Renal Disease Risk and Risk Perceptions Among African-American Women with Type 2 Diabetes

by

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Dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Nursing in the Graduate School of Duke University

2015
ABSTRACT

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Abstract

Problem: African Americans face a disparate risk for renal disease development secondary to type 2 diabetes (T2D), and African-American women have shown to be at the highest risk. Despite this, there is minimal research on African American’s awareness of renal disease and existing renal disease risk perceptions, and none focused specifically on African-American women with T2D. Although the literature has shown that a portion of this disparate risk is due to modifiable social and cultural factors, there is still a significant amount of unexplained risk. Since past research has shown that risk perceptions can influence preventative behaviors, it is important to gain an in-depth understanding of renal disease beliefs and existing risk perceptions among high-risk African-American women with T2D. Once risk perceptions are better understood in this population, interventions can be developed to correct inaccurate beliefs and risk perceptions and aim to decrease renal disease risk.

Methods: Three different methods of analyses were employed in this dissertation, including: 1) a systematic review of the literature, 2) an exploratory, descriptive, qualitative study, and 3) a quantitative secondary analysis, including descriptive statistics, a cluster analysis and mixed modeling. The Common Sense Model guided all three studies and these three methods of evaluation helped us to gain a more complete understanding of renal disease risk perceptions in African Americans, particularly African-American women with T2D, and provided guidance for future intervention research in this population.

Conclusions: The findings of this dissertation illustrated there is a significant gap in the literature on African American’s renal disease awareness and risk perceptions, yet the available research was used to guide the in-depth interviews with African-American women with T2D. Overall, African Americans underestimate their renal disease risk and
lack an understanding of the disease, even in the presence of risk factors. African-American women, in particular, related renal disease directly to the end-stages of the disease, perceived a greater risk for other complications of diabetes, and exhibited significant fear related to their perceived consequences of the disease. This fear frequently initiated maladaptive coping mechanisms, which influenced risk perceptions negatively and hindered preventative behaviors. This study also found that health care providers rarely discussed the disease and often exhibited provider control. Therefore, these findings suggest an urgent need for clinical practice suggestions and intervention research aimed at correcting inaccurate risk perceptions. The secondary analysis findings showed that a culturally relevant intervention with coping skills training resulted in significant improvements in renal disease risk factors among high-risk African-American women with T2D; however, we cannot be sure which facets of the intervention or control care for equal attention may have influenced these outcomes, and renal disease beliefs and risk perceptions were not assessed in the parent study. Therefore, the knowledge gained from this dissertation can be used to guide intervention research that evaluates change over time in renal disease risk representations, risk perceptions, coping procedures and outcomes among participants at high-risk for renal disease.
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1. Renal Disease Risk and Risk Perceptions Among African-American Women with Type 2 Diabetes

1.1 Introduction

The Centers for Disease Control and Prevention (CDC) reported that the number of cases of diabetes in the United States in 2012 reached 29.1 million, or 9.3% of the general population (Centers for Disease Control and Prevention, 2014). This complex chronic disease affects minority populations at a disproportionate rate, and African Americans are twice as likely to develop diabetes as Whites (E. A. Walker, Stevens, & Persaud, 2010). The age-adjusted rate of diagnosed diabetes for African Americans was 13.2%, compared to 9.0% for Asians, and 7.6% for whites in 2012 (Centers for Disease Control and Prevention, 2014). The incidence of diabetes has reached near epidemic proportions among African Americans, and as a result, diabetes ranks fifth in cause of death for African Americans compared to sixth for the overall United States population (E. A. Walker et al., 2010).

Type 2 diabetes (T2D) accounts for 90-95% of diabetes cases (E. A. Walker et al., 2010), and the most common complications of T2D include cardiovascular disease, stroke, neuropathy, retinopathy, and nephropathy. One of these complications, diabetic nephropathy, occurs when hyperglycemia damages the filtering properties of the glomerulus, resulting in damage to the renal system. After many years, this damage results in protein loss in the urine, known as microalbuminuria, which develops in nearly 40% of patients with diabetes and is the earliest indicator of diabetic nephropathy (Packham et al., 2012). Less than a year after the diagnosis of T2D, 20-25% of African Americans exhibit microalbuminuria, and early renal function decline is 3 times more likely in to develop in African Americans than whites (Calvin et al., 2011; Goldschmid, Domin, Ziemer, Gallina, & Phillips, 1995; Krop et al., 1999; Thaler et al., 1998). Notably,
82% of the excess risk of early renal decline among African Americans was attributed to education, household income, health insurance, fasting glucose level, systolic blood pressure, smoking history, and physical activity level in one study (Krop et al., 1999). In summary, African Americans have a disproportionately high risk of exhibiting microalbuminuria, the earliest indicator of diabetic nephropathy, early in the course of T2D, and this excess risk has been attributed to socioeconomic status and many modifiable clinical and behavioral risk factors.

Diabetic nephropathy is the most common cause of end-stage renal disease (ESRD) in the United States (McDonough et al., 2011). African Americans with T2D are four times more likely to develop ESRD when compared to white Americans with T2D (Calvin et al., 2011). African Americans represent 32% of the population with ESRD in the United States, but only 12% of the general population (Crews, Sozio, Liu, Coresh, & Powe, 2011). Once diagnosed with ESRD, the only viable treatment options are hemodialysis, peritoneal dialysis or renal transplantation, and one’s prognosis at this stage has been comparable to those with metastatic cancer (Eknoyan et al., 2004). These limited treatment options are very expensive and burdensome. In 2012, the estimated cost of ESRD treatments was $28.6 billion, an increase of 3.5% from 2011 and 5.6% of Medicare’s total spending (USRDS, 2014). Besides the expense, these treatment options carry life-long burdens of care, and research shows that African Americans experience more burdens related to ESRD than other races. Gadegbeku, Freeman, & Agodoa (2002) reported that compared to white patients, non-white patients had significantly higher serum creatinine values, lower hematocrit concentrations, and were referred to a nephrologist in later stages of renal failure. This late referral results in late initiation of treatment in ethnic minorities, which often results in sub-optimal vascular access placement and a less than desired prescribed dialysis dose, both of which can increase
the risk of mortality (Gadegbeku, Freeman, & Agodoa, 2002). Thus, ESRD is more prevalent, burdensome and costly in the African-American population, which increases the risk of mortality.

African-American women, in particular, represent one of the highest risk groups in terms of diabetes prevalence and complications, often attributed to poor glycemic control (Samuel-Hodge et al., 2000). A recent study with close to 1,500 patients with diabetes found that at 10 years, women had a 33% greater risk for incident chronic kidney disease (CKD) than men, after taking into account demographics, and traditional and behavioral risk factors (Yu & Young, 2013). In another study, diabetes accounted for 50.5% of ESRD cases among African-American women, compared to 17.6% of cases among African-American men; African-American men were more likely to develop ESRD as a result of hypertension (Crook et al., 2001). In the literature, these renal disease disparities have often been attributed to poor glycemic control (hemoglobin A1C levels > 8%) among African-American women. For example, two studies found that compared to 36.5%-41% of African-American men, 36.2%-38% of white men, and 29%-35.5% of white women, 47%-50% of African-American women demonstrated poor glucose control (Harris, Eastman, Cowie, Flegal, & Eberhardt, 1999; Weatherspoon, Kumanyika, Ludlow, & Schatz, 1994).

Despite these statistics, there is minimal research on renal disease awareness and existing risk perceptions in the African-American community, even less research on this topic among African Americans with T2D, and none focused solely on African-American women with T2D, one of the highest risk groups for disease development. This literature gap is significant because studies have established a significant correlation between risk perceptions and preventative behavior (Brewer et al., 2007; Katapodi, Lee, Facione, & Dodd, 2004; van der Pligt, 1998). Therefore, it is imperative to
gain an in-depth understanding of renal disease risk perceptions in this population, which could account for poor preventative behaviors impacting this disparate risk. Once we better understand risk perceptions within this high-risk group, interventions can be aimed at modifying risk perceptions with an ultimate goal of decreasing ESRD risk.

1.2 Theoretical Framework

1.2.1 The Common-Sense Model of Self-regulation of Health and Illness

The theoretical framework selected for this dissertation was the Common-Sense Model (CSM) of illness representations, developed by Howard Leventhal et al. (1998). The theoretical concept ‘illness representation’ was introduced in this model, and is touted as the focus of the model (Leventhal et al., 1998). The CSM is proposed as a parallel-processing model, suggesting that individuals make simultaneous cognitive and emotional representations of an illness, and together they form an individual’s representation of a specified illness (Diefenbach & Leventhal, 1996; Hagger, 2003). To further extend this parallel-processing explanation, the model conceptualizes people as problem solvers who develop personal definitions of an illness, comprised of both their perceived reality of the health threat and the emotional reactions to this health threat (Diefenbach & Leventhal, 1996).

