Ascribing Meaning to Kidney Disease: A Qualitative Study of African Americans with a First Degree Relative on Hemodialysis

Loretta Brown

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ABSTRACT

ASCRIBING MEANING TO KIDNEY DISEASE: A QUALITATIVE STUDY OF AFRICAN AMERICANS WITH A FIRST DEGREE RELATIVE ON HEMODIALYSIS

by

LORETTA J. BROWN

Chronic kidney disease (CKD) poses a serious health threat to African Americans (AA). CKD is responsible for the high incidence of end stage renal disease requiring hemodialysis among AA. CKD is a preventable condition associated with modifiable and non-modifiable risk factors. Having a family history of CKD is an independent non-modifiable risk factor for CKD yet many AA do not perceive CKD as a major health concern. Previous studies on CKD awareness and knowledge have not included the voices of individuals with a relative affected by CKD. The purpose of this interpretive phenomenological study was to explore the meaning of kidney disease in African American adults with a first degree relative on hemodialysis in an effort to gain a deeper understanding of their lived experience with CKD and their personal perspectives on kidney disease.

In-depth face-to-face interviews were conducted with 8 women and 4 men, who ranged in age from 26 to 65 years old. Interviews were audio recorded and transcribed. Data analysis was conducted using an adapted version of Heidegger’s hermeneutic analysis process that involved continuous examination of the whole and the parts of the data for insightful discovery (Diekelmann, Allen, & Tanner, 1989). Two patterns and six major themes were identified. Pattern One was How We Relate, and its associated themes were: Communication, Comparison, and Bloodline. Pattern Two was Not
Knowing — Now Knowing, and its associated themes were: Seriousness of Chronic Kidney Disease, What is Kidney Disease? and Staying Strong.

Participants formulated their CKD health beliefs by processing, interpreting, and analyzing information received through interaction with their family members. They appraised their health as better than their affected family member and believed they could implement health protective behaviors to prevent CKD. Education, practice and research implications include: stronger public health risk campaigns based on the health language of AA, education models that engage patients in discussions about family health history, and a clear definition of what constitutes genetic risk for CKD and the relationship between genomics and personal risk appraisal.
ASCRIBING MEANING TO KIDNEY DISEASE:
A QUALITATIVE STUDY OF AFRICAN AMERICANS WITH A
FIRST DEGREE RELATIVE ON HEMODIALYSIS

by

LORETTA J. BROWN

A DISSERTATION

Presented in Partial Fulfillment of Requirements for the Degree of Doctor of Philosophy
in Nursing in the Byrdine F. Lewis School of Nursing and Health Professions
Georgia State University

Atlanta, Georgia
2014
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“Not by might, nor by power, but by my spirit, saith the Lord of hosts.”

Zechariah 4:6

If it was not for the Lord on my side, I never would have made it. When God first placed the desire in my heart to pursue my Ph.D., I knew there would be trials and tribulations, I just did not know they would come in like a flow. God sent the Holy Spirit to encourage, strengthen and comfort me. I realized that the road to obtaining a Ph.D. was my journey back into the heart of God.

God sent me help through many people and one key individual was Dr. Peggy Moloney, the chair of my dissertation committee. Dr. Moloney, you took me under your wing, and one of the first things you did was encourage me. Not once did I feel judged by you. Dr. Moloney, the care you have shown toward me as a person and toward my research interest means so much to me. Thank you for always seeing the best in me.

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The wind beneath my wings blew from many directions. My mother, Frances Jackson, offered the biggest gust. Mom, you never had to say a word, yet I knew you were praying for me. My first exemplar of an outstanding nurse, my oldest sister Vanessa Jackson, thank you for being a great role model. To my youngest sister, Anita Jackson, your email and text prayers helped me to get up each morning and pursue my dream. To my South Florida family thank you for winds of love and support.
At the heart of all my support are my daughters, LaWanda and Lauren. LaWanda, you taught me about the five stones of David and that God’s grace is always with me. You ministered to me that it is not about fighting the giant, but believing I can defeat the giant before seeing the giant conquered. Lauren it was so kind of you to allow me the opportunity to pursue my Ph.D. alongside of you as you progressed through your schooling. Not once did you ever complain that my education was interfering with our time together. Daughters, I love you and am forever indebted to you for the life you gave to me, thank you.

I could have never compiled this body of knowledge without the men and women who graciously shared their personal stories with me. In my heart, I call you by name and I salute you. Last, kidney disease became a passion for me because of the lived experienced of my loved ones. I dedicate this dissertation to my family members who lost their lives to kidney disease. I hope that you are proud of the work that I have accomplished. Your spirit encourages me daily. Know that I will never give up on changing the outcome of kidney disease. Rest in peace.
This study was supported by a grant made available by the American Nephrology Nurses’ Association (ANNA). Findings of the study do not necessarily reflect the opinions of ANNA. The views expressed herein are those of the author and no official endorsement by ANNA is intended or should be inferred.
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CHAPTER I

Introduction

Focus of Inquiry

Chronic kidney disease (CKD) is a serious public health problem. The number of individuals in the U.S. with CKD continues to increase each year (Coresh et al., 2007). In the U.S. Medicare population alone, between the years of 2000 and 2010, the prevalence of CKD increased from 2.7 to 9.2 percent — representing a three-fold increase (United States Renal Data System [USRDS], 2012). A major consequence of CKD is end stage renal disease (ESRD). ESRD is associated with costly renal replacement therapies, and those affected experience increased morbidity, disability and mortality. According to the 2012 USRDS Annual Dialysis Report in 2010, Medicare costs for ESRD were $33 billion and accounted for 6.3% of the Medicare budget (USRDS, 2012). Two leading causes of CKD are diabetes and hypertension. Diabetes and hypertension share common risk factors and often co-exist in individuals with CKD.

The odds for developing CKD are greatest in African Americans (AA) when compared to other racial/ethnic groups. Although the rate of new onset ESRD has been decreasing among AA over the past 10 years, AA continue to experience the greatest ESRD incident rate and tend to progress faster to ESRD than other racial/ethnic groups (Vargas & Norris, 2012). Clinical guidelines recommend that individuals at risk for CKD should be screened for the presence of kidney disease (National Kidney Foundation...
Moreover, research suggests interventions that mitigate risk and slow the progression of CKD are most effective when CKD is detected early (Bello, Peters, Wight, de Zeeuw, & El Nahas, 2008; Crook, Washington, & Flack, 2002; Freedman et al., 2005; Hallan et al., 2006; McClellan, Ramirez, & Jurkovitz, 2003). Initiatives such as identification of CKD risk factors by health care providers, early screening to detect kidney disease, appropriate medical intervention to manage high blood pressure and diabetes, and personal adoption of personal protective health behaviors can help minimize or alleviate disability from CKD.

Epidemiological studies have clearly defined non-modifiable and modifiable factors that are associated with an increased risk for CKD (Haroun et al., 2003; McClellan & Flanders, 2003; Stengel, Tarver-Carr, Powe, Eberhardt, & Brancati, 2003; Tarver-Carr et al., 2002; Yamagata et al., 2006). Yet, AA, the largest racial/ethnic group impacted by CKD in the United States, do not perceive the disease as a major health threat (Vassalotti, Li, Chen, & Collins, 2009; Waterman, Browne, Waterman, Gladstone, & Hostetter, 2008). This lack of awareness has been attributed to limited knowledge of CKD risk factors and low CKD risk appraisal among AA (Nunes et al., 2011). Hence, this presents a striking discordance between the recommendations from clinical guidelines that identify AA as an at-risk group for CKD and AA beliefs about their CKD risk.

One contributing factor to this discordance is that an individual’s representation of what constitutes a health threat may be quite different from risk estimates. Perceived susceptibility to a health threat is strongly associated with an individual’s likelihood to take action to mitigate the threat; when individuals do not perceive personal risk for
CKD, they may be less likely to exercise behaviors that result in risk modification. Ultimately this lack of perceived risk hinders the ability of AA to adopt health protective behaviors that reduce their likelihood of developing kidney disease.

For prevention strategies to be effective in modifying CKD, they must include more than clinical and socio-demographic determinants of health. Individuals’ health perceptions, attitudes, and beliefs are shaped by many different influences (Hekler et al., 2008). Moreover, individuals conceptualize their personal risk for disease by weighing various factors beyond quantitative assessment of morbidity and mortality outcomes (Leventhal, Brissette, & Leventhal, 2003; Morton, Tong, Howard, Snelling, & Webster, 2010; Thomas-Hawkins & Zazworsky, 2005). They assess their risk based upon their own lived experiences; risk quantified by others is not the primary determinate of disease threat for an individual. Therefore, assumptions about CKD risk perceptions need to be more sensitive to the individual’s concept of risk and the factors that influence an individual’s personal risk appraisal and decision-making process. In this study, a deeper understanding of the meaning of kidney disease will be sought from the perspective of AA with a family history of CKD. Stories of the lived experiences of AA who have or have had a first degree relative (parent, sibling, or child) on hemodialysis will be interpreted for shared meaning and common language using a phenomenological approach.

**Background**

In this section I discuss information essential to understanding the significance of CKD and contributing factors that elevate CKD risk among AA. I review CKD risk factors and examine health practices associated with CKD risk reduction. Next, I discuss
risk perceptions and CKD risk awareness among AA and health care providers. Lastly, I argue the need for a deeper understanding of how AA perceive kidney disease.

**CKD Description and Significance**

Recent changes in health care policy have shifted the focus of the U.S. health system from sick care to disease prevention and health promotion. Many of our nation’s health problems are preventable, and one such condition is CKD. CKD is defined as either kidney damage or glomerular filtration rate < 60 ml/min/1.73 m$^2$ for ≥ 3 months (NKF, 2002). The degree of kidney function corresponds to five stages of disease severity, from kidney disease with a normal glomerular filtration rate ≥ 90 ml/min/1.73 m$^2$ (CKD Stage 1) to ESRD with glomerular filtration rate < 15 ml/min/1.73 m$^2$ (CKD Stage 5). CKD is a public health problem affecting more than a quarter of Americans (Ohmit, Flack, Peters, Brown et al., 2003; Whaley-Connell et al., 2008). Analysis of survey data comparing the 1988-1994 National Health and Nutrition Examination Survey (NHANES) and the 1999-2004 NHANES suggests that CKD in the U.S. increased from 10.0% to 13.1% between these time frames (Coresh et al., 2001).

CKD is a risk multiplier for morbidity and mortality and a strong predictor of major cardiovascular disease. Cardiovascular disease is the leading cause of death in the U.S. and accounts for the majority of hospitalizations in individuals with CKD (Danaei et al., 2009). Patients with CKD experience cardiovascular complications at a higher rate than patients without CKD (Mensah, Mokdad, Ford, Greenlund, & Croft, 2005; Muntner, He, Hamm, Loria, & Whelton, 2002). For example, in 2010 the prevalence rate of congestive heart failure for individuals with CKD was 44% as compared to 19% in individuals without CKD (USRDS, 2012). Excess risk for cardiovascular disease is
evident across all five stages of CKD and is most pervasive in AA regardless of CKD diagnosis (Di Angelantonio et al., 2010; Mensah et al., 2005; Perkovic & Cass, 2010; USRDS, 2012). For patients with CKD, this compounded burden of risk leads to higher hospitalization rates and in turn accounts for a large fraction of CKD health care costs (Wong et al., 2007). Individuals with CKD have yearly per person health care cost expenditures of $23,000, whereas non-CKD individuals’ expenditures are $8,000 (USRDS, 2012).

**CKD Risk Factors**

As stated previously, both non-modifiable and modifiable risk factors are associated with CKD. Non-modifiable risk factors include African American racial/ethnic group, and having a family history of CKD, diabetes, or hypertension. Modifiable risk factors include a personal history of diabetes, personal history of hypertension and being overweight and obese (Whaley-Connell et al., 2008). Having a family history of hypertension and ESRD in a first or second degree relative is a significant risk factor for being diagnosed with CKD, and having a family history of hypertension can increase the risk 14-fold (Ferguson, Grim, & Opgenorth, 1988). The prevalence of a family history of ESRD is lowest in White males and highest in Black females (Freedman et al., 2005). A family history of diabetes is positively associated with an increased risk for diabetic kidney disease (DKD) (Harjutsalo, Katoh, Sarti, Tajima, & Tuomilehto, 2004). Clustering of CKD within families with a history of hypertension, diabetes, or CKD, suggests that close relatives of patients on dialysis are at increased risk for CKD and should be targeted for screening and early intervention to
prevent or slow the progression of renal disease (Jurkovitz, Franch, Shoham, Bellenger, & McClellan, 2002; McClellan et al., 2009).

Diabetes and hypertension are the primary causes of CKD, and AA are more likely to be diagnosed with one or both of these conditions as compared to other racial/ethnic groups (Coresh et al., 2005; Coresh et al., 2007). The Centers for Disease Control and Prevention (2011) estimates that 25.8 million Americans have diabetes. When compared to White Americans, the rate of diagnosed diabetes is 77% higher among AA — a rate higher than any other racial or ethnic group. Sixty-seven percent of U.S. adults aged 60 and older have hypertension (Ostchega, Dillon, Hughes, Carroll, & Yoon, 2007), and African American men have the highest rates of hypertension (Chobanian et al., 2003; Coresh et al., 2001; Norris & Nissenson, 2008). A known precursor to diabetes and hypertension is obesity. Although a direct causal relationship is unknown, obesity has been shown to be positively associated with an increased risk for CKD (Field et al., 2001; Fox et al., 2004; Hallan, de Mutsert, Carlsen, & Dekker, 2006; Wang, Chen, Song, Caballero, & Cheskin, 2007).

**CKD Risk Reduction**

Most of the excess risk for CKD among AA is attributed to modifiable risk factors that can be managed through preventive care (blood pressure management, glycemic control, and maintenance of a healthy body mass index (BMI) (Cowie et al., 2010). The Seventh Report of the Joint National Committee [JNC-7] on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (Chobanian et al., 2003) states that the primary health outcome of antihypertensive therapy is reduction of cardiovascular and renal morbidity and mortality, and establishes a blood pressure goal of <130/80 for adults.
with CKD or diabetes. The committee suggests that lifestyle modification to reduce hypertension should include weight reduction, physical activity, and consumption of a healthy diet. In individuals with diabetes, glycemic control has been shown to be the most important factor in determining the progression to DKD, as there is a direct linear relationship between glycemic levels, microalbuminuria, and kidney function; therefore glycosylated hemoglobin adult type (HbA1C) value of <7% is considered kidney protective (Cheung et al., 2009; Hall, 2006). Glycemic control can be achieved through diet, physical activity, and with medication (Danaei et al., 2009). These health management interventions are well documented in the medical literature, yet adequate management of CKD risk factors is low among AA (Norris & Nissenson, 2008; Whaley-Connell et al., 2008).

**Risk Perceptions**

The interplay between determinants of risk and health outcomes is complex; however, at the forefront of risk factor reduction, which generally involves behavioral modification, is an understanding of risk perceptions. Early approaches to behavior risk reduction involved providing individuals one-dimensional information on the mortality and morbidity probability of hazards under the assumption that fear appeals would motivate individuals to modify their behavior to avoid the numerical risk estimates (Slovic, 1987). As research related to risk perceptions and health preventive behaviors evolved, it became apparent that risk perceptions are a multidimensional phenomenon that involves many qualitative factors as well (Jacobs, 2000). Although qualitative studies have explored risk perceptions in individuals with a family history of chronic conditions, such as, cancer, diabetes, and heart disease, there is a paucity of studies
devoted to understanding CKD risk perceptions (Baptiste-Roberts et al., 2007; Gorin & Albert, 2003; McKenzie & Skelly, 2010; Troughton et al., 2008). For the few qualitative studies that do explore CKD risk appraisal, none specifically address the personal risk perceptions of AA with a family history of CKD (Jennette et al., 2010; Wilkinson et al., 2011). Most studies are devoted to understanding CKD risk in the context of a personal diagnosis of kidney disease or in a population-based study, not specifically from the perspective of an at-risk group (AA) with a family history of CKD (Waterman et al., 2008).

**CKD Risk Awareness Among AA and Health Care Providers**

African-Americans are often unaware of their risk for CKD, and health care providers do not have a clear and accurate understanding of factors that influence how AA perceive their personal CKD risk (Fox, Brooks, Zayas, McClellan, & Murray, 2006; Lea, McClellan, Melcher, Gladstone, & Hostetter, 2006; Waterman et al., 2008). CKD often goes undiagnosed because it is largely asymptomatic (Coresh et al., 2007; McClellan et al., 2003). Many AA do not perceive CKD as a serious health threat (Waterman et al., 2008). In addition, many primary care providers are not aware that African American racial/ethnic group is considered a risk factor for CKD nor are they aware that having a family history of CKD is associated with increased disease risk (Charles et al., 2009; Lea et al., 2006). Moreover, the specialists trained to manage CKD are often not the ones who oversee care of individuals with kidney disease. After an individual is diagnosed with CKD, they are more likely to have their care managed by a primary care physician instead of a nephrologist or cardiologist (USRDS, 2012). This may result in patients not receiving treatment in accordance with clinical care guidelines;
hence interventions that could mitigate kidney disease progression may be missed or
delayed (Charles et al., 2009). Understanding risk early and intervening promptly should
be considered a first-line defense for CKD prevention interventions.

**State of the Science**

Traditional CKD prevention strategies incorporate broad public health strategies
based on larger prospective or retrospective epidemiology studies that examine the
incidence and prevalence of risk factors (Ramirez, Hsu, & McClellan, 2003; Tarver-Carr
et al., 2002). In these studies, participants respond to structured questionnaires that lack
adequate psychometric properties (Nunes et al., 2011; Waterman et al., 2008). CKD
treatment guidelines are derived from clinical trials where the majority of participants are
not AA. Therefore, these studies have not significantly changed the trajectory of CKD
outcomes for AA and have not brought us closer to understanding how AA appraise their
risk for CKD. As such, little is known about the individual’s perspective and experiences
related to kidney disease. When qualitative study designs have been used to examine
CKD, study participants are either at ESRD, the study focus is related to the needs of the
caregiver, or it is unknown as to whether or not study participants have a family history
of CKD (Morton et al., 2010). To better understand the meaning of kidney disease
among AA who have a family history of CKD, it is important to explore this
phenomenon as it is experienced by the individual. By understanding the meaning of
these experiences, health care providers will be better able to move toward more
purposeful patient-centered interventions.
Statement of Purpose

The purpose of this interpretive phenomenological study is to explore the meaning of CKD in African American adults who have or have had a first degree relative on hemodialysis and to gain a deeper understanding of their CKD lived experience and their personal perspective of the disease.

Significance to Nursing

Phenomenology is often the most appropriate approach to explore concepts in nursing for which the meaning is ambiguous and a deeper understanding of how individuals experience a phenomenon is being sought (Munhall, 2007). If we understand the meaning of risk for AA with a family history of CKD, we can begin a dialogue with them that takes into account their beliefs and appraisal of risk. By increasing understanding of the meaning of the lived experiences of AA, this study will help raise awareness among nurses as it relates to their personal knowledge of factors that influence how AA perceived their CKD risk. The body of knowledge gained from this study has the potential to be foundational in supporting development of patient-centered interventions that are based on the specific and unique CKD health beliefs of AA.

Research Questions

The following research questions will guide this research process:

RQ1: What is the meaning of kidney disease for AA with a first degree relative on hemodialysis?

RQ2: How does having a family member with kidney disease inform an individual’s beliefs about CKD?

To gain a richer understanding and to encourage interactive dialogue, the following questions will be used to frame the interview: “Tell me what it is [was] like
living with a [particular family member] on dialysis” and “Tell me how having a [particular family member] on dialysis made you feel/think about kidney disease.” As the interview progresses, other questions will be used to explicate the person’s story as it unfolds.

**Definitions of Terms**

Definitions of terminology frequently used in this study are provided for clarity.

**Chronic kidney disease (CKD)** is either kidney damage or glomerular filtration rate <60 ml/min/1.73 m2 for > 3 months (NKF, 2002).

**Body mass index (BMI)** is weight (kilograms) divided by height (centimeters) squared (National Cholesterol Education Program Expert Panel, 2002).

**Elevated BMI** is BMI of >25.

**African Americans** refer to individuals who identified as Black or Americans with African ancestry.

**End stage renal disease (ESRD)** is stage 5 CKD and requires renal replacement therapy.

**Renal replacement therapy** refers to hemodialysis, peritoneal dialysis or kidney transplant.

**First degree relative** refers to a parent, sibling or child who is related by blood.

**Summary**

In summary, AA are disproportionately affected by CKD. Many of the factors that contribute to this high burden of CKD in AA are modifiable with the exception of family history and African American racial/ethnic group. For those modifiable risk factors, studies indicate that health protective behaviors that include maintenance of a
normotensive blood pressure, a healthy BMI, and adequately controlled blood glucose levels can slow the progression of CKD or mitigate their risk entirely. In families with a history of CKD, clinical care guidelines recommend screening for kidney disease and early CKD education to ameliorate CKD risk. Yet, many AA are not screened for early signs of CKD because of their own lack of awareness of risk and lack of awareness of their health care providers. When individuals do not believe that they are at risk for CKD, they may be less likely to engage in appropriate health protective behaviors.

To be effective, interventions that reduce the risk for CKD should be patient-centered and address important characteristics of the patient’s experiences. Much of the available research on CKD risk reduction does not take into account the personal experiences of the individual. Understanding the unique health beliefs of AA with known CKD risk factors is necessary to develop interventions that AA individuals are more likely to practice. A phenomenological approach will help us more clearly understand kidney disease from the individual’s perspective. The findings from this study will better inform and direct targeted CKD prevention intervention for AA.
CHAPTER II

Review of the Literature

Introduction

In this chapter I elucidate the literary and theoretical context pertinent to understanding CKD as a health threat for AA. Through a review of the literature, I present the epidemiology of CKD, its impact on AA, primary risk factors associated with CKD, and CKD health protective behaviors. Next, I discuss the theoretical context of phenomenology and its application to understanding the meaning of kidney disease. Last, I explicate the utility of the Health Belief Model (HBM) in understanding how individuals assess risk and respond to health threats, and how the HBM has influenced my personal assumptions about the meaning of risk for AA with a family history of CKD.

