result in decreasing burgeoning healthcare costs (Amedia & Perazella, 2006). All of the comorbidities associated with CKD and ESRD and the illnesses created by the disease condition itself would be monitored and treated early under a DM system.

The KEEP 2.0 study (Schievink et al., 2015) revealed that 67% of patients starting RRT were anemic. Anemia occurs with a decrease in kidney function, something that the DM system would monitor and treat with erythropoietin and iron to maintain adequate hemoglobin levels, according to the study. Hypertension would be treated with angiotensin drugs that slow progression as well as control blood pressure, as proven by the study conducted by Schievink et al. (2015). Patients would receive the needed education to monitor and treat disease development, as well as vaccination and medication adherence.

CKD is exacerbated by the effects of the poor functioning of the kidneys. These effects can include anemia, weakening of the bones as the result of hyperparathyroidism, and cardiovascular disease. The current study demonstrated the effects of early referrals to nephrologists and early interventions, as mentioned previously by Atkins (2005), Schievink et al. (2015), and Schoolwert et al. (2006). CKD can mean economic hardship for patients and stretch the boundaries of the health care budget while steadily increasing morbidity and mortality rates of minority populations (Atkins, 2005; Schoolwert et al., 2006). According to Williams et al. (2016), by the end of 2015, more than 2.5 million individuals had been diagnosed with ESRD, a number that is increasing annually. They also asserted that 123,474 new cases of ESRD were diagnosed in 2015.

Early interventions that start with primary physicians are key to changing the poor outcomes of individuals with ESRD. Identifying individuals at high risk for hypertension and diabetes is a pertinent step in the primary prevention of renal insufficiency and facilitates the treatment of patients while they are still in the early stages of CKD. CKD can be prevented or delayed by identifying individuals at risk and treating them sooner to ensure healthier outcomes (Clarkson & Robinson, 2010; Schievink et al., 2015; Schoolwert et al., 2006; Stevens & Levin, 2013). Because upstream strategies to prevent ESRD and all other chronic diseases are not in place, African Americans are affected disproportionately, as noted by Schoolwert et al. (2006).

Racial Disparities in Care

Nelson (2002) conducted a study on racial disparities at the request of the U.S. Congress, which was interested in identifying the extent of the gap in quality health care experienced by minorities versus their European American counterparts. Nelson found a number of disparities, including stereotyping, health system bias, discrimination, and patient bias. Racial bias existed, even when there were no differences in insurance coverage, income, age, or ailment between minority and European American patients. Nelson as well as Powe (2003) noted that European Americans received better services and treatment options than minority populations in the United States, even when SES was not an issue or barrier.

In a study of patients with uncontrolled hypertension, Kendrick, Nuccio, Leiferman, and Sauaia (2015) concluded that African Americans had shorter visits with their health care providers than European American patients did. They also reported that African Americans reported worse communication than European Americans with physicians, especially regarding psychosocial and rapport-building behaviors. There is no question that disparities continue to exist, but many people remain unaware of them. Increasing awareness about health care disparities is key to decreasing them.

Powe (2003) described a typical emergency room visit for an African American patient. Powe reviewed lab results; the typical conversation between the patient and the clinician; and the limited intervention that the patient received, despite presenting with symptoms related to developing CKD. This case study demonstrated the disparities associated with prediabetic care, poor quality of care, and poor outcomes for minority patients regarding CKD. European American patients had lower GFRs at the initiation of the process than African American patients, but the African American patients progressed to ESRD at a faster rate because of poor care and the lack of early interventions (Powe, 2003).

According to Pearson (2008), African Americans progress at 90% to European Americans at 1.7%. Renin-angiotensin aldosterone systems inhibitor is prescribed for European Americans, but not African Americans, to slow the progression of the disease process, disparities also pointed out by Atkins (2005) and Schoolwert et al. (2006).

Pearson as well as Powe (2003) contended that that progression from CKD to ESRD is related to the lack of primary care services. They also noted that African American patients are more likely than European American patients to not have access to health care services because they do not have insurance.

Limited health care services have been identified as another significant barrier increasing disparities between the races. Powe (2003) emphasized that it is imperative for African Americans to receive preventative care because of the known risk factors of hypertension and diabetes. Powe supported periodic screenings for proteinuria and annual assessments for albuminuria for individuals with hypertension or diabetes. Atkins (2005) and Schoolwert et al. (2006) also supported screenings as a precautionary measure. Powe also noted that African Americans had more chance than European Americans of not receiving the necessary tests and medications, as echoed by Kendrick et al. (2015).

Powe (2003) also found that African Americana are less likely than European Americans to have discussions with their physicians about PD or transplantation. Despite the disadvantages, African American patients appear to fare better after starting RRT and entering into the Medicare ESRD Entitlement program (Powe, 2003). According to Powe, they have better access to care with the Medicare insurance benefit, and there is a decrease in the mortality rates of African Americans than European Americans on dialysis, which means that preventative care can possibly decrease the prevalence of ESRD

More funding should be provided to investigate violations and enforce regulations, according to Nelson (2002). Nelson argued that consistency in clinical care and practices, along with an increase in preventative care, would have an important impact in decreasing the gap. Nelson offered five recommendations to correct this gap: (a) Take steps to increase awareness of health care providers, the general public, and key stakeholders about racial and ethnic disparities; (b) consider legal, regulatory, and policy interventions; (c) reduce disparities by ensuring that clinical practices are uniform and based on the best available science by providing incentives to doctors to support the use of preventative services; (d) implement education programs to increase patients' knowledge of ways to best access care and participate in treatment decisions; and (e) collect adequate data to track the nation's progress in understanding and reducing the causes of disparities. However, Nelson also argued that a concerted effort by health care providers, insurance carriers, and receivers of health care services is the only way to eradicate racial disparities in the provision of health care services.

Nelson (2002) did not attempt to prove that disparities existed, but identified the wide range of disparities in existence, instead. The current study argued that health care disparities are one of the causes of increased and disproportionate rates of ESRD within the African American community. Nelson suggested that consistent medical services, accessible services, and preventative services would result in a profound decrease in chronic disease, especially CKD.

Defining PD and HD

ESRD is a slow and progressive deterioration of the kidneys that adversely affects kidney function. The deterioration moves from a state of CKD, when primary and secondary interventions can still be implemented, to ESRD, when RRT is required

(Powe, 2003). Once the kidneys are unable to function effectively, RRT is necessary to sustain life.

Indications of RRT include the following symptoms:

- Increased uremic symptoms.
- Persistently high potassium levels.
- Increased extracellular volume.
- Shortness of breath.
- Increased phosphorus levels (optional).
- Increased creatinine levels.

RRT is used to improve hemostasis by removing waste, unwanted solutes, and water through a semipermeable membrane. There are several options or services offered for RRT, including PD, HD, or transplantation (Nazly et al., 2013). For HD, viable access (AVF, AVG, or CVC) must be in place to filter blood from the patient to the dialyzer by way of extracorporeal circuits such as fistula needles, bloodlines, and dialyzer (Seccareccia & Downar, 2012). The blood is processed through the dialyzer at a rate of 300 to 600 ml/min; dialysate follows at a countercurrent of 500 to 1,000 ml/min (Foote & Manley, 2008).

The semipermeable membrane is found within the dialyzer, creating compartments for blood and dialysate. Unwanted particles move from the blood and then cross over the membrane and into the dialysate solution to be removed. This process occurs by diffusion and convection (Foote & Manley, 2008). Foote and Manley (2008) emphasized the National Kidney Foundation’s Kidney Disease Outcome Quality

Initiative (KDOQI) guidelines for adequate HD, which is a clearance rate of at least 1.2, and is evident on lab results.

There are complications associated specifically with HD that can include cramps, nausea, vomiting, headaches, chest pain, back pain, fever, and chills. Seccareccia and Downar (2012) noted that HD can affect QOL by causing fatigue, fluctuating blood pressure, problems with vascular access, and infections. Foote and Manley (2008) suggested that the management of the complications drives the increase in HD costs. Collopy et al. (2013) stated that rapid shifts of fluid and electrolytes during HD causes a reaction, most often hypotension, which Foote and Manley (2008) cited as the most common complication. Davenport (2014) stated that ischemic damage in the brain develops after the start of HD, a claim supported by cardiac studies. Pruritus and infections associated with HD and PD are considered complications of the disease process rather than the treatment process.

Foote and Manley (2008) suggested that either patients who suffer from severe hypotension and instability and who maintain residual function or patients who would like to maintain autonomy are better candidates for PD than HD. PD uses an abdominal catheter to infuse the dialysate solution and the peritoneum as the semipermeable membrane to ultrafilter solutes. Just as HD has a dialysate compartment and a blood compartment, so does PD. However, PD does not have the countercurrent to increase diffusion and ultrafiltration that HD does have. The solution remains in the peritoneal cavity and solutes move from an area of low concentration (i.e., in the blood vessels) to an area of higher concentration (i.e., the dialysate solution). The dialysate, along with the unwanted solutes, is drained out through the catheter port. PD patients generally perform these exchanges three to four times per day to prevent the buildup of toxins (Foote & Manley, 2008). If a PD patient does not meet the 1.7 (i.e., higher than HD) clearance goal set by KDOQI, the number of exchanges can be increased, the volume of the solution can be increased, and even the strength of the solution can be increased. The dialysate solution has four strengths (1.5%, 2.5%, 3.86%, and 4.25%) to support toxin and fluid removal (Foote & Manley, 2008). PD is less traumatic on the body because there is no countercurrent pressure.

The ultimate goal of both therapies is to remove unwanted toxins, waste products, and excess fluid from the blood. However, Collopy et al. (2013) emphasized that people's lives do change once they are placed on HD. The major internal change is from the kidneys' ability to constantly remove toxins to a recurrent buildup and rapid removal of toxins by HD machines. This rapid removal affects nearly every organ system (Collopy et al., 2013).

PD therapy also is not without specific complications. Mechanical problems with PD catheters are common. The catheters can have internal kinks that obstruct the flow, both in and out, of dialysate. In other words, the kinks can prevent dialysis treatments altogether until repaired (Foote & Manley, 2008). The skin is expected to heal around the exit sites of catheters and create a kind of seal. Foote and Manley (2008) suggested that catheters can have too much movement without the seal and can cause tissue irritation and possible infection. PD patients also can experience pain during infusion because of rapid flow (Foote & Manley, 2008).

Catheter infection is the major problem with PD. Infections in PD have been identified as a cause of morbidity and mortality in PD patients (Foote & Manley, 2008). Foote and Manley (2008) stated that infections occur in one in every 24 to 48 patient months in the United States. It is important that patients learn good infection control techniques to prevent infections.

Conceptualizing PD and HD Experiences

HD is a treatment option available to maintain life; however, HD patients also encounter lifestyle changes and challenges (Guerra-Guerrerro, Plazas, Cameron, Salas, & Gonzalez, 2014). Klang, Bjorvell, and Clyne (1999) noted that people who have suffered renal failure have had to undergo a number of treatments indirectly related to their dialysis treatments and have had to learn to cope. Additional treatments can include frequent hospitalizations, surgical procedures for access placement, angioplasty for clotted accesses, and blood transfusions. Klang et al. also suggested that predialytic training and education can help to alleviate some anxiety and assist with preparation. African Americans most often do not receive education prior to starting HD; this lack of education can create additional stress as they begin life-sustaining treatments. The thought of being connected to a machine three times per week was another struggle for the HD patients in Klang et al.'s study.

Knowing that using the machine means being fatigued and unable to participate in a number of daily activities was frustrating but something the patients had to accept (Guerra-Guerrerro et al., 2014). Many patients also are unable to maintain employment because of the debilitating effects of HD. ESRD is a disease associated with a significant decrease in QOL (Clarkson & Robinson, 2010). Guerra-Guerrerro et al. (2014) sought to explore and explain the experiences of HD patients by way of a hermeneutic phenomenological approach. They interviewed 15 patients from three HD facilities in Chile. Results demonstrated the wide range of ages, number of years on dialysis, and income levels of the patients. The patients in their study emphasized that their lives were into two phases. The first phase occurred prior to being diagnosed with renal failure, when they were full of life and able to participate in it. The second phase started after diagnosis, with their lives changing from what they knew them to be (Guerra-Guerrerro et al., 2014). The first theme to emerge from the study was the need for patients to embrace the final stage of renal disease and the treatment process. The initial struggle of most patients was accepting the diagnosis of ESRD and what that meant.

The second theme that emerged involved preventing the progression of the disease by managing the symptoms (Guerra-Guerrerro et al., 2014). The researchers emphasized the love-hate relationship between dialysis patients and their life-sustaining treatments. The patients knew that the HD treatments prolonged their lives and that if they missed any treatments, toxins would build up in the blood and could possibly cause more damage or death. If diet and fluid restrictions were not followed, even more problems could result for the HD patients. Results of the study showed that even though the patients hated the changes, they had to embrace them to continue to live at optimum levels.