According to the model, the following five domains underlie cognitive illness representations: identity, cause, timeline, consequences, and controllability (Leventhal, Brissette, & Leventhal, 2003). These five domains can be assessed to describe an individual’s cognitive renal disease representation. These domains are defined in Table 1, along with the other model concepts adapted to study risk perceptions. Regarding renal disease cognitive representations, the domains are defined as follows: identity refers to an individuals’ beliefs about the label of renal disease and knowledge about its
symptoms; cause refers to an individuals’ beliefs about the factors responsible for causing renal disease; timeline refers to an individuals’ beliefs about the course of renal disease, including the perceived timeline of when it strikes, and the speed and nature of the development and progression of renal disease; consequences refer to an individuals’ beliefs about the impact of renal disease on quality of life and how it may affect functionality; and controllability refers to an individuals’ beliefs about whether renal disease can be cured or controlled through self-initiated behavior, medication, surgery, or other treatments (Cameron, 2003; Hagger, 2003; Leventhal et al., 2003; Leventhal et al., 1998). Therefore, the CSM proposes that individuals form a common-sense definition, or understanding, of renal disease by incorporating these five domains of renal disease into their cognition.
Table 1: CSM concept definitions adapted to study risk perceptions in this dissertation

<table>
<thead>
<tr>
<th>CONCEPT</th>
<th>DEFINITION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness Stimuli</td>
<td>Basic sources of information that shape and influence cognitive and emotional illness representations, categorized in 3 categories:</td>
</tr>
<tr>
<td>Lay information</td>
<td>General, or ‘lay’ information that an individual has already assimilated from cultural knowledge, practices, and previous communication, and includes media sources</td>
</tr>
<tr>
<td>External sources</td>
<td>Information gained from interaction with sources in the external social environment, including significant others, family, friends, and health care providers</td>
</tr>
<tr>
<td>Current experience with the illness</td>
<td>An individual’s current experience with the illness, which includes bodily symptoms and sensations, memories of past symptoms, and illness experiences</td>
</tr>
<tr>
<td>Cognitive Illness Representation</td>
<td>An individual’s cognitive, common-sense definition of a health threat, stored and represented within 5 content domains:</td>
</tr>
<tr>
<td>Identity</td>
<td>Beliefs about the label of the illness and knowledge about its symptoms</td>
</tr>
<tr>
<td>Cause</td>
<td>Beliefs about the factors responsible for causing the illness</td>
</tr>
<tr>
<td>Timeline</td>
<td>Beliefs about the course of the illness, including perceived timeline of when illness strikes, and the speed and nature of the development and progression of the illness</td>
</tr>
<tr>
<td>Consequences</td>
<td>Beliefs about the impact of the illness on quality of life and how it may affect functionality</td>
</tr>
<tr>
<td>Controllability</td>
<td>Beliefs about whether the illness can be cured or controlled through self-initiated behavior, medication, surgery, or other sorts of treatments</td>
</tr>
<tr>
<td>Emotional Illness Representation</td>
<td>The regulation of emotional responses to a health threat, which can be shaped by and also influence the cognitive illness representation, and influence responses to risk perception</td>
</tr>
<tr>
<td>Coping Procedures</td>
<td>Cognitive or behavioral actions taken (or not taken) to improve health and to prevent, treat or recuperate from an illness</td>
</tr>
<tr>
<td>Risk Perception</td>
<td>An individual’s awareness of personal susceptibility to an illness, interpreted in the light of experience</td>
</tr>
<tr>
<td>Health Outcomes</td>
<td>Psychological and physical adjustment to an illness influenced by coping procedures</td>
</tr>
</tbody>
</table>
Initially, research conducted with the CSM focused on individuals already diagnosed with the target illness, and these five domains were studied as predictors of behavior (Cameron, 2003). However, Cameron (2003) more recently suggested that the CSM includes important aspects of risk perceptions and has key features that may be relevant to advance the conceptualization and assessment of risk perceptions. She noted that the same five domains could form the critical basis of illness risk representations (Cameron, 2003). Therefore, her suggestions have been incorporated into an adapted CSM to study renal disease risk perceptions in this dissertation (Figure 1). Since then, the CSM has been used in research to explore and describe risk perceptions in participants with BRCA1/2 mutations (Kelly et al., 2005), in participants at risk for venous thrombosis (Kaptein et al., 2007), and most relevant to this study, in African American participants with diabetes at risk for diabetic complications, including ESRD (Calvin et al., 2011). In fact, Kelly et al. (2005) noted that the CSM is a good model to use to examine risk perceptions because information in these five domains may influence peoples’ perceptions of risk, shape how they express perceptions of risk, and affect the relationship of perceived risk to behavior.
Cognitive illness representations are a significant component of an individual's illness representation; however, the emotional component is also important when exploring illness representations. Emotional illness representations have been defined as the regulation of emotional reactions to a specified health threat, and can be shaped by and influence the cognitive illness representation, and also influence risk perceptions (Cameron, 2003; Hagger, 2003; Leventhal et al., 2003; Leventhal et al., 1998). According to the CSM, emotional representations are part of the overall illness representation and can provide valuable insight to understanding risk perceptions of renal disease in this population. As Cameron (2003) noted, research in general has identified a number of
established influences of anxiety on responses to health risks. Therefore, it is important to measure emotional responses to renal disease in addition to the five domains of cognitive renal disease representations in order to gather an overall disease representation.

Illness representations have been broadly defined as the way people understand and make sense of diseases (Pagels, Soderquist, & Heiwe, 2012), and very often “disease” is used interchangeably with “illness” when this model is discussed. A meta-analysis of the CSM by Hagger (2003) specifically noted that the CSM involves processing of information by an individual regarding a disease or illness, implying that this model can be used for any altered state of health, whether an individual defines it as a disease or an illness. An individual’s renal disease representation can be described as their personal definition, or understanding, of renal disease, incorporating both their cognitive and emotional representations of the disease, whether the individual defines it as an illness or disease.

To date, representations of renal disease have only been studied in patients already diagnosed with renal disease. The literature includes studies exploring the association of renal disease representations with the following: survival among patients with ESRD, depressive symptoms in hemodialysis patients, fluid non-adherence in hemodialysis patients, self-care behaviors in ESRD patients, and quality of life in ESRD patients (Chilcot, Wellsted, Davenport, & Farrington, 2011; Chilcot, Wellsted, & Farrington, 2010; Covic, Seica, Gusbeth-Tatomir, Gavrilojici, & Goldsmith, 2004; Fowler & Baas, 2006; Griva, Jayasena, Davenport, Harrison, & Newman, 2009; O’Connor, Jardine, & Millar, 2008; Parfeni, Nistor, & Covic, 2013; van Dijk et al., 2009). However, the literature lacks studies that measure renal disease representations in patients at risk for the disease, which would be beneficial in determining how renal disease
representations are related to risk perceptions, especially in a high-risk group such as African-American women with T2D.

Assessment of illness representations was initially conducted through open-ended interviews, which were designed to encourage patients to elaborate on their common sense ideas about a specified disease; however, the Illness Perception Questionnaire (IPQ) and then the Revised Illness Perception Questionnaire (IPQ-R) were eventually developed, and various versions exist to measure illness representations in a variety of illnesses (R. Moss-Morris et al., 2002). This measure assesses perceptions of each of the five domains by asking patients for their own beliefs about their conditions, and scores these domains, but there is no version for renal disease (R. Moss-Morris et al., 2002). However, researchers in Sweden recently conducted a study to assess the usability and psychometric properties of the generic IPQ-R on adults with stages 2-5 CKD (Pagels et al., 2012). They found that using the IPQ-R in patients with CKD lacked construct validity support on the domains of controllability and timeline, and they suggested cautious use of this measure in CKD patients, most notably those in the earlier stages when fewer symptoms are present (Pagels et al., 2012). Therefore, open-ended questions that incorporated the five domains of the CSM were used in this dissertation to elicit participants’ cognitive and emotional renal disease representations.

A qualitative assessment of participants’ renal disease representations is imperative for the following reasons: renal disease representations have not been studied to date in patients at risk, and therefore qualitative exploration would be an important first step; the generic IPQ-R lacked validity when tested on patients with few symptoms of renal disease, and women in this sample exhibited few, if any, symptoms of renal disease; and finally, we can gather more in-depth information from open-ended questions on both the five domains and emotional responses to the disease.
The CSM hypothesizes that individuals create mental illness representations based on information available to them from the following three sources: previous social communication and cultural knowledge (i.e., ‘lay’ information), the external social environment from perceived significant others or authoritative sources such as doctors, and their current experience with the illness (Hagger, 2003), or a summation of their previous experiences. Therefore, social and cultural factors are depicted as shaping individuals’ illness representations, which in turn shape risk perceptions (Leventhal et al., 2003). The illness representation is very personal, and may differ, depending on experience and culture, which leads to different responses to the same health threat (Rees, Fry, & Cull, 2001). Therefore, it is important to explore sociocultural factors that influence representations.