Literary Context

In this section, I open by describing the prevalence of CKD among AA. I further discuss the non-modifiable and modifiable risk factors that contribute to CKD. Lastly, I describe health protective behaviors that are associated with CKD risk modification.

Epidemiology and Impact of CKD among African Americans

The serious public health impact of CKD across all racial and ethnic groups has been elucidated in many studies (Coresh et al., 2007; Nickolas, Frisch, Opotowsky, Arons, & Radhakrishnan, 2004; Whaley-Connell et al., 2008). Studies indicate that AA are disproportionately impacted by CKD (Norris & Nissenson, 2008; Tarver-Carr et al.,
These findings are consistent with a national report concluding that racial and ethnic minorities experience the greatest disparity in health care quality and this inequality is evident across a range of conditions and clinical services (Smedley, Stith, & Nelson, 2009). The report findings were based on quantitative analysis of health care delivery systems and patient encounters for treatment of illness. Absent from the report were data on equality in disease prevention initiatives and a qualitative perspective on how patients perceive their health and health care.

For AA, the chance of being diagnosed with CKD is similar to rates found in non-Hispanic White populations (Coresh et al., 2007). However, AA diagnosed with CKD are more likely to progress to ESRD at a rate five times faster than Whites (Hoerger et al., 2012; Hsu, Lin, Vittinghoff, & Shlipak, 2003). By age 56, AA have a cumulative risk of ESRD that exceeds the lifetime risk of ESRD in Whites (Kiberd & Clase, 2002). ESRD risk is 1 in 40 for White men and 1 in 50 for White women as compared to 1 in 12 for African American men and women. Lost life-years attributable to ESRD in African American men is 2.75 times greater than that of White men, and 2.9 times greater in African American women compared to White women (Kiberd & Clase, 2002). ESRD in AA accounts for as much loss of life-years as breast cancer in African American women and more loss of life-years than colorectal or prostate cancer in African American men. In addition, costs associated with maintenance renal replacement therapy for ESRD in AA are five times more costly than treatment for breast cancer for African American women and four times higher than for prostate cancer care for AA men (Kiberd & Clase, 2002).
The high disease-specific mortality associated with CKD in AA is exacerbated when coupled with cardiovascular disease—the leading cause of death in the U.S. (Danaei et al., 2009). An analysis of national epidemiological databases to evaluate the disparities in cardiovascular disease and its associated risk factors in the U.S. indicated that cardiovascular death across all ages is highest among AA (Mehrotra, Kermah, Fried, Adler, & Norris, 2008; Mensah et al., 2005). In a 16 year follow-up longitudinal study using NHANES II data, the risk for death from cardiovascular events was greatest among individuals with CKD, and increased as glomerular filtration rates decreased (Muntner et al., 2002). Even when there is no known cardiovascular disease, excess risk of vascular disease begins to manifest even in the early stages of CKD (Di Angelantonio, et al., 2010). When cardiovascular disease manifests as a stroke, the risk for AA is 50% higher as compared to Whites (USRDS, 2012). The epidemiological data are clear; AA bear the greatest burden of all-cause cardiovascular disease in the U.S. When cardiovascular disease co-exists with CKD, mortality rates for AA are disproportionately higher than for any other racial and ethnic group.

**CKD Non-Modifiable Risk Factors**

The literature indicates that there are non-modifiable risk factors that contribute to the development of CKD. In this section I discuss two non-modifiable CKD risk factors—family history of CKD and African ancestry. I explore findings from quantitative and qualitative studies that explicate the relationship between these non-modifiable risk factors and CKD.
Family History of CKD

An important determinant of risk for CKD is an individual’s family history of kidney disease (Satko, Sedor, Iyengar, & Freedman, 2007). Chronic disease is a family affair and the presence of chronic illness in a family is a key sign of significant risk to other family members (Fisher, 2007). African American individuals with a family history of CKD are disproportionately affected by kidney disease and represent an at-risk population ideal for targeted CKD screening and intervention (McClellan et al., 2009; Satko & Freedman, 2004). In the absence of diabetes or hypertension (both modifiable CKD risk factors), AA are 3.5 times more likely to develop ESRD than Whites (Xue, Eggers, Agodoa, Foley, & Collins, 2007). Familial clustering of CKD has been observed in several studies (Freedman et al., 2005; Lei, Perneger, Klag, Whelton, & Coresh, 1998; Seaquist, Goetz, Rich, & Barbosa, 1989). The risk for CKD is even higher when two or more first-degree relatives have CKD (Lei et al., 1998). The chance of an individual with a family history of kidney disease developing CKD that progresses to ESRD is nine-fold higher than for an individual with no family history of CKD (Ferguson et al., 1988; Freedman, Soucie, & McClellan, 1997; McClellan et al., 2009; McClellan et al., 2012).

The likelihood of developing CKD is determined by interaction between genetics and environment (Satko, Freedman, & Moossavi, 2005). A genomewide linkage analysis of serum creatinine, estimated glomerular filtration rates, and urine albumin creatinine ratio indicated heritability of serum creatinine in both Whites and Black groups; but urine albumin creatinine ratio was only heritable in Blacks (Turner et al., 2006). Furthermore, a family history of chronic disease reflects not only inherited genetic susceptibilities, but also shared cultural, ethnic and behavioral attributes (Walter & Emery, 2006). The
family is a primary source of health beliefs. Similar health risk beliefs have been shown to be held by individuals with a family history of chronic conditions such as prostate, colon cancer, diabetes and heart disease (Graham et al., 2006). In studies examining the influence of a positive family history for chronic conditions, such as cancer, heart disease or diabetes, on disease awareness, most participants felt their understanding of disease was based on personal experiences of family members and friends with the condition (Baptiste-Roberts et al., 2007; Walter & Emery, 2006; Walter, Emery, Braithwaite, & Marteau, 2004). Although the studies explored perceptions of illness risk among individuals with a family history of chronic disease, no studies were found that described how the lived experience of AA with a family history of CKD informed their personal perception of CKD risk.

**African Ancestry**

As previously stated, the increased burden of CKD among AA may be attributed to genetic predisposition (Cooper, Kaufman, & Ward, 2003; Peralta et al., 2006). Advances in genomics have made significant contributions to understanding the genesis for this disparity. Recent significant findings include the strong association of markers on human chromosome 22q with human immunodeficiency virus-associated nephropathy, idiopathic focal segmental glomerulosclerosis, and DKD in AA (Tzur et al., 2010). This strong association was initially focused on genomic variants within MYH9 encoding a non-muscle myosin heavy chain expressed in the glomerular; however, later developments demonstrated that an even stronger relationship was with an apolipoprotein (APOL1). APOL1 kidney risk alleles are found only on chromosomes of individuals with African ancestry (Friedman, Kozlitina, Genovese, Jog, & Pollak, 2011). Individuals
with two APOL1 risk alleles have an almost 4% life-time risk for developing idiopathic focal segmental glomerulosclerosis, and those with untreated human immunodeficiency virus have a 50% risk for developing nephropathy (Kopp et al., 2011). Much remains to be uncovered regarding the predictability of APOL1 in CKD; however, with 13% of AA (>3.5 million individuals) carrying two risk alleles, this genetic discovery further supports the importance of early intervention for this at-risk group.

Family history of a chronic illness serves as a predictor of heritable disease and influences an individual’s health beliefs. Aggregation of CKD in families is seen more often in non-Hispanic African American racial/ethnic groups. This may be explained in part by genetic transmission. In addition, a family history of chronic illness has informed the health beliefs of individuals with a family history of cancer, diabetes, and heart disease. Given the significant contribution of family history on the risk of developing kidney disease, it is important to explore how individuals with a family history of CKD perceive their personal risk for kidney disease.

**Modifiable CKD Risk Factors**

The literature is replete with studies that describe the association between CKD and modifiable risk factors. Diabetes, hypertension, and elevated BMI have received the most attention, and therefore will be explicated in this section. I explore findings from quantitative and qualitative studies that add understanding to the relationship between modifiable risk factors and CKD.

**Diabetes**

Diabetes is a metabolic disorder characterized by hyperglycemia as a consequence of defects in insulin secretion, insulin action, or the combination of both. More than 40%
of adult Americans have some form of hyperglycemia, whether diagnosed diabetes, undiagnosed diabetes, or pre-diabetes (Cowie et al., 2009). Diabetes is the leading cause of CKD in the U.S., accounting for 44% of new cases in 2010 (USRDS, 2012). CKD resulting from diabetes is termed DKD. Along with Mexican Americans, AA are twice as likely to be diagnosed with diabetes compared to non-Hispanic Whites, and AA have a much higher risk of developing DKD than Whites (Cowie et al., 2009). Irreversible long-term consequences of chronic hyperglycemia from diabetes include retinopathy, neuropathy, cardiovascular disease, and nephropathy. Diabetes often goes undetected for years because of the insidious chronic hyperglycemia state. An early clinical sign of nephropathy is the appearance of small amounts of albumin in the urine (less than 30 mg/day). Many individuals are found to have microalbuminuria shortly after diagnosis with diabetes because microvascular and macrovascular injuries have persisted for years before diagnosis of diabetes (American Diabetes Association, 2004).

Although the symptomatology of DKD may appear subtle, there are predictive risk factors associated with the development of nephropathy in diabetic patients (Rossing, Hougaard, & Parving, 2002). These risk factors include increased urinary albumin excretion, poor glycemic control, dyslipidemia, elevated blood pressure and smoking (Raile et al., 2007). For each of these predictive risk factors, which are all modifiable, glycemic control has been shown to be the most important factor in determining the progression to DKD (Diabetes Control and Complications Trial Research Group, 1993; Kanwar et al., 2008; Koro, Bowlin, Bourgeois, & Fedder, 2004).

Effective management of diabetes is essential in minimizing macrovascular and microvascular complications that lead to CKD. Yet there is considerable racial and
ethnic variability in this regard, with AA being less likely to achieve therapeutic target glycemic control compared to Whites, and therefore more likely to progress to DKD (Cheung et al., 2009; Koro et al., 2004). Therapeutic glycemic control is primarily maintained through self-management. Qualitative studies suggest that dysfunctional patient-provider relationships, patient knowledge deficits and their inability to process and understand glucose values are primary contributing factors to unstable glucose levels (Peel, Douglas, & Lawton, 2007; Rankin, Heller, & Lawton, 2011).

**Hypertension**

Hypertension affects 1 in 3 adults in the U.S., and 1 of every 5 deaths in U.S. adults is attributable to hypertension (Danaei et al., 2009). African-Americans have a significantly higher prevalence (median prevalence of 50.8%) of hypertension compared to other racial and ethnic groups (Olives, Myerson, Mokdad, Murray, & Lim, 2013). Hypertension is the single largest modifiable risk factor for cardiovascular mortality in individuals with CKD, and the second leading cause of ESRD in the U.S. (USRDS, 2012; Weiner et al., 2004). Prevalence of CKD is high in individuals with undiagnosed hypertension, pre-hypertension, and diagnosed hypertension in the U.S. (Crews et al., 2010b; Peralta et al., 2005). Furthermore, hypertension is associated with a more rapid progression to ESRD (Norris et al., 2006). So not only are AA more likely to be diagnosed with hypertension, when they do have hypertension, and in the presence of CKD, AA progress more rapidly to ESRD.

Although hypertension is a modifiable risk factor for cardiovascular and kidney disease, control of hypertension is inadequate in individuals at risk for CKD (Appel, 2003; Appel et al., 1997; Chobanian et al., 2003; Danaei et al., 2009). Even with clinical markers for CKD (glomerular filtration rate >60 mL/min per 1.73 m$^2$ or albuminuria), a
little over a third of adults have blood pressure controlled to treatment goal (based on a blood pressure target of ≤130/80 mm Hg), and those with poorly controlled blood pressure are twice as likely to be AA (Peralta et al., 2005). Moreover, with and without cardiovascular disease, high rates of hypertension (81.8%), low treatment rates (65.9%), and low control rates (23.3%) persist among individuals with CKD (Wong et al., 2007). This is alarming given the increased risk for mortality for individuals with a dual diagnosis of CKD and cardiovascular disease. Disease management barriers identified in qualitative studies include patient distrust of health care providers, lack of access to care and health insurance, no social support, and medication miscommunication (Boutin-Foster, Ogedegbe, Ravenell, Robbins, & Charlson, 2007; Ford, Kim, & Dancy, 2009; Schlomann & Schmitke, 2007). Overall, quantitative studies demonstrate that uncontrolled blood pressure is associated with CKD, development of cardiovascular disease, and, likely, higher mortality in individuals with CKD, and qualitative studies add to our understanding of health care delivery systems and family dynamics that may hinder the ability of individuals to self-manage their blood pressure.

**Body Mass Index**

Obesity is the second leading cause of preventable disease and death in the U.S. (Wang et al., 2007). Being overweight or obese is predictive of developing type 2 diabetes mellitus and predictive of developing hypertension (Field et al., 2001; Hossain, Kawar, & El Nahas, 2007; Hsu, McCulloch, Iribarren, Darbinian, & Go, 2006). Evidence suggests that obesity can directly contribute to kidney damage through obesity related glomerulopathy, mechanical compression and other hemodynamic and metabolic mechanisms; thereby, adversely affecting the progression of kidney disease in individuals
with CKD (Fox et al., 2004; Hallan, de Mutsert, Carlsen, & Dekker, 2006; Hsu et al., 2003). A meta-analysis examined the relative risk of CKD for normal weight individuals with that of individuals in various BMI classes, and found a significant percentage of CKD was attributable to overweight and obesity (Wang et al., 2007).

The individual effect of years of life lost due to obesity appears to be greatest in African American women (Fontaine, Redden, Wang, Westfall, & Allison, 2003; Wang, McPherson, Marsh, Gortmaker, & Brown, 2011). However there may be incongruence between how health care professionals classify an individual’s health risk based on BMI and the social and cultural context by which AA perceive themselves as overweight or obese. Even though AA may be clinically overweight, their social norms may support health beliefs that a larger body size is acceptable and attractive (Befort, Thomas, Daley, Rhode, & Ahluwalia, 2008; Blixen, Singh, & Thacker, 2006; Paeratakul, White, Williamson, Ryan, & Bray, 2002). Moreover, dissonance between AA beliefs and health care BMI guidelines may ultimately impact the willingness of AA to engage in behavior modification to reduce their risk. Hence, it is important to understand factors that influence the capacity for AA to accurately perceive their CKD risk.

**CKD Health Protective Behaviors**

In this section I discuss the literature related to approaches to CKD risk modification. Risk reduction interventions discussed include early detection and screening, health protective behaviors that lower BMI, interventions that adequately control blood pressure, and treatments that reduce glycemic levels.
Early Detection and Screening

Screening at-risk groups for CKD risk factors may be an effective strategy for early CKD detection and management (Hallan et al., 2006; Powe & Boulware, 2009; Saaristo et al., 2010). An early CKD diagnosis allows for implementation of preventive measures that could positively influence patient outcomes, improve health care quality of life for individuals who may progress to ESRD, and lower health care costs associated with CKD (Crook et al., 2002; Mathew et al., 2010). Practice guidelines recommend screening based on clinical (diabetes, hypertension, family history of CKD) and sociodemographic (African American ethnicity) factors, and preventive education with ongoing follow up for individuals at risk (NKF, 2002). For individuals at risk, an estimated glomerular filtration rate (eGFR) should be performed to determine the level of kidney function, and kidney damage should be assessed using a spot urine test for proteinuria. In kidney disease resulting from diabetes and hypertension, proteinuria is the earliest marker of injury and the predictive value of proteinuria is independent of eGFR (Gansevoort, Nauta, & Bakker, 2010; Keane et al., 2003; Norris et al., 2006).

Routine screening for CKD in the U.S. is not widely practiced. There is disagreement as to whether routine screening is worthwhile (Boulware, Jaar, Tarver-Carr, Brancati, & Powe, 2003; Vassalotti, Stevens, & Levey, 2007). It is suggested that any screening for CKD in asymptomatic individuals must improve the long-term outcome of the disease, and the risk and benefits of the screening must be clearly outlined (Glassock & Winearls, 2008). Some argue that universal screening for CKD based on eGFR alone cannot be recommended, and is not cost-effective; however, it is generally agreed that any screening approach should target an at-risk segment of the population based on the
presence of hypertension, diabetes, or a family history of CKD (Boulware et al., 2003; Powe & Boulware, 2009). This position statement means that AA would be a targeted population for CKD screening.

Although there is no consensus in the U.S. on the priority for CKD population-based screening, early detection is being carried out in the U.S. and in other countries. Both Australia and China have evaluated the utility of CKD population-based screening (Li et al., 2005; Mathew et al., 2010). The Australian program successfully detected signs of kidney disease (albuminuria) in participants. China’s program found that in the general population CKD risk factors (diabetes and hypertension) were present across all age groups. In the U.S., the National Kidney Foundation Kidney Early Evaluation Program (KEEP) is a community-based screening initiative that began in 2000 and has since screened over 100,000 individuals in 49 states (Brown et al., 2003; Vassalotti et al., 2009). The program targets individuals with a personal history of diabetes or hypertension, or a family history of diabetes, hypertension or CKD. About one-third of KEEP participants are AA; CKD prevalence is around 28%, most participants have hypertension (66%), 30% have diabetes, and 76% are overweight or obese (Vassalotti et al., 2009; Whaley-Connell et al., 2008).

Despite the appeal and potential benefits of population-based screening programs, the basis for prevention strategies based on screening high-risk populations has not been fully established (McClellan et al., 2003). There are many unanswered questions regarding the affordability of such programs, and the ability of population screening to curtail the negative sequela of CKD over the long-term. In the interim, what may offer the most benefit is targeted surveillance of individuals with a family member on dialysis.
This early recognition allows specific opportunities for disease management in a known at-risk group where an individual is more likely to have at least two CKD risk factors.

**Maintaining a Healthy BMI as a Health Protective Behavior in CKD**

Clinically significant improvement in blood pressure control and reduction in risk for hypertension-related comorbidities can be achieved with modest weight loss (Bo et al., 2007; Grundy, 2007; Stevens, Obarzanek, Cook, & Lee, 2001). In a study examining the effects of a low-caloric normal protein diet on progression of renal disease in overweight (BMI > 27 kg/m2) individuals with proteinuria, a significant decrease in BMI and improvement in proteinuria was observed (Morales, Valero, León, Hernández, & Praga, 2003). The efficacy of weight reduction to reduce CKD risk was explored in a longitudinal study (Trials of Hypertension Prevention II) (Stevens et al., 2001). Participants \(N = 1,191\) were assigned to one of four study groups: 1) weight loss only, 2) sodium reduction only, 3) combined weight loss and sodium reduction, or 4) usual care. The greatest reduction in blood pressure and weight was experienced by individuals in the intervention weight loss group. For participants in the weight loss intervention group who lost at least 4.5 kg at 6 months and maintained this weight loss over 30 months, the relative risk for hypertension was significantly lower as compared to the other study groups.

A considerable portion of the U.S. population is either overweight or obese, and for over a decade this trend has persisted (Flegal, Carroll, Ogden, & Curtin, 2010). More recent studies indicate that the trend may be slowing; however, there is disagreement as to whether this is a valid assumption based on available comparative information.
(Flegal, Carroll, Kit, & Ogden, 2012; Flegal et al., 2010). Nonetheless, even without reaching an ideal weight, research has shown that a moderate weight loss can be beneficial in terms of reducing modifiable risk factors, such as high blood pressure and diabetes, and can prevent chronic illnesses such as cardiovascular disease and CKD (Kenchaiah, Sesso, & Gaziano, 2009; Morales et al., 2003; Noel & Pugh, 2002). Ultimately, understanding how individuals perceive the relationship between elevated BMI and CKD is an essential step in helping them adopt behaviors to reduce their risk.

**Controlling Hypertension as a Health Protective Behavior in CKD**

Reducing the cardiovascular risk in individuals with CKD is essential to decreasing the years of life lost attributable to CKD. Leading clinical practice expert committees have classified CKD as a chronic condition that requires intensive hypertension treatment to mitigate morbidity and mortality outcomes (Chobanian et al., 2003; NKF, 2002). In particular, specific guidance has been established for AA because of their high risk for cardiovascular mortality, diabetes complications, and risk for CKD (Douglas et al., 2003). Several studies have shown that treating hypertension in individuals with CKD and proteinuria slows the decline in glomerular filtration rate (Appel et al., 2008; Thornley-Brown et al., 2006; Wright Jr et al., 2002). The African American Study of Kidney (AASK) Disease and Hypertension was a landmark multicenter trial of 1,017 AA adults with CKD related to hypertension (Thornley-Brown et al., 2006). Initially, the AASK study demonstrated that treatment with angiotensin-converting enzyme inhibitors significantly lowered the progression of CKD in AA with hypertension compared to calcium channel blockers or beta-blockers. However, those outcomes were not sustained at follow-up (Appel et al., 2008). The primary outcome of
doubling of serum creatinine level from trial baseline, incident ESRD, or death, was evident in about 52% of study participants. Furthermore, AA continued to experience renal failure even with the use of angiotensin-converting enzyme inhibitors. Current recommendations by The Seventh Report of the Joint National Committee [JNC-7] on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure establishes a blood pressure goal of <130/80 for adults with CKD or diabetes and the use of angiotensin-converting enzyme inhibitors as first-line therapy in the treatment of hypertension in AA (Chobanian et al., 2003). Guidelines issued by the International Society on Hypertension in Blacks (Flack et al., 2010) list angiotensin-converting enzyme inhibitors as alternative monotherapy options because of its inconsistency to achieve reduction in blood pressure as compared to other monotherapy hypertension medications. When therapeutic blood pressure control cannot be achieved with monotherapy, a calcium channel blocker or diuretic as add-on therapy is recommended.