HD patients have reported other concerns and barriers. For example, patients who have used ICHD have discussed the strict scheduling restraints (Nazly et al., 2013) that can decrease their ability to travel and be spontaneous. The kidneys' inability to filter fluid and solutes also means fluid and dietary restrictions (Clarkson & Robinson, 2010). Engaging in ICHD might decrease the ability of patients to socialize and visit family and friends outside of the clinic setting (Clarkson & Robinson, 2010; Nazly et al., 2013). Although not often discussed, patients in Nazly et al.'s (2013) study mentioned time costs related to traveling to and from the facility and then being dialyzed for 3 to 4 hours, depending on specific patient prescriptions. This 3-day ritual each week was considered a time-consuming waste of the day by some participants (Nazly et al., 2013). Adherence to a dialysis schedule also caused some patients in Lindqvist et al.'s (2000) study to feel a loss of independence and control. This loss of control was mirrored in a study by Koester (2013). Koester noted that patients often have a total loss of control because they are told where to dialyze, what time to come in, where to sit, and who is going to take care of them.

Guerra-Guerrerro et al. (2014) discussed the decrease in QOL of patients receiving HD treatments. The debilitating physical and psychological changes that the ESRD population experienced as the result of the disease and treatment was emphasized in their study and echoed by Williams et al. (2016). I contend that there is a need for social change to address kidney failure and the diminished lifestyle associated with it. Results of my study will help to support the need for change to preserve healthy living.

Herlin and Wann-Hansson (2010) used a phenomenological approach to understand the experiences of persons between the ages of 35 and 45 years who were dependent on HD. The time frame on HD ranged from 6 months to 3 years. In this short time, participants described feelings of living double lives and not really having the opportunity to live a single life to its fullest (Herlin & Wann-Hansson, 2010). The participants characterized living with HD as a restricted lifestyle; however, they also understood the need for HD treatments, even if the treatments did not allow them to live well. They felt that their freedom was lost and that they were being forced to live with the disease and the treatment process. Only one of the participants was married. The other eight were single and expressed feelings of loneliness. Although the patients' ages varied, the participants were in the prime of life and living at a time when most were getting married and starting families. This single group complained that the disease process crippled their ability to find life partners. The single patients were afraid to find potential mates and then have to talk about ESRD and dialysis treatments (Herlin & Wann-Hansson, 2010).

The participants emphasized that their lives centered on receiving kidneys and then starting to live again. They currently felt that living with HD did not reflect their real lives. The participants believed that once they received new kidneys, they would be free of the needles that they dreaded getting with each treatment, free of the fear of acquiring other diseases while at the HD center, and free of the worry of retaining competent HD staff to care for them (Herlin & Wann-Hansson, 2010).

This article about Herlin and Wann-Hansson's (2010) study highlighted the attitudes and opinions of people who were enduring HD treatments. I conducted this study because I believe that the QOL of HD sufferers is compromised and that social change is needed. This article emphasized that for HD patients, life remains at a standstill until transplantation.

Lindqvist et al. (2000) supported transplantation as the best option for people with kidney insufficiencies, followed by PD and then HD. Because transplantation is not readily available to African American patients experiencing renal insufficiency, dialysis is the most viable choice (Powe, 2003). In the United States, according to Assari (2016), African Americans are at higher risk than European Americans of morbidity and mortality associated with CKD. Although only 13% of Americans are African Americans, 32% of kidney failures occur among this population. This problem becomes even more tragic when considering the lower access that African Americans have to kidney transplantation (Assari, 2016).

According S. Wells (2009), African Americans are less likely than European Americans to be placed on the kidney transplant waiting list (12.3% vs. 17.7%, respectively). Late referrals eliminate the possibility of preemptive kidney transplant prior to dialysis; therefore, African Americans are 70% less likely to receive preemptive kidney transplants (S. Wells, 2009). With the lack of early interventions, racism, and late referrals, African Americans are rarely presented with PD, transplantation, or the option to choose a treatment of any kind (Clarkson & Robinson, 2010; Powe, 2003). African Americans are 56% less likely to receive PD (Powe, 2003). Therefore, ICHD is the primary treatment option for African Americans, which is why it was necessary to understand the lived experiences of this population.

It was imperative for me to understand the impact of HD on African Americans through a subjective lens. Knowing that some perceived experiences are culturally specific could facilitate the emergence of health care services that could enhance and support direct patient care and meet their health care needs. In addition, exploring this phenomenon from the African American perspective could facilitate the identification of features specific to the African American population that could aid in the development of programs and strategies to decrease the prevalence and incidence of ESRD among members of this population.

Sadala, Bruzos, Peireira, and Bucuvic (2012) noted that even though PD is a treatment therapy rarely used in Brazil, it is considered a treatment advantageous to QOL that can be provided at decreased cost. There were 19 participants in their study between the ages of 20 and 77 years; eight were male, and 11 were female. Seven participants were independent, and the remaining 12 depended on their families for support. The participant pool had different levels of education that ranged from college to the illiteracy. The economic level varied from working to retired. The participants had to have had at least 6 months of PD experience to participate in the study. The interviews were conducted during home visits.

Sadala et al. (2012) were able to describe in rich detail the experiences of these participants, illustrating each person's pain and suffering, loss of self, loss of independence, and uncertainty about the future. The participants were grateful for the treatment, family support, and care of health care practitioners. However, the participants also felt that they were a burden and longed for their old ways of life, a sentiment also expressed by the participants in the studies by Clark and Robinson (2010), Guerra-Guerrerro et al. (2014), Herlin and Wann-Hansson (2010), Lindqvist et al. (2000), and Nazly et al. (2013). In their old ways of life, the participants were not hooked up to a machine, and their homes were not filled with medical equipment. One participant described body disfigurement because of the catheter placement and the solutions carried around in the catheter (Sadala et al., 2012). Although the PD patients were able to dialyze in the comfort of their own homes, they described it as a masked autonomy of sorts: The sense of isolation, loss of self, and physical pain of the disease remained a problem with this modality, giving credence to the fact that prevention of this disease and social justice are necessary in CKD.

Curtin, Johnson, and Schatell (2004) discussed the experience of PD patients who had 4 years or more of experience with the modality. Curtis et al. proposed that patients with 4 or more years of experience would be able to provide better accounts of their everyday lives. Eighteen participants were interviewed for this exploratory study: Six were African Americans, 11 were European Americans, and one was Hispanic American. Unlike the studies conducted by Sadala et al. (2012) and Herlin and Wanna-Hannson (2010), which illustrated a struggle with everyday life living with ESRD and the treatment regimen, Curtin et al. proposed the opposite. Twelve of the 18 patients were given modality information at the beginning of the process, and PD was their initial option because it gave them the ability to maintain some autonomy over their care (Curtin et al., 2004). The participants voiced that their everyday lives had changed and had become organized around ESRD and the mandatory treatments. The participants in

Guerra-Guerrerro et al.'s (2014) study described this change as a negative one because they were being controlled by the machine and were being forced to adapt to a new way of life. Sadala et al.'s participants emphasized that it took effort to regain control of their lives and that the control was intertwined with their ability to adapt to the changes. However, the patients felt that the change was a fundamental type of suffering.

Unlike these studies, the patients in Curtin et al.'s (2004) study felt that PD gave them autonomy to implement decisions about care, explore and have lives with fewer restraints, and realize opportunities to dialyze when and how they wanted to. Curtin et al. emphasized that these patients received modality training and were able to make informed decisions about their care and choose their treatment option. They also mentioned that the autonomy helped to improve patients' responses and successful transitions. Fifteen of the 18 patients were solely responsible for their own treatment exchanges and individual care; in the study by Sadala et al. (2012), only seven of 12 patients were responsible for their own care. The participants relied heavily on family support and emphasized their loss of self within the family structure (Sadala et al., 2012). According to Williams et al. (2016), because of the debilitating effects of the disease, many patients with ESRD require assistance from family caregivers with dialysis treatments, medication administration, and activities of daily living.

However, it should be noted that Curtin et al.'s (2004) study was funded by Baxter Healthcare, the company that manufactures PD solutions and products. In addition, only Curtin conducted the interviews. The major themes of the study were verified by two more PD patients with 17 and 12 years of experience, respectively. A PD nurse also verified the themes that emerged from the analysis of the interview responses. Curtin et al. used rich description and member checking to bring credibility to the study. I believe that the results of their study were justified.

Race-Based Variations in Dialysis Experience

Polaschek (2003) described the dialysis experiences of six European American participants who performed HD. In describing their experiences, Polaschek sought to determine whether a difference existed between cultural group and gender. Six concerns were identified through the research process. The men voiced concern about suffering from the disease and treatment processes. The European American male participants described the limitations on their lives as the result of the treatment regimen. Third, the participants voiced concern that the dialysis would consume their lives forever. Last, they felt a sense of ambiguity between independence and autonomy. The participants emphasized autonomy in regard to their ability to create their own routines, but at the same time, they realized that they were dependent upon the machine until transplantation or death occurred.

According to Schneider (2010), low SES increases the risk of developing diabetes, hypertension, and obesity, all of which are prerequisites for CKD (Atkins, 2005). However, Gallegos (2007) discussed ways that prevention of the diseases meets resistance because primary care and quality care are usually inaccessible to the minority populations that ESRD affects. CKD has become a global and costly epidemic (Atkins, 2005; Ledebo, 2008; Schoolwert et al., 2006, Williams et al., 2016). European Americans have a higher incidence than African Americans of CKD development. However, African

Americans are more likely to progress to ESRD and be in need of RRT, with rates being 90% and 1.7%, respectively (Pearson, 2008). Pearson (2008) and Powe (2003) stated that the progression is related to the lack of primary care services. Having access to primary care is a huge barrier for many African Americans, making predialytic care impossible, resulting in progression to ESRD and the inevitable need for treatment.

Lipworth et al. (2012) sought to determine whether patterns of risk for ESRD were different for the African American and the European American participants in their study because there was such a high incident of ESRD among the African American population. The prospective Southern Community Cohort Study followed 79,943 participants from the southeastern region of the United States, an area known for an increased rate of ESRD development (Lipworth et al., 2012). The participants, all of whom were obtained from the USRDS from 2002 to 2009, were monitored from the time of entry until a diagnosis of ESRD, a date of death, or completion of the study. Demographic information relevant to SES, educational status, past medical history, past family medical history, height, weight, and tobacco and alcohol use was gathered for comparison. Eighty-six percent of the participants were solicited from their primary health care centers, which serviced the poor population; the other 14% were solicited through the mail. Sixty-eight percent of the participants were African American; the remainder were European American participants. "After 329,003 person-years of follow-up, 687 incident cases of ESRD were identified in the cohort, yielding an overall age-adjusted IR of 214 (per 100,000 person-years)" (Lipworth et al., 2012, p. 2). The IRs were 273 (88.2%) for the African American participants and 78 (47%) for the European

American participants. The IR was found to be linked directly to the educational and income levels of the participants. The incidence of ESRD was more pronounced among participants with hypertension and diabetes, 5 and 6 times higher, respectively.

Results also showed an IR 8 times higher among participants with both hypertension and diabetes (Lipworth et al., 2012), results also found by Atkins (2005) and Powe (2003). The African American participants with both comorbidities had an even higher IR of 814, a rate 3.5 times higher than that of the European American participants. Lipworth et al. (2012) referred to the San Francisco Community Health Network Study, which found that even though the early stages of CKD were the highest among European American populations, a claim also made by Pearson (2008), these patients were slower than African American patients to progress to ESRD. However, the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study monitored 27,911 participants and found the same high IR among the African American population. Moreover, the REGARDS study also showed that the fourfold greater risk of developing ESRD among African Americans than European Americans decreased to 1.4 after adjusting for hypertension, diabetes, income, and education, as well as eGF and the albumin:creatinine ratio.

Lipworth et al. (2012) also suggested that a more intense surveillance of European Americans could be contributing to their decreased rate of progression to ESRD. The researchers offered another hypothesis, namely, that European Americans become symptomatic to the symptoms of CKD earlier on, which prompts earlier care. Results indicated a higher incidence of ESRD among African Americans than European Americans, even after assessing the risk factors associated with ESRD.

Lipworth et al. (2012) analyzed the risk factors associated with CKD between European Americans and African Americans with homogeneous characteristics. They used qualitative data to support their position. The study was a large prospective cohort study with participants from more than 12 southern states and spanning the years 2002 to 2009. Lipworth et al. retrieved more background information about the participants from medical records, hospital records, and the USRDS. Participants who did not have a diagnosis of CKD or ESRD were enrolled and then monitored by the aforementioned criteria. Lipworth et al. identified a huge disparity between the two groups, a result similar to that of previous research. Evidence of a higher incidence of progression to ESRD within the African American community was pertinent to my study, which proposed that it is necessary to develop upstream strategies and interventions to decrease the prevalence of CKD and increase awareness of the African American population. Prevention efforts are needed for this particular population.