Both cognitive and emotional representations activate behaviors adopted in response to the illness, and these are termed ‘coping procedures’ according to the CSM (Hagger, 2003; Leventhal, Meyer, & Nerenz, 1980). Coping procedures are cognitive or behavioral actions taken (or not taken) to improve health and to prevent, treat or recuperate from a specified illness (Leventhal et al., 1998). A meta-analysis of research conducted with the CSM found that the following coping procedures were exhibited most often: avoidance/denial, cognitive reappraisal, expressing emotion, problem-focused coping, and seeking social support (Hagger, 2003). The CSM purports that individuals choose coping procedures in response to their perceived representation of an illness and the relationship is causal, or the effect on coping procedures is in proportion to the perceived severity of the illness (Hagger, 2003; Reynolds & Alonzo, 2000).

Coping procedures influence health outcomes, which are defined as psychological and physical adjustments to health threats, and include objective
measures of illness status, such as hemoglobin A1C (Hagger, 2003; Leventhal et al., 1980). Therefore, the CSM purports that renal disease risk perceptions are influenced by cognitive renal disease representations, which impact and are impacted by emotional renal disease representations, and these risk perceptions in turn influence the development of coping procedures (which can also be impacted directly by emotions) which ultimately impact renal disease risk outcomes. These interrelationships among the components of the model illustrate the importance of exploring and describing renal disease risk perceptions in an in-depth manner to determine the most appropriate interventions to improve health outcomes.

As previously mentioned, the CSM has proven to be an effective theoretical model to guide assessment of risk perceptions, a primary purpose of this dissertation. According to the model, cognitive illness representations directly impact risk perceptions, and there is limited research on renal disease risk perceptions. For this dissertation, risk perception was defined as the following: awareness of personal susceptibility of disease (in this case, renal disease), interpreted in the light of experience. Therefore, this dissertation used the CSM to explore individuals’ representations of renal disease and determine how these representations influenced risk perceptions.

In summary, using the CSM to explore renal disease representations and risk perceptions in this population will fill a gap in the nursing literature. As previously mentioned, illness representations of renal disease have been explored in patients already in active renal failure but never in patients at risk for renal disease. The literature shows that illness representations are significantly associated with various outcomes in patients with chronic kidney disease; however, the literature lacks studies that determined if and how illness representations relate to renal disease risk.
perceptions. Also, the CSM has only recently been used to study illness representations in patients at risk for a specified illness; therefore, using the CSM to study renal disease representations and their association with risk perceptions will add to the evidence that this model can effectively be used to study risk perceptions. Finally, from a nursing practice perspective, once we understand this high-risk groups’ renal disease representations and how they relate to risk perceptions, and how those representations developed, we can move forward with interventions aimed at correcting inaccurate representations which, according the CSM, should in turn influence coping procedures and health outcomes.

1.3 Dissertation Purpose Statement

The purpose of this dissertation was to gain an understanding of the current state of the science in African American’s renal disease awareness and risk perceptions; explore and describe renal disease risk perceptions and representations among African-American women with T2D; and explore and describe the presence of risk factors and the effects of tailored interventions on African-American women with T2D. In order to address this purpose, three different methods of analyses were employed in this dissertation, including the following: a systematic review of the literature; an exploratory, descriptive, qualitative study; and a quantitative secondary analysis, including descriptive statistics, a cluster analysis and mixed modeling. These three methods of evaluation helped to gain a more complete understanding of renal disease risk perceptions in African Americans, particularly African-American women with T2D, and provided guidance for future intervention research in this population.

1.3.1 Specific Aims

The specific aims of this dissertation follow:
Aim 1) Review and synthesize the literature on African Americans’ awareness of renal disease and existing risk perceptions, capturing sociocultural factors in the African American community that could influence the development of those risk perceptions.

Aim 2) Explore and describe renal disease representations, perceptions of individual renal disease risk, and factors influencing renal disease risk perceptions among African-American women with T2D.

Aim 3) Explore and describe the prevalence of renal disease risk factors and the categorization of renal disease risk groups among African-American women with T2D who participated in a diabetes self-management and coping skills training intervention; and also explore and describe the change in renal disease risk factors within and between risk groups, determining if participation in a culturally relevant intervention decreased renal disease risk.

1.3.2 Research Questions by Dissertation Chapter

1.3.2.1 Chapter 2: Perceptions of Renal Disease Risk Among African Americans: A Review of the Literature

Chapter 2 addressed specific aim 1 and was guided by the following research question: What is the state of the science in African American’s awareness of renal disease and existing risk perceptions and sociocultural factors in the African American community that have influenced knowledge, awareness and/or risk perceptions of chronic diseases related to or comorbid with diabetes and ESRD? To answer this research question, the literature review:

(a) Systematically explored peer-reviewed research that described African Americans’ awareness of renal disease and existing risk perceptions.

(b) Systematically explored peer-reviewed research that described the influence of sociocultural factors on chronic disease risk perceptions among African Americans.

(b) Included a matrix with the articles included for analysis and the themes
present in each article.

(c) Used the CSM components to categorize findings and established subthemes within the CSM components by synthesizing the most common elements.

The sociocultural search was expanded to include chronic diseases related to or comorbid with ESRD due to the lack of renal disease literature. The literature review incorporated the CSM as a guiding framework by exploring the literature for existing risk perceptions, components of cognitive and emotional renal disease representations that impacted risk perceptions and illness stimuli that influenced representations, with a primary focus on sociocultural influences (Figure 1). Numerous subthemes emerged in the literature under the primary CSM components. This understanding helped to guide the in-depth qualitative interviews in chapter 3. This literature review was submitted to the Journal of Health Disparities Research and Practice, and has been peer-reviewed and resubmitted with suggested edits. It is currently awaiting publication.

1.3.2.2 Chapter 3: Renal Disease Risk Perceptions Among African-American Women with Type 2 Diabetes

Chapter 3 addressed specific aim 2 and explored and described renal disease representations, perceptions of individual renal disease risk, and factors influencing renal disease risk perceptions among African-American women with T2D. The following research questions guided this study:

1) How do African-American women with T2D perceive their individual risk for renal disease?

2) How do African-American women with T2D perceive their risk for renal disease relative to other complications of diabetes (i.e. heart disease, stroke, retinopathy, and neuropathy)?
3) How do African-American women with T2D describe their cognitive renal disease representations through the five domains of illness representations: identity (symptoms), cause, timeline, consequences, and controllability?

4) What has influenced the development of these representations?

5) What emotional representations of renal disease do African-American women with T2D portray?

A qualitative descriptive design was used in this study and the CSM was the guiding theoretical framework (Figure 1). The research questions are transposed onto the adapted CSM in Figure 2 below. The CSM categories were used as an a priori coding guide, however, numerous subthemes arose from the data. The findings of this study allowed us to gain an in-depth understanding of renal disease risk perceptions in high-risk African-American women with T2D and will help guide future interventions to increase awareness, correct inaccurate risk perceptions, and ultimately aim to prevent disease development. This study was approved by the Duke University Health System IRB (Pro00042330) and was funded by a grant from the American Nephrology Nurses’ Association (ANNA).
Chapter 4: Trajectories of Renal Disease Risk Factors Among Risk Groups Comprised of African-American Women with Type 2 Diabetes Who Participated in a Self-Management and Coping Skills Training Intervention: A Secondary Analysis

Chapter 4 addressed specific aim 3 and explored and described the prevalence of and change in renal disease risk factors among African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention. The women were categorized into renal disease risk groups in order to explore changes in renal disease risk factors within and between risk groups over time. Although the women’s risk perceptions and representations were not explored in the
parent study, access to this dataset allowed us to incorporate three components of the CSM (Figure 1), and explore whether a culturally relevant intervention that included coping-skills training decreased renal disease risk, hence improved health outcomes, among a subset of African-American women with T2D. This was conducted via a secondary analysis using data generated in a longitudinal, randomized controlled intervention study (R01NR05341-01A1; PI: Melkus). Common renal disease risk factors from the literature were explored in this subset of African-American women to determine their prevalence and to categorize women into risk groups using cluster analysis. Cluster analysis is commonly used in biomedical research to group together units, and changes in cluster characteristics over time points can be measured in a longitudinal study (Schneiderman, Willis, & Kowalski, 1993). This secondary analysis provided an understanding of risk factors present in a sample of African-American women with T2D, described how women clustered together into risk groups, and also determined if health outcomes within and between risk groups changed over time. The following research questions guided this chapter:

1. What are the most prevalent renal disease risk factors in a sample of African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention?