**Controlling Glycemic Levels as a Health Protective Behavior in CKD**

In individuals with diabetes mellitus type 1 or type 2, glycemic control has been shown to be the most important factor in determining the progression to diabetic nephropathy (Diabetes Control and Complications Trial Research Group, 1993; Jafar et al., 2001). Prevention of DKD is best achieved when diabetes is diagnosed at early stage CKD. Randomized clinical controlled trials have shown that intensive glycemic management is effective in decreasing the decline in glomerular filtration rates (Stettler et al., 2006; Wang, Lau, & Chalmers, 1993). These early trials proved effective in halting the progression of DKD, and helped pave the way for translational studies that focused
on long term sustainability of lifestyle interventions to minimize diabetes complications in clinical practice environments (Knowler et al., 2002; Saaristo et al., 2010).

Effective control of diabetes relies heavily on self-management by the individual. Patients must monitor their glucose levels, select glycemic friendly food, and administer appropriate amounts of insulin-lowering medication. When patients have adequate knowledge about disease susceptibility and severity, they are better able to practice preventive health behaviors (Saaristo et al., 2010; Stettler et al., 2006). Stories from patients indicate that they are uncertain about the seriousness of diabetes and unsure about how to take action (Troughton et al., 2008). Education about quantitative risk is not enough to alter illness perceptions. Perceptions conceptualized by individuals contribute the deepest understanding as to what behaviors individuals will likely adopt to self-manage diabetes.

In summary, large population-based and clinical trial studies are valuable in describing a phenomenon. They are able to validate effectiveness of health intervention and through the use of predictive modeling, they can identify factors that most influence a variable such as risk. What the studies are unable to do is provide meaning to those factors that cannot be measured objectively, but instead must be communicated through language by the individual experiencing them. The current body of knowledge thoroughly describes CKD risk factors and has identified appropriate preventive health behaviors; yet, AA have low awareness of risk and their health outcomes have not significantly improved. This may be due in part to the absence of the individual’s voice from the understanding of kidney disease. This is a gap that this study will address by
fully describing the meaning of kidney disease as experienced by individuals who have or have had a family member on hemodialysis.

**Theoretical Context**

This study will be guided by the underpinnings of interpretive phenomenology. Phenomenology focuses on exploring the relationship of individuals to their life-world, and is grounded in the perspectives of existentialism where truth is viewed as subjective and individuals can only be understood through their lived and experienced realities—not from theoretical analysis. Heidegger (1962) uses the term life-world to communicate the idea that individuals’ realities are intricately influenced by the world in which they live. Phenomenology maintains a post-positivist stance that there is no absolute truth and, instead, all observations are questionable and all theories can be rejected (Munhall, 2007). Interpretive phenomenology is used to help us understand the viewpoints of the individual who experiences the phenomenon. This approach allows us to gain insight into a phenomenon through a process that involves reflectively appropriating, carefully clarifying, and clearly making explicit the substance of meaning of the lived experience (Van Manen, 1990). By examining the thoughts, feelings, and questions that are intricately woven into the context of the life-world of AA with a family history of CKD, we gain insight into what it means to be human in this experience. We are then afforded a deeper dive into understanding the experiences, the meaning of the experiences, and how these meanings drive an individual’s appraisal of the experiences.

The focus of an interpretive inquiry is not the mere particulars of an individual’s account of what they experienced, but rather, what the individual’s story implies about what one experiences everyday (Lopez & Willis, 2004). Lived experiences are
recollections of experiences that have already been lived through (Van Manen, 1990).
Individuals cannot reflect on lived experiences while in the presence of the experience;
stories emerge by reflecting on lived experiences that have passed. It is not introspective
(not reflecting on sadness while in a sad moment) but retrospective (reflecting on sadness
after the moment has passed). An interpretive phenomenological approach will lead to a
richer description of the ways AA experience the world pre-reflectively.

Assumptions

According to van Manen (1990), our suppositions and the existing body of
research knowledge influence how we interpret a phenomenon before we have an
opportunity to grasp the magnitude of the phenomenological question. Our ideas about
the world are inseparably connected to how we live in the world and give meaning to
experiences. We must expose and acknowledge our pre-understandings, beliefs,
assumptions, and theories about the phenomenon we aim to study if we hope to gain a
deeper understanding of the individual’s life-world as experienced rather than
conceptualized or theorized (Munhall, 2007).

In this section I discuss how the Health Belief Model (HBM) can serve as a
framework for understanding individual risk appraisal and adoption of preventive health
behaviors in response to health threat. In addition, I will discuss how the HBM has
influenced my personal assumptions about the meaning of risk on AA with a family
history of CKD.

The Health Belief Model

The HBM is useful in understanding how individuals perceive their risk for
disease (Jette, Cummings, Brock, Phelps, & Naessens, 1981). The initial HBM five
constructs purport to predict why individuals take action to prevent disease or manage an illness. These five constructs are: (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, (d) perceived barriers, and (e) cues to action (see Figure 1).

Figure 1. Health Belief Model (Janz & Becker, 1984)

The theoretical framework proposes that before individuals take action on preventive recommendations, they must first believe that a condition poses a risk to them and that the risk is serious. When a condition is seen as a threat to an individual’s well-being, only then will the individual conduct a risk/benefits analysis of adopting a behavior to mitigate a health threat. The two constructs (perceived susceptibility and perceived severity) that converge to manifest a perceived health threat are the constructs...
that have the greatest influence on risk perception; and therefore, will be the only HBM constructs discussed in this section.

**Background on Assumptions**

Van Manen (1990) emphasizes the importance of revealing one’s own understanding, beliefs, biases and assumptions when conducting qualitative research. He states that one should not forget these presuppositions, but instead work to abate them when attempting to understand the phenomenon as presented by study participants. Lopez and Willis (2004) believe that the researcher’s experiences contribute to specific thoughts about how the research should proceed to generate meaningful content. The interpretive process is made more meaningful when one’s prior understandings are blended with what is learned from the participants’ lived experiences. This fusion (co-constitution) of meaning communicated by the researcher and participants provides a richer and fuller description of the phenomenon (Lopez & Willis, 2004; Wojnar & Swanson, 2007). So here, I present my personal assumptions as an African American woman with a family history of CKD who has practiced nephrology nursing for 20 years, and whose conceptualization of CKD risk has been influenced by the HBM.

My understanding of the HBM and its application to understanding CKD risk perceptions is that individuals are more likely to take action to prevent CKD when they believe they are susceptible to CKD, and having some understanding of CKD is necessary to perceive susceptibility. For individuals to perceive CKD as a health threat, in addition to perceived susceptibility, they must believe CKD has consequences and that they are susceptible to those consequences. When individuals perceive CKD as a health threat, they are more likely to take action to maintain health. I believe most AA with a
family history of kidney disease do not believe CKD poses a health threat, hence, they choose not to engage in health practices to mitigate risk. Therefore, I believe that to reduce the burden of CKD in AA, we need to better understand the meaning of kidney disease from their perspective.

**Assumptions**

I. CKD health beliefs are influenced by family characteristics and dynamics.

II. Perceived CKD susceptibility and severity are shaped by information from various media and social sources (family, friends, medical care systems), from an individual’s past illness experience, and from current symptomatic sensations.

III. Knowledge of CKD and appraisal of CKD risk influences the African American individual’s decision to engage in CKD health protective behaviors.

IV. AA are concerned about their health and want to practice CKD health protective behaviors that will improve their health status and decrease their risk for CKD.

**Summary**

Epidemiology studies have thoroughly described the prevalence and incidence of CKD and its risk factors, and clinical trials provide support for the utility of medical interventions and lifestyle interventions to decrease the progression of CKD. Diabetes, high blood pressure, and elevated BMI are known modifiable risk factors that contribute to the development of CKD. In addition, having a family history of CKD is recognized as a non-modifiable risk factor that may be an even greater contributor of CKD in AA. Even though early stages of CKD have asymptomatic phases that may progress for years before individuals experience signs and symptoms of renal failure, there are clinical
markers that can be screened for and monitored early during the disease process. Detection of markers through screening makes way for early intervention of health protective behaviors that can delay or prevent disease progression (Chobanian, 2003; National Cholesterol Education Program Expert Panel, 2003; NKF, 2002). Evaluation of awareness of CKD risk has been included in both population-based and epidemiological studies that have consistently reported low levels of knowledge of risk among AA.

Limitations of existing studies are that they lack the individual’s voice, and have not been able to significantly change the trajectory of CKD onset and progression for AA. This may be due in part to the lack of understanding of how individuals conceptualize kidney disease. For health interventions to be effective they should be patient-centered and take into account the experiences and beliefs of the individual. No study has used a qualitative approach to further understand the CKD health beliefs of AA through their own voices. AA have unique experiences that influence how they perceive their risk for CKD and choose health protective behaviors. A deeper understanding of AA’s CKD health beliefs and their perception of risk for CKD is critical to designing strategies that increase their awareness of risk while addressing knowledge gaps. Phenomenology attempts to explicate the meaning as individuals live in their everyday life-world (van Manen, 1990, pg. 11). By utilizing interpretive phenomenology to fully understand the individual’s story, this study seeks to fill part of the gap in the body of knowledge related to the lived experience of AA with a family history of CKD.
CHAPTER III

Research Plan

Purpose

The overall purpose of this interpretive phenomenology study is to explore the meaning of kidney disease in African American adults who have or have had a first degree relative on hemodialysis. Secondary purposes are to gain an understanding of the personal CKD health beliefs of AA with a family history of kidney disease and better understand how their beliefs influence their personal CKD risk appraisal and health protective behaviors. There is a paucity of literature on how AA with a family history of kidney disease perceive their risk for CKD or if their health practices are affected by having a first degree relative on renal replacement therapy. To gain a better understanding of the nature and meaning of kidney disease for AA we need to know more about the lived experiences of AA with a family history of CKD. For this study, an interpretive phenomenological approach was chosen because of its usefulness in uncovering everyday experiences of individuals and its utility in describing how individuals perceive their risk within their own personal context. In this chapter I explain the research plan for this study to include: research design, setting, sample, data generation strategies, data analysis, authenticity and trustworthiness, and protection of human participants.
Design

An interpretive phenomenological approach will be used to elucidate the experiences of AA with a family history of CKD. Interviews with individuals who have a family history of CKD will be used to explore in detail the meaning they ascribe to kidney disease. The interpretive process requires the researcher to assume an attentive posture, observing for vocal pitch, emotional expressions, and gestures that may not be audible on recorded interviews but will need to be included in field notes. Another core component of interpretive phenomenology is reflection. To make salient the meaning of stories obtained through participant interviews, the interpretive approach requires researchers to immerse themselves in the data by reading and re-reading transcripts to clarify, classify, and ultimately discover themes that give insight into the meaning of the phenomenon (Creswell, 2007). Because this methodology increases sensitivity to understanding individuals’ ways of being-in-the–world, this approach will be used to explore the meaning of kidney disease in the personal context of the lived experiences of AA with a family history of CKD. The central qualitative research question for this study is, “What is the meaning of kidney disease for AA who have or have had a first degree relative on hemodialysis?”

Sample

A purposive sample will be used for this study. This sampling approach is beneficial because it allows purposeful sampling from participants who can best articulate their lived experience related to the phenomenon of interest (meaning of kidney disease). Previous studies (Delgado, Delgado, Betancourt, & Orozco, 2010; McKenzie & Skelly, 2010) that have explored individual perceptions and a chronic condition reported
sample sizes of 6 to 15 study participants. To allow for prolonged engagement with participants and detailed analysis of the data generated, it is anticipated that a minimum purposive sample of 12 participants will be used for this study. All participants in the study must have or have had a first degree relative (biological parent, sibling, or offspring) on hemodialysis, and possess the ability to clearly articulate their lived experience. Final sample size will be determined once the study is in progress, and will be based on the criteria of information saturation — interviews will cease when no new information is learned.

**Recruitment Criteria**

To be included in this study, individuals must meet the following inclusion criteria: (a) 18 years of age or older, (b) biological parent, offspring, or sibling who is a prior or current recipient of maintenance hemodialysis, (c) identifies racial/ethnic group as AA or Black non-Hispanic, (d) lives within a 50 mile radius of Atlanta, (e) speaks and understands English clearly, and (d) consents to participate in the study. The average age for AA with ESRD is 57; however, there are adults over the age of 70 receiving hemodialysis in the U.S. (USRDS, 2012). These individuals may have older family members who may be at risk for kidney disease. Older African American adults may have different experiences than younger adults, and a broader age range allows for exploration of the experiences of African American adults. The recollection of experiences is essential to understanding the meaning of kidney disease and this retrospection is best gained from adults instead of individuals younger than 18 years of age who often have their health care and lifestyle needs managed by their parents or guardian. Participants must have a biological parent, offspring, or sibling who is a prior
or current recipient of maintenance hemodialysis. Because the most common causes of kidney disease in children are congenital urologic dysfunctions and nephropathies, for individuals with an offspring on dialysis, the etiology of the renal failure cannot be congenital (non-modifiable) (Whyte & Fine, 2008). Hemodialysis is the most frequently prescribed renal replacement for AA, involving thrice weekly treatments, and individuals receiving hemodialysis often involve family members in their care; hence family members are more likely to have awareness that there is a family history of kidney disease. AA are less likely to manage their ESRD with peritoneal dialysis and transplant. In addition, these treatment options often require less involvement from family members. Limiting the study population to only individuals who have or have had a family member on hemodialysis enhances the chance of recruiting individuals with a more in-depth experience of kidney disease. Participants must identify as African American or Black non-Hispanic because AA experience the greatest burden of CKD in the U.S. Study data will be collected using face-to-face interviewing; therefore, only individuals living within commuting distance (50 mile radius) of the researcher will be able to participate in the study. As individuals must be able to articulate their stories in full detail so that their meaning can be interpreted, only participants who clearly speak and understand English will be permitted to enroll.

Exclusion criteria will include: (a) diagnosis of CKD, (b) receiving renal replacement therapy, (c) awaiting renal transplant, (c) with mental disability, and (d) severely impaired hearing. Individuals diagnosed with CKD by a health care provider have received general knowledge of their degree of kidney disease along with information on the associated health protective treatment options, and therefore will be
excluded from the study. Additionally, individuals receiving renal replacement therapy (hemodialysis, peritoneal dialysis or renal transplant) or awaiting renal transplant will be excluded from the study as they are in ESRD and under the care of a health care provider. Mentally disabled individuals and/or individuals with severely impaired hearing will also be excluded because of the likelihood that they cannot thoroughly consent or articulate their story.

Upon approval from the Georgia State University Institutional Review Board, participants will be recruited from a church in metro-Atlanta. The church has an African American membership of 12,000 with an average of 2,000 members attending Sunday services. Letters of support to conduct study recruitment have been secured from the church leader (see Appendix A and B). Study flyers will be used to recruit participants. Flyers will be passed out during Sunday service and during Wednesday night bible study. Flyers will also be placed on church bulletin boards. Using snowballing, additional volunteers will be sought via current study participants and from the researcher’s acquaintances and colleagues. The study flyer will be written at an eighth grade reading level (see Appendix C). The flyer will explain (a) the study purpose, (b) general enrollment criteria, and (c) how to contact me by phone and email. When individuals contact me by phone they will be screened (see Appendix D) for study eligibility criteria. When an individual uses email to contact me, I will work with the individual to determine a mutually agreed upon date and time to discuss eligibility criteria via a phone conversation.
Setting

Individuals meeting criteria will be invited to enroll in the study. The researcher will explain the nature of the study, participant expectations and answer participant’s questions in a conversational voice that helps to establish trust, rapport, and openness. A jointly agreed upon meeting date, time, and location for an in-person interview will be determined. The location will allow for privacy and safety for both researcher and participant, and will be a comfortable environment that facilitates storytelling by the individual. Possible settings to conduct interviews will include a private room in the church educational wing or a private meeting room at a public library. Those individuals invited to participate in the study will be emailed or postal mailed a study consent form to review prior to the interview. In the event a consent form cannot be emailed or mailed prior to the interview, ample time will be provided for the study participant to review the form and ask questions at the initial in-person meeting.

Data Generation Strategies

An open-ended phenomenological interview will be used in this study. Interviewing creates live streaming of information between the participant and the researcher for the purpose of co-creating an understanding of the phenomenon (Wojnar & Swanson, 2007). The personal face-to-face interview, unlike telephone interviews, increases the interviewer’s sensitivity to the participants’ experiences that are expressed through vocal intonations, physical gestures, facial expressions, and other non-verbal communication behaviors (Kleiman, 2003). For this study, an in-depth, unstructured face-to-face interview will be used to allow a fluid and dynamic interaction between the participant and the researcher as we co-create an understanding of CKD risk among AA.
In this study, I will use repeated interviews with study participants to gain a more in-depth understanding of the phenomenon. Repeated dialogue between the participant and the researcher about the interview transcript will help participants feel like active study collaborators (Van Manen, 1990). Trustworthiness and credibility of the narrative is increased when the interviewer and interviewee validate the integrity of the transcript (Munhall, 2007). It is anticipated that the first interview will last about 30-90 minutes. This interview will allow for in-depth exploration into the lived experience and the meanings associated with it. A follow-up interview will be conducted with as many participants as will agree to a second interview. The second interview will be to verify the integrity of the narrative and validate the researcher’s interpretations. It is anticipated that this interview will last approximately 30-60 minutes. Both interview encounters will be audio-recorded using a digital recorder equipped with a built-in microphone to capture participants’ stories.

Before beginning the interview, I will review the informed consent form (see Appendix E), clearly and thoroughly explaining the risks and benefits, and I will answer all questions that participants may have. Once the individuals agree to participate in the study, they will sign two consent forms. The participant will be provided one form and I will maintain the other form. To establish personal rapport and co-constitutionality between the individual and the researcher, I will inform the participants that I am a nurse who has cared for patients on hemodialysis and that I have a family history of kidney disease. After the recorded interview, demographic information will be collected using a form developed by the researcher (see Appendix F). Field notes will be used to capture observed vocal pitches, subtle undertones of language and body gestures that might not
be clear from audio recordings (Crist & Tanner, 2003). Field notes will be annotated during and after the interview.

During the initial interview, I will maintain an attitude and posture of attentiveness and openness. I will begin the interview by asking the participants to “Tell me about when your [particular family member] first started dialysis and what that was like for you.” As the interview progresses, additional open-ended questions that encourage participants to be open and reflective will be used to explicate the individual’s story as it unfolds (see Appendix G). Leading questions will be avoided, and instead, questions will be framed that inspire a natural in-depth recollection of the lived experience and its associated meaning. In an effort to stay close to experiences as lived by the individual, and to keep the interview moving forward, participants will be asked to tell a story related to a specific instance or situation that illustrates the phenomenon of living with a family member on dialysis. The act of listening attentively in patience and silence will be utilized. Using this approach is beneficial in allowing participants time to reflect and recall an event (Seidman, 2012; Van Manen, 1990). As dialogue between the participant and me evolves, I will regularly seek affirmation from the participant that what is being heard and understood by me is an accurate representation of their experience.

Narratives from the first few interviews will be used to guide subsequent interviews, inform the researcher regarding her interview skills, and focus interviews and observations with subsequent informants (Creswell, 2007). At the conclusion of the initial interview, participants will be asked if they have any additional information they would like to share, they will be thanked for their time, and a tentative mutually selected
date and time for the follow-up interview will be determined. As time will be needed to transcribe the narratives, there may be several weeks delay between the first and second interview.

Prior to the second interview I will immerse myself in the data. Those individuals who agree to participate in the follow-up interview will be emailed or postal mailed their study transcript to review prior to the interview. During the follow-up interview I will reassess the participant’s willingness to continue in the study, being sensitive to any changes in the participant’s ability to provide informed consent. Participants will be provided an opportunity to discuss the interview transcript, validate the integrity of interpretation, and provide additional detail. At the conclusion of the first interview, study participants will receive a $10 grocery store gift card for participating in the study. Individuals who participate in a follow-up interview will receive an additional $10 grocery store gift card.

**Data Analysis**

The interpretive process of hermeneutic phenomenology is non-linear; rather, it is fluid and iterative to allow full exploration and interpretation of the phenomenon. An adapted version of Heidegger’s hermeneutic analysis process will be used to elucidate the lived experiences of AA (Diekelmann, Allen, & Tanner, 1989). This process will involve continuous examination of the whole and the parts of the data for insightful discovery. It is a multistage interpretation process that exposes conflict and discrepancies through re-appraisal and comparison of text; thereby, substantiates the meaning of the text by exposing inaccuracies.
I will download the digitally recorded interviews to a computer. The computer files will be emailed to a contracted transcriptionist who will transcribe the audio recordings verbatim to text. If it is believed that the individual contracted to transcribe the audio recordings personally knows a participant then I will transcribe the audio recording. Transcriptions will be electronically managed using QSR International’s NVivo 10 software (NVivo, 2012). This computer-aided qualitative data analysis software will facilitate in-depth analysis of participants’ interviews and will aid in organization of data, classification of data, and coding of data. I will read each transcript as a whole to gain an overall understanding of the content and review transcripts for any inaccuracies. I will use NVivo 10 software to summarize sections of the transcript and identify categories. Independent analysis of my interpretation will be offered by other researchers, including my committee chair and committee members. Any discrepancies will be clarified by referencing the text. I will continue to immerse myself repeatedly into the details of the text through repetitious reading and will add to the margins of field notes as winnowing of data occurs during the discovery process for relational themes. As themes emerge that are apparent across text, essential patterns in all the documents that express the relationship of the themes will be decided. Professors familiar with the research method will provide feedback about my analysis.

**Authenticity and Trustworthiness**

Establishing rigor is essential when conducting research. It is a way of communicating the validity and reliability of data. Rigor helps to determine the trustworthiness of the data. Four criteria used to assess rigor in qualitative research are:
(a) credibility, (b) transferability, (c) dependability, and (d) confirmability (Lincoln & Guba, 1986). These four standards and their principles will be applied to this study.