Health Belief Model

Public health developed an increased interest in the early detection and prevention of diseases after recognizing that screenings were an effective method to do so, according to Hochbaum (1958). With that interest, programs were established with various screenings and surveys that were open to the public. Although members of the public stand to gain the most from the success of health programs, their willingness to participate has all too often been disappointing, despite well-organized attempts to arouse popular interest and make participation easy (Hochbaum, 1958). Hochbaum conducted a study to understand why people would not participate in screenings that would make them aware of their health. Three cities were selected to participate: Cleveland, Boston, and Detroit (Hochbaum, 1958). Data were collected from interviews with 1,201 participants. Results identified a psychological readiness and the belief that individuals could actually contract the disease.

The HBM has been used to predict and explain health behaviors. Holland, Carthron, Duren-Whitfield, and Lawrence (2014) conducted a study using the HBM with a sample of African American college students concerning cardiovascular health. Positive behavioral changes relevant to cardiovascular took place as a result of the HBM intervention in the areas of physical activity, healthier eating habits, increased water consumption, and decrease sugar consumption. After the intervention, the students showed significant improvements in their overall knowledge of the heart and their own family health history postintervention.

Abood et al. (2003) used the HBM to conduct a nutritional intervention with university staff that targeted their health beliefs in an effort to change their dietary behaviors. The HBM focused on benefits and barriers while providing pertinent information related to nutrition and dietary behaviors. This intervention proved to be successful in increasing the participants' knowledge, decreasing their fat and saturated fat consumption, and decreasing their cholesterol intake to levels consistent with the national average (Abood et al., 2003).

Koch (2002) conducted research with a convenience sample of 31 African American women with diabetes mellitus. The women were categorized as exercisers and nonexercisers. Koch evaluated whether the women who exercised had different health beliefs from those of the women who did not exercise and whether the women who exercised experienced better glycemic control. Koch stated that the theoretical framework from which the study was developed illustrated the complete relationship among motivation, health behaviors, and health outcomes.

Creswell (2009) described a conceptual framework as a theoretical lens that becomes an advocacy perspective that shapes the types of questions asked, informs the data collection and analysis processes, and provides a call for action or change. The HBM was the most appropriate theoretical lens for my study. The HBM has been used to support and predict health behavioral changes with proven success, especially in regard to the prerequisites to ESRD: diabetes, hypertension, and obesity. The constructs of the HBM supports awareness of ESRD and alerts study participants of the benefits of change. Research has proven that even though ESRD is a preventable chronic disease, the IR of ESRD has reached epidemic proportions. Use of the HBM in my study helped to determine whether African Americans who had been made aware of their susceptibility to ESRD responded with behavioral changes.

Summary

A review of the literature identified a number of recurring themes related to CKD development and progression to ESRD. The main theme to emerge from the review was that primary care is a key factor in decreasing the development of CKD and progression to ESRD. Early monitoring of risk factors (e.g., albumin, blood pressure, and glucose levels) and the education of minority populations are key to decreasing or even eradicating the disease manifestations of ESRD. However, poor care and the lack of access to health care pose great challenges to patients requiring primary care. Previous research has shown that poor health care was increasingly related to racial disparities that were unnoticed by practitioners and that the results manifested in poor outcomes in minority populations. Once disparities in care were eliminated, improvements in health outcomes were significant, but when disparities were not eliminated, then chronic disease such as ESRD developed. According to the review, HD and PD treatments have complications specific to each modality as well as generalized difficulties. In addition, patients undergoing both treatment modalities feel tied to the machine, indicating a clear decrease in their QOL.

ESRD is considered a public health issue because of its increasing global prevalence and its increased IR among minority populations. The two major causes of ESRD have been identified as hypertension and diabetes. What has not been known is whether African Americans would change their health behaviors if they had increased awareness of ESRD. I evaluated the perceived threat and perceived severity of ESRD among patients receiving dialysis treatments in DeKalb County, Georgia, at the time of the study. It was important to find out whether these patients received education prior to diagnosis or related complications. Chapter 3 includes information about the methodology, how I solicited and chose the participants, the interview protocols that I used, and the data collection and analysis processes that I used.

Chapter 3: Research Method

Introduction

The two prior chapters emphasized experiences related to ESRD, HD, PD, and treatment options. Patients might suffer from fatigue, leg cramps, headaches, and depression. Patients also have been known to complain of a lack of energy, an inability to maintain employment, and a loss of self. They also can experience frequent hospitalizations and pain from needle insertions that are scheduled three times per week. A major concern of patients is the fear of not surviving a treatment. What is not known is the lived experiences of African Americans in DeKalb County, Georgia, and the perceived severity and perceived susceptibility of ESRD related to their compliance with ICHD. The HBM might help to diffuse an unknown experience. This chapter frames the qualitative method used to serve in understanding such patient experiences.

Research Design

According to Creswell (2013),

> Qualitative research is conducted because a problem or an issue needs to be explored. This exploration is necessary, in turn, because of a need to study a group or population, identify variables that cannot be easily measured, or hear silenced voices. (p. 47)

Therefore, I chose a phenomenological approach because it was necessary to explore the phenomenon subjectively and hear the words of the participants rather than view the statistical data demanded of a quantitative approach. “The aim was to determine what the experience means for individuals undergoing the experience who also could provide comprehensive descriptions of it. From the individual descriptions, universal meanings are derived, in other words, the essences or structures of the experience" (Moustakas, 1994, p. 13). Phenomenological inquiry can shed light on the lived experiences of the people undergoing ICHD treatments in the DeKalb County, Georgia, area.

Role of the Researcher

In a qualitative study, the researcher serves as the data collection instrument. According to Creswell (2009), "Qualitative researchers collect data themselves through examining documents, observing behavior, or interviewing participants. They may use a protocol, an instrument for collecting data, but the researchers are the ones who actually gather the information" (p. 175). More importantly, the researcher must remain unbiased.

As the primary investigator, I had to acknowledge that I have been employed in the field of HD for approximately 20 years. However, this study and its results are not for company purposes. I have provided direct care to ICHD patients in the DeKalb County area. I also have served as the administrator for 4 years at a particular facility in DeKalb County. I am currently employed by one of the major companies in the dialysis arena as a clinical services specialist. This is not a backyard study; therefore, there was no need to compromise or withhold information. Although I do not provide direct patient care, I do have minimal contact with patients. My professional experience has enticed me to gain an increased understanding of this population and their experiences. I was able to control biases by documenting each step of the research procedures. Using an interview protocol was another way to control biases. I also implemented reliability procedures to control biases.

Research Methodology

The primary purpose of this qualitative study was to examine the perceptions and lived experiences of a sample of African Americans in the DeKalb County region of Georgia who are currently receiving ICHD. The secondary purpose was to explore their perceived barriers to the use of PD and HHD. In this chapter, I describe the qualitative approach that I took to conduct in the study and the purpose for choosing this paradigm. I also explain the methodology for this study, including details of the participants, the selection process, my role as the researcher, and the ethical considerations. I also provide information about the data collection and analysis protocols. Finally, possible threats to the quality of the data are discussed.

Participants

The participants had a shared experience of receiving HD treatments at a dialysis facility. The participants were selected from DeKalb County, Georgia, communities. A purposive sample of 10 individuals who self-identified as currently undergoing ICHD treatments were studied. “Purposive sampling is a technique that is targeted and specifies pre-established criteria for recruiting the sample,” (Crosby, DiClemente, & Salazar, 2006, p. 303). Participants were recruited by the facility administrators and social workers at the two designated facilities. However, the recruitment process began only after the research department provided approval.

The selected potential participants were given a flyer that listed a phone number that potential candidates could call for more information. The inclusion criteria gave age and treatment site details. The participants had to be African Americans who were at least 18 years of age at the time of the study. They also had to have been receiving HD for at least 6 months and currently receiving treatments at a DeKalb County, Georgia, facility. Once the potential candidate made contact with me, I gave them additional information about the study design, and I confirmed their demographic information to ensure that they met the study's criteria. If the candidates met the eligibility requirements and agreed to participate in the study, I mailed them a packet containing detailed information about the study to reiterate the information that I had provided initially over the phone. Also included in the information packet was the consent form and instructions to call me if they had any questions. The packet contained instructions to sign and mail the consent form to me using the self-addressed and stamped envelope provided.

Once I received the signed consent forms, I scheduled face-to-face interviews with the participants. Mutually agreeable places to meet were established. The interviews were recorded on an iPad that only I had access to. Once the interviews were finished, I transcribed the interviews verbatim and added handwritten notes to ensure that all available content would be analyzed. The facility was safe and comfortable for the participants.

Measures

The purpose of this study was to explore African Americans' experiences with ICHD treatments at two DeKalb County, Georgia, facilities. The specific questions for the telephone and face-to-face interviews are listed in Appendices D and E. The RQs supporting the exploration of African Americans' experiences were as follows:

RQ1: What are the lived experiences of the African Americans in the DeKalb County area who undergo ICHD treatments?

RQ2: What are the common themes related to the perceived threat (perceived susceptibility and perceived severity) of ESRD in African Americans participating in ICHD?

RQ3: What are the perceived barriers that led to the decision to use ICHD instead of HHD or PD?

Ethical Protection of Participants

The participants who volunteered to be in the study were African Americans who were at least 18 years of age at the time of the study. There were minimal risks involved to being in this study. The only minimal risk was the possibility of emotional and mental distress reliving the experience; this possibility was disclosed to each participant. As already mentioned, the participants signed the consent form before being interviewed. This process was a requirement of Walden University's Institutional Review Board (IRB approval #l 09-03-15-0279181). Confidentiality was maintained for all potentially identifiable items and materials such as field notes, audio recordings and video tapes, and transcriptions. I will keep all nonelectronic items in locked storage, and I will keep all computer files in a password-protected computer until the study is completed. Only I have access to the locked items.

Procedures

The following procedure describes in sequential order the process for participant recruitment, provision of information, data collection, data analysis, and data validation:

1. The facility administrator and the social worker identified potential participants in the dialysis facilities and provided them with the flyer for further details. I accepted participants until data saturation was reached. Creswell (1998) noted that a sample of five to 25 participants in a phenomenological study would yield no new evidence.
2. Potential participants called the number or wrote to the e-mail address provided on the flyer if they were interested in joining the study. The phone number and e-mail address were used for the study only. The call was the initial contact. I provided an overview of the study and obtained demographic information. I used a prepared protocol to ensure standardization of the telephone and face-to-face interviews (see Appendix D).
3. All potential participants who met the criteria were mailed detailed information about the study. A packet with detailed information about the study and a consent form was mailed within 3 to 5 business days. Only 40% of the potential participants returned the consent forms in the self-addressed stamped envelope provided in the packet to be mailed to a DeKalb County post office box. The other 60% of consent forms were retrieved on site.
4. Once I received the consent forms, I contacted the participants to schedule the face-to-face videorecorded interviews. I followed an interview protocol.

5. The interviews were scheduled within 1 week of receiving the mailed consents. If they agreed, participants who signed the consent on site were interviewed at that time. If they did not agree, then the interviews were rescheduled for more convenient times.
6. After all interviews had been conducted, I transcribed them. I then took the opportunity to analyze the responses to ensure their accuracy and completeness. I also contacted the participants and reviewed their exact statements to ensure that the statements mirrored their actual meaning and intent. According to Munhall (2012), follow-up interviews give the participants the opportunity to share more information.

Data Collection

Data collection took place in two phases. The first goal of Phase 1 was to obtain demographic information to ensure that the volunteers met the criteria to participate in the study. Phase 1 was conducted as a telephone interview. The second goal was to identify commonalities among the volunteers, such as age, length of experience with ICHD, more than one modality used, and education, just to name a few possibilities. Identifying commonalities could have shed light on potential underlying causes of ESRD. I again provided specific details about the study and allowed the participants to ask questions or voice concerns. I tried to further establish rapport by sharing my own work history as an HD nurse and administrator.

Phase 2 was a more in-depth interview process meant to obtain more personal information about the life experiences of the participants prior to ICHD. It was necessary to understand the participants' prior knowledge of hypertension and diabetes, as well as explore the disease prevalence within each participant's family. It was equally important to understand the participants' perceived susceptibility to the diseases or conditions identified in the family history. The participants describe their lives prior to ICHD. In this experience sharing, the participants revealed a decrease in QOL. A few participants shared coping mechanisms and support systems that might have evolved because of ICHD. In Phase 2, I asked open-ended interview questions to retrieve information about the participants' personal medical histories. More specifically, the participants acknowledged their own diseases and conditions, as well as the perceived severity.

Before reaching the stage of dialysis-dependent ESRD, patients with chronic kidney disease who receive early nephrology referral and multidisciplinary predialysis education are associated with improved survival, cost savings, and a significantly increased PD selection rate (Kendrick, 2015). It was noteworthy to discover whether the participants in this study engaged in modality education in order to choose their own treatment options or whether modalities were chosen for them. Lack of modality education solidified the knowledge gap and the reason for the increased employment of ICHD. It was just as important to review the barriers to home therapy use. Most importantly, Phase 2 gave the participants the opportunity to express subjective looks at their encounters with ICHD.

The interview sites were determined by mutual agreement. However, not every interview was hosted in a private setting free of distractions. A number of interviews were conducted on the treatment floor while the patients were receiving dialysis treatment. All telephone interviews were audiorecorded, and all face-to-face interviews were videotaped. Each participant signed consents for audiovisuals and statements of confidentiality. I took handwritten notes to supplement the audiovisuals and to ensure that nonverbal communication was captured and documented. Each interview was transcribed verbatim, and the information placed into a password-protected computer. A copy of the final results will be provided to the participants.