2. How are renal disease risk groups categorized within this sample of African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention?

3. How do renal disease risk factors change over time within risk groups comprised of African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention?
4. Was the culturally relevant self-management and coping skills training intervention more effective in reducing risk for a certain risk group than another over time?

1.3.2.4 Chapter 5

The final chapter is a conclusion chapter that summarizes all of the findings from the previous chapters and identifies future research goals. Now that renal disease risk factors, awareness, representations, and risk perceptions were explored and described in this population burdened by disparities in rates of T2D and ESRD, and the effectiveness of a coping-skills training intervention on renal disease risk outcomes was explored, appropriate interventions can be developed in an attempt to curtail the progression to ESRD and avoid associated costly treatments, morbidity and mortality.

1.4 Summary

An alarming health disparity exists in the African-American community in regard to renal disease. Diabetic nephropathy in African Americans has been the number one cause of ESRD in this population since 1997 (Crook & Patel, 2004), and African Americans with T2D are four times more likely to develop ESRD than white Americans with T2D (Calvin et al., 2011). However, there is a lack of research on African American’s awareness of renal disease and existing risk perceptions. Therefore, it was first important to review the existing literature on African Americans’ awareness of renal disease and their risk perceptions of this burdensome disease. According to the CSM, illness perceptions are influenced by outside sources, including cultural factors; therefore, it was also important to explore the literature on sociocultural factors that may be influential to African Americans’ renal disease awareness and risk perceptions. Once renal disease awareness and risk perceptions were better understood in the broader
African-American community, we could focus on high-risk African-American women with T2D.

African-American women, in particular, have been found to experience the highest rates of diabetes complications, including diabetic nephropathy, a precursor to ESRD (Crook & Patel, 2004; Crook, Wofford, & Oliver, 2003; Samuel-Hodge et al., 2000). Therefore, it was important to explore and describe these women’s renal disease representations, risk perceptions and influencing factors. The literature review helped guide this study, alerting us to general risk perceptions and influencing sociocultural factors evident in the African American community regarding renal disease. This exploration was accomplished through an in-depth qualitative descriptive study due to the lack of literature on this topic. The CSM guided this study as well, and it has shown to be an effective model in other literature exploring risk perceptions through the domains of illness representations. This allowed us to gain a better understanding of renal disease representations among high-risk African-American women and determine how they relate to risk perceptions and initiate coping procedures.

Recognizing the impact of illness representations and risk perceptions on coping procedures, a secondary analysis of a coping-skills training intervention study sample was conducted. Although risk perceptions were not explored, data from this randomized controlled intervention trial was used to determine if coping-skills training effectively improved health outcomes, and if so, which risk group was impacted the most. This provided us with an understanding of the appropriate group of women to focus future intervention research on and also determine if a culturally relevant coping-skills training intervention may be effective in reducing renal disease risk, acknowledging that future interventions should also explore risk perceptions.
2. Perceptions of Renal Disease Risk Among African Americans: A Review of the Literature

2.1 Introduction

African Americans with type 2 diabetes (T2D) have a disproportionately high risk of developing diabetic nephropathy, which is the most common cause of end-stage renal disease (ESRD) in the United States (McDonough et al., 2011). Compared to white Americans with T2D, African Americans with T2D are four times more likely to develop ESRD (Calvin et al., 2011). Once diagnosed with ESRD, dialysis therapy or renal transplantation are the only viable treatment options, both of which are costly healthcare treatments. In 2006, the estimated cost for ESRD treatment in the United States was $23 billion, and this cost continues to rise (Hung et al., 2012). African Americans make up 12.5% of the US population; however, they represent 38.2% of the hemodialysis population (Calvin et al., 2011), demonstrating the burden of ESRD in the African American community.

Current research suggests that various sociocultural factors in the African-American community may influence the existing renal disease disparity. For example, Bruce et al. (2009) outlined multiple pathways through which economic and social environmental stressors and also psychological factors can impact renal disease and its progression among African Americans. They reported that economic and social disparities faced by African Americans, including poor residential conditions, economic deprivation at the household level, and social stressors such as racism and discrimination, can influence renal disease development, progression and complications or lead to harmful psychological conditions, including depression, anxiety, anger and stress, which can also influence renal disease development and progression (Bruce et al., 2009). In fact, research shows that suboptimal health care, suboptimal environmental
conditions, and unhealthy lifestyles account for 50% of the excess risk for renal disease among African Americans compared to whites (Calvin et al., 2011). However, it is also important to explore African American’s renal disease awareness and risk perceptions and determine if sociocultural factors influence and shape African Americans’ renal disease awareness and risk perceptions. We can use well-validated theoretical frameworks, such as the Common Sense Model of Illness Representation (Leventhal et al., 1998), to explore renal disease risk perceptions among African Americans and the sociocultural factors that may influence these perceptions in order to promote patient activation to improve perceptions and ultimately lower disease risk.

Despite the staggering renal disease disparity, Calvin et al. (2011) are the only authors that have investigated renal disease awareness and risk perceptions in African Americans with T2D. Their study measured perceptions of risk for various diabetes complications, including ESRD, in a sample composed solely of African Americans with T2D. The Common Sense Model of Illness Representation (CSM) developed by Leventhal et al. (1998) was used as the theoretical framework in Calvin et al. (2011)’s study and will guide this literature review as well. The CSM is a dynamic systems model of the processes involved in common-sense management of health threats in everyday life, and suggests that illness representations form individuals’ common-sense definitions of health threats, and these in turn influence behavior (Leventhal, Leventhal, & Breland, 2011; Leventhal et al., 1998).

Since the above study is the sole study found in the literature that focused on renal disease risk perceptions among high-risk African Americans with T2D, we felt it was important to broadly search the literature for renal disease awareness and risk perceptions among all African Americans, and explore sociocultural factors that may be influential to awareness and risk perceptions of chronic diseases related to or comorbid
with diabetes and ESRD in order to better understand this topic. Therefore, the purpose of this literature review was to review and synthesize the literature on African Americans’ awareness of renal disease and existing risk perceptions, capturing sociocultural factors in the African-American community that could influence the development of those risk perceptions. Once we better understand existing risk perceptions among African Americans, sociocultural-based interventions can be developed to increase renal disease awareness and correct any inaccurate risk perceptions in this population, and may be used as a basis for risk reduction interventions.

2.2 Theoretical Framework

Cognitive illness representations are the core of the CSM, and they encompass the following five content domains: cause, identity, timeline, consequences, and controllability (Leventhal et al., 1998). Initially, research guided by the CSM focused on the five domains as predictors of behavior, and was conducted with individuals already diagnosed with the target illness (Cameron, 2003). However, Cameron (2003) suggested that the CSM includes important facets of risk perceptions and has key features that can be relevant to advancing the conceptualization and assessment of risk perceptions and the same five domains should form the critical basis of illness risk representations. Therefore, the CSM has since been adapted to study how illness representations influence risk perceptions and Figure 3 illustrates the components of the model used to guide this review.
Individuals’ beliefs within the five cognitive illness domains may influence their perceptions of risk, shape how they express perceptions of risk, and affect the relationship of perceived risk to behavior (Kelly et al., 2005). Cognitive illness representations are a significant component of the overall illness representation; however, emotional illness representations are also important when describing illness representations in regard to renal disease. The CSM posits that health threats generate not only a cognitive representation of the specified illness, but also elicit emotional states, such as those of fear or distress, described as the emotional illness representation, which can be shaped by and also influence the cognitive illness representation, and influence risk perceptions (Cameron, 2003; Hagger, 2003; Leventhal et al., 2003; Leventhal et al., 1998). These emotional representations are part of the overall illness representation according to the CSM, and could provide valuable insight to understanding risk perceptions of renal disease in this population.
According to the CSM, both cognitive and emotional illness representations are shaped by three basic sources of information, known as illness stimuli (Hagger, 2003). Lay information is the first illness stimuli and includes general, or ‘lay’ information that an individual has already assimilated from cultural knowledge, practices, and previous communication (Hagger, 2003). External sources, or information gained from sources in the external social environment, including significant others, family, friends, and health care providers are the second illness stimuli (Hagger, 2003). The third illness stimuli is current experience, which incorporates an individual’s current experience with the specified illness, including personal experience with the illness itself or risk factors, experience with family members or friends with the illness, or work-related exposure to the illness (Hagger, 2003). Information from all three of these sources contribute to an individual’s illness representation of a specified illness, or making sense of that illness (Hagger, 2003).