Credibility refers to the fit between the informant’s story and the researcher’s representation of the story (Ryan, Coughlan, & Cronin, 2007). Credibility in this study will be achieved through prolonged engagement with participants, persistent observation in the field, triangulation of data sources, peer debriefings, and member checks. The researcher will create a conversational environment conducive for prolonged engagement by assuming a position of genuine attentiveness and openness that allows the unrestricted flow of information between the participant and the researcher; and this will be done over two interviews whenever possible. Participants will have as much time as they need to articulate their stories without being rushed or coerced. Participants will be co-creators of the narrative and will be able to review the transcript for accuracy. If discrepancies exist, I will ask the participant clarifying questions and through consensus we will include the correct text. Data collection will be accomplished through the use of audio-recorded interviews and researcher field notes. By using these two methods to corroborate study findings, study triangulation will be enhanced and credibility improved. Member checking will be accomplished throughout the interview by seeking affirmation from the participant that what is being heard and understood by me is an accurate representation of experience. University faculty members and professional nurse colleagues familiar with the phenomenon will provide peer debriefing of the research process and data.

Transferability is used to determine whether the findings in a study fit outside the context of the study (Morrow, 2005). A rich description of the setting, participants, and
themes will be provided. Notes from the interviews and journal entries about my thoughts and other detail that emerges during the process will provide the substance to increase the likelihood that this criterion is met. This thick account of study details will be useful in creating a sense of verisimilitude among those analyzing the narrative accounts (Creswell & Miller, 2000). Providing a deep, vivid description of the study process, collaborator relationship, and study context will enable others to determine how the findings may apply to other groups.

Dependability of qualitative research is measured by the criterion of auditability. Auditability is apparent when others can examine the documentation of methods, and results and follow the decision trail of the researcher (Tobin & Begley, 2004). To increase dependability, a log containing a detailed chronology of all research activities will be maintained, narratives will be transcribed verbatim, and a reflective journal will be used to examine potential bias of the researcher. Time lags between the first and second interviews will allow the researcher time to transcribe and reflect on data collected from the initial interview. As stated previously, I anticipate that the second interview will occur within several weeks of the first interview. I will continually return to the transcripts to verify participants’ responses and validate interpretation of their responses.

Confirmability is measured by the degree to which the researcher clearly articulates that content and findings are indeed from the study data and not the beliefs and biases of the researcher (Morrow, 2005). Confirmability will be reinforced through tactics exercised to meet credibility, transferability, and dependability. This includes self-critique and disclosure of personal beliefs about the phenomenon, establishing an
audit trail, member checking, peer debriefing, and annotating a dense, detailed account of the study procedures and findings. The audit trail will provide clear communication of all study decisions and procedures. Like confirmability, authenticity is also concerned with “truth” of data (Seale, 1999). The ongoing process of revisiting the data after each interview will inform subsequent interviews and assist the researcher in focusing participants to convey a more refined understanding of the phenomenon.

**Protection of Human Subjects**

**Ethical Considerations**

Ethically sound research helps to ensure the protection of human rights. This study proposal will be submitted to the Georgia State University Institutional Review Board. Once approval is obtained from the Georgia State University Institutional Review Board, study enrollment will begin. As the student investigator, I will clearly explain (orally) the study in detail to each individual participating in the study, and will provide participants with written information related to study purpose and eligibility criteria. I will inform participants that enrollment in the study is purely voluntary and that they can decide not to participate at any time without penalty. I will explain to participants that I will use an audio recorder to record our conversation. Nominal risks associated with participation in this study include the recollection of past events and recall of potentially emotionally sensitive information. Throughout the interview, the investigator will maintain awareness of participants’ interactions. If at any time the participant appears to be physically or emotionally shaken while sharing their story, the researcher will pause the interview and ask the participant if they are comfortable continuing the interview or if they would like to end the interview. If the participant expresses a desire to speak with
someone concerning their emotional state, I will consult with the faculty principal investigator to discuss the participant’s emotional state. Support services that individuals might be referred to include the NKF Cares information line, where they can speak with a trained professional to answer their questions and listen to their concerns, and free pastoral counseling services from the church.

**Risks and Benefits**

All risks and benefits, methods to ensure confidentiality, and process for managing data will be explained to participants. A benefit to participants is the internal reward participants may gain by sharing their story about their lived experiences. A benefit to society is that others may now come to know the authentic voice of AA and their lived experience, and can then use the deeper understanding to implement interventions to reduce CKD risk for this vulnerable population and help other AA know about kidney disease. A benefit to nursing is that the results of this study may help inform the development of patient-centered interventions that can assist AA in adopting CKD risk modification behaviors.

Even with efforts to maintain participants’ anonymity, content presented or reported may contain information by which participants can be identified. Participants will be informed that although absolute confidentiality cannot be guaranteed I will take steps to protect their privacy. Participants’ identities will be protected by using identification numbers instead of participant names. A roster of participant names and corresponding number will only be available to the student researcher and the dissertation chair. The participant roster with assigned numbers will be kept in a locked file cabinet separately from the study data. As stated previously, if it is believed that the individual
contracted to transcribe the audio recording personally knows a participant then the researcher will transcribe the audio recording. All identifying information will be removed from the transcripts and pseudonyms will be used in any publication or presentation of study content. Furthermore, the name of the recruitment site will not be included in any reports. Participants will be informed that all study data will be kept for five years.

If participants desire additional information on CKD, they will be offered phone and website contact information for the NKF. The NKF provides free CKD screening through their KEEP outreach efforts and support to kidney patients and their families through their NKF Cares program. They will also be offered CKD educational materials from the Department of Health and Human Services National Kidney Disease Education Program. Those who complete the initial interview will receive a $10 grocery store gift card. An additional $10 grocery store gift card will be provided to those who complete a follow-up interview.

**Summary**

In summary, an interpretive phenomenological approach is the most appropriate research design for this study. Rationale for study design, sampling, data collection, and data analysis support the phenomenological underpinnings for the rich generation of data to elucidate the meaning of kidney disease for AA with a family history of CKD. The researcher will also take steps to provide ethical and legal protection of human rights.
CHAPTER IV

Research Process

In this chapter, I describe how the research plan was carried out. Here, I discuss participant recruitment, data generation, data collection settings, and data analysis. I cover tactics used for ethical and legal protection of human rights. Content in this chapter explains the audit trail that guided my process of inquiry.

Participant Recruitment

The Georgia State University Institutional Review Board granted approval to recruit for this study. Participants were recruited using purposive sampling. This purposive recruitment technique was applied to maximize the likelihood of enrolling individuals who could provide a rich description of the phenomenon of interest. My primary means of study recruitment was through dissemination of flyers at a metro-Atlanta church with a predominately African American congregation. I passed out flyers during two consecutive church services on a first and fourth Sunday. Also, on two different occasions I disseminated flyers during evening bible study sessions. I placed flyers on church bulletin boards. Information on study recruitment was included in the church bulletin for one Sunday as well. In addition, I sought study participants through snowball sampling from current study participants and referrals from personal acquaintances and colleagues.

Initial study enrollment was slow. This may have been in part related to two snow and ice storms that shut down metro-Atlanta. The storms were two weeks apart and
severely hindered travel, work operations and activities of daily living. When individuals did contact me to express interest in enrolling in the study, they did so by phone or email. For those who contacted me by email, I set up a date and time to speak with the individual by phone. During the phone conversation I discussed the study purpose and screened individuals to determine if they met inclusion criteria. Seven individuals did not meet inclusion criteria. Not having a first degree relative with CKD excluded five individuals, and one individual was excluded because her child had CKD as a result of a pediatric congenital condition. Another individual was excluded because he was biracial and did not identify African American as his ethnic/racial group — he identified as Native American. Twelve individuals met eligibility criteria and were enrolled in the study.

Once individuals were deemed eligible to participate in the study, I discussed the informed consent process with them, and explained the risk and benefits of participating in the study. I informed volunteers that they could stop taking part in the study at any point without penalty and that they would receive a $10 grocery gift card for each interview they participated in. After volunteers confirmed that they wanted to participate in the study, I set up the initial interview at a mutually agreed upon location. I emailed a consent form at least one week prior to the meeting, which provided adequate time for the participant to review the form and ask questions before the interview. No participant offered questions prior to the initial interview.

**Data Generation from Initial Interviews**

Initial interviews took place in one of four settings: (a) the participant’s home, (b) my home, (c) a church education room, or (d) a private room in the library of my
workplace. Conducting interviews in a safe and private environment was paramount. The participant’s home was used when the individual was referred by a close friend or colleague. This offered a quiet and familiar environment for the participant where they could feel relaxed. My home served as a site for data collection for one participant. This participant was a family member of a dear friend. We were both at ease with using my home as a place to meet. A room in the educational wing at the church served as an interview location for two participants. One participant did not have transportation to the church; therefore, I picked the participant up from their home and transported them to and from the church. This provided an opportunity for us to build rapport. Lastly, a room in the library at my place of employment was used as an interview location. Since the participant and I worked on the same campus, I chose a room in a different building from where the participant worked to safeguard the participant’s privacy while supporting an environment conducive to information sharing.

Before beginning the interview I thanked participants for agreeing to take part in the study. We had general conversation about travel to the interview and talked about the weather. I shared with them that I am a nursing student at Georgia State University and interested in the experiences of AA who had or have a loved one on dialysis. We then shifted to review of the consent form. I explained the study purpose, risks and benefits, confidentiality, study procedure, and reminded them that their participation was voluntary, and they could decide not to participate in the study at any time without repercussion. I answered all questions. Participants validated their agreement to take part in the study by signing two consent forms. I in turn signed the two forms and kept one and handed the other one to the participant.
During the initial interview I explained to participants that I would be using a few questions to guide our discussion and that I would be taking a few notes as we conversed. I placed a digital audio recorder between me and the participant and initiated the interview by asking the participants to “Tell me about when your [particular] family member first started dialysis and what that was like for you.” As the interview progressed, I used additional open-ended questions from my interview guide to encourage participants to expound upon their story. I used probing questions to help gain a better understanding of the meaning of their story. For the most part, I avoided leading questions; however, there were occasions where in an effort to help a participant more clearly communicate their thoughts, I framed a question in a leading manner. This was noted by the participant who stated “Now that you put it that way.” In the end this did help the participant recall the experience and articulate its meaning.

To help keep the interview fluid and the experience alive, I asked participants to tell me more about an instance that illustrated a phenomenon associated with their belief about CKD. This was accomplished by participants sharing a story or giving an example of when and how they experienced an event. Women participants more readily articulated their story. When interviewing men I used more probing questions to help elucidate the details of their story. A few participants spoke in a low monotone voice, almost a whisper, when sharing particular details of their story. In the first few interviews I noticed from the transcripts that I injected “okay” and “yeah” while attentively listening. This interfered with the flow of storytelling and was corrected with future interviews. Instead, I used supportive facial expressions and physical gestures that demonstrated sensitivity to the participants’ experiences. Most participants used non-
verbal communication behaviors to further express their story. Some laughed, others offered a smile when speaking about their loved one, and a few tapped a table with their fingers to emphasize a point. Silence was used when participants needed time to reflect and recall an experience. Two participants became tearful during the interview. I stopped the tape, offered a tissue, gave them a moment to recover, and then asked if they are comfortable continuing the interview. They stated yes and we continued with the interview.

Throughout the interviews I sought affirmation from participants that what I heard and understood was an accurate interpretation of their story. I reviewed audio recordings and transcripts as I went along, looking for expression of concepts by participants that could be explored in subsequent interviews. For example, during the first interview the participant referred to the body as a temple. I explored this concept in future interviews as a question I proposed or a commentary offered by participants. In the second interview the participant spoke about how they connected their personal health status with family members who have had years of long life and not with family members who have chronic conditions such as CKD. In future interviews with other participants, I began exploring this phenomenon of creating a favorable personal health outlook by connecting with those family members who had longevity of health while disassociating from those who had less years of life because of unfavorable health histories.

Prior to concluding the interviews, I asked participants if there was any additional information they would like to share. This often generated additional storytelling. A few participants had nothing further to add. I concluded each interview by thanking participants for sharing their story. I collected demographic information from
participants, offered them a CKD educational pamphlet from the Department of Health and Human Services National Kidney Disease Education Program, and provided them with a $10 grocery store gift card. I informed participants that it would take several weeks for the audio recording to be transcribed, and once transcribed, I would send the narrative to them via email and at that time invite them to take part in a second interview. Most interviews lasted 50-75 minutes.

Some participants continued sharing after the audio recording was stopped. One participant took me on a tour of their home to show me a special room where they relaxed and entertained. This information was captured in field notes. Many participants hugged me and thanked me for giving them the opportunity to share their story. A few participants commented that, until they shared their story with me, they had not given thought to the meaning of many of the details in their story. During one of the initial interviews the audio recording malfunctioned and the entire interview was lost. Field notes were used to summarize the interview.

**Data Generation from Follow-up Interviews**

Before follow-up interviews were conducted, I had the audio recordings transcribed and validated the integrity of the narratives. This took 3-8 weeks. The details of how this was carried out are explained in the data analysis section. Once the transcripts were validated, I emailed the narrative to participants with a message asking them to review the transcript to make sure it reflected what they had hoped to share with me and invited them to take part in a second interview. Three participants responded when they received the initial email and arranged for a second interview. Most required additional outreach via email or text messaging. I was careful to be polite and non-
coercive in my outreach. I let them know that I was just checking in and was available if they wanted to speak with me again. Five additional participants agreed to a second interview after they received their second outreach message. For the four participants who did not take part in a second story, one person indicated that they were out of town caring for their ill loved one. For another participant, sharing their story a second time may have been too difficult as they indicated during the initial interview that they had mentally blocked out most of their story because it was painful to talk about. The other two participants did not respond to the invitations to participate in a second interview.

The same settings used for the initial interviews served as meeting locations for the follow-up interviews with the exception of the educational rooms at the church. I reassessed the participant’s willingness to continue in the study before beginning the follow-up interviews. We engaged in basic conversation about how things were going. One person shared how they began talking to their family more about their health. After small talk, I proceeded by asking them what questions or comments they had about the transcript and if the transcript was an accurate reflection of what they had hoped to share with me. Most had no comments. One person stated that they did not realize they had stated some of the things in the transcript; however, they added that the transcript was accurate. Another person commented on how long and detailed our conversation was. In all, everyone was satisfied with the integrity of the transcript.

Next, I shared with them things I had gotten from their story and allowed them an opportunity to comment on my interpretation. During this discussion, participants provided more detail and deeper exploration of their story. I shared with them themes I learned from other participants that were similar to thoughts they may have vaguely
expressed in their story, yet seemed to have an influence on their CKD health beliefs. For example, the theme of not communicating about health was present across many interviews. Another was how a person determines that a disease runs in the family. The second interviews offered participants an opportunity to expound upon particular themes and communicate how particular phenomena help shape their understanding of kidney disease. The interviews were 30-60 minutes in duration. Satisfied that no new themes were emerging and data saturation had been met, I did not seek additional interviews. Individuals who participated in a second interview received a $10 grocery store gift card.

Van Manen (1990) emphasizes the importance of revealing one’s own understanding, beliefs, biases and assumptions when conducting qualitative research. He states that one should not forget these presuppositions, but instead work to abate them when attempting to understand the phenomenon as presented by study participants. Throughout the research process I reviewed my assumptions about CKD knowledge and risk behaviors. I evaluated my desire to educate participants about CKD, and worked to place it aside so that I could be fully available to understand the personal experiences shared by each participant.

**Data Analysis**

Before conducting follow up interviews, audio recordings were transcribed verbatim. I contracted with an online transcription company to convert the audio recording to text. Each audio recording was downloaded to my password protected personal computer. I assigned an identification number to each audio file. Audio files were converted from a wave file to a windows media audio file. This allowed for faster upload. Files were then uploaded to an online transcription site. It took 3-7 business
days for audio recordings to be transcribed. Once transcription was completed, I reviewed each narrative without making corrections. I read the story as a whole for insightful discovery. Next, I read the narrative while listening to the audio. During this process I made grammatical corrections, removed any identifying information, and wrote notes in the margins of the narrative. Next, I uploaded transcripts into a computer-aided qualitative data analysis software, QSR International’s NVivo 10 software (NVivo, 2012). I used the computer-aided program to organize and code data from the transcripts. This continuous examination of the whole and the parts of data is consistent with the fluid and iterative hermeneutic phenomenological approach for in-depth exploration and interpretation of a phenomenon. This multistep interpretation process helped me identify inaccuracies and discrepancies through re-assessment and comparison of text.

I revisited my field notes and my reflexive journal. I summarized my interpretations of the transcripts, my field notes, and my journal, and shared my independent analysis with my committee chair. Other committee members, and two professional nursing colleagues, familiar with kidney disease, were asked to review transcripts and offer feedback. Further review and discussion of the transcripts was done to resolve any discrepancies. All discrepancies were clarified. I continued to immerse myself repeatedly in the text, winnowing the data, grouping codes into themes, and in the end, I identified cross-cutting patterns communicated in each narrative that expressed the relationship of the themes.

**Authenticity and Trustworthiness**

In this study, rigor was applied to substantiate the validity and reliability of data. This approach to strengthening data authenticity and trustworthiness was achieved by
creating a relaxing conversational environment conducive for prolonged engagement with participants. I remained opened and attentive during each interview. This supported an unrestricted flow of information between the participant and me. I provided participants with as much time as needed for them to communicate their stories, without hurrying or pressuring them. In-depth interviews lasted from 50-75 minutes. Member checking was conducted throughout the interviews by asking participants to validate whether my interpretation of their story was accurate. In addition, each participant had the opportunity to read their transcript and assess its integrity. By utilizing audio-recorded interviews and field notes, I was able to apply triangulation of data to enhance authenticity and trustworthiness. The chair of my committee read each interview and provided feedback on data generation process and data analysis. Two nephrology nurse colleagues read transcripts and offered critiques of the data.

Each audio recording was transcribed verbatim, and I continually returned to the transcripts to verify participants’ responses, validate my interpretation of the data, and inform subsequent interviews. I maintained a detailed log of my research activities and used a reflexive journal to write notes on my thoughts about the phenomenon and data. By creating a transparent audit trail of all study decisions and procedures, I further strengthened study authenticity and trustworthiness. Time gaps of 3-8 weeks between the initial and follow-up interview provided me the opportunity to reflect on the data and write journal notes as I immersed myself in the text. This helped me to become deeply familiar with the whole and the parts of the data, and enriched my understanding of the phenomenon.
Summary

In summary, I have provided detailed discussion on how the research plan was actually executed. I discussed my decision making process with participant recruitment, data generation, data collection settings, and data analysis. In this chapter, I also described measures used for ethical and legal protection of human rights. Lastly, I explained how rigor was applied to the study and steps taken to strengthen authenticity and trustworthiness.
CHAPTER V

Findings and Discussion

In this section, I describe the demographics of the research population. I then present the findings of the study, delineating the meaningful patterns and themes that emerged from the data related to the study’s two research questions: (1) What is the meaning of kidney disease for AA with a first degree relative on hemodialysis? and (2) How does having a family member with kidney disease inform an individual’s beliefs about CKD?

Sample Demographics

In-depth interviews were conducted with 12 adults who all identified their racial/ethnic group as African American/Black. Table 1 summarizes the sample demographic characteristics. Three participants had work experience in a nephrology setting. More than half of the participants (n=7) self-identified as having at least one modifiable CKD risk factor (e.g., pre-diabetes, hypertension, or elevated BMI). Number of years on dialysis ranged from less than 1 year to 7 years for participants’ affected family member. Geographical distancing varied between participants and their living first degree relative. Three participants lived in the same city as their family member but did not share the same residence, two shared the same home, and two lived 4 hours or more apart.
Table 1

Demographic Characteristics of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Men (n = 4)</th>
<th>Women (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Years) Range</td>
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<td>26-65</td>
</tr>
<tr>
<td>Education Level</td>
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<td>2</td>
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<tr>
<td>Some college/technical training</td>
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<td>4</td>
</tr>
<tr>
<td>College graduate</td>
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<td>2</td>
</tr>
<tr>
<td>Marital Status</td>
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<td></td>
</tr>
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<td>3</td>
</tr>
<tr>
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<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Divorced</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Employment Status</td>
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</tr>
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<td>2</td>
</tr>
<tr>
<td>Part time</td>
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</tr>
<tr>
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<td>3</td>
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<tr>
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</tr>
<tr>
<td>Disabled</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Affected Relative</td>
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<td></td>
</tr>
<tr>
<td>Parent</td>
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<td>5</td>
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<tr>
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</tr>
<tr>
<td>Child</td>
<td></td>
<td>1</td>
</tr>
<tr>
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<td>6</td>
</tr>
<tr>
<td>Deceased</td>
<td>3</td>
<td>2</td>
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<tr>
<td>Personal CKD Modifiable Risk Factors</td>
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<tr>
<td>Pre-diabetes</td>
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<td></td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Overweight/Obese</td>
<td>2</td>
<td>5</td>
</tr>
</tbody>
</table>

*CKD modifiable risk factors were identified from in-depth interviews and were not collected from the demographic questionnaire. CKD – chronic kidney disease
Patterns and Themes

Participants provided a vivid description of their lived experiences and from my analysis of the data, I interpreted their lived experiences into textual expressions as patterns with relational themes. I identified two patterns that cut across each narrative and contributed to understanding the meaning of the phenomenon. The two patterns were: (1) How We Relate, and (2) Not Knowing – Now Knowing. Patterns and the associated themes are shown in Table 2. In this section, I fully describe the patterns and associated themes that explicate the meaning of experiences. Illustrative quotes from narratives are provided for patterns and themes. Quotes are used to substantiate my interpretation of the data, and are represented by identification numbers and not participant names.