Expert Panel

The expert panel tested the interview questions and ensure the feasibility of the instrument, that is, to ensure that the questions were understandable, were without bias, and provided the information to answer the RQs. Establishment surveys often rely on expert panels or stakeholders' meetings to review proposed survey items and to help researchers use language and terminology in the questionnaire and other materials that will be relevant and appropriate (Lavrakas., 2008). The overall result improved the instrument prior to implementation in my study.

For this study, I solicited my expert panel using three methods. First, I sent e-mails to professors in the Health Sciences Program at Walden University. Second, I solicited a number of authors listed in the literature review by way of e-mail. Third, I sent e-mails to colleagues in Walden University's Health Sciences Program. The e-mail request contained the purpose and the objectives of the panel, along with the test questions. Forty e-mails were sent requesting support, but only three people responded. Those responses led to more questions being added to both protocols as well as a few questions being deleted.

Data Analysis

Data analysis in qualitative research begins with data organization. I reviewed the transcribed interviews before organizing the information into categories. At this point in the study, I attempted to gain a general understanding of the collected data, following Moustakas's (1994) directions to "list each non-repetitive, non-overlapping statement. These are the invariant horizons or meaning units of the experience" (p. 122). I tried to capture the essence of the participants' experiences from the data while eliminating iterative statements and phrases. In other words, I sought general meaning from the data.

Next, I highlighted statements that related or made reference to the specific phenomenon being studied. Coding begins "the process of organizing the material into chunks or segments of text before brining meaning to information" (Creswell, 2009, p. 186). Some researchers have been known to fit the data to existing codes, according to Creswell (2009). I formulated new codes in the study; the coding then gave way to categorization. Lastly, I labeled the categorized data by theme. At this juncture, I was able to provide a personal interpretation of the data. Once I understood the data enough to present and interpret them, the next step was to decide whether the new information was discovered or simply affirming previous data.

Verification of Findings

I followed the same interview protocol for each interview to maintain consistency. Creswell (1998) recommended eight possible steps to verify the findings: persistent observation, triangulation, peer review, negative case analysis, clarification of research bias, member checks, rich and thick description, and external audits. I used four of the eight steps of persistent observation, triangulation, clarification of researcher bias, member checks, and rich and thick descriptions in this study.

In accordance with Creswell's (2009) observation that "the more experiences that a researcher has with the participants in their actual setting, the more accurate or valid will be the findings," (p. 192), I spent extensive hours in the field, recording field notes along the way. The ICHD facilities were conveniently accessible to me, thus facilitating observatory and participatory practices. I worked in the ICHD setting for a number of years. Most of that time was spent providing hands-on patient care in the ICHD facilities. Presently, I work as a clinical services specialist, which is a nurse educator for staff, still within the HD setting.

I used a number of methods to collect the data, thus engaging in triangulation to increase validity. I analyzed all of the collected data and used them to develop the themes. If themes can be established based on converging several sources of data or participants' perspectives, then this process can be seen as adding to the validity of the study (Creswell, 2009).

Having participants check the transcribed data is an important step in qualitative research. Member checking entailed taking a polished product back to the participants to receive their approval. Moreover, it gave the participants the opportunity to assess the themes or final reports and to agree or disagree with the findings.

Using rich and thick descriptions increased the validity of the data and potentially allowed for greater transferability. Rich and thick description entails providing as many details about the setting and occurrences as possible, details that can merge through physical description, movement description, and activity description. It can also involve describing ideas from the general to the specific, interconnecting details, using strong action verbs, and including direct quotations (Creswell, 2013).

Summary

The phenomenological approach to this qualitative study allowed the participants to describe their ICHD experiences in their own words. Their experiences might lead to a sustainable intervention to decrease the number of DeKalb County residents affected in the future. The participants' information and identities were protected throughout the study, and the data collection processes remained consistent. I used NVivo to organize and analyze the data so that themes could emerge. Chapter 4 provides specific details and the results.

Chapter 4: Results

Introduction

HD was first used in 1966 as a treatment option for CKD (Blaxter, 1997). The process, treatment options, and equipment have evolved since then, but the decreased QOL remains a major issue. Researchers such as Clarkson and Robinson (2010), Guerra-Guerrerro et al. (2014), and Nazly et al. (2013) have reported on the physical, psychological, and familial effects of HD on its recipients. There has been a gap in the literature demonstrating the impact of HD on DeKalb County residents specifically. This study was the first to attempt to bridge the gap and try to understand what these patients experience. The 10 interviewed participants provided detailed information about their HD experiences. This chapter gives an account of the recruitment process; provides details about the participants, including patient histories; explains the data collection, storage, and analysis protocols; presents the process to prove validity and reliability of the data; and includes the development of the themes.

Recruitment of Participants

Qualitative research involves studying a research site or sites and gaining permission to study the site(s) in a way that will enable the easy collection of data (Creswell, 2013). Davita offered a convenient sample of potential participants. Moreover, Davita requires approval from the regional operations director (ROD), as well as the medical director (MD) to use the site or sites for research. I contacted the ROD for the 11 DeKalb County facilities. I explained that I was a Walden University student and what I was trying to accomplish. I expressed that I needed her help to proceed. The ROD gave consent without hesitation, with the only requirement that I make contact with each facility to gain further permission and access to patients. My long-term history with the company and the ROD might have influenced her decision.

The second task was to gain MD approval through the administrators of the 11 facilities. Except for four of the 11 facilities, I contacted them via the telephone. Again, I explained that I was a Walden student in the process of completing my dissertation and needed their help. I explained the purpose of the study and what I needed to do to conduct the study. I explained that I needed them to obtain MD approval for me. I forwarded the consent forms, the interview protocols, and flyers for MD talking points. Two facilities were excluded because of my long work history with them. Another two facilities were excluded because they did not have active administrators who could facilitate the process.

Copies of the data collection tool, consent form, and the flyer were e-mailed to the remaining seven facilities as talking points for the MDs. Only two administrators were able to gain MD consent. Once I received ROD and MD consent, I submitted the approval application to Davita, which then sent the proposal to its research department and ethics department to ensure that I would guarantee patient safety and confidentiality. Davita’s approval process was from January to April; Davita also requested an $80.00 payment to cover the cost of the employee passing out the flyers and for the processing of the application.

Once I received the approval e-mail from Davita’s research department, I called the two facilities to which I had been granted access. I notified the administrators of the approval and that I would be on site to provide copies of the flyers within the week.

When I arrived on site, I asked the administrator for the name and contact of the social worker who would provide support. I spoke with the social worker while on site and explained the procedure. Administrators and social workers at the two facilities recruited patients for the study and then provided them with the flyer. Participants were able to contact me by phone or e-mail.

Data Analysis

The 10 patients participated in a two-part interview process. The first step was a telephone interview to establish their eligibility to be in the study. The patients were asked to identify their current dialysis facilities and how long they had been treated at those specific facilities. They provided the total length of time that they had been on HD. Patients also were asked to provide information about age and education to identify any commonalities among the participants. The potential participants were asked if they had always used HD, the treatment option discussed in Chapter 2. This question was a derivative of RQ3: What are the perceived barriers that led to the decision to use ICHD instead of HHD or PD? If the participants met the criteria, then more information was provided about the study, and the consent form was reviewed. It was an opportunity for the participants to ask questions or voice concerns. I used this time to try to establish rapport with the potential participants. An important step in the process is to find people or places to study, to gain access, and to establish rapport with participants so that they will provide good data (Creswell, 2013).

I reviewed the audiorecordings of the interviews numerous times to hear and understand what was being said. I then transcribed the recordings and highlighted pertinent statements. I also reviewed the transcriptions for commonalities in the traits of the participants.

Demographic factors such as race, gender, and marital status have been identified as consistently influencing health. The most important predictor of health is socioeconomic status, a concept that includes income, education, and occupational status, factors that tend to be strongly interrelated (Schneider, 2010). For example, were the participants all within a certain age group, or did they all start as HD patients because they were not educated about HHD or PD treatment options? According to Patton (2002), the challenge of qualitative analysis lies in making sense of massive amounts of data. This sense making involves reducing the volume of raw data, separating trivial from significant data, identifying significant patterns, and constructing a framework for communicating the essence of what the data reveal (Patton, 2002). I was able to obtain a general understanding of and evaluate commonalities associated with the age range, gender, educational level, and modality choices of the participants (see Table 1).

Table 1

Demographic Information of the Participants

Age	Gender	Education	Time on dialysis	ICHD only	Zip code
67	M	Grade 12	2.5 yrs	yes	30034
56	F	2 yrs college	2 yrs	No/PD	30034
65	F	Grade 7	7 yrs	Yes	30083
54	M	Grade 12	20 yrs	Yes	30058
59	M	1 yr college	14 yrs	Yes	30021
48	M	2 yr college	3 yrs	Yes	30088
63	F	2 AA degrees	9 yrs	Yes	30013
39	F	2.5 yrs college	6 months	Yes	30058
34	F	BA	16 yrs	No/HHD	30094
61	F	Some college	8 yrs	No/HHD	30038

The participants chose interview sites where they felt the most comfortable; only 20% requested off-site locations. I video recorded the face-to-face interviews. The participants reviewed their childhood knowledge about diabetes and hypertension within the family structure and their perceived threat and perceived susceptibility, if any. The patients were asked if they had been diagnosed with hypertension or diabetes; in responses, 70% said yes, and 30% said no. Forty percent denied education surrounding behavioral changes after diagnosis of hypertension or diabetes. Both questions were based on RQ2: What are the common themes related to the perceived threat (perceived susceptibility and perceived severity) of ESRD in African Americans participating in ICHD? Participants described their lifestyles prior to HD and the consequential adjustments. This question was related to RQ1: What are the lived experiences of the African Americans in the DeKalb County area who undergo ICHD treatments? They were able to provide details about their day-to-day experiences of receiving treatment in DeKalb County facilities and the effects.

I asked the participants about some possible ways to create an awareness of CKD and ESRD and the best places to disseminate information. More importantly, I asked the participants to reveal their knowledge and history of PD and HHD treatments because I wanted to know whether they had been offered them as treatment options initially. Eighty percent of the participants received education about PD and HHD prior to becoming ICHD patients. This question was based on RQ3: What are the perceived barriers that led to the decision to use ICHD instead of HHD or PD? The data were kept locked in a secure location in my office.

Only two participants chose an offsite facility for the interview. Privacy also might have been a factor for the interviews not to be conducted at the facility; however, it was each patient's choice. Each face-to-face interview was video recorded. 1 used Creswell's (2013) process to organize the data, read and reread the data, code the data, analyze the data, develop themes, and interpret the data. I reviewed the videorecordings multiple times to understand their meanings; however, they still seemed unclear.

Returning to the general coding process, some researchers have found it useful to hand code qualitative transcriptions or information, sometimes using color-coded schemes and to cut and paste text segments onto note cards (Creswell, 2009). To tease out the relevant statements, I designed a white board. All 18 interview questions were placed at the top of the board in chronological order. Moustakas (1994) suggested listing every expression relevant to the experience. To be relevant, it had to contain a moment of the experience and be possible to abstract and label. All transcripts were then printed. I reread all transcripts, and all relevant statements for each question were cut and pasted on the board under the question it represented. I used hand coding to become familiar with the NVivo software without delaying the study. Initially, the NVivo software was challenging.

Once I completed the tutorials and had a better understanding of the tool, I used NVivo to support the coding and labeling of the data. According to Creswell (2013), NVivo is helpful to manage, shape, and analyze qualitative data. It also provides security by storing the database and files together in a single file, enables researchers to use multiple languages, has a merge function for team research, and allows researchers to manipulate the data easily and conduct searches (Creswell, 2013).

Validity

Creswell (2013) focused on eight different strategies to verify qualitative data: prolonged engagement and persistent observation, triangulation, peer review or debriefing, negative case analysis, clarification of researcher bias, member checks, rich and thick description, and external audits. I used four of the eight strategies to verify data in this study. I have worked and engaged with this population for the past 20 years in different settings. I disclosed early in the study my long work history as a dialysis nurse and facility administrator.

Member checking with the participants was another method that I used to validate the accuracy and interpretation of the transcriptions. Validity, on the other hand, is one of the strengths of qualitative research, and it is based on determining whether the findings are accurate from the standpoint of the researcher, the participants, or the readers of the account (Creswell, 2009). Rich and thick descriptions of the step-by-step account of the study have been provided for transferability.

Demographic Characteristics

Six women and four men participated in the study. Six of the participants were from Facility 1, and the other four were from Facility 2. Participants ranged in age from 34 to 67 years. Length of time on dialysis was a little as 7 months and as long as 24 years. Participants' education ranged from Grade 7 to some college experience. Only two mentioned having a degree.