Guided by the CSM, this search will incorporate the research on sociocultural influences on chronic disease knowledge and risk perceptions in the African American community within the themes of the illness stimuli component of the CSM; whereas the research found on existing renal disease awareness and knowledge will be incorporated into the cognitive illness representation component, and the literature found on risk perceptions will be incorporated into the risk perception component. The literature will also be explored for any emotional illness representation components. Ultimately, the CSM will help us gain an overall understanding of the development of risk perceptions among high-risk African Americans from the extant literature. In order to address risk perceptions and provide culturally appropriate risk counseling or education to attempt to reduce the disparity in diabetic ESRD among African-Americans with T2D, we first
need to understand risk perceptions in the general African-American community and explore where these perceptions are originating.

**2.3 Search Strategy**

Two systematic searches were conducted using the MEDLINE (PubMed) database. The following combination of MeSH terms was used for the MEDLINE search on the influence of sociocultural factors on chronic disease awareness and risk perceptions among African Americans: (("Chronic Disease" OR "Diabetes" OR "Kidney Diseases" OR "Albuminuria") AND ("Risk") AND ("Comprehension" OR "Awareness OR "Perception" OR "Health Knowledge, Attitudes, Practice" OR "Knowledge") AND ("Culture" OR "Ethnology") AND ("African Americans"). This search was limited to the English language, human participants, and articles published in the last ten years. As summarized in the flow diagram (Figure 4), this initial search yielded 259 articles. The titles and abstracts of all of these articles were reviewed for relevance. The following were the inclusion criteria for this search: 1) studies that included African American participants in the sample population, and 2) studies that measured or described sociocultural factors that may influence awareness and/or risk perceptions of chronic diseases related to or comorbid with diabetes and ESRD, including hypertension, cardiovascular disease and stroke. Exclusion criteria were: 1) studies that focused on participants with diseases not directly related to renal disease such as cancer, HIV, mental health disorders, and arthritis, 2) clinical reviews or guidelines, 3) studies of chronic disease epidemiology, prevalence, incidence, treatment options, treatment outcomes, and treatment adherence, and 4) studies that measured or identified risk factors for chronic diseases.
The following combination of MeSH terms was used for the MEDLINE search on African Americans’ awareness of renal disease and existing risk perceptions: ("Kidney Diseases" OR "Albuminuria") AND ("Risk") AND ("Comprehension" OR "Awareness OR "Perception" OR "Health Knowledge, Attitudes, Practice" OR "Knowledge") AND
("African Americans"). The search was also limited to the English language, human participants, and articles published in the last ten years. As summarized in the flow diagram (Figure 4), this initial search yielded 133 articles. The titles and abstracts of all of these articles were reviewed according to the criteria that follow. Inclusion criteria for this search were: 1) studies that included African American participants in the sample population, 2) studies that measured or described awareness and/or perceptions of personal or group (i.e., ethnic group) risk of renal disease, and 3) studies that included participants who had no known prior diagnosis of renal disease. Exclusion criteria were: 1) studies that explored risk perceptions or awareness of diseases other than renal disease, 2) studies that tested or described treatment options for renal disease or other diseases, 3) epidemiological, prevalence, or incidence studies, 4) studies that explored renal transplant disparities, and 5) studies that measured or identified risk factors for renal disease instead of awareness of renal disease risk and existing risk perceptions.

Applying these criteria in review of the titles and abstracts of all of the initial articles, 57 articles met the inclusion criteria for the first search, and 14 articles met the inclusion criteria for the second search. However, after looking at these articles more closely, 42 articles were removed from the first search and eight articles were removed from the second search. Articles were removed for various reasons according to the inclusion and exclusion criteria, described in the detailed flow diagram in Figure 4. After this review, 14 articles met all criteria for the first search, and six articles met all criteria for the second search, three of which overlapped in the two searches. Therefore, a total of 17 articles were included in the final synthesis. The 17 articles that met all of the criteria were summarized into a matrix (Table 2). This matrix was then used to examine the study characteristics and to identify CSM themes and sub themes across the studies.
<table>
<thead>
<tr>
<th>Year</th>
<th>Author(s)</th>
<th>Sample Size &amp; Demographics</th>
<th>Clinical Characteristics of Sample</th>
<th>Study Purpose</th>
<th>Study Design &amp; Measures</th>
<th>CSM Theme(s)</th>
<th>Sub-theme(s)</th>
</tr>
</thead>
</table>
| 2012 | Giardina, E.V. et al. | 681 (all females), 7.5% AA | Female patients attending outpatient clinic services of Columbia University Medical Center, with the exclusion of women with CVD or at a high-risk for CVD | Assess CVD knowledge among overweight and obese participants who may be uninformed of the CVD risk associated with excess weight | Design: Cross-sectional, exploratory, descriptive secondary analysis of data from the longitudinal Heart Health in Action study  
Measure: A validated, standardized face-to-face questionnaire assessing medical history, socio-demographics, sources of nutrition counseling & diet information & physiologic measures including weight, height, waist circumference and BP | Illness Stimuli  
-Lay information | -Lower education level  
-Weight status and weight optimism |
| 2011 | Alkadry, M.G. et al. | 897, 44.6% AA | Random sample  
To assess disparities in awareness of stroke risks, signs, and treatment | Design: Cross-sectional, exploratory, descriptive  
Measure: A survey, conducted via mail with some participants and via face-to-face with others, due to initial low response rate, assessing stroke risk factor awareness | Illness Stimuli  
-Lay information | -Weight status and weight optimism  
-Smoking status  
-Lack of insurance |
| 2011 | Calvin, D. et al. | 143, 100% AA | Type 2 diabetes for 5 years or less  
To describe the perceived risk for diabetes complications (including ESRD) among African Americans with T2D and to explore interrelationships | Design: Cross-sectional, exploratory, descriptive, correlational  
-CURRENT experience with the illness  
Risk Perceptions | -Evidence of renal disease risk factors  
-Low perceived susceptibility to renal disease |
| 2011 | Green, J.A. et al. | 288, 40% AA | Patients receiving hemodialysis treatment  
To explore the prevalence of health literacy and the associations of health literacy with demographic and clinical characteristics in patients with ESRD | Design: Cross-sectional, exploratory, descriptive analysis of patients already enrolled in a parent RCT  
Measures: Baseline clinical characteristics via chart review, recent lab values from RCT baseline, quality of life via Short Form12, depression via Patient Health Questionnaire 9, symptom burden via Dialysis Symptom Index, and Rapid Estimate of Adult Health Literacy in Medicine (REALM) | Illness Stimuli  
-Lay information | -Limited health literacy |
<table>
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<tr>
<th>Year</th>
<th>Author(s)</th>
<th>Race (AA)</th>
<th>Ethnicity</th>
<th>Sample Size</th>
<th>Sample Characteristics</th>
<th>Design</th>
<th>Illness Stimuli</th>
<th>Relevant Illness Factors</th>
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<tbody>
<tr>
<td>2010</td>
<td>Jennette, C.E. et al.</td>
<td>74% AA</td>
<td>Rural community members</td>
<td>To assess community perceptions of kidney disease, barriers to health care and strategies for raising awareness</td>
<td>Cross-sectional, focus group study based on the grounded theory approach</td>
<td>Pilot-tested scripted discussion guide</td>
<td>-External sources</td>
<td>-Relationship with PCP</td>
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<td>-Current experience with the illness</td>
<td>-Relationship with someone diagnosed with renal disease</td>
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<td></td>
<td>-Cause</td>
<td>-Poor renal disease risk factor knowledge</td>
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<td></td>
<td>-Consequences</td>
<td>-Difficulty of life on dialysis</td>
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<td></td>
<td>McKenaze, C. &amp; Skelly, A.H.</td>
<td>100% AA</td>
<td>Females with self-reported type 2 diabetes ≥ 1 year</td>
<td>To explore AA women with T2DM’s perceptions of heart disease risk</td>
<td>Cross-sectional, qualitative phase of a larger study that first conducted quantitative analysis to stratify the women into groups and then combined quantitative and qualitative data after this qualitative phase</td>
<td>Measure: In-depth, pilot-tested semi-structured interviews in-person with 2 women from each stratification group</td>
<td>Illness Stimuli</td>
<td>-External sources</td>
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<td>-Lower level</td>
<td>-Relationship with WCP</td>
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<td></td>
<td></td>
<td>-Smoking status</td>
<td>-Feath</td>
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<td>2010</td>
<td>Tan, A.U., Hoffman, R. &amp; Ronas, S.E.</td>
<td>AA</td>
<td>Diagnosis of CKD, stage 3 or 4</td>
<td>To assess knowledge re: risk factors that contribute to the progression of CKD and mortality and any racial differences in CKD knowledge among patients with early CKD</td>
<td>Cross-sectional, exploratory, descriptive</td>
<td>A questionnaire based on a literature search of past knowledge assessment studies &amp; self-reported BP, glucose, and creatinine levels</td>
<td>Illness Stimuli</td>
<td>-Lower education level</td>
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<td>-Lay information</td>
<td>-Lower education level</td>
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<tr>
<td>2009</td>
<td>Ayotte, B.J., Trivedi, R., &amp; Bosworth, H.B.</td>
<td>AA</td>
<td>Patients with a diagnosis of HTN who had filled a prescription for HTN medication in the past year</td>
<td>To extend previous research on racial differences in HTN knowledge</td>
<td>Cross-sectional, descriptive, secondary analysis from 2 RCTs that were conducted to improve BP control</td>
<td>Measures: Demographic data from RCTs &amp; a HTN item response questionnaire</td>
<td>Illness Stimuli</td>
<td>-Lay information</td>
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<td>-Lower education level</td>
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<td>2009</td>
<td>Boulware, L.E. et al.</td>
<td>AA</td>
<td>HTN diagnosis</td>
<td>To assess perceived risk and concern regarding CKD progression or development among high-risk patients and identify predictors of perceptions and correlate perceptions to BP management</td>
<td>Cross-sectional, descriptive, secondary analysis of patients enrolled in an RCT (The Patient-Physician Partnership to Improve High BP Adherence)</td>
<td>Measures: Demographic measure, Rapid Estimate of Adult Literacy in Medicine Questionnaire, Compliance to High Blood Pressure Therapy Scale, physiological measures including BP, BMI, serum creatinine, urine microalbumin, in-person or telephone questionnaire to assess perceived CKD and other chronic disease susceptibility &amp; concern.</td>
<td>Illness Stimuli</td>
<td>-Current experience with the illness</td>
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<td>-Emotional Illness Representation</td>
<td>-Limit health literacy</td>
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<td>-Risk Perceptions</td>
<td>-Evidence of renal disease risk factors</td>
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<td></td>
<td>-Low concern for renal disease</td>
<td>-Low perceived susceptibility to renal disease</td>
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<tr>
<td>2008</td>
<td>Burroughs, V.J. et al.</td>
<td>AA</td>
<td>Self-described overweight AA or Hispanic adults</td>
<td>To examine the correlation between self-described weight status and BMI, the prevalence of self-reported comorbidities and the relationship between comorbidities and self-rated health in an overweight, minority sample</td>
<td>Cross-sectional, exploratory, descriptive</td>
<td>Measures: Telephone survey, self-reported height and weight (to calculate BMI)</td>
<td>Illness Stimuli</td>
<td>-Lay information</td>
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<td></td>
<td>-Weight status and weight optimism</td>
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<tr>
<td>Year</td>
<td>Authors</td>
<td>Sample Size</td>
<td>Sample Characteristics</td>
<td>Methodology and Design</td>
<td>Illness Stimuli</td>
<td>Illness Reactions</td>
<td>Research Focus</td>
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<td>2008</td>
<td>Pace, R. et al.</td>
<td>127, 100% AA</td>
<td>African Americans with a history of high blood pressure or high cholesterol (smokers and drinkers excluded)</td>
<td>Design: Cross-sectional, exploratory, descriptive. Measure: A newly developed questionnaire addressing knowledge of diet and chronic disease associations, perceptions of the impact selected chronic disease and prevalence of selected eating behaviors.</td>
<td>-Lower education level</td>
<td>-Lower education level</td>
<td>-Evidence of renal disease risk factors -Discussion of renal disease with medical professionals -Poor renal disease risk factor knowledge -Preventable and treatable disease beliefs -Low concern for renal disease -Low perceived susceptibility to renal disease</td>
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<tr>
<td>2008</td>
<td>Waterman, A.D. et al.</td>
<td>2,017, 100% AA</td>
<td>Random sample To examine African Americans’ awareness and attitudes about kidney disease</td>
<td>Design: Cross-sectional, exploratory, descriptive. Measure: A pre-tested survey assessing knowledge and attitudes about kidney disease among AAs via random-digit dialing.</td>
<td>Illness Stimuli - Lay information - Current experience with the illness</td>
<td>Cognitive Illness Representation - Cause - Controllability</td>
<td>Emotional Illness Representation - Risk Perceptions</td>
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<tr>
<td>2007</td>
<td>Burnet, D.L. et al.</td>
<td>67 focus group participant, 100% AA 9 interview participant, race not disclosed</td>
<td>Families with a 9-13 year old child in the self-reported 85th weight percentile or above</td>
<td>Design: Cross-sectional, exploratory, descriptive. Measure: Semi-structured focus group interviews conducted by community leaders.</td>
<td>Illness Stimuli - Lay information - External sources</td>
<td>-Weight status and weight optimism - Relationship with PTP</td>
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<td>2006</td>
<td>Breero, J. et al.</td>
<td>37, 100% AA</td>
<td>African Americans who were either outputters, or their friends/relatives in a family health clinic, no specific clinical condition required</td>
<td>Design: Cross-sectional, exploratory, descriptive, correlational. Measure: an expert-structured questionnaire (one version for participants with T2D and another for those without)</td>
<td>Illness Stimuli - Lay information</td>
<td>-Ethnic identity</td>
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<td>2005</td>
<td>DeSalvo, K.B. et al.</td>
<td>128 (all females), 100% AA</td>
<td>African American females presenting for care at an urban community clinic (sample taken from a larger RCT sample)</td>
<td>Design: Cross-sectional, exploratory, descriptive. Measure: A multipart survey measuring demographic, socioeconomic, medical history, and psychosocial variables, a single question to measure perceived risk for cardiovascular disease, and medical chart review (to obtain weight)</td>
<td>Emotional Illness Representation</td>
<td>-Stress</td>
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2.4 Results