Table 2

Major Patterns, Themes, and Occurrences

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Themes</th>
<th>Occurrence^a</th>
</tr>
</thead>
<tbody>
<tr>
<td>How We Relate</td>
<td>Communication</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Comparison</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Bloodline</td>
<td>12</td>
</tr>
<tr>
<td>Not Knowing – Now Knowing</td>
<td>Kidney Disease is Serious</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>What is Kidney Disease?</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Staying Strong</td>
<td>11</td>
</tr>
</tbody>
</table>

^aOccurrence refers to the number of participants whose interview included the theme

Pattern One: How We Relate

Analysis of the data revealed three themes associated with this pattern. The themes were: (1) Communication, (2) Comparison, and (3) Bloodline. Throughout each participant’s story a central determinate of their CKD health beliefs and risk perceptions
was linked to how they connected to their first degree relative. How participants related to their family member influenced how participants represented their meaning of kidney disease and appraised their personal risk for CKD.

**Theme one: Communication.**

Within this constitutive pattern, communication was a prominent theme expressed by all participants. Communication was central to the level of personal and emotional connectedness between participants and their family member. Information sharing and the frequency of sharing influenced how they modeled closeness and concern for each other. Communication was expressed differently across relationships. Each participant told stories of how they communicated with their first degree relative. A sister described her relationship with her brother as “thick as thieves”. She spoke of how they grew up very close but over time the relationship changed:

> I found out that he would be starting dialysis after everyone else, because I live in Savannah, obviously. So I was a little out of the loop of what was going on. I didn't know — and my brother grew up — we're five years apart but we grew up pretty close because it was just the two of us. And, after he got married, our relationship got kind of strange but we still kind of talked a lot. So, I was kind of in shock that I didn't quite know what was going on with him until after the fact.

(Participant 10)

In relationships between a child and a parent, where the parent had CKD, these participants spoke about how their relationship with their parent changed as they matured from children to adults. A son (Participant 12) told of how he was a rebellious teen and not very close to his father growing up, yet when his father needed a place to stay, he
opened up his home, "Because although we had a little rocky relationship, you know, there's still love there. That's my dad.” Regardless of how relationships changed overtime, once the clarion call was made that a family member was in need, communication brought the family together. Participant 4 said it this way:

Yeah, and everybody gets, gets the information. You don't leave anybody out of the loop, whether it's good or bad. Because like I said, my sister's been in and out of the hospital and my job is to call so and so and her husband's job is to call to make other sides of the family. Did you call? You know, so everybody knows, you know, basically what's, what's going on. (Participant 4)

For some families lack of communication was the norm, “I was always protected. And then I think my family dynamics was — they didn't talk” (Participant 8). Health information was not something that was routinely shared, except according to Participant 6, “Unless we're talking about how someone died. That's the only time health is going to come up.” Many participants believed that some people did not share health information because of privacy:

She really didn't. We really didn't know that much about it. My mom was a kind of private person. She really didn't talk too much about her health and the only way I really knew that she was taking medication is that she gave me a prescription to refill for her and I accidentally left it in the car and I went in the house to start cleaning up or whatever and then I left and went somewhere. And when I got home, she was just really upset and she said that I didn't bring her medicine and that she could die if she didn't take her pills. (Participant 8)
Other reasons participants gave for why they believed their family members did not share health information with them were not wanting to burden their family members, not wanting to be judged by them, and to protect them from worrying; however, those left out of the information loop viewed this as keeping secrets: “Actually, like I say, he still kind of kept it all secretive. He kept everything a secret” (Participant 12). A few participants called this lack of information sharing destructive. They believed that if a family member had information that could help prevent illness in other family members, then that information should be communicated:

Because of the way — my family is a big loving family. And some things that they do to them it's for protection. But it can hurt someone by not knowing the severity of things so that's why I wanted to get involved. And say, you know, it's not bad to say you have this going on. (Participant 6)

Another factor associated with how participants related to family members through communication was whether they perceived that their family member was open-minded about change. Some participants referred to the family member as “hard-headed,” “knuckle-headed,” “can’t tell them anything,” and “they’re going to do what they want to do.” Geographical distancing also influenced communication. Living with or near family members had a positive impact on connectedness:

She started dialysis, we were in New York and I wasn't really involved too much because we lived separately. And mostly her husband was taking her back and forward to dialysis. The only thing that it would be that if I'd talk to her or something, I could tell that she would be . . . she was kind of tired from going out that type of thing. But now I'm more involved being that we live together. (Participant 4)
Participants used communication to connect with their family member. They shared stories about barriers to communication that limited the exchange of information; however, this did not hinder their willingness to be there for their loved one. Participants experienced a closer connection with their family member when they could communicate with them in person and not be constrained by distance. Although families communicated about many aspects in their lives, the majority of participants stated that talking openly about health was challenging.

**Theme two: Comparison.**

Another means by which participants related to their first degree relative was based on the degree to which they perceived their family member’s lifestyle resembled their lifestyle. Participants examined commonalities between them and their affected relatives on such factors as, connectedness between them and their affected relative, their relatives’ health behaviors, and circumstances leading up to their relatives’ CKD diagnoses. Participants used this information to help gauge their personal susceptibility for CKD. When participants positively identified with their family member, participants perceived that what was happening with their family member could very well happen to them. This positive comparison was influenced by strong family bonding, feelings of being “close-knitted” and engagement in each other’s lives over the years:

Because like now, I've got like — I get swelling in my legs sometimes and I think it's because my mom had a fistula done last week. . . So like, okay, could I have it, too. So it's like every little thing that happens with me, I kind of freak out about it because I don't know if it's following behind them, so I think about my health more. (Participant 11)
A daughter (Participant 6,) whose father had CKD, described herself as a “daddy’s girl” since the day she was born. She elaborated that although she talked to her mother daily, it was the bond with her father that was most special. This early connection with her father during her childhood helped foster a close adulthood relationship with him. Because her father had CKD, she believed that she was at risk for kidney disease as well. She further explained how she wanted to do whatever she could to support her father, including donating her kidney:

Yeah. Still. Just praying every day that, you know, either a kidney comes through, or he decides to take my kidney. I kind of stopped harassing him about it. Before it used to be a conversation we had all the time, and I knew it would get him upset. . . . He’s actually getting ready to come down next week. I'll probably bring it up again. I asked him for my birthday could I give him my kidney, and he, no. . . . So I'm just going to keep, whenever he asks, you know, and that's pretty much what I say, “What do you want for Christmas”? “What do you want for a holiday gift? A kidney? (Participant 6)

Although a family member may have described their relationship with their relative as close, this did not automatically constitute a health connection. A common thought among participants was that their family member had CKD because they did not take care of their bodies, they did not eat right, they did not exercise, they lived a stressful life, and they did not have a relationship with God. Participants believed they were making better lifestyle choices as compared to their relative; and therefore, were not at risk for kidney disease. Participant 5 said, “[I’m] better than my dad. And grandfather, yeah, 'cause I had one thing, I exercised.” Participant 12 used the phrase “totally
different” to make the comparison between him and his first degree relative. Another participant commented that:

Just seeing my mom going through a lot, you know, Not only her but her sisters, you know. . . . She had both her breasts removed you know what I mean. And she still had like, high blood pressure and cholesterol. . . . It's like, you look at them like, I'm not gonna be like that. . . . I wanna be healthy. . . . I have to be careful what I eat. . . . I'm not gonna sit and eat a whole bag [chips], I won't do that, cause I know what the effect of it is. (Participant 1)

When participants did not perceive a relationship as close, they were even more inclined to not view a connection between the family member’s health and their health — they downplayed their risk for CKD. Several participants perceived the lifestyle behaviors of their family members as destructive; and therefore, it was their own fault that their careless behaviors resulted in kidney failure. Participants rationalized that because they do not have the same reckless behaviors as their family member, being diagnosed with CKD was not a concern for them. Participant 5 said, “I didn't really understand, I didn't need to, you know. But then he, you know, he was doing drugs and stuff, so he wasn't taking care of himself either.” This was even in light of the fact that a few of the participants had CKD risk factors such as high blood pressure, pre-diabetes, and elevated BMI. Kidney disease was something people brought on themselves:

He needs to take responsibility for what happened because of something that's preventable. So, you know, someday I may feel sorry for him on Monday. But then on Tuesday, Wednesday I'm like no, you know, you brought this on yourself. And nobody did it to you. It's not like you were in an accident and your kidney
got punctured. You know, this is something that you literally did to yourself. . . .

So, you know, I mean of course I understand. I know that it's hard but this is where we are, you brought it on yourself, so now you have to deal with the consequences of it. . . . But sometimes, people just have to learn the hard way and he's the one of them. And if I could take it all back, I wouldn't because I don't think [her brother] would be where he is today, health-wise. If this didn't happen to him, he would still be doing what he want to do, still be waiting for the gout flare, you know, still be — and is just — it's ridiculous. (Participant 10)

In discussing their relationship with a family member, all of the participants appraised their risk for CKD based on the extent to which they believed their family member’s lifestyle resembled their lifestyle. The level of closeness was a factor for a few individuals. Closeness did not factor in if individuals perceived that kidney disease was the result of careless behavior on the part of the family member. Many participants viewed themselves as completely different from their relative. Most took the position that they made better lifestyle choices that protected them from CKD, despite the fact that a majority of them had at least one CKD modifiable risk factor.

**Theme three: Bloodline.**

This theme was pervasive across all the interviews. All of the participants spoke about how they represented their risk for CKD based upon their perceptions of their entire family health history, not just their first degree relative on hemodialysis. They conceptualized the presence of kidney disease in their bloodline in several ways: the number of family members who had kidney disease; how ubiquitous kidney disease was in their family; how kidney disease ranked in importance to other health conditions in the
family; how current health practices cancelled out genetic risk; how they re-defined their bloodline; and the absence of kidney disease in some family members who lived long lives.

Several participants assessed their risk for CKD based on counting the number of relatives in their family with kidney disease. The absence of CKD in other family members indicated that kidney disease was not genetic and was a disease of chance, as stated by Participant 5: “Only because I don't know anybody else who's had it. So I don't think that it's something that's inevitable. I just think that he was one of the luck of the draw.” For two participants, kidney disease did not register a significant concern for them when non-first degree relatives were receiving dialysis. It was not until their parent was diagnosed with kidney disease that participants began to add up the number of family members with kidney disease and assess their personal risk for CKD:

To me, it's like, there's two more people in the family, whether it is direct related brother or sister or an aunt, uncle or cousin, if there is any — Two works for me. If two or more people have a family condition, then I'm looking for it in me because we're all connected and just because it doesn't show up in one person doesn't mean it won't show up in somebody else and so yeah, just because especially like genetics or something, I think about, okay, well, you know, if she had it then that means I might be predisposed to it, so now I have to consider that too. . . . When it was mom, it really hit close to home. (Participant 11)

CKD bloodline heredity for Participant 7 was based on the number of people with the disease and who those particular individuals were. She considered a disease to be related to the bloodline if her mother and sister had it. It was less of a concern if an uncle or
cousin had the disease. However, if multiple individuals across the family have a disease then she viewed this as a genetic condition and everyone could be susceptible.

On the other hand, counting numbers was also important in ruling out CKD as a health concern. One participant when speaking about his risk for CKD said:

There's a chance but I always think a lot of things could be genetic. And so she [my mother] the only somebody in our family that’s really doing it [dialysis] like. So I figure it wasn’t a real genetic thing because she the only somebody who got it in the family. (Participant 2)

Many participants told stories of how pervasive other health conditions like cancer, diabetes, and high blood pressure were in their families. Participant 1 spoke about her grandmother, her mother, her aunt, her sister, her daughter, and her brothers all having some form of cancer. Because she only saw two people with kidney disease in her family (her mother and an uncle), she believed that kidney disease did not “run in the family.” It was clear to her that cancer ran in her family and that was where she focused her prevention screening — getting mammograms. Kidney disease was not a health threat for her:

Well, I don't think I will end up with it [kidney disease] because I'm on the right path of trying to eat right. And it's not like it's, I look at it, how, there's nine of us. Nobody has kidney disease, since I was a kid. So we're all, six of us all in our 50s. My one sister, she's 58, she don't have it. She don't even have diabetes, you know what I mean. She don't even eat right and she don't have it. She doesn’t have high blood pressure, but she has asthma. So I don't think I'll get that because I don't think, I’ll get that like one of them, far as probably cancer, now two of my
brothers and one of my sisters. One of my brothers and one of my sisters both had cancer. So I look at cancer more than the, the [kidney disease]. (Participant 1)

For several participants, health behaviors were more important in determining CKD risk than the family’s bloodline. Participant 2 said, “I more or less weigh not necessarily history as what did I know about the family and how are they taking care of themselves. I think I look more at that than if it falls into the family history.” She believed that her family were not “junk-a-holics” and that they were physically active. Her thoughts were similar to Participant 4 who felt that eating right, avoiding excessive alcohol, and drinking plenty of water would prevent kidney disease:

Not really. Only for the fact that, like I said I've never heard of it like in our family or anything like that and hopefully, you know, drinking water and doing some of the some of the things hopefully will keep the kidneys going and okay. (Participant 4)

Looking at kidney disease along a chronological age continuum was how some participants determined whether kidney disease represented a health threat. They compared the age of onset that a relative was diagnosed with a health condition to their current age. If they were past that age and were free of disease, they believed that although the disease may run in the bloodline, they had beaten the odds. Participant 10 believed that it was inevitable that she would have high blood pressure because it was in her mother’s bloodline and she would get it around the same age as her mother. She attributed her risk to the belief that genetically she was more identical to her mother, who had high blood pressure, than her father, who had diabetes:
It's inevitable [high blood pressure] for me but I think that the way that I live my life is a lot different [from father and brother] than I shouldn't [get diabetes]. I don't see it [CKD] happening in my timeline as I did at my brother’s. I saw it happening for my brother more so, than for myself because he is my dad basically. He's just a younger version of my dad and I'm more so, a younger version of my mom. So that's why I see hypertension more likely for me than I do diabetes for me. (Participant 10)

Family bloodline was redefined by one participant. She viewed herself as a Christian and believed that once she accepted Christ, her bloodline was now through Jesus Christ. Her new bloodline meant that she could live a healed life absent of disease. She saw no health connection between her bloodline and the bloodline of her family:

To be honest, no, I really don't. To be honest, I know they say it's a family — it can run in the family. But I truly believe that it stopped with my mom. I actually believe, me personally, that I am given a second chance, that I'm born again and that my blood line is through Jesus. . . . And I believe that if I do what I'm supposed to do, that God will do what he is to do. And so I don't believe that their health — now, maybe what I learned from them, poor eating habits and all of those things can affect me. But as far as the bloodline that it's definitely going to happen because of what happened to them, no, I don't believe that. (Participant 8)

Other participants looked for longevity in the bloodline to relate their health history to. Four participants told stories of how a parent or grandparent lived an active, long life free of kidney disease. This genetic lineage offered a promise of longevity and
good health. They preferred to identify with this bloodline rather than with family members who were ill:

She’s the first person [my mother] . . . [that we’ve] Seen before in my family generation, my mother and my grandfather side, all them together passed until they was almost 100 years old. Whether sick or not they was all in their 90's when they all passed. . . . There's a strong genetic, you know, something in our family. . . . Family, if all brothers and sisters and stuff like that, you know, [do not] pass until almost 100, in their late 90's . . . I'm hoping that some of that [longevity] will pass along to some of us. (Participant 2)

Participant 2 believed so much in the longevity of his bloodline that he stated the only reason his mother had kidney disease was because of the doctors. He felt the doctors’ greed and lack of knowledge lead them to place a vascular access graft too early in his mother’s arm. Despite his mother having high blood pressure, diabetes and elevated BMI, he believed it was this procedure that made her sick and necessitated the need for dialysis.

Focusing only on longevity caused Participant 5 to block out disease patterns in his genetics. Hoping that he would live long years, like his grandmother, this participant did not relate his heart attack to that of his grandfather. He also disconnected his father’s CKD from his health history. For him, the diseased bloodline was not in his current knowledge base, he simply forgot about it. He had never met his grandfather because his grandfather died before he was born. He had only heard stories about him. Miles separated him and his father; therefore, he was not deeply involved in his father’s life.
He also attributed his father’s kidney disease to bad lifestyle choices (alcohol and drug addiction):

And actually no, because I found out, ‘cause my, my grandfather died of a heart attack at the same age that I had mine, at 48. . . . So I remember that hearing that legend, that story, right, but then I never thought about it in the sense that, that means you’re going to get heart disease. I was always talking about my grand, my grandmother who died at 103 or 104. So I was always saying man I got longevity. I'm good to go, you know, and so whenever I'd get asked on all those Navy questionnaires and all that, physicals and, history of heart disease, nope. History of longevity, yes. (Participant 5)

The bloodline helped participants appraise their risk for CKD. They each had a belief of what the bloodline represented. For many it was a source of health as they saw longevity in their family. The number of family members with disease in the bloodline served as an early warning signal for illness. Others disconnected from the family bloodline, and instead, believed that health protective behaviors and a relationship with Jesus determined their health outcomes. Hence, the bloodline is an important link in how participants relate to their family members with a history of CKD.

**Pattern Two: Not Knowing — Now Knowing**

Within this pattern were three prominent themes:  (1) Kidney Disease is Serious, (2) What is Kidney Disease, and (3) Staying Strong. In their stories, participants revealed their lack of knowledge related to CKD and how their lived experience with having a first degree relative on hemodialysis increased their awareness and understanding of the
seriousness of kidney disease. They explained how this new knowledge influenced their personal health practices.

**Theme one: Kidney disease is serious.**

An emphasis on the seriousness of kidney disease was underscored throughout each participant’s story. They discussed the seriousness of kidney disease in comparison to other chronic illnesses, in terms of how debilitating dialysis is, and the impact from seeing their loved one live through the experience. In their stories, participants communicated in rich detail how their early inadequate knowledge of CKD lead them to perceive kidney disease as non-threatening. Once their first degree relative was diagnosed with CKD, participants gained new knowledge that influenced their understanding of kidney disease.

Before their affected family member needed dialysis, the majority of participants had no idea that their family member had kidney disease. A few participants had been aware that their family member had diabetes and/or hypertension. In general, participants were not aware that diabetes and hypertension can result in kidney failure; and most were shocked to learn that their family member would need dialysis. Of the 12 participants, only two had knowledge that their family member might need dialysis before the actual treatment began, as this participant stated:

No I was not prepared for her to start. I didn't know too much about what she had to go through and what they were doing with the dialysis, because I just thought it was, you know, something that she needed to do, and started learning a little bit more about what they had to do to make that, make her comfortable, and then she did go through the dialysis. (Participant 9)
Seeing the debilitating effects of kidney disease in their family members emphasized the seriousness of dialysis. Participant 6 thought it was like getting ready for a new life, “But he had a lot of sores all over his body and he didn't want to do all the regular activities because he didn't want people to look at him. So, it was just — it was different.” Vibrant, active family members were now fatigued, helpless individuals. Dialysis treatments robbed their family members of energy and was now the focus of their lives; whereas before dialysis, family members had rewarding careers and an array of social activities. These once independent relatives were now dependent on others for almost everything, such as cooking, housing, and running errands:

You know, that kinda thing . . . and it's hard. It's hard to see her. She gets frustrated because she cannot do the things that she used to do. She will come in here [home] from dialysis and try and go in that kitchen. I was like, you just need to go upstairs and just rest. You just walked in the door. And I keep thinking about, she has a great appetite. So she's thinking food. She'll make a plate; she can't eat all of it.

But, her mind is like all, I'm hungry I'm thinking what I'm going to eat. And she'll come in and be ready. Oh what are we going to have there? I was like, you know what, you just need to go upstairs and lay down. Give yourself a minute or something. Yeah, so in her mind she can still do things but physically, she really, really can't. (Participant 4)

Despite the consequences of dialysis, participants knew that dialysis afforded their family members life. Dialysis was keeping them alive. Participant 11 said:
Yeah, it's not. [Silence] It's almost like a burden. It really is because it's like a job you hate but you go anyway because it pays well. You know, yeah, it's kind of like that. It's like you do it because you have to because the pay is good and that, the pay being it’s keeping you alive. (Participant 11)

Reasons given by a few participants for not perceiving kidney disease as serious were generally related to the participant being of young age when initially hearing of someone receiving dialysis. For participant 5, his first experience with dialysis was as a kid with a childhood friend needing dialysis:

Well, since I was a Navy man for years, so you know, I had people that I knew personally in dialysis. I had an idea of how, 'cause I had a childhood friend who, at a young age, had to get dialysis, you know. . . . But I still didn't know how often he had to go, how long the procedure would be, and how it makes you feel afterwards. That I didn't know. (Participant 5)

Another reason for lack of concern was centered around the participant’s relationship to the individual on dialysis, “And I didn't realize that kidney disease was so abundant until, you know, it gives you things to think about when someone close to you has it.” (Participant 10)

Participant 6 was introduced to kidney disease as a young child. Her first encounter with dialysis was with a non-first degree relative, her aunt. Being chronically ill was how she had always known her aunt, from having diabetes, to having amputations, and being a kidney transplant recipient — having a sick aunt was her norm. When she learned her father needed dialysis, she referred to it as a “common cold,” no big deal:
So, for her, I mean, since she was — I believe it was 11 she had diabetes. And so, for me, because I was born into it, it was just kind of like, Oh, yeah. My aunt has diabetes. It was never something that was, Oh, wow. She has diabetes. Or this person. It was just, okay, they have diabetes. It wasn't a big deal…. It was just — the way my family is high blood pressure and diabetes is just like a common cold. So, it was, Oh. Okay. Well, I just have high blood pressure so it was never — I didn't realize the significance of this is what I have and this is why I would take these pills. (Participant 6)

Knowing several people with kidney disease did not amplify its significance for Participant 12. Across this participant’s life span, there were several encounters with individuals requiring hemodialysis. Hemodialysis was regarded as a normal part of life; it was just something people took time out of their day to do. It did not hinder the individual’s ability to socialize and enjoy life. His perspective was that dialysis was not taking anything away from a person’s quality of life:

Well, I just knew, like, a lady who my mom used to sit for sometimes, she went all the time. And she actually was on dialysis for a long time. I think, like, they say almost thirty years before she died. She was elderly. But she'd just go back and forth. And, you know, we see them go back and forth; they seem like a normal person. So we just look over it. . . . Okay. You get up in the morning. It's like you're going to school. It's like I'm going to school, put in your couple of hours. You go to dialysis clinic, you're going to see the doctor and do whatever y'all do there. And you come back home, you fine. . . . Her life didn't stop. She did — at least from what I know I was young as far as a kid. So she did
everything all the other older ladies did. She wasn't different. She just was her.