Qualitative Data Analysis

Organizing and coding data are the initial steps of an analysis. Subthemes are then developed from the major findings. For this particular project**,** lifestyle changes and lack of education prior to ESRD were identified as the two main themes. Theme 1, Lifestyle Changes, had two subthemes, namely, (a) life prior to HD, and (b) perceived threat/susceptibility. Theme 2, Lack of Education, had three subthemes, namely, (a) lack of awareness in communities, (b) modality choice, and (c) dialysis experience. According to Mitchell (2015), people of color in the United States are more likely than their European American counterparts to experience poorer health outcomes and higher mortality rates from preventable conditions. Many communities of color also have a higher IR of diabetes, ESRD, tuberculosis, hypertension, asthma, obesity, and HIV, and are more likely to die from heart disease than their European American counterparts (Mitchell, 2015). The disparities were evident in the subthemes that emerged from the data.

Theme 1: Lifestyle Changes

Subtheme 1: Life prior to HD. Participants described their life prior to starting HD as normal. They were going about their daily lives as they saw fit. Participant 4 said, “Before dialysis I could get up and go when I wanted to, before dialysis. But now, I was limited because I was depressed for a while because I couldn’t work no more.” Participant 7 stated, “I was just living, living like a normal person. I had one child, I worked, I was just living. I did whatever I wanted to.” Participant 3 mentioned that she was laid off because the manager reported to the supervisor that she was having problems with dizziness on the job, a complication of dialysis.

Participants recognized that they could no longer do a number of things that they enjoyed before HD. If they were able to do it, it was not at the same pace as before.

“Freedom” is how Participant 5 described life prior to dialysis:

> Go where I want. Do what I want, didn’t have to worry about interrupting my activities to go sit in a chair. I could eat what I want, which was great. It was just a fun time. It was great.

Participant 3 complained about life changes:

> Well you know you can’t do the things you use to do. It’s like a change. I tried to work, I couldn’t work, it’s a big change. Me and my husband like to fish. I can still do it, but you gotta go to dialysis. When you get off, you don’t feel well. It’s change. Couldn’t work, I didn’t feel good. I worked that job 17 years.

Food and fluid restrictions were unheard of prior to HD, the hardest adjustments for all participants. They understood the purpose of the fluid and food restrictions, but they were still seen as one of the major disadvantages of the disease progression and treatment process. Most participants had modified their diets, but had not necessarily conformed completely.

Participant 2 described it as “work, yard work, housework, spending time with family members. Which is hard now ’cause you can’t drink. They (family) have outings and I can’t drink. It’s hot and humid. It changed, but I’m trying to go with it.”

A number of participants mentioned that drinking too much would cause cramping during the treatment.

Participant 8 explained:

> You cramp if you come in here with a lot of fluid, and they pull too much. But I don’t come in here with a lot of fluid. I mean I have cramped before. I try to limit my fluid … A lot of people do the weekend and come in with four (kilograms). That’s why they cramp … When them cramps hit you [shaking his head from side to side].

Participant 9 said:

> Some days it seems like it hadn’t affected me at all. Other days I just can’t do what I wanna do. Can’t eat what I wanna eat. So that’s kind of a problem. I use to love meat, since I been on dialysis meat is not one of my favorite foods. Most of the time when I eat meat, I get constipated, so I just try to avoid it. Seems like I just can’t eat enough protein.

Participant 10 saw the change in a different way: “No difference, been on for 16 years, it fits in my schedule. Just have to allot 4 hours every Monday, Wednesday, and Friday. Added dialysis into daily routine, like going to hairdresser or something like that.”

Prior to dialysis, the participants could come and go as they desired. Unfortunately, HD restricted travel for this population, or they bore the burden of making arrangements prior to being able to leave. Participant 10, one of the younger participants, said, “Dialysis affected my travel; that’s the main thing. Treatments three times per week limit traveling. Friends want to go to Las Vegas or on a cruise, I can’t.”

Participant 7 stated:

> I have to come here three times per week so that kind of slowed me down. I don’t like to travel as much because I gotta set-up the appointment where ever I go. So I try to travel when I don’t have an appointment, when I don’t have treatment.

Subtheme 2: Perceived threat/susceptibility. Under this subtheme, eight participants identified other family members as having hypertension or diabetes. None of the eight participants perceived a threat or susceptibility to themselves. In other words, the decision to engage in a health action is determined by perceptions of personal susceptibility to, and severity of, a particular condition or illness balanced against perceive benefits and barriers (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Participant 4 stated, “I thought something was going on in the family, I didn’t make any life changes. A lot of people don’t. I was a good baseball player in high school and college so I didn’t think about it no more.”

Participant 6 remarked:

> My father's sister was a dialysis patient. And it was still in a lot of learning stages way back then. I was a preteen at the time when she became a dialysis patient. And I recall seeing her access look like a big piece of liver on the outside of her skin. It was really ugly looking. It had formulated where she was being stuck at [with fistula needles]. I used to worry about it all the time.

She never perceived the illness as a threat to her own health and well being. Participant 2 commented, "My mother, brother, grandmother, it's all in my family. No, I didn't even think about it. I wish I had cause I could have did a lot of things to cut it down."

Seven of the participants were diagnosed with hypertension or diabetes prior to ESRD, but they still perceived no threat of CKD.

Participant 6 stated that she was educated after being diagnosed, but to no avail:

> Yes, use less salt if I was eating a lot of salt, which I've never eaten a lot of salt. And I just didn't believe I had no high blood pressure cause at the time my blood pressure was running like 140/85 and I didn't figure that was high blood pressure, according to me.

Participant 5 blamed his noncompliance for his kidney failure. He stated that he changed his lifestyle somewhat after being diagnosed with diabetes. He said, "Somewhat changed. Got worse with diagnosis of high blood pressure, I just didn't take my medications. Which is why I always tell people, being on dialysis is my fault!"

Theme 2: Lack of Education

As mentioned earlier, seven of the participants had been diagnosed with hypertension or diabetes prior to CKD and then becoming HD patients. However, in the third theme, patients discussed a lack of education when diagnosed with diabetes, hypertension, and CKD, and the consequences of noncompliance.

Participant 5 stated:

> Education mostly, because when a person is really diagnosed with either diabetes or high blood pressure, the doctor should sit down with them and tell them what could happen. Explain it as best the patient can understand so they'll know what to do and how to and change their lifestyle and might possibly avoid it [hemodialysis].

Participant 4 noted, "At 30% kidney function I was not told about lifestyle changes. Gave me some medicine, and sent me on out the door. I took medicine, but still had the problem."

Two more patients had similar stories. Participant 7 shared the following:

> I changed my eating. I was taking medicine. I don't know if it was a low dose of medicine, but it wasn't working. I was allergic to one medication, so I had to switch. I had regular appointments then stopped going after I had the baby…Blood pressure, one was water pill…blood pressure still high even with medication. Maybe I'm not taking enough, on low dose. Never thought to change doctors, just stopped. Didn't have a regular doctor at Kaiser, just saw whoever was on duty.

Participant 9 said:

> I was seeing a primary doctor because of high blood pressure. He kept saying you got a stubborn blood pressure. Never did switch the medicine. So after so many years, let me see, I can't remember. I believe it was maybe in my 40s, I just decided to switch doctors. And when I switched doctors she immediately told me I had protein in my urine. I still didn't know what that meant. She said you need to go to a nephrologist.

A number of participants believed that it would be a good idea to take patients newly diagnosed with hypertension and diabetes to dialysis facilities so that they could visualize what would happen next if they did not change their unhealthy habits.

Subtheme 1: Lack of awareness in community. In this subtheme, only four participants had heard of CKD or ESRD prior to being diagnosed themselves. They had this prior knowledge only because family members had been diagnosed with ESRD, not because they had any awareness of the disease or contributing factors. Participant 5 explained it by stating, "Need more education out there. They always talking 'bout cancer and all this other stuff, but nobody really talks about dialysis. They'll brush over diabetes, but they just never give you the complications of it."

A number of participants had not seen or heard any public service announcements about kidney disease.

Participant 10 stated:

> More education, verbally, TV wise, and workshops. Any kind of way you can get the information out in the community. Because when I first started dialysis I

> visited five different dialysis places. And I went into each one and counted the number of Black people that were on dialysis. And as far as I'm concern and my statics 99.9%, no matter where you go in the United States are all Black. And the small percentage of Whites and other ethnic backgrounds is very low.

Participant 2 was the only participant that had expected to have kidney disease because of a family history of polycystic kidney disease. The other nine were not expecting it and had never heard of the disease. It was apparent that knowledge about CKD and ESRD were not common in this community.

Participant 8 said, "I know a lot about it now since I'm on it."

Participant 5 felt like the awareness should start early on, in hopes of better outcomes:

> I think it should start in school with the health classes. It should really start there, 'cause when I was in school each health class taught us basic first aid and how to tie knots and all that stuff. They need to do a lot better than that.

Subtheme 2: Modality choice. In this subtheme, eight participants were offered home therapy prior to starting ICHD, but only three agreed. PD was the treatment of choice for one participant; however, she had a number of complications and was unable to continue. Two participants initiated treatment with HHD. One participant had complications with the modality and a problem with the treatment partner. The other participant just decided that it was not for her right after training. However, participant 9 was considering trying HHD again. The other participants were not interested in any home therapy.

Participant 7 said, “I can’t stick myself, and I didn’t want that catheter thing sticking out of me.”

Participants 5 and 6 complained about not having enough space for supplies and equipment.

Participant 8 said:

> Well, I compared them. I didn’t really wanna deal with peritoneal with that tube in my stomach. And I know I couldn’t do it at home ‘cause I’m not really a home person. And it’s too much stuff to be in the house anyway. I’ve seen the small machines for in home but, I’d rather be in-center. Talk to people; get to know folk and stuff like that.

Participant 3 stated, “No I don’t want to do home treatment. I want to be here where somebody can take care of me. I don’t want to take care of myself. I might get something infected.”

Participant 8 said, “‘Cause I heard those things get infected (peritoneal catheter). And plus I’m active. I like to get out; I don’t want that tube to get caught. I’m round dogs.”

All participants had been on the transplant list at one time while on dialysis. Some were still on the list, but a few had been denied for various reasons, mostly because they were overweight. Interestingly enough, Participant 8 was on the list but was undecided about whether he should have the surgery. He stated, “Working on transplant, but I really don’t want one cause you gotta be consistent. You gotta take 20 pills. And I’m the type of person, Oh, I forgot. So I’m undecided.”

Subtheme 3: Dialysis experience. Lastly, patients described great experiences at the facilities. The majority of the participants identified the time at the dialysis facilities as social time. Some admitted to staying around in the lobby, even after treatments, to socialize.

Participant 8 remarked:

> Well, I been here almost 20 years at this same clinic. What we do out in the lobby when we get off the machine: drank coffee and we discuss stuff like phosphorus, who died, who sick, cause they don't tell us that here. I mean I like sitting out there. I like talking to my friends, cause I've seen a lot of people die here…That's why we sit out there "dialysis gossip!" …I'd rather hang here and talk to my friends rather than go out there (pointing towards door) and be doing wrong. I'll end up drinking. You know, cause I have a lot of friends that drink. Ain't nobody on dialysis, I'm the only one that dialyze out of all my friends, and all of 'em drink.

Participant 9 stated:

> I don't see anything wrong with the center. They try to make you comfortable. But some of the techs and nurses do not get along. And you see that and that make it worse for everything. That's probably why they have a big turnover. I don't know what it is.

Participant 9 also stated that it makes her and other patients uncomfortable when they witness the bickering:

You're sitting here looking at it and you can't go nowhere else, you have to see it. Isn't that awful? Oh, honey, I've seen them almost fight. One standing and talking and not waiting on the patients. The other one might say something to them, and they get it. We do have a patient advocate, and she usually be the one take it to management. It don't seem to help too much, so I don't know. That's something they need to…maybe it will be better now cause a lot of the techs is gone and a lot of the nurses is gone. It's frightening (inconsistent staffing) because you don't know who can stick and who can't. You don't know if they're gonna watch you like they're supposed to.

Participant 6 had a genuine concern about the well-being of patients and staff:

Some of these people work so long hours, I don't see how they can give the patients their 100%, because you lose a [little] something after you work so many hours. The patient needs you; if there's an emergency, you'll miss something. And you can miss something from overworked. They come in here at 4 o'clock in the morning and get these machines ready to prepare for us to come in at 5:30. And then they're here till 8:30, 9:30, and 10 o'clock at night and then gotta go home and try to prepare their homes and families. Then gotta get in the bed by 11 so they can get back up at 2 to get ready to be here at 4. They're not getting enough rest and I worry about them. And I pray for everybody. Cause they have they're life at stake and ours at stake to. Cause I worry about them not having enough sleep and having to drive distance to come to us. It's a hard thing. And then we be coming in with family issues and we be sharing with them. They don't

> have to listen to us but they do. And we appreciate it, but it's hard to separate so much stuff 'cause we all got so much going on in our lives. The employees and the patients and we all just want the best for one another in here.