2.4.1 Demographics

Out of the 17 studies that met the inclusion criteria for this search, eight included an all-African American sample population (Brezo, Royal, Ampy, & Headings, 2006; Burnet et al., 2008; Calvin et al., 2011; DeSalvo et al., 2005; McKenzie & Skelly, 2010; Pace, Dawkins, Wang, Person, & Shikany, 2008; Skelly et al., 2006; Waterman, Browne, Waterman, Gladstone, & Hostetter, 2008). Three of the studies included a majority African American sample population, in which 50.5% to 74% of the participants were African American (Boulware, Carson, Troll, Powe, & Cooper, 2009; Burroughs et al., 2008; Jennette et al., 2010). Out of these three studies, both Boulware et al. (2009) and Burroughs et al. (2008) analyzed the results by race; however Jennette et al. (2010) did not.
not. The other six studies included sample populations in which 7.3% to 46% of the participants were African American (Alkadry, Bhandari, Wilson, & Blessett, 2011; Ayotte, Trivedi, & Bosworth, 2009; Giardina et al., 2012; Green et al., 2011; Jurkovitz, Hylton, & McClellan, 2005; Tan, Hoffman, & Rosas, 2010). Although African Americans comprised a minority of the sample population in these six studies, all six of them analyzed the results by race. Three of the 17 studies included an all-female sample population (DeSalvo et al., 2005; Giardina et al., 2012; McKenzie & Skelly, 2010). Therefore, the majority of results from this search can be discussed in the context of African Americans.

### 2.4.2 Illness Stimuli

According to the CSM, three sources of information are available to individuals in order to create mental representations of an illness, and those are identified as illness stimuli (Hagger, 2003). As previously discussed, those three sources of information are lay information, external sources, and current experience (Hagger, 2003). This review explored the literature for sociocultural factors that were influential to knowledge and risk perceptions of chronic diseases related to or comorbid with diabetes and ESRD among African Americans and categorized them within the three sources of illness stimuli.

#### 2.4.2.1 Lay information (cultural knowledge)

The following sociocultural factors were categorized under the illness stimuli lay information: lower education level, limited health literacy, weight status and weight optimism, smoking status, lack of insurance, and ethnic identity.

<table>
<thead>
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<th>2.4.2.1.1 Lower education level</th>
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<td>In five of the 14 studies, disease knowledge and accurate risk perceptions were associated with education level (Ayotte et al., 2009; Giardina et al., 2012; Pace et al., 2008;</td>
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</table>
Tan et al., 2010; Waterman et al., 2008). African Americans with at least a bachelor’s degree were more likely to correctly perceive their risk for kidney disease (Waterman et al., 2008), and those with more than a high school education were more likely to have better knowledge of the effects of diet on heart disease (Pace et al., 2008). The other three studies showed the following with regard to education: cardiovascular disease (CVD) knowledge was significantly associated with years of education (Giardina et al., 2012), a college degree was an independent predictor of overall chronic kidney disease (CKD) knowledge (Tan et al., 2010), and participants with at least a high school diploma had higher hypertension knowledge (Ayotte et al., 2009). Also, out of these three studies, two showed that African American participants had significantly fewer years of education than White participants (Ayotte et al., 2009; Giardina et al., 2012), while the third study did not report this demographic characteristic by race (Tan et al., 2010). In summary, a higher education level was associated with greater chronic disease knowledge and more accurate risk perceptions, and African Americans had less educational attainment in those studies that analyzed the results by race.