They went to the old folks daycare, and she went to her dialysis treatment.

(Participant 12)

He goes on to say that the image that someone is managing well on dialysis gives the perspective that dialysis is not life threatening. Once he gained new knowledge about the real impact of kidney disease, it raised the seriousness level of kidney disease for him:

I think if you really don't get into it, it will give you the wrong impression that, okay, it's not a big concern. It's not a big issue to someone who had it. . . . Once I actually got into the dialysis [as a technician], and seen it first-hand, and started meeting patients, and seeing what they go through, that's what changed.

(Participant 12)

The role that health care providers play in determining how important kidney disease is was illustrated in one participant’s story. A nephrologist not seeming concerned about kidney disease led Participant 11 to believe that kidney disease was nothing to worry about:

You know, her primary care sent us to a nephrologist because they saw some decrease in the kidney function and the nephrologist would say it's not bad enough for you to need to see me. Come back when you need dialysis, essentially. So we didn't really think about it that much because especially with them saying it's not that bad, it's not that bad, don't worry about it. (Participant 11)

In weighing the seriousness of kidney disease, some participants compared it to other chronic conditions. Kidney disease was often compared to cancer. Most believed
cancer was a bigger concern. Others were relieved to learn their family member did not have cancer, but instead had kidney disease — kidney disease seemed less serious:

In the beginning, it was okay. This is what it is ‘cause I had an aunt but she was a diabetic. And she had a kidney transplant so it was, Okay. I'm kind of glad it's not cancer. But then as I started doing the research and I really realized what was going on it just felt like, Okay. It felt worse. Compared to me once I found out.

(Participant 6)

Cancer has a high significance value for Participant 1 because there were multiple family members across generations who had cancer, “When you look at [family health history], it's like, when I look at my family's history and I see the cancer and I see how, the kidney disease was [there], that was missed [small amounts], that was very missed, but mostly all [more amounts] the cancer.” Cancer was also thought to be considered more important than kidney disease because it was discussed more in the media:

That it's real. You know, it's a real disease. You don't hear about it [kidney disease] as much as you hear about other diseases and, you know, cancer is like the major disease that everybody talks about or probably knows more about than anything else. But [kidney disease] is a real disease and it's debilitating. It's very debilitating and, as we were saying, there are things that we can do to try and keep ourselves healthy that maybe we won't have to even really deal with it. But, like I said, until she was going through this, kidneys — I didn't really think about it too much, you know. (Participant 4)

For one participant, it was not a comparison of kidney disease to another chronic condition that lead to kidney disease being insignificant, it was the kidneys themselves.
Participant 11 believed that the heart, brain, and lungs were the most important organs in the body. She could feel her heart beating, she used her brain to think, and her lungs provided her breath. These organs performed a tangible function; therefore, she was more concerned about the health of her highest ranking organs. Kidney function was not something she thought about:

> You know your heart is important. That's what's keeping you alive, so I think you take heart disease more seriously because if you got something going on with your heart, everything pretty much shuts down, whereas if you think about our kidneys or what they do that much, it's kind of a peripheral thing that's like, you can live with one kidney. I mean because sometimes you think it's something you can live without or at least without one of them, so it's not that important.

(Participant 11)

In all, having a first degree relative with CKD heightened the seriousness of the disease for all participants. Witnessing the impact of CKD on their family members’ quality of life and physical well-being made the disease real. This lived experience provided them with new knowledge about CKD. One participant said it was a wake-up call:

> It's, how should I put this? It's a wake up because you see the fact that the disease doesn't have an age limit. It doesn't have a race limit. It's universal. Anybody can get it at any time if they don't, you know, be proactive and doing what they need to do, watching their diet, taking their meds. If you know you have diabetes, high blood pressure, whatever, and you don't do anything to try to steer your body in the right direction, it's almost inevitable that you're going to get one of the
diseases down the line. So you say I see this happening, I can do something about it. I don't need to wait until it's too late. It happened to a young man and I know there was a friend of mine who worked at the doctor's office said that there was a young guy and they're like 26-27 on it. So, it tells us that because I'm in my late 50s don't mean I'm exempt — if this 26-year-old, 27-year-old and sometimes even younger people can get it, then so can I. So I just need to be more mindful that it's serious. It's not just, oh, okay, it's just a disease. No, it's serious, it's a life-threatening disease. (Participant 3)

Having a first degree relative with CKD influenced how participants perceived the seriousness of dialysis. Initially, dialysis was seen as just an everyday condition. As participants began to see the life-changing effects that dialysis imposed upon their family member’s life, participants gained a realization that kidney disease was serious and life-threatening.

**Theme two: What is kidney disease?**

The question of ‘what is kidney disease’ riveted the thoughts of participants when they learned that their first degree relative needed dialysis. Although many of them spoke of how they had previously heard of dialysis, many expressed that they really did not know what kidney disease was; as one person said, “To be honest, I don't know that much about it” (Participant 8). All the participants knew the kidneys were needed for urine production, but only two spoke about the regulatory and filtering functions of the kidney (one participant said she learned this only after agreeing to participate in the study). Some indicated that they did not know dialysis was related to kidney disease,
they thought diabetes was the reason people needed dialysis. Others thought kidney disease was a condition easily remedied by a kidney transplant:

Yeah. I didn't know what that was [kidney disease] or what that meant, really. And when she said she was diabetic, she was on [dialysis] or she had kidney failure, I was like, all right, well you need a kidney, I have two. We could, you can have one of mine. It was a thing like that. You can have one of mine. And she was like, oh no, 'cause. I said, well I, you know, God gave us two, so if you need one, and we're tested and good, 'cause I'm O, I'm O positive, my blood's go with anything, you can have one of mine. It’s not going to be, I don't consider it a big deal. . . . I was, it was, it was just like, it didn't seem like a big deal to me. You have kidney disease, your kidneys are failing, okay, well, you can have one of mine. It was like, you know, here, have some of my soda. (Participant 7)

Dialysis and transplantation were not true life-savers; many participants knew that even with dialysis, death was a real consequence of CKD, “Because if you've got kidney disease, it's only so long that you're going to be able to go on dialysis until you've got to get a transplant. Eventually that kidney might stop functioning on dialysis and you'll die” (Participant 2). Five participants had first degree relatives on dialysis who were now deceased. Participants with living family members on dialysis were constantly aware of the negative impact of dialysis:

Yeah. I am not sure if I shared this in the last interview, but one day while my dad was at dialysis, he let me know that someone had died in the chair behind him. So I just, once again, it was just, like, oh, man. Even if you're on dialysis, something can still happen. You know, you need dialysis. It'll save your life, and people are
on it for years, but it's just, it's scary because something can still happen, and in
the beginning when I didn't know, I wasn't educated, it was, OK. Well, this is
what we have, take the medicine, you'll be OK, and not realizing that it's pretty, I
mean, it’s life or death. You need your kidneys. So it just, it really hit home.

(Participant 6)

One of the biggest misconceptions about CKD reported by participants was that
diabetes was the primary cause for their first degree relative needing dialysis. They were
not aware that diabetes could lead to kidney disease and that the diagnosis of CKD was
the real reason their family member needed dialysis. Kidney disease was an obscure,
inconspicuous condition that was not associated with dialysis:

This is something different, this is something a lot more serious than just regular
diabetes, right. . . . When you have diabetes, you give yourself insulin; but, or you
might have to go to, you know . . . [go] to the clinic and have them, that’s my
thinking of it. It [dialysis] was just a part of having diabetes, her going to the
clinic and getting put on the machine, or even the PD [peritoneal dialysis]. I’m
thinking that's just part of her diabetes, I mean, they're saying renal disease, but
still kidneys. . . . There’s, there's no, no, the distinct stop and start or it did
something worse. It's just like, okay, well this is just the normal flow of having
diabetes, and your kidneys, you know, failing, and you have to get a new kidney
if you wanna be back in good health. But you have to go through all of this. This
complete kidney failure, I think is something that's part of being diabetic. . . . Like
I said, my cousin's wife, who was diabetic, and she was on a, she had to go to the
clinic to get put on the machine. She never said, I have renal disease. (Participant 7)

Although a majority of participants believed an inevitable end point of diabetes was dialysis, how or why diabetes (and high blood pressure) progressed to kidney disease was puzzling for many participants. Participants knew their relatives had kidney disease, but exactly what that meant was unclear to them. Many participants told of how drinking alcoholic beverages, drinking too much tea, and not drinking enough water were causes of kidney failure, as one participant remembered:

Mm-hmm, hot Lipton tea. Every morning, and sometimes at night. And she thought because she drank tea and in it, there's like, sometimes tea will make you go to the bathroom a lot. Because she didn't drink water while she was drinking her tea, she didn't drink a lot of water during the day, that that's why she went into kidney failure. So on her death bed — well, I wasn't there when she died, but a couple of days before she died, when I was talking with her, she made me promise that I would drink lots of water because she thought the lack of drinking water, a lot of water, caused her to go into kidney failure. It was never explained to her about diabetes. And I didn't know that much about diabetes. (Participant 8)

Working in a nephrology setting did not offer an advantage in the area of greater depth and breadth of CKD knowledge. In her story, Participant 10 told of how she was oblivious to what kidney disease really was even though she worked as a receptionist in a renal clinic:

And I didn't realize that kidney disease was so abundant until, you know, it gives you things to think about when someone close to you has it, because before I went
in there [dialysis center] or even thought to look up anything about kidney
disease. And when he told me, I was like "What are you talking about, you know,
how do you get kidney disease? How do you — What do you mean your kidney is
not like. I don't understand.” I was confused, and I'm like, "OK, you have kidney
disease. Is it in both kidneys? Because if I can donate a kidney to you and live
with one, why can't you live with one?" You know, I had a bunch of questions.
But, I mean, it broke it down for me. A lot of people told me a lot of things. So, I
mean, I just feel better about it, you know, as a whole. And I'm not as — I'm not
blinded by it as I was before because I thought I knew, but I didn't know.

(Participant 10)

It was new knowledge obtained from training to become a hemodialysis technician that
provided two participants with a better understanding of what kidney disease was. Prior
to training, both participants shared how they only thought of the kidneys as making
urine:

Because when I first went to class, I didn't know nothing. I just knew dialysis is
for people who kidney don't work and they can't pee. I was so — I didn't even
know that some people still pee when they're on dialysis — that's how ignorant to
the fact I was. Like, I didn't know nothing. I just know your kidneys don't work.
You go here, and they clean it out some kind of way. So it was, like, interesting
to learn the whole routine, what it is, what it do, everything. . . . Because before
then, kidney disease — your kidney stopped working. Like, it's a wrap. And now
I know that there's stages. Like, you could still go to dialysis and have half of
your kidney working and everything. So that's the difference I see in it.

(Participant 12)

Participants discussed where they got their information about kidney disease. Sources of CKD information included family members, television, Internet, and health care providers — with the majority of participants getting their information from the Internet. Many participants commented that there was just not enough information in mainstream media about kidney disease, “You know, it's a real disease. You don't hear about it as much as you hear about other diseases and, you know, cancer is like the major disease that everybody talks about or probably knows more about than anything else” (Participant 4). Shortcomings in media as a conveyor of CKD information did not hinder Participant 10, who found a reliable source of information in her brother. She spent time at the dialysis unit, often sitting next to the machine while her brother received his treatment, as she described:

But as far as kidney disease, I don't even know nothing about it like it — oh, it totally took me by surprise but I'm so more forward with calling and asking now, well, what's going on, well, how are you feeling today? . . . Before, it's just I wasn't asking because I didn't know to ask. But now, even though I don't know what to ask, I'm asking everything. What are you doing? What's going on? What is this potassium thing? You know, I'm asking questions and he's such a beacon of information, because he sits there, he reads about this stuff the whole time we're there and we're learning together what it takes to be successful after a kidney donation. (Participant 10)
Health care providers were mentioned less often as a source of information. Participants reported that health care providers did not ask about a family history of CKD or discuss with participants the different types of CKD tests. However, most participants shared that their health care provider’s health history form had a query about a family history of CKD. Participant 9 said, “Well that [family history of kidney disease] sometimes is on the paper. I usually put no, but as far as the diabetes, with her being a diabetic, you know, I do put that on there.” Cardiovascular disease according to Participant 5 was the area of focus for his health care providers:

Well you know, that was, that was, that was a shock because I guess two diseases that I, that I hear can fry your kidneys is, you know, diabetes and hypertension, you know. But I didn't know that then, and even now when I've been consulting with my hypertension, it's not something that comes up, you know, the most often, something they talk about, hypertension is. You know, stroke, you know, stroke or heart disease, you know. (Participant 5)

Many participants trusted their health care providers would inform them if they were at risk for CKD, but otherwise they were not concerned that their doctors did not discuss CKD. This passive approach to screening and educating participants about CKD was evident in one participant’s story. Despite having several CKD risk factors, including African American racial/ethnic group, high blood pressure, and elevated BMI, this participant described how her doctor only became alarmed about her CKD risk after she told the doctor her son was on dialysis:

No, because like I say they look at your chart and say this runs in your family but there was no kidney disease in the family. So, there's diabetes, heart disease and
all that, but there's no kidney disease that I remember in the family. So, the fact that he's just turned 39 and diagnosed at 37 with renal failure, I guess that sort of sent off a signal in her [the doctor] head as well as mind that, okay, we need to be proactive, you know, we need to get a handle on this because you know what it takes to control and you know what you need to do and let's help you do it.

(Participant 3)

Health care providers were an important source of health information. Getting more information from health care providers was something participants desired.

As participants learned more about kidney disease, they were better able to help their family members. Having a family member on dialysis propelled participants into action. In an effort to better help their loved ones, participants sought new information to help increase their understanding of kidney disease, as reported by this participant:

I don't really know how to explain it but like I said, I know better now what the disease is about. I can now really have better conversations with my sister because it's like now I know what I'm talking about. Because you could tell me anything and I didn't really know. Yeah exactly. Oh no, I can do this. Oh really? Okay, I didn't know that. But I, I think now you can't really pull the wool over my eyes anymore. . . . You know, so we try and — because it's easier and you know something and you're knowledgeable and you have facts, you can tell somebody something. So when you don't know, they can tell you anything and you go, oh really uh huh, until you go and look it up. So, I'm trying to use whatever I've learned now to help her and to just kind of keep a better eye on her, what's going on. (Participant 4)
For all participants, learning that their family member had kidney disease exposed their own lack of knowledge of CKD. The connection between dialysis and kidney disease did not exist for some participants. In order to better help their family members, participants realized that they had to gain more knowledge on what kidney disease was.

**Theme three: Staying strong.**

Staying strong captured the desires of participants to maintain good health. Participants did not want to experience what their relatives endured — CKD and dialysis. As one person put it, “That it is deadly and you know I don't think anyone wants to spend most of their time like I say going somewhere laying on a machine three and four hours a day. And then when you get up you ain't got strength to deal with anything.” (Participant 2). Each participant articulated how they wanted to avoid being on dialysis, and staying strong was their plan for doing just that:

Well, kidney disease means to me, it's a total shutdown of both of the kidneys. It's something I don't want to have to go through. I do not want to have to go through but if I had to someone would be willing to give up their kidney for me, someone be able to do that and that's all — somebody willing to do that. I know it's something that I wouldn't want to have or wish on my worst enemy, but it seems like it could be livable but it's such a hassle. It puts boundaries and limits on your life. It's just like any other disease or illness, you know, so that's why I try to stay strong. Stay strong and stay healthy. (Participant 7)

Although having a first degree relative on dialysis made salient the negative impact of kidney disease on one’s quality of life, the vast majority of participants shared stories of how their desire to stay strong was born out of a personal decision. One participant had
experienced liver failure, another had a heart attack, and two others had experienced weight gain that impacted their activities of daily living. During these health challenges, participants were able to modify their behaviors to improve their health status; therefore, they believed that they had the ability to control their risk for CKD through lifestyle modification. Hence, as noted earlier, CKD did not represent a health threat to them because their health practices were different from their family member who had CKD:

But yeah, I get — I see, you know, my mom and her sisters and you know the whole thing of the diabetes and the kidneys, you know, and the cancer, all that stuff, you know. They just didn't keep themselves healthy. I think that is the key. Not, I mean — exercise is a key but the key is eating right, being healthy. See that. You know even like my cousins, you know, to when you go to the nutritionist and they show you so much the way that you eat and even choices of food like the white bread and all the white pastas and you know, that has a lot of to do with it. You know, but being like with him [husband who has diabetes], my mom and I see all this stuff, so I know. I mean even when I went to Weight Watchers I gained weight. You know and they talk about moderation, moderation because I don’t sit and eat a whole lot, but moderation. You know so that I keep all that in front of me. (Participant 1)

The dietary and physical activity behaviors described by participants were consistent with clinical health guidelines and recommendations. “Because I think I'm doing more to be proactive following, you know, the guidelines, trying to stay ahead of the game so to speak, and watching my diet and exercise and, you know, getting check-ups.” (Participant 3). Eating a balanced diet, and getting adequate amounts of physical
activity to maintain a healthy weight was something all the participants agreed was essential to good health and for the prevention of CKD:

And now, there are so many resources. It's inevitable the things that you can find to be healthy, to be fit and that it not just stay horrible. I don't like oatmeal at all. I tried to eat some the other day and threw it right back up. I don't like it. I've tried it. It didn't work for me. But I did some chicken breaded oatmeal the other day. Put some oatmeal on my diet and it wasn't nasty. Actually, it tastes pretty good. I didn't think I was going to like the little egg white that you pour from the little thing. I can't even tell the difference so things stay fine. So, it's like — it's all about taking the initiative and being responsible and being an adult basically and just doing it and stop putting so much thought into it and making excuses about it when there is no excuse to be made. If this is what you need to do, you know what you need to do, so do it. (Participant 10)

Participants believed they were able to avoid kidney disease by adopting health protective behaviors and their belief helped to minimize their own risk for CKD. All participants agreed that CKD was preventable, “The solution for the problem is to try to prevent it in the beginning so do what you need to do to prevent it and then we won't have to go this round.” (Participant 3) Yet, the majority of participants did not know what laboratory tests were performed to check for kidney disease, and many participants were unsure if they had ever been screened for kidney disease.

When to take prescription pills to manage CKD risk factors was debatable for a few participants. Some participants did not agree that staying strong involved taking blood pressure medication or other medication, which they believed to be damaging to
the kidneys, simply because a doctor prescribed it. For them staying strong involved taking charge of your health:

And I think that's the biggest thing — to take it serious, and take our health serious and question the doctors, you know, when we go to the doctors. Ask questions. And also, medications. If you have questions about the medications, if it's making you sick or — don't keep taking it for the doctor to give you another medication to get rid of those symptoms. Because when I first got sick, I was so sick physically. I was sick mentally, too. I had a whole bag of medicine because this was causing this problem so he gave me another pill and my weight bloomed up to 228. I couldn't hardly breathe. I couldn't move. I couldn't walk. I had bags of medicine, and every time I went to the doctor, they gave me something else.

(Participant 8)

Participants preferred to take natural supplements instead of prescription drugs. They believed the prescription drugs had side effects that caused their bodies more harm than good, “I'll take the vitamin but I'm not taking all this medicine that has all these side and effect.” (Participant 1) Still others believed taking medication was important. Participant 3 saw what not taking medication did to her family member, “It was kind of mind-boggling because I just kind of grasped the concept of him having to go on dialysis at such a young age. . . .And he was telling how, you know, he dropped the ball, you know, didn't take some of his meds he was supposed to take, 'cause it's just too expensive.” Taking medication was one way she saw as staying off dialysis.