Summary

Included in this chapter were verbatim descriptions of the experiences of HD patients in DeKalb County, Georgia. The results indicated that these individuals did experience a decrease in QOL. However, most participants had developed ways of coping with the disease because it had become such an intrinsic part of their lives. It appeared that incorporating the HD treatments into their activities of daily living made coping with them a bit easier. Most of the experiences within the facilities were pleasant, but it was evident that some issues made the patients uneasy at times. In Chapter 5, I discuss the findings and the need for social change. I also offer recommendations and end the study with a conclusion.

Chapter 5: Discussion, Conclusion, and Recommendations

Introduction

Chapter 5 is an overview of the completed study. I present the findings, discuss the implications for social change, and offer recommendations for further research. Lastly, I reflect on the study limitations, personal biases, and values of the research.

Diabetes and hypertension are known causes of kidney failure. These two chronic conditions, among others, are highly prevalent in African American communities. More importantly, members of this community need to understand how to prevent these life-threatening conditions. However, once diagnosed with one or both, there should be upstream strategies in place to prevent the progression to ESRD. Constraints can impede patients' ability to retrieve all information; likewise, not understanding the information limits the ability of patients to change behavioral habits and throws them into the need to make total lifestyle changes with little preparation (Clarkson & Robinson, 2010).

The lives of patients receiving HD treatments are hugely altered. They encounter physiological stressors and disruptions to their daily lives (Nazly et al., 2013) that include fatigue, reduced mobility, hypotension, muscle cramps, nausea and vomiting, fluid and food restrictions, and employment problems. Prior to this study, the impact of HD on patients who receive treatments in DeKalb County, Georgia, had not been documented in the literature.

I followed a phenomenological approach to understand the experience of 10 African American participants who received HD in DeKalb County. The purpose of this study was to understand their experiences and identify commonalities within their subjective accounts of information to provide better support and sustainable interventions. This method of inquiry was chosen because of its ability to be a gateway to examine the participants' lived experiences. There has been literature on the lived experiences of patients receiving HD treatments, but little of it has focused on the African American population. Another gap in the literature involved the common themes related to the perceived threat of and perceived susceptibility to ESRD in this population.

Ten telephone interviews were conducted to obtain demographic information and assess the potential participants' eligibility to be in the study. All 10 met the criteria, so the private, face-to-face interviews were scheduled. I followed the same interview protocol for all 10 interviews. All interview responses were transcribed verbatim. After transcriptions were complete, I used hand coding until I had a clearer understanding of NVivo, which I used to complete the final analysis. I followed Creswell's (2009) six steps to analyze the data. Steps also were taken to protect the patients' privacy. All electronic information was stored on a password-protected computer. All hard copies were protected under lock and key in my office, to which only I had access.

Interpretation of the Findings

The purpose of this study was to understand the physiological and psychological impact of HD treatments and to understand whether the participants perceived a threat of or susceptibility to ESRD once diagnosed with the major causes of renal disease or whether it was reflective of their family medical histories. Lastly, the purpose of the study was to assess the barriers to home treatments. I found that the participants in this study experienced depression resulting from a sense of loss and felt that they were not really living because of the restrictions, despite being able to cope. Most did not have a perceived threat of or susceptibility to renal failure or ESRD because of a lack of education. The participants acknowledged that the lack of education was evident across their communities and was the reason for the increased IR of the disease in their respective communities. HD was the preferred treatment of choice by most, but not all, participants. All of them, however, showed an interest in transplantation, albeit with some reservations. The dialysis experiences were mainly the same among this group but slightly different from prior research.

Theme 1: Lifestyle Changes

Subtheme 1: Life prior to HD. The participants had the opportunity to reflect on their lives and lifestyles prior to having ESRD. The overall theme was that of freedom, that is, the ability to make choices and do as they pleased. They remembered a time when they did not have to consider or include HD treatments in their schedules. Receiving HD treatments led to limitations in their ability to just live as they wanted to. Three participants reflected on the time when they could travel without having to arrange dialysis treatments. A younger participant recalled when she could be spontaneous with friends and take unplanned trips. Two participants mentioned missing treatments to travel or traveling on nondialysis treatment days. The ability to participate in hobbies was eliminated or decreased.

The participants reflected on the fact that they could eat and drink whatever they wanted prior to ESRD. The food and fluid restrictions made it difficult to enjoy social outings, according to one participant. Employment was not a problem for this population prior to HD, but now, only two participants were able to maintain employment because of the complications of HD treatments.

The results were consistent with Herlin and Wann-Hansson's (2010) study in a number of ways, mainly that individuals undergoing HD treatments experience severe limitations and a reduced QOL. The participants in their study had been on HD between 9 months and 3 years. In this short time, participants described feeling that they were living double lives and not really having the opportunity to live a single life to its fullest. The participants characterized living with HD as a restricted lifestyle, but they understood the need for HD treatments, even if HD did not allow them to live well. To the participants, their freedom had been lost, and they were being forced to live with the disease and the treatment process (Herlin & Wann-Hansson, 2010).

Results also were consistent with Clarkson and Robinson's (2010) study that illustrated the physical effects on the body that started after dialysis and continued the next day, resulting in the inability of the participants to complete daily activities or maintain employment and leading to depression. The participants in my study expressed that they were experiencing the same restricted lifestyles. Guerra-Guerrerro et al. (2014) emphasized that patients' lives had been divided into two phases. The first phase occurred prior to being diagnosed with ESRD, when they were full of life and able to participate in it. The second phase started after diagnosis, when their lives changed from what they used to be. Results were consistent with Nazly et al.'s (2013) findings showing that restricted schedules decreased the ability to travel and be spontaneous.

Subtheme 2: Perceived threat/susceptibility. Only one participant perceived a threat of ESRD because of a family history of polycystic kidney disease. Another participant recognized that even though there was a family health issue, he still perceived no threat or susceptibility to himself because he played sports. Five more patients had been diagnosed with hypertension or diabetes, but they also did not perceive any threat or susceptibility to CKD. No participant reported knowing that hypertension and diabetes were causes of ESRD. Five participants had never heard about ESRD or dialysis treatments prior to being diagnosed, so they had no reason to perceive a threat or feel susceptible to threat**.** Participants stated that they were taking blood pressure pills, with no change in the outcome and no mention of ESRD early on.

Another participant decided to change doctors after she continued to present with hypertension, but by then, it was too late. This result was consistent with the findings of Amedia and Perazella (2006) as well as Clarkson and Robinson (2010) that primary physicians usually do not recognize the changes in eGFR and albumin levels, resulting in late referrals to nephrologists. My results also were consistent with those of Schoolwert et al. (2006), who asserted that although there are known strategies to prevent CKD development (e.g., early identification of those at risk and close monitoring, and education about lifestyle and dietary changes), those strategies are not in place in high-risk populations, as evidenced by late referrals, suboptimal care, and undiagnosed and untreated CKD.

In 2003, Powe conducted a study whose results also were consistent with my findings. Powe described the lack of intervention and attention to visible signs and symptoms of developing CKD by a physician treating an African American patient. The findings in my study are consistent with the review in Chapter 2.

Theme 2: Lack of Education

Seven participants were diagnosed with hypertension or diabetes prior to being diagnosed with ESRD. Three of the seven reported receiving no education, just medication. Nephrologists are able to provide their patients with education to manage hypertension and glucose levels to support the delay of CKD and prevent the progression to ESRD (Stevens & Levin, 2013). A number of the participants stated that the medication was not working and that they continued to experience hypertension. Even with education, none of the participants was ever told that medication, in combination with lifestyle and dietary changes, would prevent CKD development and the need for RRT.

Five participants had never heard of CKD/ESRD prior to their own diagnosis. Four had heard about CKD/ESRD because of the health issues facing other family members, but they never knew the predisposing risk factors. My findings are consistent with Pearson’s (2008) study that renin-angiotensin aldosterone systems inhibitor was prescribed for European American patients, but not African American patients, to slow the progression of the disease, disparities that were also pointed out by Atkins (2005) and Schoolwert et al. (2006). Clark and Robinson (2010) reported on the lack of education in the African American community, results that supported my findings.

Subtheme 1: Lack of awareness in communities. Public service announcements are used to educate the public about drug use, smoking, strokes, and so on. Television commercials can be a useful source of information about different types of cancer, strokes, smoking, and chronic obstructive pulmonary disease. The participants complained that there had not been any information about CKD/ESRD disseminated within the community or at any physicians' offices that they had visited. Participants voiced the need for workshops and public screenings to detect and educate the communities. One participant suggested passing out flyers at the local mall to increase community awareness. Another participant suggested allowing people to watch an HD treatment as part of the education process. Atkins (2005) suggested that detection and prevention programs to eradicate or decrease the prevalence of diabetes, hypertension, and CKD could be developed through a concerted effort from global institutions, governmental entities, health care providers, and practitioners. He also suggested lifestyle modifications and increases in education in communities with a high prevalence of CKD.

Powe (2003) advocated periodic screenings for proteinuria and annual assessments for albuminuria for individuals with hypertension and diabetes; Atkins (2005) and Schoolwert et al. (2006) had made the same suggestion as a precautionary measure. Again, this is consistent with Schoolwert et al.'s suggestion to have upstream strategies in place to prevent CKD. Appropriate education prior to dialysis can result in significant cost savings in regard to reduced length of hospital stays (Clarkson & Robinson, 2010).

Subtheme 2: Modality choice. Powe (2003) asserted that African American patients are less likely to have discussions about PD or transplantation with their physicians. According to McIntyre (2010), ICHD is preferred by physician groups because it allows a large number of patients to be treated at one time. Therefore, home therapy is not routinely provided as an option. In my study, eight participants admitted to having modality education prior to starting HD. In other words, those eight patients were allowed to decide which treatment modality would fit their lifestyles. Three participants initiated treatments with a home modality, one with PD and two with HHD. Only one participant stated that it was contraindicated. Two participants reported not receiving modality education or being given an option; they were simply put on HD.

All participants stated that they had been provided with frequent modality education since being in the dialysis facilities. However, even with the education, two patients on the transplant list were still undecided about whether to actually accept the transplant if contacted. My results did not mirror those of either Powe or McIntyre.

Participants continued on ICHD for a number of reasons, even after being educated. Three participants remained on HD because it gave them the ability to socialize; dialyzing at home would have isolated them from other patients. The thought of the peritoneal catheter hanging from an opening in the abdomen did not appeal to a number of participants. Three participants mentioned not having enough space to store the needed supplies and equipment. One participant mentioned that his house was not clean enough for home treatments. My results were consistent with those reported by Sadala et al. (2012) that described patients’ responses to home therapy. In their previous ways of life, the participants were not tied to machines, and their homes were not cluttered with medical equipment.

One participant described body disfigurement because of the catheter placement and solutions carried around in the catheter (Sadala et al., 2012). Ding (2013) conducted a narrative study of a nurse with ESRD who had used conventional HD and home therapy. The results identified the same barriers to using home therapy that I discussed, namely, late referrals, fear of self-cannulation, fear of performing dialysis at home, lack of an appropriate home environment, and medical contraindications. The participant felt strongly that nephrology nurses were the key to patients' use of home modalities because they were the ones conducting patient education and having close relationships with the patients. However, it was important for conventional nephrology nurses to become more competent in the therapy in order to promote it. Once the nurses became more familiar with the therapy, they could help patients to make more educated modality choices to better fit their needs and lifestyles.

Curtin et al. (2004) had completely different outcomes. Curtin et al. described the perspective of 12 patients who had been provided with modality education from the beginning of the process. PD was their initial option because they could make decisions about their care and treatments, and they experienced fewer restraints. They voiced that their lives did change because everything had to be organized around treatments. However, they also were able to adapt to the change and regain control of their lives. They were provided with health education so that they could make informed decisions, unlike a number of participants in my study. The loss of control expressed by the participants in my study was consistent with the results shared by Koester in 2013.

Subtheme 3: Dialysis experience. For the most part, the participants were satisfied with the facilities and their staff. However, they might have been reluctant to share in-depth information, knowing that I was an employee of the company. Regardless, they still disclosed that the staff meant a lot to them and that the practitioners and immediate staff played significant roles in their ability to cope. Maintaining constant communication and keeping them informed, as well as expressing empathy for their situations, was an important, positive factor for the patients (Bass et al., 1999).

Participants saw it as a huge problem when staffing was not consistent. One participant expressed fear of having new staff members or rapid turnover. It was acknowledged that staff and patients build relationships and bonds, important factors in their care and well-being. This postulation was supported by the participants in Kaba et al.'s (2007) study, who voiced the same concerns about staff and their experiences. Participants described the unit as a familiar and safe place where life-saving activity took place. They mentioned how important it was to feel welcomed by staff as well as be taken care of by staff who had expertise (Kaba et al., 2007). Some relationships or bonds between staff and patients are so profound that one participant voiced a concern for staff safety regarding the long work hours and early-morning work shifts. Staff conflict was another concern to the participants. One participant expressed concerns about verbal confrontations that happen on the treatment floor in front of patients and the loss of control during those moments.

Theoretical Considerations

In my study, the participants did not perceive any susceptibility or threat to ESRD. Five participants had never heard of CKD or ESRD. The other four participants who had heard of dialysis or transplant did not know that diabetes and hypertension were the leading causes of ESRD. Only one participant had a family history of polycystic kidney disease, yet she remained uneducated about the marginal factors that could slow the progression of the disease and maintain QOL.