### 2.4.2.1.2 Limited health literacy

Limited health literacy is a public health concern, since patients with limited health literacy face difficulty navigating the complex healthcare system, understanding written medical information, and communicating with health care providers (Green et al., 2011). Two studies from this search focused on limited health literacy, which can have an impact on chronic disease knowledge, understanding and risk perceptions. In one of these studies, African American race was independently associated with limited health literacy in participants receiving outpatient hemodialysis (Green et al., 2011). While a correlation between limited health literacy and race was established, kidney disease knowledge, understanding and risk perceptions were not studied. In the other study, low health literacy was independently associated with lower perceived likelihood
of renal disease development or progression and was an independent predictor of low renal disease concern (Boulware et al., 2009), however these findings were not analyzed by race. In summary, these studies independently revealed that African American race was associated with limited health literacy, and that limited health literacy was associated with inaccurate risk perceptions and low concern; however, a causal link between these two is not clear from the current research.

2.4.2.1.3 Weight status and weight optimism

Although findings on the association between actual weight and disease awareness were inconsistent (Alkadry et al., 2011; Giardina et al., 2012), weight optimism was consistently linked to inaccurate risk perceptions and inflated health perceptions (Burnet et al., 2008; Burroughs et al., 2008; Skelly et al., 2006). Giardina et al. (2012) found that awareness of cardiovascular disease (CVD) as the leading cause of death was significantly lower in overweight and obese participants than normal weight participants and awareness of early warning symptoms of a heart attack was significantly lower in overweight participants. Conversely, another study found that overweight participants were significantly more aware of stroke signs (Alkadry et al., 2011). Both of these studies had significantly more obese African American participants than non-Hispanic white participants.

Regarding weight optimism, one study found that 66% of African Americans who were classified as obese still rated their overall health as excellent, very good, or good, compared to 49% of Hispanics (Burroughs et al., 2008). Another study showed that in a sample of African American students and parents, parents did not define being overweight as problematic and reported that bigger people are just built differently (Burnet et al., 2008). In a third study, excess weight was not generally recognized as a risk factor for diabetes by African Americans (Skelly et al., 2006). This overly optimistic view of weight may be related to cultural beliefs and values, and these studies showed
that this overly optimistic view could influence chronic disease knowledge and risk perceptions.

### 2.4.2.1.4 Smoking status

Two studies in this search found that smoking status may affect chronic disease knowledge. Alkadry et al. (2011) found that participants who smoked had significantly less awareness of stroke signs (OR= 0.478, 95% CI 0.236 to 0.967), and there were significantly more African American smokers in the sample population (16.7% compared to 2.9%). Comparatively, Tan et al. (2010) did not report the proportion of smokers by ethnicity, but they did find that the only statistically significant racial difference in CKD knowledge was knowledge of smoking abstinence as a method to slow disease progression (75% of African Americans compared to 86.1% of all other participants). These results show that smoking status may influence disease knowledge and that African Americans are less aware of smoking abstinence as a preventative measure, which can both influence personal risk perceptions regarding chronic diseases.

### 2.4.2.1.5 Lack of insurance and ethnic identity

These two sociocultural factors were identified independently in one study each; however, they are still very important factors to discuss. Alkadry et al. (2011) reported that participants without health insurance were significantly less aware of non-modifiable risk factors for stroke (OR= 0.484, 95% CI 0.247-0.949), and there were significantly more African Americans without health insurance in this study compared to Whites (16.1% versus 10.1%).

Focusing on ethnic identity, Brezo, Royal, Ampy and Headings (2006) found that African Americans’ personal sense of ethnic identity was directly correlated with awareness of T2D risk factors and family-based health discussion. Ethnic identity was defined as “a dimension of ethnicity indicating the extent and type of involvement with one’s ethnic group or heritage” or the cultural belief system of an individual (Brezo
et al., 2006, p. 625). Therefore Brezo, et al. (2006) agreed that ethnic identity was a useful marker to explore aspects of intergroup differences in health attitudes, showing that disease knowledge and willingness to share a personal diagnosis can be influenced significantly by personal ethnic identity.

2.4.2.2 External sources

The following two sociocultural factors from the literature were categorized under the illness stimuli external sources: relationship with primary care provider and faith.

2.4.2.2.1 Relationship with primary care provider

Three studies indicated primary care provider involvement influenced disease knowledge and risk perceptions (Burnet et al., 2008; Jennette et al., 2010; McKenzie & Skelly, 2010). Among focus group participants, not knowing what to ask their physician was an important aspect routinely mentioned by participants regarding health care knowledge, and in all 17 focus groups, physician communication was noted as a barrier to receiving and understanding health information (Jennette et al., 2010). Also, Burnet et al. (2008) reported that parents in focus groups wanted information about healthy nutrition and weight in their children, but they felt many doctors did not advise enough about these concerns, limiting the parent’s knowledge. Regarding risk perceptions, McKenzie and Skelly (2010) reported that if participants’ primary care providers did not tell them they were at risk for coronary heart disease (CHD), then they did not see themselves at risk. In summary, these three studies found that many African Americans felt health discussions with their physicians were lacking, and those who had not discussed chronic disease risk with primary care providers lacked understanding about chronic disease and also their risk and their children’s risk for these diseases.
2.4.2.2 Faith

Two studies found that African-American women’s faith influenced their risk perceptions for CHD and diabetes (McKenzie & Skelly, 2010; Skelly et al., 2006). McKenzie and Skelly (2010) conducted interviews with African-American women and found that many women did not want to “claim” the risk of heart disease or cancer, and they labeled this theme as “not claiming”. Upon exploring this theme further, the authors found that women with strong faith may fluctuate between denial and “not claiming” a disease; not claiming the disease can affect the identity the woman forms with the disease, and cause the woman to give her symptoms over to God rather than see them as risk factors (McKenzie & Skelly, 2010). In the second study, only African-American women classified in the older age group expressed religious beliefs regarding diabetes, stating that they felt that God intervened to prevent or cure diabetes and that God acts through the individual and the doctor (Skelly et al., 2006). Both of these studies found that African-American women turn to their faith when chronic disease perceptions are discussed, which may influence their personal perceptions and sense of personal control or modification of the risk.

2.4.2.3 Current experience with the illness

Evidence of renal disease risk factors, discussion of renal disease with medical professionals, and relationship with someone diagnosed with kidney disease were sociocultural factors from the literature categorized under the illness stimuli current experience with the illness.

2.4.2.3.1 Evidence of renal disease risk factors

In four studies (Boulware et al., 2009; Calvin et al., 2011; Jurkovitz et al., 2005; Waterman et al., 2008), 28% to 66.7% of participants had risk factors for renal disease present. Two of these studies collected serum and urine samples from participants to determine the presence of physiological ESRD risk factors (Boulware et al., 2009; Calvin
et al., 2011), while the other two studies determined risk factors via self-reported survey data (Jurkovitz et al., 2005; Waterman et al., 2008). In terms of physiologic measures, in Calvin et al. (2011), 29% of participants had microalbuminuria, 61.3% had hypertension, and 66.7% had A1C levels >7%, all evident risk factors for renal disease. In Boulware et al. (2009), 28% of participants had clinical evidence of chronic kidney disease (CKD), determined by a GFR < 60 ml/min/1.73m or the presence of proteinuria. The two studies that assessed self-reported risk factors including hypertension, diabetes, or a family history of renal disease both found that ~43% of African American participants had at least one of these risk factors (Jurkovitz et al., 2005; Waterman et al., 2008). Jurkovitz et al. (2005) also showed that African Americans had a significantly higher incidence of risk factors compared to non-African American participants (43.4% compared to 30.8%). These findings verify the presence of a considerable number of risk factors for renal disease among African Americans determined by both physiological measures and self-report demographic characteristics, although participants may not be aware of their current experience with these risk factors.

### 2.4.2.3.2 Discussion of renal disease with medical professionals

Waterman et al. (2008) conducted the single study under this sub-theme and found that participants who had spoken with a medical professional about renal disease were more likely to correctly perceive themselves to be at an increased risk. However, only 9.1% of participants had spoken to their physician in the past year about renal disease, compared to 12.9% who had spoken to friends and family about it and 28.6% who had read about it (Waterman et al., 2008). Although speaking to a medical professional about renal disease improved risk perceptions, only a very small percentage of participants had acknowledged this current experience in the past year, and the majority of participants had not spoken to any external sources about the disease.
2.4.2.3 Relationship with someone diagnosed with renal disease

Two studies reported that a number of participants had friends or family members with renal disease (Jennette et al., 2010; Jurkovitz et al., 2005). Specifically, Jurkovitz et al. (2005) reported that 21.1% of African American participants had an immediate family member with renal disease, of which 10.5% reported the respective family member was receiving dialysis treatment. Similarly, Jennette et al. (2010) found that 76% of focus groups contained at least one participant with a friend or family member diagnosed with ESRD. These results show that a number of participants from these two studies have had current experience with renal disease through friends or family.