One participant discussed her strategy for staving off CKD and more closely related it to denial. In her story, she told of her lack of health insurance, unemployment,
dependency on her mother for income, and the stress of serving as caregiver for her mother. All of these factors contributed to her poorly controlled blood pressure and elevated BMI — and obesity. She was able to clearly articulate the lifestyle modifications required to have better health, yet she was not motivated to make the changes — her reasoning, denial:

I think it's a denial and I think it's funny because it's one of the things we talked about when I was in school for it; you get away with it until you don't get away with it anymore. . . . Like, okay I'm okay today, I'll be okay tomorrow. You kind of keep going like that until it all catches up to you and crashes in on you. And I think it's just that, I don't say it's a drive, but it's just a necessity to keep going to at least be able to keep doing what you're doing now. . . . It's like as long as I can do, as long as tomorrow I can do the same things I did today, be able to take care of her and be able to do all the stuff that I need to do, then, you know, I can wait to deal with that and I think that's what it is. . . . I'm not that bad even though I can look at her and say, yeah before she got that bad, she wasn't that bad. I'll get there, I don't know when, hopefully it's before it becomes a crisis. . . . It's just something you don't think about until it's something you have to think about because now it's there in your face and you have to deal with it. (Participant 11)

Although Participant 11 was the only participant to explicitly discuss denial as a coping strategy for minimizing her risk of CKD, it is likely that most participants were overly optimistic in describing their healthy lifestyle behaviors. This overestimation of healthy living was evident in the fact that 58% of participant self-identified that they had a personal history of either high blood pressure, pre-diabetes, or overweight/obesity.
Education on how to stay healthy was mentioned by most participants. Giving people the right information on things they can do to keep well was deemed important. Before people were willing to receive education, one participant believed that people needed to feel comfortable with sharing their health information:

I mean whatever it is it's a safe zone. You can be open and honest with me whatever it is. You know, I'm not gonna judge you. There's overweight people in my family. So if they say well, you know, they said I have a diabetes. I'm not going to judge you, but I do want to find out whatever is going on so that we can be educated about it and just make the family aware that if something happens this is why this is happening. (Participant 6)

Education was viewed as essential in order to help facilitate change:

I guess what they need to do is they always ask about, you know, different diseases in your family history and sort of, okay, you know, this could be hereditary, there's a 50% chance that you may get it as well, but tell me why you think that. Give me more, or should I say give me more of what I need to know or what I need to do to prevent it. Give me more support even if you have to write it down or say, okay, you go to this website and look up this information, read it, study it and come to your next appointment and we'll talk about it or if you have questions in between call me or my nurse and we'll get with you and help you discuss what you don't understand. (Participant 3)

Having a family member on dialysis was a wake-up call that needed to be answered by families taking action. This action was for healthier living and was not entirely connected to the belief that participants were at risk for CKD. Yet, most
participants knew education would not be enough to galvanize family members into action:

I think a lot of times people they know they have issues like my husband knows he is pre-diabetic but it won't stop him from eating from those Hungry Man TV dinners, which are loaded in sodium and it won't stop him from eating his pork chops or his bacon, which is going to give him a massive headache in the morning. (Participant 7)

Motivation to stay strong came from several sources. Having an image of what healthy looked like served as a source of encouragement for some, “And that's how I want to be in my early seventies. You know, uh, you know, be fit, you know, be able to walk, no wheelchair, no cane, you know.” (Participant 9) Participants did not want to endure the pain and suffering the family member experienced with dialysis. Staying active across their life years was something everyone shared in their stories:

I'm strong and I try and remain strong and I was telling my husband I was like you have to keep up with your health because you never know what God has for you when you get older and you have to be able to do it . . . when you're in your 40s, that's the decade if you're going to remain strong as you go into your 50s and your 60s, what you're doing now between your 40s and your mid-50s is going to really determine how you're going to be in your 60s and 70s and 80s and 90s. Because my grandmother, she's 92 years old, and I still want to be able to move around and get down a flight of stairs like she does. She, you know, she worked in the yard, she had a garden, she was doing that in her 80s. I was like, I want to be like you. I don't want to be in a house or in a wheelchair or on a cane, on a
walker like that when I get in my late 80s, God willing, I don’t get that a way. I think it's very important to stay strong. (Participant 7)

A desire to be at their best kept participants motivated to stay strong, particularly as they aged. Some participants commented on how growing older and seeing weight gains prompted them to shift their health practices to improve their health outcomes. As this person noted:

Mine has been more along the lines of, I'm doing better now than I ever did before. I'm, I'm — the best I ever did before, you know, so that I want to be in a position to enjoy things. . . . So I look at it more like a health thing. I wanna feel good for my age; I wanna look good for my age, kinda like that. . . . Look good, feel good, which means better health, you know what I mean. (Participant 5)

Staying healthy and strong for her child was the motivation for Participant 10. “But I know that I can't live my life like this and I know that I want to be healthy for my child. So, that . . . he is my driving force to stay healthy, to be healthy, to stay healthy and to shoot for the stars.”

Staying strong for some was guided by a sense of spirituality where the body was viewed as a temple to be cared for and honored as unto God. “Well your body's supposed to be a temple, you know, you're supposed to take care of the body that God has given you.” (Participant 9) The obedience to God’s commandment to honor their body is what Participant 1 believed freed her from illness:

I think, I know for a fact, my belief in God. I know that's, that's what turned everything, completely turned my life around. When I started walking with the Lord and seeing the diff. . . . There was a big difference when I, you know, started
putting cigarettes down and putting the alcohol and all that down, and turned my life over to the Lord. (Participant 1)

Participant 8 wanted people to be educated on how food could work as medicine along with faith, and she believed it was her mother’s lack of seeing her body as a temple that misguided her decisions about her health and caused her to live a lifestyle contrary to healthy. In general, participants shared diverse levels of spirituality; some frequently attended church, others did not regularly attend church but prayed regularly, and some were just getting back in to attending church; however, them all hoped that their health would be better than their affected relative’s health.

Participants believed they could self-manage their health and avoid CKD. For most participants, the lived experience of having a family member with CKD created a comparative illness schema where participants perceived their own health practices as being better than their family members. This optimistic appraisal by participants, although health protective in the sense that participants believed they had self-efficacy to make better health choices, in the end, deluded them into believing that they had zero risk for CKD.

**Summary**

In this section, I presented the results of the interviews of AA with a first degree relative on hemodialysis (see Table 3). From the participants’ stories emerged two patterns: (1) How We Relate, and (2) Not Knowing — Now Knowing. The patterns and their associated themes provide a foundation for a deeper understanding of the meaning of kidney disease for AA with a family history of CKD.

Table 3
### Summary of Study Findings

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Findings</th>
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<tr>
<td><strong>How We Relate</strong></td>
<td>Limited family talk about personal health</td>
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<tr>
<td><strong>Status</strong></td>
<td>Family history of CKD did not necessarily influence personal perceived risk for disease</td>
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<tr>
<td></td>
<td>CKD is not hereditary</td>
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<tr>
<td><strong>Not Knowing – Now Knowing</strong></td>
<td>CKD is not perceived as a personal health threat</td>
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<td></td>
<td>Low CKD knowledge</td>
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<td></td>
<td>Lack of CKD education from HCP</td>
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<td></td>
<td>Absence of CKD information in media</td>
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<td></td>
<td>Believe they have self-efficacy to prevent CKD</td>
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Note: CKD – chronic kidney disease; HCP – health care provider

In the first pattern, participants ascribed meaning to CKD through their connectedness with their family members. The style, type, and depth of communication defined the closeness between participants and their family member. Talking about health was a means of showing support. How participants perceived their relationships with family members and their assessment of how well a relative managed their own health was one way participants gauged the relevance of kidney disease as a personal health threat. The degree to which CKD was seen as “running in the family” through the bloodline provided participants with a scale to determine their personal risk. Health beliefs and personal risk for CKD was closely related to how participants viewed their relationship with their first degree relative on hemodialysis and the meaning participants
gave to inherited disease and self-inflicted disease.

The second pattern spoke to participants’ lack of knowledge about CKD and the acquisition of new knowledge gained through having a first degree relative on hemodialysis. CKD was not initially seen as serious; however, as participants experienced the untoward health outcomes in their family members, they acknowledged that CKD was very serious. Understanding what having kidney disease really meant was confusing for all participants. They were familiar with diabetes and hypertension, yet kidney disease was a conundrum. Family members were described more as dialysis patients than as kidney patients. Despite a lack of understanding of what kidney disease was, a theme of staying strong was shared by all participants as a way to avert the need for dialysis. Although stressful, having a family member on dialysis was a teachable moment for participants. They became more open to learning about what kidney disease was and how to control it; hence, a diagnosis of CKD created a window of opportunity to introduce families to new knowledge.

Discussion

In this study, the voices of AA who had a lived experience with a first degree relative on hemodialysis provide insight into the meaning of CKD. The 12 stories shared in this study elucidated this phenomenon and provided a better understanding of CKD health beliefs and risk perceptions among AA. Family closeness created through communication and family ties were woven by connectedness through perceptions of similitude and genetics. These were central to formation of CKD health beliefs. Perceived CKD health threat was largely based on comparative risk between participants and other family members. In this section I discuss family and health risk
communication in relationship to health beliefs. Lastly, I describe coping strategies that influence risk perceptions.

**Health Beliefs**

The patterns and themes that emerged from participants’ stories reflect their experience and meaning of kidney disease. According to the HBM, this information is critical in determining how an individual appraises their susceptibility for a disease and the likelihood of taking action to prevent illness. In this section I will discuss the influence of family communication and health risk communication on health beliefs.

**Family Communication**

Pervasive throughout the participants’ stories was the concept of relating through communication. According to the Theory of Family Communication (Koerner & Fitzpatrick, 2002), individuals process information from their relationships and interpersonal behaviors with their family members. They then cognitively process and rank the information to form a family relationship schema that informs their communication behavior with family members. The relationship between the messenger and the receiver influences communication. In this study, some participants believed they were very emotionally close to their first degree relative and this level of connectedness created a supportive environment with good communication to learn about kidney disease. Emotional distance was a barrier for several participants, and therefore limited the degree of communication between them and their relative. For example, Participant 6 remembered that since she lived out of state, it was easy for her family members to hide the problems.
Health beliefs are influenced by family communication. Beliefs conceptualized in the family relationship schema include beliefs about intimacy, individuality, affection, external factors, conversation orientation, and conformity orientation (Koerner & Fitzpatrick, 2002). Conversation orientation relates to the extent to which family members support each other in open and frequent dialogue about any topic, and conformity orientation is how different or similar family members are in their beliefs, attitudes, values, and opinions (Baiocchi-Wagner & Talley, 2012). This adds meaning as to why most participants were shocked to learn their family member needed dialysis.

In some of the families there was less frequent and spontaneous information exchange; therefore, family members were not cognizant of the family member health status. Participant 10 shared that she and her brother were very close growing up and when she moved away, she no longer spoke to her brother on a regular basis. In families with high conversation orientation, a difference in values, attitudes and beliefs resulted in low conformity and weaken family structure. Participant 11, experienced conflict with her relative during disagreements about food choices; eventually resulting in the participant “letting her [affected relative] have her way” in consuming high sodium foods.

An assumption may be that families who, in general, communicate frequently, will likely discuss health (Baiocchi-Wagner & Talley, 2012). These health-specific moments of communication, therefore, may be more directly responsible for outcomes related to individuals’ health attitudes and behaviors than general family communication. However, it appears that for most families in this study, while talking openly about many topics (a sign of being close-knit), health was private. On the other hand, communication
about health was no longer an off-limits topics once a relative was receiving hemodialysis. As one participant stated, her family openly talked about health when someone was sick or in the hospital.

Family environments, which do not support open conversation across a multitude of topics, discourage participatory decision making and disallow others to express differing opinions and thoughts. These environments are somewhat more likely to impede the general well-being and health of family members (Schrodt, Witt, & Messersmith, 2008). When communication, particularly about health information, was withheld from participants, this served as a source of frustration and was sometimes viewed as keeping secrets. Imber-Black (2014) explored chronic illness and secrecy in family communication. In this study, families shared how secrecy lead to misguided information and eroded trust in the relationships. Participants perceived the act of keeping secrets could be harmful because it separated family members from vital information that could help them accurately assess their risk.

Although secrets can be found in many families, in families where there are closed communications more secrecy may exist. In a study examining family secrets, Bowens Family Systems Theory was used to explore family relationships and communication (Knauth, 2003). The theory postulates that family members must be able to differentiate the emotional connectedness from the intellectual systems in order to be responsible for their own actions. Secrets take place when individuals cannot differentiate from the emotional components in family and relationship problems such as emotional distance, marital conflict and dysfunctional children may arise. Similar family dynamics were recounted by participants in this current study. In families where there
was closed communication and where participants were less likely to identify with a family member’s health status there were typically patterns of divorce, acts of rebellion by children, and emotional distance. Closed communication impacted the exchange of family health history and communication about disease risk.

**Health Risk Communications**

Family members share not only genetic but often other determinants of health such as environment and health practices. The medical history of relatives affected by CKD can serve as an important source of health risk information for other family members. Having a relative with ESRD is a risk factor for being diagnosed with kidney disease. Yet many participants in this current study were unsure of the number of family members with a history of CKD. Their knowledge of the family health history was limited by participants’ lack of awareness and understanding of what kidney disease was and the restricted information sharing of health history throughout the family. Before family history information can be used as a determinant of CKD risk, the accuracy of self-reported family history should be checked to help facilitate identification of at-risk individuals (Alspach, 2011). This information can be used to plan the type and frequency of kidney screening, tailor appropriate health modification behavior messaging, and recommend personalized treatments.

Health risk communication involves health care providers giving individuals objective and clear feedback on the risk associated with their family history and other determinants of health (Claassen et al., 2010). In this current study participants reported that their health care providers did not assess their family history for CKD. Health care providers are trusted agents for health risk information. When they fail to advise patients
on their health risks, this sends a message to patients that a particular disease is not a concern for them, which may be incorrect information.

This was the case for Participant 3. In her story, she discussed how her physician only began to advise her on CKD risk factors once the participant’s son was on dialysis, despite the participant having several personal risk factors for CKD. The participant believed that her physician might be busy, and therefore, did not have time to educate patients about disease risk. Time constraints, lack of reimbursement for patient education, and complexity of understanding and interpreting familial risk are reasons cited in the literature as barriers to health risk communication by health care providers (Claassen et al., 2010).

In addition to probability data on disease risk, health care providers should inform participants about the causes and consequences of the disease, and approaches that could increase their confidence in making and maintaining lifestyle modification behaviors. The vast majority of participants in the study did not understand the functions of the kidneys, besides urine production, did not know how to distinguish kidney disease from diabetes, and could not thoroughly identify modifiable and non-modifiable risk factors associated with kidney disease. The identification of health beliefs that influence an individual's perception of disease susceptibility can be used to help tailor health messages to the specific characteristics and knowledge-bases of individuals at risk for CKD (Claassen et al., 2010).

Although epidemiological models recognize family genetics as a determinant of health risk, many individuals do not. In a systematic review and synthesis of qualitative studies about familial risk and chronic disease, the analysis indicated that family
members appraised their risk for disease through various lenses (Walter, Emery, Braithwaite, & Marteau, 2004). The lenses looked for the presence of disease across the family and lifestyle resemblance among family members. In this current study, similar to the systematic review, individuals determined if a relative’s disease contributed to their own health risk based on the number of family members affected, age of disease onset, severity of the illness, and similarities in personality, physical characteristics, and lifestyle behavior between them and the affected family member. With the exception of severity of illness, factors in the systematic study that influenced how participants related their family history to their own health risk, were all factors found in this current study. Participants in this current study also ignored their family health history when they had confidence they could implement health protective behaviors to avoid the risk of CKD. How an individual appraises their genetic health history is an important factor to consider when utilizing family health history to predict disease risk.

**Risk Perceptions**

Risk is an important predictor of health behavior and a main construct in the HBM. Before individuals take action to prevent a disease, they must first believe that they are at risk (susceptible). A person might believe a condition is serious, but until they see themselves as susceptible to the disease and the disease as a concern, the condition does not represent a threat to them and they will not began to evaluate the benefits and barriers of taking action. The meaning given to the seriousness and susceptibility of CKD by participants in this current study will be discussed in this section.
Seriousness and Susceptibility

CKD represented a health threat for only three participants. They believed they were vulnerable to kidney disease because it was running through their family bloodline, they perceived their health to be similar to their family members’ health with whom they had a close-knit relationship, and they believed CKD was a severe disease that was life-threatening. Others recognized the seriousness of CKD; however, they believed they were not susceptible to kidney disease. Reasons cited for their low risk appraisal were lack of resemblance to their affected family member, not having a large number of relatives affected by kidney disease, belief that they inherited a genetic tendency toward longevity, and confidence in their ability to control their kidney disease risk by adopting health protective behaviors. In addition, other conditions such as cancer and cardiovascular disease presented a greater threat to them and they were more likely to engage in early detection and lifestyle modification behaviors aimed at preventing these conditions rather than kidney disease.

Comparative Risk and Social Comparison

In the HBM, risk assessment is proximal to determining the likelihood of implementing health protective behaviors (Janz & Becker, 1984). Studies examining the utility of the HBM and other health behavior theories suggest that other factors, such as social relationships, contribute to perceived susceptibility (Gholizadeh, Davidson, Salamonson, & Worrall-Carter, 2010; Janz, Champion, & Strecher, 2002; Leventhal et al., 2003). Social relationships help to establish norms that individuals strive to achieve and these social norms influence the adoption of coping strategies to manage health conditions (Ajzen, 1991; Leventhal, Benyamini, & Brownlee, 1997). In these social
networks, individuals create social comparisons in order to make themselves feel better rather than obtaining an accurate conception of their own health (Menon, Kyung, & Agrawal, 2009). These social comparisons can lead to two kinds of biases: A comparative optimism bias (belief that one is at less risk for experiencing negative events) or a comparative pessimism bias (belief that they are more likely to experience negative events) (Weinstein, 1982). Many participants in this study shared how they assessed their risk for kidney disease through social comparison, commenting that their health behaviors were better than their family members. When individuals believe they make more positive lifestyle choices than others, consequently, the more unrealistic they become in believing their condition is being controlled by their choices. This overly optimistic appraisal about personal risk represents a barrier for the prevention and control of disease (Diefenbach, Leventhal, Leventhal, & Patrick-Miller, 1996; Menon et al., 2009; Thompson & Ting, 2012)

**Risk Perception and Optimistic Bias**

This tendency toward optimistic bias may be related to lack of information. In a study that explored both perceived and actual risk of diabetes and high blood pressure among African American adults, a significant number of individuals who were at high risk for diabetes or high blood pressure were unaware of their risk for these diseases (Graham et al., 2006). Similar to the African American adults in that study, most participants in the current study believed that CKD did not represent a personal health threat; yet, many of them had at least one modifiable CKD risk factor. This at-risk, optimistically biased group warrants the most concern and need for CKD education.
Many participants spoke about the scarcity of kidney disease information. They did not receive kidney disease education from their physicians and they found very little information in the media. A related issue is that when individuals receive information and do not have guidance with interpreting how the information relates to them, this can further add to their under appraisal of risk and over confidence in their health practices to control their disease risk. The link between education and risk perception was noted by participant 10 who also noted, “A lot of times, we choose not to educate ourselves until it happens.” Furthermore, individuals with a tendency toward optimistic bias may not see a need to access health care, or may respond to health risk communication differently. Without provider-patient collaboration in the exploration of factors that contribute to personal risk perception, participants could not be sure of what course of action to take to bring perceived risk perceptions closer to actual risk.

**Risk Perception and Defensive Denial**

When a person says they are not at risk, they may be using avoidance/denial as a maladaptive response to their family health history. Denial derived from danger and anxiety in response to a health threat is different from denial that arises from an optimistic perception of personal susceptibility (Thompson & Ting, 2012). In defense denial when people first learn their health is at risk they commonly play down the seriousness of the threat. In studies of health threat appraisal, people acknowledged they were at risk but they denied the severity of the implications (Leventhal, Diefenbach, & Leventhal, 1992).

Overall there is evidence that suggests that when individuals are confronted with a personal health threat, their initial reaction is to activate defensive coping strategies to
minimize the threat (DiMatteo, Haskard, & Williams, 2007; Hagger & Orbell, 2003; Walsh, Lynch, Murphy, & Daly, 2004; Weinstein, 1982). In this current study cancer, high blood pressure, cardiovascular disease, and diabetes were reported as personal health threats by participants. Although some participants had no indication that they had any of these conditions (family members did), a few participated in screenings to check for cancer, diabetes and high blood pressure. The willingness to be screened for chronic health conditions that were part of a family health history excluded CKD detection. Many participants said they had no knowledge of what tests were used to assess kidney function. Moreover, they did not believe they needed to be tested for CKD since they knew it was something they did not have.

Screening is seen as an effective tool for early detection and control of disease for many chronic conditions such as breast cancer, colorectal cancer, diabetes, and prostate cancer (Baptiste-Roberts et al., 2007; Cyr, Dunnagan, & Haynes, 2010; Hariri et al., 2006; Palmquist et al., 2011). Although lack of CKD seriousness, awareness, and knowledge among participants may explain their reticence to participate in early CKD detection and screening, risk denial may play a role as well. This could be in part related to how participants experienced the severity of CKD in their family member.

Disease detection presents individuals with an emotional prospect of revealing the presence of disease (Cameron & Leventhal, 2003; Thompson & Ting, 2012). Many participants talked about how dreadful dialysis was and that they never wanted to endure having to be put on a machine. Unlike cancer where they knew chemotherapy had an end, participants knew dialysis did not end. For participants, the thought that they might
experience the same debilitating health effects of CKD as their affected relative may have contributed to their denial of disease risk and avoidance of disease detection.

**Risk Perception and Fatalism**

“It’s inevitable,” is how one participant in the current study described her chance of being diagnosed with high blood pressure. Based on her family health history, Participant 10 believed it was not a question of if she would get high blood pressure, it was when she would get high blood pressure. This sense of foreseeable doom is referred to as fatalism and can influence disease risk appraisal (Walker et al., 2012).

In a study exploring the relationship between diabetes fatalism, medication adherence and self-care behaviors in adults with diabetes, diabetes fatalism was positively associated with poor medication adherence and self-care behaviors (Walker et al., 2012). This suggests that ultimately, individuals with fatalistic tendencies may be less inclined to adopt health protective behaviors. However this report has not been supported in other studies. A relationship between fatalistic beliefs, decreased health care utilization, unhealthy behaviors, and increased chronic illness was not fully observed in a study examining these variables among participants (n=1273) in the Nashville’s REACH 2010 project (Franklin et al., 2007). The strongest relationships were between fatalism and chronic illness, suggesting that fatalism may be a reaction to poor health or chronic disease. In this current study the “fatalistic like” viewpoint expressed by a few participants may not be associated with their decision to not engage in CKD preventive action as the participants were not presently experiencing a chronic condition.

Furthermore, fatalistic thoughts may have occurred in conjunction with positive statements about self-efficacy in accomplishing risk-reduction behaviors (Keeley,
Wright, & Condit, 2009). In this context, fatalistic beliefs are not oppositional to beliefs of self-efficacy; instead, fatalistic comments routinely are made alongside statements supporting health protective behaviors. This view of fatalism was observed in comments made by Participant 10 who expressed that high blood pressure was inevitable, however, she believed she could implement preventive health behaviors. Caution is given to health care providers in concluding that fatalism stands in opposition to health protective behaviors (Keeley et al., 2009). Health care providers should consider other health determinants that may influence health behavior self-efficacy in individuals who approach health concerns from a fatalistic viewpoint. In this current study, only one participant identified lack of health care insurance, unemployment, and caregiver stress as factors that limit one’s ability to implement health protective behaviors. The vast majority of participants believed they could perform CKD health protective behaviors.