Based on the HBM, the public health approach to changing health behaviors would be to convince people that they are vulnerable, the threat is severe, and certain actions are effective preventive measures (Schneider, 2010). A number of participants had been faithful to primary care appointments because of diagnoses of diabetes or hypertension. During those visits, according to the participants, they were not convinced to change their behavioral habits. They were not threatened with the possibility of ESRD and the associated disease process and complications. Bartholomew et al. (2011) stated that the decision to engage in a health action is determined by perceptions of personal susceptibility to, along with the severity of, a particular condition or illness balanced against perceived benefits and barriers.

ESRD is not a disease that can be eradicated by educating one person at a time; rather, entire communities need to be educated and informed (Prilleltensky, 2009). According to Prilleltensky (2009), afflictions such as HIV/AIDS, poverty, child abuse, and powerlessness have never been controlled or eliminated by treating the affected individuals one person at a time. In this case, it is important to review and use the empowerment theory to gain insight into the root causes in order to eradicate or decrease the prevalence of ESRD. Empowerment is a process that focuses on individual, organizational, and community levels (Bartholomew et al., 2011). Helping individuals to understand the causes of ESRD and the contributing environmental factors is empowerment at the individual level. It is possible that increased awareness at the individual level will lead to organizational and community empowerment and changes. At the organizational and community levels, empowerment involves collective problem solving; shared leadership and decision making; and access to government, the media, and other resources (Bartholomew et al., 2011).

Implications for Social Change

The findings have various implications for positive social change. The first implication is the placement of upstream strategies to decrease the prevalence of ESRD or slow the progression of CKD within the African American population. It is clear that strategies to monitor and educate this population are lacking. Not knowing that diabetes and hypertension were the main causes of chronic renal failure, or the lack of education prior to diagnosis, weighed heavily on the participants. The implications for social change include the potential impact of increasing the understanding of hypertension and diabetes, their influences on ESRD development, and the potential to minimize the negative impact of ESRD on QOL. Community awareness and education are key to positive social change. The implications for positive social change include community education to increase awareness and decrease the prevalence of ESRD.

Participants mentioned the importance of having consistent staff who are knowledgeable. There was an increased level of concern when staff had conflicts and voiced those conflicts within hearing range of the patients. The positive social change implications include knowledge useful for nephrologists, in-center staff, educators, program developers, and other researchers who are researching ways to improve interactions with in-center patients, change patients' experiences, and create a special place. The results of my study the importance of having a more in-depth understanding of the positive impact that competent staff and positive interactions can have on patient outcomes and QOL.

The last implication for positive social change involves increasing the knowledge base of ICHD nursing staff about home therapy options so that they can better educate in-center patients. The findings show that patients have a fear of home treatments for a number of reasons. The patients trust the in-center nursing staff, so they would be the most appropriate providers to educate patients.

Recommendations

The purpose of the study was multidimensional, that is, to give a voice to this group of patients, increase compliance, increase community awareness, encourage the placement of upstream strategies, and increase the use of home therapy. I took a phenomenological approach to gain subjective insight and understanding of the experiences and perceptions of the 10 participants. The results began to fill the gap in the current literature, but they also introduced new and unanswered questions. The following are recommendations for future studies.

According to their home zip codes and the locations of the facilities, these participants were localized to the southern regions of DeKalb County. According to the DeKalb County Status of Health report (2015), cities in the southern part of the county have a higher IR of chronic disease than northern cities, along with an overall poorer health status. Transferability is possible because the participants included men and women from a broad range of ages, levels of education, and SES. Therefore, the results can be generalized to the northern region of DeKalb County. Conducting this same study with participants from the northern region of DeKalb County could yield different results.

It was apparent from the subjective data collected that upstream strategies are not in place for the DeKalb County residents to prevent CKD. A longitudinal study of patients in the first three stages of CKD exposed to appropriate education conducive to life style changes and appropriate medication and monitoring should be considered. Would this exposure yield different results for participants from this same area? This type of study could prove instrumental in the development of programs or interventions to decrease the IR of ESRD in this population.

Results strongly identified a gap in individual education and community awareness of ESRD as well as the harm of diabetes and hypertension. Lastly, would a longitudinal study of patients diagnosed with hypertension or diabetes and provided with appropriate education decrease the progression to ESRD and produce overall behavioral change resulting in better health outcomes? Would an increase in awareness mean a decrease in the IR of diabetes, hypertension, and ESRD in this population?

Reflections on the Research Experience

This experience has been intense and demanding, requiring strength and perseverance. Regardless, it has been a stimulating and engaging experience for me. The research was intriguing but difficult. Conducting a literature review for the first time was not an easy task. Fortunately, it allowed me to gain insight into a topic that demands social change. While I was reviewing the literature, I found that no studies had been conducted on ESRD patients in the DeKalb County, Georgia, area. This gap was the impetus for conducting this study.

Despite having been a dialysis nurse since 1997, I took on the research task with no impartial judgments or prejudices. The participants were made aware of my current position and past experience as a dialysis nurse to increase comfort levels and engagement. To ensure that all personal biases were delineated, I used an interview protocol for the telephone and face-to-face interviews. I gave each participant a $10 token of appreciation upon completion of their respective interviews. The money was placed in a thank-you card.

The telephone interviews were transcribed and analyzed for demographic comparisons. All face-to-face interviews were transcribed and analyzed to obtain a more in-depth understanding of the responses and develop the themes. Analyzing the data was a huge challenge for me. I did not understand how to develop the themes; sometimes, the themes did not appear to me. I found NVivo difficult, so I had to review tutorials to gain a better understanding of the software before using it. I did not want to waste time while reviewing the instructional videos, so I created a board and listed all responses from the participants to the specific questions. I created another list documenting common responses to specific questions. I was able to input this information into NVivo to achieve a more structured analysis of the data.

Although this program was worthwhile, it was very challenging. It decreased my QOL and placed a strain on my ability to balance work, family, and school responsibilities. I had to place a number of enjoyable activities with family on hold or cut them short. This project taught me that an intense review of the literature, unbiased data collection, and specific RQs are key to producing sound research. This study raised other questions concerning educational awareness and intervention programs. A follow-up study exploring this phenomenon could prove beneficial in the HD arena.

Conclusion

Lifestyle and QOL are impacted by ESRD, regardless of the choice of modality. However, Lindqvist et al. (2000) suggested that the impact on QOL is far greater for ICHD patients than for patients using any other modality. It would seem that home treatments would at least decrease some stressors and give patients a somewhat better QOL and more control. The fear of doing something wrong, being alone, needing assistance during home treatments, and lacking the chance to socialize meant that a number of ICHD patients elected to receive treatment at the centers, regardless of the consequences, according to my findings.

Results were consistent with those from earlier research on the effects of HD on in-center patients and the ESRD process. Poor primary care, or lack thereof, also was identified in the study. It included, but was not limited to, inappropriate education, medication, and monitoring prior to diagnosis. Results mirrored the importance of implementing upstream strategies to decrease the prevalence of the disease. Those necessary upstream strategies for prevention were mentioned by Schoolwert et al. (2006). Implementing upstream strategies would heighten awareness within African American communities, and community awareness could possibly be the genesis of social change within this population.

References

Abood, D., Black, D., & Ferral, D. (2003). Nutrition education worksite intervention for university staff: Application of the health belief model. *Journal of Nutrition Education and Behavior, 35*(5), 260-267.

Amedia, C., & Perazella, M. (2006). Transition of patients from chronic kidney disease to end-stage renal disease: Better practices for better outcomes. *Disease Management, 9*(6), 311-313. doi:10.1089/dis.2006.9.311

Assari, S. (2016). Racial disparities in chronic kidney disease in the United States: A pressing public health challenge with social, behavioral and medical causes. *Journal of Nephropharmacology, 5*(1), 4-6.

Atkins, R. (2005). The epidemiology of chronic kidney disease. *Kidney International, 67*(94), 14-18. doi:10.1111/j.1523-1755.2005.09403.x

Audulv, A. (2013). The overtime development of chronic illness self-management patterns: A longitudinal qualitative study. *BioMed Central Public Health, 13*(1), 1-15. doi:10.1186/1471-2458-13-452

Baillie, J., Lankshear, A., & Featherstone, K. (2011). Perspectives on peritoneal dialysis at home: Implications for the management of a chronic condition: A study protocol. *Journal of Advanced Nursing, 68*(8), 1847-1857. doi:10.1111/j.1365-2648.2011.05907.x

Bartholomew, L., Parcel, G., Kok, G., Gottlieb, N., & Fernandez, E. (2011). *Planning health promotion programs: An intervention mapping approach* (3rd ed.). San Francisco, CA: Jossey-Bass.

Bass, E., Jenckes, M., Fink, N., Cagney, K., Wu, A., Sadler, J., … Powe, N. (1999). Use of focus groups to identify concerns about dialysis. *Medical Decision Making, 19*(3), 287-295. doi:10.1177/0272989X9901900307

Bednar, B., & Latham, C. (2014). The changing landscape of the nephrology nursing care environment in the United States over the last 45 years. *Journal of the American Nephrology Nurses' association, 41*(2), 183-190.

Blagg, C. (2011). Dialysis composite rate bundling: Potential effects on the utilization of home hemodialysis, daily and nocturnal hemodialysis, and peritoneal dialysis. *Seminars in Dialysis, 24*(6), 674-677. doi:10.1111/j.1525-139x2011.00993.x

Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science and Medicine, 44*(6), 747-756. doi:10/1016/S0277-9536(96)00192-X

Bostock, I. C., Alberú, J., Arvizu, A., Hernández-Mendez, E. A., De-Santiago, A., González-Tableros, N., … Vilatobá, M. (2013). Probability of decreased donor kidney transplantation based on % PRA. *Transplant Immunology, 28*(4), 154-158. doi:10.1016/j.trim.2013.05.002

Centers for Disease Control and Prevention. (2007). Health disparities in kidney transplantation: An equity analysis. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2012). Chronic kidney disease initiative: Protecting kidney health. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2014). National chronic kidney disease fact sheet. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2016). High blood pressure fact sheet. Retrieved from http://www.cdc.gov

Choi, J., Jang, H., Park, J., Kim, Y., Kang, S., Yang, C., … Kim, Y. (2013) Survival advantage of peritoneal dialysis relative to hemodialysis in early period of incident dialysis patients: A nationwide prospective propensity-matched study in Korea. *PloS One, 8*(12), 1-9.

Clarkson, K., & Robinson, K. (2010). Life on dialysis: A lived experience. *Nephrology Nursing Journal, 37*(1), 29-35. Retrieved from http://library.walden.edu

Collopy, K., Kivlehan, S., & Snyder, S. (2013). Exploring chronic kidney disease. What EMS should know? *EMS World, 42*(3), 51-57.

Creswell, J. (1998). *Qualitative inquiry & research: Choosing among the five traditions.* Thousand Oaks, CA: Sage.

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Los Angeles: CA. Sage.

Crosby, R., DiClemente, R., & Salazar, L. (2006). *Research methods in health promotion.* San Francisco, CA: Jossey-Bass.

Curtin, R., Johnson, H., & Schatell, D. (2004). The peritoneal dialysis experience: Insights from the long-term patients. *Journal of the American Nephrology Nurses' Association, 31*(6), 615-624.

Davenport, A. (2014). Balancing risks: Blood pressure targets, intradialytic hypotension, and ischemic brain injury. *Seminars in Dialysis, 27*(1), 13-15. doi:10.1111/sdi. 12153

DeKalb County Board of Health. (2015). 2015 Status of health in DeKalb report. Retrieved from https://dekalbhealth.net/hap/

Ding, D. (2013). Perspectives and experiences of a nephrology nurse on home hemodialysis. *Journal of the American Nephrology Nurses' Association, 40*(1), 51-54.

Foote, E., & Manley, H. (2008). Hemodialysis and peritoneal dialysis. In *Pharmacotherapy* (Section 5, Online Chapter 48, pp. 103-117). Columbus, OH: McGraw-Hill Higher Education.

Fortin, M., Chouinard, C., Bouhali, T., Dubois, F., Gagnon, C., & Belanger, M. (2013). Evaluating the integration of chronic disease prevention and management services into primary health care. *BMC Health Services Research, 52*(4), 227-234.

Gallegos, A. (2007). Retail medicine: The cure for healthcare disparities? *Journal of Healthcare Management, 52*(4), 227.

Georgia Department of Public Health. (2006). Georgia data summary. Retrieved from http://health.state.ga.us

Guerra-Guerrerro, V., Plazas, M., Cameron, B., Salas, A., & González, C. (2014). Understanding the life experience of people on hemodialysis: Adherence to treatment and quality of life. *Journal of the American Nephrology Nurses' Association, 41*(3), 289-297.

Harwood, L., & Clark, A. (2011). Understanding health decisions using critical realism: Home-dialysis decision-making during chronic kidney disease. *Nursing Inquiry 19*(1), 29-38.