Risk Perception and Spirituality

A number of participants spoke to their sense of spirituality in relationship to their ability to protect their health and prevent disease. Some referred to their body as a temple. It was their obedience to Jesus Christ that motivated them to take good care of their body which was viewed as a temple from which God would use them to do his work (missionary). This concept of the body as a temple and the association of spirituality and health has been explored in the literature (King, Burgess, Akinyela, Counts-Spriggs, & Parker, 2005). Various spiritual practices have been reported in the literature as being associated with the degree to which individuals consume a healthy diet and take part in physical activity (Debnam et al., 2012). How beliefs about spiritual health locus of control influence varying health behaviors is not well understood. Findings in the current
study represent various relationships between spiritual beliefs and health behaviors. A few participants believed that without Christ they could do nothing, others believed God gives us free will to make our own decisions, and still another believed one needs to surrender to the will of God and his desires to build discipline to resist temptations (unhealthy behaviors). This is consistent with the literature where the association between the role of a higher power, risk perception, and preventive behaviors is considered complex (Franklin et al., 2007; King et al., 2005).

**Strengths and Limitations**

Participants in this study shared their personal health beliefs and risk perceptions about kidney disease. Their stories reflected the lived experiences of a diverse population (AA) with various religious and cultural beliefs that influence their understanding of kidney disease and CKD preventive health behaviors. These beliefs may differ from those of other racial/ethnic groups; and therefore, represent a limitation in this study. However, little is known about why AA with a family history of CKD do not believe they are at risk for the disease, and this is the first qualitative study to add understanding to this phenomenon. In addition, participants were recruited from a defined metropolitan area and were well educated. The findings of this current study may not be applicable to other populations in other geographical locations or with less well-educated groups.

Strengths of this study include the rich data generated through long, thoughtful engagements with participants. The use of in-depth interview as the data collection tool provided participants the ability to openly and freely stream information. By conducting follow-up interviews, I was able to validate the integrity of the data and authenticate my
interpretation of the data. This approach to examining CKD among AA with an affected relative on hemodialysis had not been accomplished before.

The data generated from the participants’ stories offered vivid insight into how AA with a family history appraise their personal risk for kidney disease. Findings from this study helped bring light to the human responses AA exhibit when they encounter a CKD health threat. Throughout the stories, factors that underpin CKD health beliefs emerged into patterns and themes, which have been substantiated in the literature on other chronic diseases. This study illustrated the need for greater outreach and diverse kidney disease awareness and prevention programs. Seeing was not believing for many participants in this story. Having a family member with CKD did not greatly impact personal perception of disease risk of participants. Underscored in this study is the importance of CKD education that is personalized to the beliefs and values of the individual.
CHAPTER VI

Conclusions and Recommendations

The purpose of this study was to explore the meaning of kidney disease in African American adults with a first degree relative on hemodialysis, and gain a deeper understanding of their lived experience with CKD and their personal perspectives on kidney disease. Through the voices of the participants, this study elucidated beliefs about kidney disease held by African American adults that are incongruent with medical models of care. Clinical practice guidelines identify certain factors which increase the risk for CKD, including attributes such as being African American, family history of CKD, diabetes, and/or hypertension. Most African American adults in this study did not believe having a first degree relative on hemodialysis increased their personal vulnerability to kidney disease. They also did not understand the relationship between diabetes, hypertension and CKD. Although participants felt concern for their affected relative with CKD, their underlying philosophy related to kidney disease was that CKD is preventable regardless of race or ethnicity. Participants believed that, unlike their family member, they possessed the health protective behaviors to decrease their susceptibility for CKD.

A multitude of factors converged to inform participants’ beliefs about their vulnerability for kidney disease. Family communications influenced information processing and validation. Although families talked about many life events, personal health was generally not discussed. Two participants were unaware that their family
member had been diagnosed with diabetes for several years prior to needing dialysis. Knowing that their relative had to start dialysis came as a shock to the majority of participants. Most thought that lack of information sharing was destructive. They believed the affected relative had information that could be used to inform other family members about health risk. Many participants wanted to create a non-judgmental environment within their family so members could openly discuss health status.

Over half of the participants had at least one modifiable CKD risk factor; yet most had not received information from their health care providers about kidney disease. Participants were queried on health assessment forms about family history of kidney disease; however, they were not clear what constituted a family history of kidney disease or how having a family history of CKD impacted their personal health status. In addition to clinical settings, information about kidney disease is absent in most public health chronic disease prevention campaigns. Lack of concern about CKD by health care providers, and a deficit of kidney disease coverage in the media, further substantiated participants’ belief that kidney disease was not very relevant.

The majority of participants in this study, believed that they had self-efficacy to implement CKD health preventive behaviors, and although they perceived kidney disease as serious, CKD did not pose a personal health threat for them. Optimistic bias was often used as a coping strategy to help participants emotionally and cognitively manage their risk for CKD. Ultimately, participants were unable to fully appraise their actual risk for CKD because they lacked access to evidenced-based CKD information that appealed to their unique health beliefs. From this research it seems clear that without access to information that is sensitive to the individual’s health beliefs, AA may make lifestyle
choices based on erroneous evidence in an effort to decrease emotional distress associated with chronic disease. They may not perceive CKD to be serious enough to warrant behavior modification until they need dialysis.

**Implications for Education**

There is a need for more CKD education for both health care providers and at-risk populations. Previous studies point to a lack of knowledge of CKD risk factors as a principal contributor to health care providers’ inability to recognize, screen for, and recommend appropriate health interventions for AA at risk for kidney disease (Fox et al., 2006; Israni, Shea, Joffe, & Feldman, 2009; Lenz & Fornoni, 2006). CKD education should be offered to health care providers who practice in the health care delivery system points of entry where patients initially access care. These points of entry include primary care, obstetrics and gynecological care, internal medicine, and emergency medicine. Moreover, nephrology specialists are the experts in kidney care and can help improve kidney care among non-nephrology practitioners by establishing partnerships with non-kidney disease health professional associations. Through this partnership, nephrology specialists can share kidney care guidelines and mentor health care providers in appropriate CKD prevention and treatment strategies.

The public health impact of CKD is huge and worthy of a broader and stronger public health risk communications campaign. Many participants in this study reported that they found a minuscule amount of CKD education in the media. This is in contrast to the astronomical financial burden of CKD on the U.S. health care delivery system (USRDS, 2009). Health risk education specific to the sociocultural beliefs of AA, and communicated in their health language, needs to be developed and delivered across
various forms of traditional media and social media. Furthermore, strategies to help increase dialogue about health between relatives affected by CKD and other family members, with the hope of increasing understanding of CKD risk among family members, needs to be investigated.

**Implications for Practice**

It is not enough for health care providers to ask individuals to indicate a family health history of CKD on an intake form and use that information as the sole source for determining an individual’s risk for kidney disease. Many studies suggest using family history to leverage health protective behaviors; however, this may not be effective in AA with a family history of CKD, as this current study indicates, perceptions of risk may not be associated with the presence of kidney disease among family members (Claassen et al., 2010; Yoon, Scheuner, Jorgensen, & Khoury, 2009). When caring for AA, health care providers will need to explore factors that influence the degree to which individuals believe a family history of CKD is related to their personal vulnerability for kidney disease. Health care providers can then use this information to dispel misconceptions held by individuals, help family members appropriately appraise their CKD risk, and assist individuals in devising appropriate self-management interventions to prevent kidney disease.

Some health care providers have experienced success by using electronic risk assessment tools to document, analyze, and prevent disease risk as a function of family health history (Ruffin et al., 2011). In a comparative study, a physician-delivered education intervention was used to facilitate physician-patient kidney disease communication (Nunes et al., 2011). Nephrology Fellows in an outpatient renal clinic
used a one-page worksheet to assess kidney-specific knowledge in patients with CKD. The intervention took only 1-2 minutes, was easy to administer, did not interfere with routine clinic visits, and was perceived by physicians to be a beneficial tool for communicating health information to patients. Helping patients find meaning in their lived experience requires health care providers to engage patients in discussion about their health beliefs, and personal risk appraisal. The use of electronic educational tools and quick guides in kidney disease risk communications needs to be explored across various clinical settings and across diverse populations.

Although health care providers may have a desire to delve deeper into the meaning of family history and health risk among patients, often barriers exist in clinical practice settings that hinder the ability to do so. During a clinical visit, health care providers may not have enough time to assess patients’ needs or have tools that can individualize care based on a patient’s health beliefs. Innovative approaches to health risk communication that overcome time restraints and other barriers in clinical practice are needed. Models of health risk communication in practice settings should consider the use of nurses to help elicit and respond to patients’ perceptions of CKD. Nurses are educated to deliver culturally sensitive information and their knowledge of motivational interviewing could be used to assist individuals with a family history of CKD make informed health decisions. More research is needed to understand the role of nurses in CKD patient education.

**Implications for Research**

Participants in this current study were familiar with health threats associated with genetically linked diseases such as cancer and heart disease. They also willingly engaged
in disease detection and screening procedures to identify their risk for these conditions. There is strong evidence linking CKD to genetic variants in the gene encoding APOL1 (Parsa et al., 2013). Black patients with CKD and renal risk variants in APOL1 experience higher rates of progression to ESRD as compared with White patients. In this current study, individuals’ perceptions of genetic risk for CKD varied. Having a clear definition of what constitutes a genetic risk for CKD would help narrow the gap between provider perception of risk and individual perception of risk. Also, being able to genetically test for CKD may influence the likelihood of AA engaging in early CKD detection and screening. Research on the relationship between CKD genomics and AA personal risk appraisal is needed.

Finally, findings in this current study are consistent with previous research that indicates low CKD awareness, limited CKD knowledge, and lack of perceived risk for CKD among AA. Symptoms of kidney disease are typically not experienced by individuals during stages 1-3 of CKD. Early CKD education among at-risk populations may be useful in helping individuals delay the onset or progression of CKD. Currently the Centers for Medicare & Medicaid Services only reimburse providers for educating individuals diagnosed with CKD Stage 4 (Young, Chan, Yevzlin, & Becker, 2010). Stage 4 is the final phase before ESRD. Although educating individuals at this stage could slow progression to ESRD, information provided during the stage is directed toward anemia management, vascular access choices, and treatment modalities — more preparation for dialysis than prevention. If we hope to alleviate the burden of CKD among AA, more research is needed to understand approaches that are effective in halting kidney disease early in the disease trajectory.
Summary

In summary, this study described the lived experiences of African American adults with a family history of CKD and the meaning these life experiences contributed to their CKD health beliefs and risk perceptions. Using a qualitative approach to examine this phenomenon provided insight into how AA formulate and process health beliefs to determine their susceptibility for CKD. African Americans, more than any other racial/ethnic group, are affected by CKD and its associated morbidities; yet the voices of AA are often excluded from kidney disease research. When AA are included in studies, the studies are generally large quantitative studies that focused on outcomes related to dialysis or caregiver roles. This study is unique in that it addressed the perspectives of the family members of individuals with CKD to elucidate factors that contribute to CKD awareness, knowledge, beliefs, and risk perceptions among an at-risk population.

It is concerning that individuals received very little information about CKD from their health care providers or from public health service announcements. It is well recognized that CKD is a slow, insidious condition with few or no symptoms. Halting disease onset and progression requires early detection of disease presence; therefore individuals and health care providers must be educated on evidence-based CKD control and prevention strategies to lessen the incidence of disease. Without evidenced-based information, individuals with a family history of CKD may continue to formulate health schemas through a comparative risk assessment where they appraise their health status as better than others. Essentially this overly optimistic view of their personal health risk and health behaviors may misinform their lifestyle choices and result in similar outcomes as their family members — ESRD.
Individuals develop a perception of disease susceptibility through a dynamic process based on ongoing processing, interpretation, and evaluation of new experiences and information (Walter & Emery, 2006). Results of this study indicate that these individuals desired information on kidney disease and wanted more discussion about health throughout their families. Although medical care models show a relationship between a family history of CKD and susceptibility to CKD, this may not be a meaningful risk indicator for family members. Health care providers need to engage patients in discussions about their family health history, understanding of disease consequences, and health actions that minimize CKD risk. By understanding how AA with a family history of CKD use their health beliefs to inform their risk appraisal and health practices, health care providers and public health professionals can use this information to develop a mutual language of CKD risk perceptions. African Americans may be more likely to view health risk information as relevant if it is based on health language they value and understand. When patients and providers use shared language to communicate health risk, this allows for a more accurate assessment and interpretation of patients’ health beliefs. Having a common language of CKD health risk will better position health care providers to deliver health messaging that directs individuals toward appropriate CKD health protective behaviors — helping them stay strong for a lifetime.
References


APPENDICES
Appendix A
Study Participant Recruitment Letter of Support

From: Pastor Arnold Davis
To: 'Loretta Jackson Brown'
Sent: Wednesday, June 26, 2013 5:59 PM
Subject: RE: Conducting Research Participant Recruitment Through HMBC

Hello Loretta

I spoke to Bishop Sheals, and he has agreed for you to conduct your Research at Hopewell Missionary Baptist Church. Our suggested time to conduct your research will have to be on or around August 14th when Bible study classes resume. If you have any questions please feel free to call or e-mail me. Thank you for including our church in your research, we look forward to working with you in August.

Sincerely,

Pastor Davis

________________________________________________________

From: Loretta Jackson Brown [mailto:Lorettajbrown@bellsouth.net]
Sent: Wednesday, June 26, 2013 3:18 PM
To: Lorettajbrown@bellsouth.net; adavis@hopewellmissionarybaptist.org
Subject: Conducting Research Participant Recruitment Through HMBC

Pastor Davis

Please see the email at the bottom for detail. Just to reiterate, I will not be speaking directly to the members only recruiting members to participate. The study would be announced through a flyer during service and bible study. Those interested would contact me and we would meet privately.

I am happy to share my results from the study with the church.

Thank you again for your help.

LJBrown
Loretta Jackson Brown
lorettajbrown@bellsouth.net
----- Forwarded Message -----  
From: lorettajbrown <lorettajbrown@bellsouth.net>  
To: Tonya Smith <tsmith@hopewellmissionarybaptist.org>  
Sent: Monday, April 1, 2013 9:05 AM  
Subject: Conducting Research Participant Recruitment Through HMBC  

Dear Tonya Smith

I am Loretta Jackson Brown, a PhD Candidate in the Byrdine F. Lewis School of Nursing at Georgia State University. To fulfill my dissertation requirement for my PhD degree, I will be conducting a qualitative research study on understanding the meaning of risk for African American individuals with a family history of kidney disease.

The research procedure would involve me recording interviews with study participants as they share their lived experience with having a family member on dialysis. I would like to recruit study participants from the Hopewell family.

I will be seeking approval to conduct this study from the Georgia State University Institutional Review Board. Please let me know the research review board process for seeking approval to conduct participant recruitment through Hopewell Missionary Baptist Church. Also, to help me with my planning, if this study is something that is feasible to conduct at Hopewell, please provide a letter of support for my research study.

Very Respectfully,

LJBrown  
Loretta Jackson Brown  
lorettajbrown@bellsouth.net
Appendix B
Additional Study Participant Recruitment Letter of Support

November 4, 2013

RE: Letter of Support for Loretta Brown

We the Hopewell Baptist Family are happy to support Ms. Loretta Brown as she conducts her research. If you have any further questions, please give us a call, 770-448-5475.

Sincerely,

Pastor Arnold Davis
Church Administrator
Has Anyone in Your Family Ever Been on Dialysis?

If you are at least 18 years old, you are invited to take part in a research study to help better understand what kidney disease means to African Americans who have or have had a loved one on dialysis.

What will I have to do?
In a private setting, you will have 2 occasions to talk about your experience of having a family member on hemodialysis. It may take 30-90 minutes.

Learn more about the study
Contact: Loretta Jackson Brown
Georgia State University School of Nursing
Email: lorettajbrown@bellsouth.net
Phone: 770-337-9233
Appendix D
Enrollment Criteria Form

Number___________
Date Enrolled_________
Reason for non-enrollment_____________________________________________

Inclusion Criteria

- 18 years of age or older
- Biological □ parent, □ sibling □ offspring (cause of kidney disease_______) who is or has been on maintenance hemodialysis.
- AA or Black non-Hispanic racial/ethnic group
- Lives within a 50 mile radius of Atlanta ____________ city
- Speaks and understands English clearly
- Able to articulate their stories in full detail so that their meaning can be interpreted
- Clearly speaks and understands English to consents to participate in the study

Exclusion Criteria

- Personal diagnosis of chronic kidney disease by health care provider
- Receiving treatment for end stage kidney disease (hemodialysis, peritoneal dialysis or has a transplanted kidney)
- Awaiting kidney transplant
- Mental disability
- Severely impaired hearing
Appendix E
Informed Consent Form

Georgia State University
Byrdine F. Lewis School of Nursing and Health Professions

Title: Ascribing Meaning to Kidney Disease: A Qualitative Study of African Americans with a First Degree Relative on Hemodialysis

Faculty Investigator: Margaret Moloney, PhD, RN

Student Investigator: Loretta J. Brown

I. Purpose:
You are invited to take part in a research study. The purpose of the study is to learn more about the experiences of African American adults with a family history of kidney disease. You are invited to take part because you are an African American adult, who is at least 18 years of age and your parent, sibling or child has received or is receiving hemodialysis. About 12 adults will be invited to take part in this study. The study requires about 30-90 minutes of your time on one day. If you agree, we may ask to take part again. This would require about 30-60 minutes of your time on another day.

II. Procedures:
If you decide to take part, you will be interviewed by the student PI, Ms. Brown at a safe place that you and Ms. Brown agreed to. The talks will be audio taped in order to get your exact words. Ms. Brown may take notes. We may ask to talk with you a second time. For each talk you will receive a $10 food store gift card for taking part in this study.

III. Risks:
There is the chance that taking part in this study may cause you to have difficult feelings about your family member’s health. If you have difficult feelings, we will ask you if you want to continue the study and will end the study if you no longer want to continue. If your feelings are difficult and you would like to talk to someone, we might help you to find a counselor, through a free service offered by the National Kidney Foundation or pastoral counseling offered by a church.

IV. Benefits:
Taking part in this study may not benefit you personally. Our hope is to learn more about
the experiences of African American adults with a family history of kidney disease. This information might help other African Americans know more about kidney disease.

V. **Voluntary Participation and Withdrawal:**

Taking part in this study is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions during the talk or stop taking part at any time. Whatever you decide, you will not lose any benefits to which you are otherwise entitled.

VI. **Confidentiality:**

We will keep your records private to the extent allowed by law. Only Ms. Brown and Dr. Margaret Moloney will know your identity. Information may also be shared with those who make sure the study is done right (Georgia State University Institutional Review Board, the Office for Human Research Protection). We will use a number rather than your name on study forms. Names and related numbers will be kept in separate locked cabinet. Your recorded talk will not be transcribed by a person who would be able to identify you. Transcripts will be saved in a password secure computer. All study data will be destroyed five years after the interview. Your name and other facts that might point to you will not appear when we present this study or publish its results.

VII. **Contact Persons:**

If you have questions, concerns, or complaints about this study, contact Dr. Margaret Moloney in the Georgia State University School of Nursing and Health Professions at 404-413-1170 or mmoloneyv@gsu.edu. You can also call if you think you have been harmed by the study. Call Susan Vogtner in the Georgia State University Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu if you want to talk to someone who is not part of the study team. You can talk about questions, concerns, offer input, obtain information, or suggestions about the study. You can also call Susan Vogtner if you have questions or concerns about your rights in this study.

VIII. **Copy of Consent Form to Subject:**

We will give you a copy of this consent form to keep.

If you are willing to volunteer for this research and be audio recorded, please sign below.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Date</th>
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<tr>
<th>Researcher Obtaining Consent</th>
<th>Date</th>
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**Appendix F**

Demographic Questionnaire

No.__________

Researcher will ask the questions of the participant.

Please answer the following questions:

1. Your Sex: □ Male  □ Female

2. How old are you? ___________ years old

3. What is your current marital status (choose one)?
   □ Single, never married  □ Married  □ Living with a Partner  □ Separated  □ Divorced
   □ Widowed  □ Other: _______________________

4. How much schooling have you had (choose one)?
   □ 8th grade or less  □ Some high school  □ High school graduate or GED
   □ Some college or technical school  □ College graduate (bachelor’s degree)
   □ Graduate degree (master’s or doctorate)

5. Which of the following best describes your current employment status (choose one)?
   □ Working full time  □ Working part time  □ Unemployed
   □ Homemaker  □ In School  □ Retired  □ Disabled, not able to work

6. Occupation________________________________________________________

7. Total number of family members who are or have been on hemodialysis__________

<table>
<thead>
<tr>
<th>Family member</th>
<th>Year started</th>
<th>Number of years</th>
<th>Living (L)</th>
<th>Deceased (D)</th>
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<tbody>
<tr>
<td>parent (P), sibling (S), child (C)</td>
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Appendix G
Interview Schedule

Ascribing Meaning to Kidney Disease: A Qualitative Study of African Americans with a First Degree Relative on Hemodialysis

**Initial Question:** “Tell me about when your [particular family member] first started dialysis.”

Probing/Clarifying Questions:

- “What was it like for you to have [particular family member] on dialysis?”
- “Why do you think [particular family member] needed dialysis?”
- “Has having a family member on dialysis changed the way you take care of yourself?” “Tell me more about that.”
- “Tell me about things a person can do to avoid dialysis [kidney disease].”
- “You have had loved ones on dialysis. Do you think about other family members needing dialysis?” “Tell me more about that.”
- For you is kidney disease a serious concern?” “Tell me more about that”
- “How likely do you think you are to get kidney disease?” Tell me more about that.”
- “What things do you want your family members to know about dialysis [kidney disease]?”
- “What do you want to know about kidney disease?”
- “How have you learned about kidney disease information?”