Heaf, J., & Wehberg, S. (2014). Relative survival of peritoneal dialysis and hemodialysis patients: Effect of cohort and mode of dialysis initiation. *PloS One, 9*(3).

Herlin, C., & Wann-Hansson, C. (2010). The experience of being 30-45 years of age and depending on hemodialysis treatment: A phenomenological study. *Scandinavian Journal of Caring Sciences, 24*(4), 693-699.

Hochbaum, G. (1958). *Public participation in medical screening programs: A socio-psychological study.* Washington, DC: U.S. Department of Health, Education, and Welfare.

Holland, C., Carthron, D., Duren-Whitfield, V., & Lawrence, N. (2014). An experimental cardiovascular health education program for African American college students. *Journal of the Association of Black Nursing Faculty, 25*(2), 52-56.

Kaba, E., Bellou, P., Iordanou, P., Andrea, S., Kyritsi, E., Gerogianni, G., … Swigart, V. (2007). Problems experienced by haemodialysis patients in Greece. *British Journal of Nursing, 16*(14), 868-872.

Kendrick, J., Nuccio, E., Leiferman, J., & Sauaia, A. (2015). Primary care perceptions of racial/ethnic and socioeconomic disparities in hypertension control. *American Journal of Hypertension, 28*(9), 1091-1097.

Kim, A., Kumanyika, S., & Kim, H. (2010). Coverage and framing of racial and ethnic health disparities in the U.S. newspapers, 1996-2005. *American Journal of Public Health, 100*(S1), S224-S231.

Klang, B., Bjorvell, H., & Clyne, N. (1999). Predialysis education helps patients choose dialysis modality and increases disease-specific knowledge. *Journal of Advance Nursing, 29*(4), 869-876. doi:10.1046/j.1365-2648.1999.00957.x

Koch, J. (2002). The role of exercise in the African American woman with type two diabetes mellitus: Application of the health belief model. *Journal of the American Academy of Nurse Practitioner, 14*(3), 126.

Koester, L. (2013). Exploring the reasons for the tiny percentage of patients on home hemodialysis. *Journal of Nephrology Nursing, 40*(1), 43-48.

Lavrakas, P. (2008). Encyclopedia of survey research methods. Thousand Oaks CA: Sage.

Ledebo, I. (2008). What limits the expansion of self-care dialysis at home? *Hemodialysis International, 12,* S55-S60. doi:10.1111/j.1542-4758.2008.00298.X

Lee, A., Gudex, C., Polvlsen, J., Bonnevie, B., & Nielsen, C. (2008). Patient's views regarding choice of dialysis modality. *Nephrology Dialysis Transplantation, 23*(12), 3953-3959. doi:10.1093/ndt/gfn365

Lindqvist, R., Carlsson, M., & Sjoden, P. (2000). Perceived consequences of being a renal failure patient. *Nephrology Nursing Journal, 27*(3), 291-298. Retrieved from http://library.walden.edu

Lipworth, L., Mumma, M., Cavanaugh, K., Edwards, T., Ikizler, T., Tarone, R., … Blot, W. (2012). Incidence and predictors of end stage renal disease among low-income Blacks and Whites. *PloS One, 7*(10), 1-7.

Logan, H., Guo, Y., Dodd, V., Muller, K., & Riley, J. (2013). The burden of chronic diseases in a rural North Florida sample. *BioMed Central, 13,* 906.

Longo, J., & Hain, D. (2014). Bullying: A hidden threat to patient safety. *Journal of the American Nephrology Nurses Association Journal, 41*(*2*), 193-199.

Mark, P., Molzahn, A., Berry-Hauf, R., Hutchings, L., & Hughes, S. (2014). Exploring safety and quality in a hemodialysis environment with participatory photographic methods: A restorative approach. *Nephrology Nursing Journal, 41*(1), 25-35.

McIntyre, C. (2010). Recurrent circulatory stress: The dark side of dialysis. *Seminars in Dialysis, 23*(*5*), 449-451. doi:10.1111/j.1525-139x.2010.00782.x

McKenzie, J., Neiger, B., & Thackeray, R. (2009). *Planning, implementing, & evaluating: Health promotion programs* (5th ed.). San Francisco, CA: Pearson & Benjamin Cummings.

Mitchell, F. (2015). Racial and ethnic disparities in an era of healthcare reform. *National Association of Social Work, 40*(3). http://dx.doi.org.ezp.waldenulibrary.org/hsw/hlv038

Moustakas, C. (1994). *Phenomenology research methods.* Thousand Oaks, CA: Sage.

Munhall, P. (2012). *Nursing research: A qualitative perspective* (5th ed.). Sundry, MA: Jones & Bartlett.

National Kidney Foundation of Georgia and Georgia Department of Human Resources, Division of Public Health. (2005). Kidney Disease in Georgia 2005: The people at risk, the power to prevent. Retrieved from http://dph.georgia.gov

Nazly, E., Ahmad, M., Musil, C., & Nabolsi, M. (2013). Hemodialysis stressors and coping strategies among Jordanian patients on hemodialysis: A qualitative study. *Journal of the American Nephrology Nurses' Association, 40*(4), 321-327.

Nelson, A. (2002). Unequal treatment: Confronting racial and ethnic disparities in health care. *Journal of the National Medical Association, 94*(8), 666-668.

Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Pearson, M. (2008). Racial disparities in chronic kidney disease: Current data and nursing roles. *Journal of the American Nephrology Nurses' Association, 35*(5), 485-489.

Polaschek, N. (2003). Living on dialysis: Concerns of clients in a renal setting. *Journal of Advanced Nursing, 41*(1), 44-52. doi:10.1046/j.1523-1755.2003.00138.x.

Powe, N. (2003). To have and have not: Health and health care disparities in chronic kidney disease. *Kidney International, 64,* 763-772.

Prilleltensky, I. (2009). Using strengths, prevention, empowerment and community change (SPEC) to promote family well-being. Retrieved from https://www.melissainstitute.org/

Sadala, M., Bruzos, G. A. S., Peireira, E., & Bucuvic, E. (2012). Patients' experiences of peritoneal dialysis at home: A phenomenological approach. *Latino-Americana de Enfermagem, 20*(1), 68-75.

Schievink, B., Kropelin, T., Mulder, S., Parving, H., Remuzz, G., Dwyer, J., … Heerspink, H. (2015). Early renin-angiotensin system interventions is more beneficial than late intervention in delaying end-stage renal disease in patients with type two diabetes. *Diabetes, Obesity and Metabolism, 18,* 64-71.

Schneider, M. (2010). *Introduction to public health* (3rd ed.). Sudbury, MA: Jones & Bartlett.

Schoolwert, A., Engelgau, M., Rufo, K., Vincor, F., Hostetter, T., Chianchiano, D., … Warnock, D. (2006). Chronic kidney disease: A public health problem that needs a public health action plan. *Preventing Chronic Disease, 3*(2), A57.

Seccareccia, D., & Downar, J. (2012). "Should I go on dialysis, Doc?" Initiating dialysis in elderly patients with end stage renal disease. *Canadian Family Physicians, 58*(12), 1353-1356.

Sorensen, G., Landsbergis, P., Hammer, L., Amick, B., Linnan, L., Yancey, A., … Pratt, C. (2011). Preventing chronic disease in the workplace: A workshop report and recommendation. *American Journal of Public Health, 101*(S1), 196-207. doi:org/10.2105/AJPH.2010.300075

Southeastern Kidney Council. (2010). ESRD Network 6 2010 annual report. Retrieved from http://www.esrd.network6.org

Southeastern Kidney Council. (2012). ESRD Network 6 2012 annual report. Retrieved from http://www.esrd.network6.org

Stevens, P., & Levin, A. (2013). Evaluation and management of chronic kidney disease: Synopsis of the kidney disease: Improving global outcomes 2012 clinical practice guideline. *Annals of Internal Medicine, 158*(11), 825-830. doi:10.7326/0003-4819-158-11-201306040-00007

U.S. Department of Health and Human Services. (2007). Theory at a glance: A guide for health promotion practice. Retrieved from www.sbccimplementationkits.org/

U.S. Department of Health and Human Services. (2012). The National Kidney and Urologic Disease Information Clearinghouse (NKUDIC). Retrieved from http://kidney.niddk.nih.gov

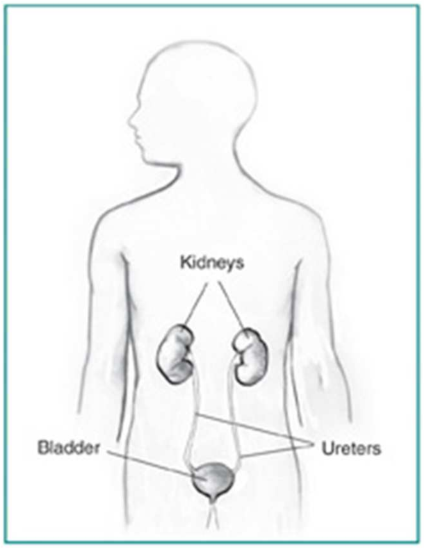
U.S. Department of Health and Human Services. National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases. (2013). Digestive diseases. Retrieved from http://www.niddk.nih.gov

Wells, J. (2011). Hemodialysis knowledge and medical adherence in African Americans diagnosed with end stage renal disease: Results of an educational intervention. *Journal of the American Nephrology Nurses' Association, 38*(2), 155-163.

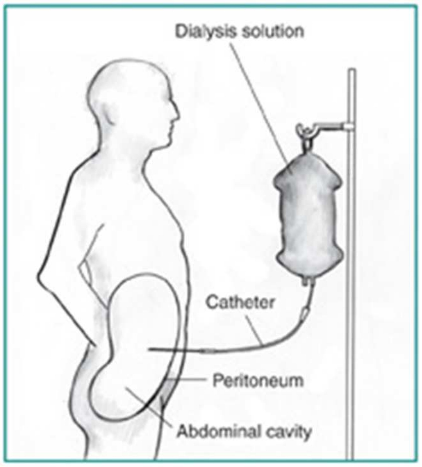
Wells, S. (2009). Health disparities in kidney transplantation: An equity analysis. *Journal of Health Disparities Research and Analysis, 3*(2), 1-12. Retrieved from http://library.walden.edu.

Williams, L., Wicks, M., Graff, J., Cowan, P., White-Means, S., Caldwell, L., & Tolley, E. (2016). Male caregivers of persons with end stage renal disease: A literature review. *Nephrology Nursing Journal, 43*(6), 495-519.

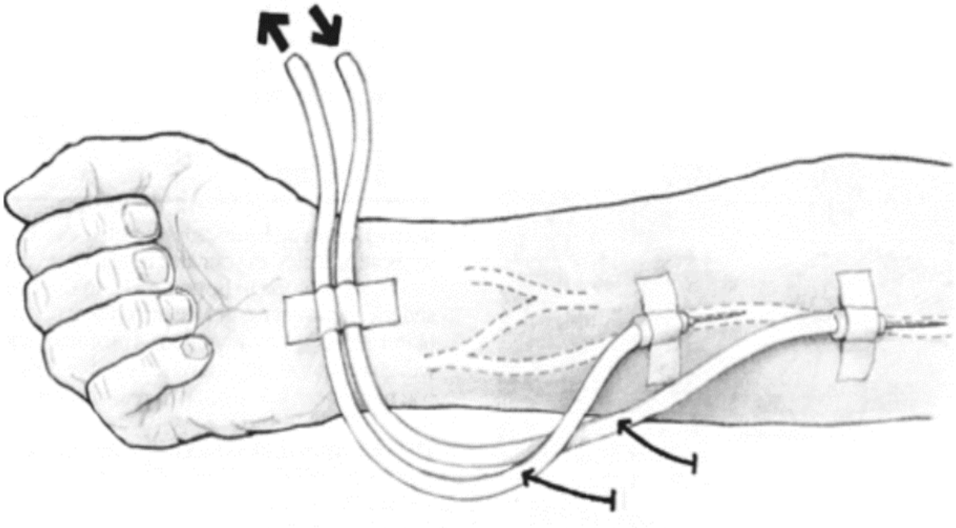
Appendix A: The Kidneys



Appendix B: Peritoneal Dialysis Solution Infusion



Appendix C: Needle Placement for Hemodialysis



Appendix D: Protocols for Interview Questions

Telephone Interview

- Are you currently receiving hemodialysis in-center?
- Are you receiving treatments in a facility located in DeKalb, County?
- How long have you been on dialysis?
- How long have you been at your current facility?
- How old are you?
- What is your gender?
- What is your salary range (Less than 10,000; 10,000 to 25,000; 25,000 to 45,000; 45,000 to 50,000, greater than 50,000)?
- What type of dialysis access do you have?
- Have you always used hemodialysis?

Face-to-Face Interview

- When you were a small child or teenager, did you know of any family members that had diabetes (sugar) or high blood pressure?
- Describe your lifestyle prior to CKD.
- Were you ever told that you had high blood pressure and or diabetes?
- If you were told, did you receive education about lifestyle changes?
- How has kidney disease affected your life?
- Describe your experience as an ICHD patient?

Student,

Stacey Cooper