2.4.3 Cognitive Illness Representations

Cognitive illness representations encompass an individual’s beliefs about a specified illness which can be influential to their individual risk perceptions and are comprised of five domains (Cameron, 2003). The cognitive illness domains represented in this literature search were cause, consequences and controllability.

2.4.3.1 Cause

According to the CSM, cause refers to individuals’ beliefs regarding the factors responsible for causing the specified illness and is one of the five domains encompassing cognitive illness representations (Cameron, 2003; Hagger, 2003; Leventhal et al., 2011). Poor renal disease risk factor knowledge was the single sub-theme found under the domain of cause.

2.4.3.1.1 Poor renal disease risk factor knowledge

In two studies, participants were fairly knowledgeable regarding the definition of kidney disease and the function of the kidneys (Jennette et al., 2010; Waterman et al., 2008). Almost 49% of the African American sample knew the correct definition of kidney disease in one study (Waterman, et al., 2008), and Jennette et al. (2010) found that
participants in the majority of focus groups understood the function of the kidneys. Despite this knowledge, participants in both studies lacked important knowledge about renal disease risk factors. Jennette et al. (2010) found that focus group participants consistently reported that obesity, diet, alcohol and soda intake, and urination problems were the biggest risk factors, and most participants failed to acknowledge hypertension, diabetes, family history and race as risk factors. Similarly, Waterman et al. (2008) found that few African Americans knew diabetes and hypertension (14%), family history (2.4%) and African American race (18.1%) were risk factors for kidney disease. On the other hand, another study that focused on racial differences in hypertension knowledge found that even though African Americans showed a lower level of latent hypertension knowledge, they were more aware of the association between high blood pressure and renal disease than white participants (Ayotte et al., 2009). In summary, the research shows that in general, the knowledge of risk factors for renal disease is low; however, African Americans already diagnosed with hypertension appear to have a heightened awareness that this prominent risk factor is a precursor to renal disease.

2.4.3.2 Consequences

Consequences are described by the CSM as an individual’s beliefs regarding the impact of the specified illness on overall quality of life, social consequences, and other outcomes of the illness (Cameron, 2003; Hagger, 2003). The single sub-theme found under this CSM domain was difficulty of life on dialysis.

2.4.3.2.1 Difficulty of life on dialysis

A single study in this search found that focus group participants routinely thought of dialysis when they heard the term kidney disease, and many of them had experienced dialysis through friends or family members (Jennette et al., 2010). A majority of participants who had experienced dialysis through others described it as a life-altering, negative experience that was stressful to patients and their family members...
Specifically, participants spoke about dialysis taking a toll on family members’ bodies and noticing them being drained after dialysis and losing their color (Jennette et al., 2010). One participant was even stated that his father passed away shortly after beginning dialysis (Jennette et al., 2010). In summary, participants from this one focus group study discussed the negative effects of dialysis, or consequences of renal failure as evidenced through friends or family members.

### 2.4.3.3 Controllability

The CSM defines controllability as an individual’s beliefs regarding whether the specified illness can be cured or controlled through surgery, treatment, or medication (Cameron, 2003). The single sub-theme found in this literature under controllability was preventable and treatable disease beliefs.

#### 2.4.3.3.1 Preventable and treatable disease beliefs

According to a single study by Waterman et al. (2008), on average participants believed that renal disease was both preventable and treatable, and there were no significant differences between participants with and without risk factors. Although participants were not asked how they felt renal disease could be controlled in this study, the findings show that the majority of participants still felt the disease was preventable and treatable, regardless of the presence of risk factors.

### 2.4.4 Emotional Illness Representations

The following two sub-themes were identified in this literature and categorized under the emotional illness representation component of the CSM: low concern for renal disease and stress.
2.4.4.1 Low concern for renal disease

Two studies showed that participants had low concern for renal disease (Boulware et al., 2009; Waterman et al., 2008). In Waterman et al. (2008), a mere 2.8% of participants reported that renal disease was an important health problem in their community. Another study found that 33% of participants were “very concerned” about developing renal disease, but this held the lowest relative concern compared to other diseases including cancer (40%), eye problems (41%), heart attack (44%), and stroke (45%) (Boulware et al., 2009). Therefore, even though risk factors for renal disease were present among participants in both of these studies, participants still held low concern for disease development.

2.4.4.2 Stress

A single study by DeSalvo et al. (2005) found that despite a high prevalence of cardiac risk factors in African American females, only a third of participants reported themselves to be at high risk for heart disease. Interestingly, they found that participants who perceived themselves as stressed were significantly more likely to underestimate their disease risk (DeSalvo et al., 2005). Although this was only evident in one study, these findings show that stress can have a significant impact on risk perceptions.

2.4.5 Risk Perceptions

Four studies were found in this search that explored the CSM component of renal disease risk perceptions and the results displayed a low perceived susceptibility to the disease.

2.4.5.1 Low perceived susceptibility to renal disease

The four studies that revealed the presence of renal disease risk factors among participants also showed that despite these risk factors, participants had a low perceived susceptibility to renal disease (Boulware et al., 2009; Calvin et al., 2011; Jurkovitz et al.,
Calvin et al. (2011) found that even though physiological risk factors were prevalent in participants, the mean score for perceived personal risk for ESRD was low at 2.4 (range of 1-4), with an average score below all other diabetes complications except amputation (Calvin et al., 2011). In terms of relative risk perceptions, African Americans ranked their perceived risk for ESRD below various other diabetes complications, including vision problems or blindness, heart attack, stroke, numb feet, and premature death in two studies (Calvin et al., 2011; Waterman et al., 2008).

Three studies also showed that few participants perceived that they were likely to develop renal disease, despite the presence of risk factors (Boulware et al., 2009; Jurkovitz et al., 2005; Waterman et al., 2008). All three of these studies assessed participant’s perceived likelihood of developing renal disease risk through similar ordinal-scaled questions. Boulware et al. (2009) asked participants “How likely do you think it is that you could develop chronic kidney disease in the next ten years? (Answers: not likely, slightly likely, moderately likely, or very likely)”. Jurkovitz et al. (2005) asked participants “How likely are people like you to get kidney disease as I’ve just described it sometime during their lives? (Answers: likely, unlikely, don’t know)”. Waterman et al. (2008) asked participants for their “perceived risk of getting kidney disease compared with others (Answers: higher than average, lower than average, or average)”. Only 30.3%-39% of participants considered themselves likely to develop renal disease or to have a higher than average perceived risk; and those without diabetes or other risk factors were significantly more likely to have a low perceived likelihood of disease development (Boulware, et al, 2009; Waterman, et al., 2008; (Jurkovitz et al., 2005). Participants were less likely to consider themselves “very likely” to develop renal disease compared to all other conditions mentioned except cancer (including stroke,
heart attack, and eye problems; Boulware et al., 2009). Finally, Jurkowitz et al. (2005) noted that even though African American participants were much more likely to report any risk factor for renal disease, they were less likely to perceive themselves at greater risk for renal disease development; specifically, 28.9% of African Americans responded it was “unlikely” individuals like themselves would develop kidney disease. In summary, although the research proved that African Americans were at an increased risk for renal disease, they exhibited low perceived susceptibility, and the presence of diabetes or other risk factors appears to only slightly increase their perceived susceptibility. These are alarming findings because of African Americans’ increased risk for this disease, especially in the presence of diabetes and other risk factors common in this population.

2.5 Discussion

This review synthesized the extant literature on renal disease knowledge and risk perceptions among African Americans and sociocultural factors which may be influential to chronic disease knowledge and risk perceptions. The findings were categorized under the main components of the CSM. There was a significant amount of literature that could be categorized under the three illness stimuli, but a lack of literature on cognitive and emotional illness representations and risk perceptions in the African American population in general, all important components of the CSM. The components that are lacking in the literature are important to explore further in order to understand the development of renal disease risk perceptions among African Americans, and to ultimately develop appropriate interventions to correct inaccurate risk perceptions and attempt to halt the development of ESRD.

Multiple sociocultural factors were identified as illness stimuli in this search that may be influential in shaping renal disease representations and risk perceptions among
African Americans, and help guide future research. Lower education level, limited health literacy, weight status and weight optimism, smoking status, lack of insurance, and ethnic identity were all identified as influential sociocultural factors under the illness stimuli lay information.

Lower educational attainment among African Americans was linked to poor disease knowledge and inaccurate risk perceptions in the literature, however social barriers to educational attainment must also be considered when studying this factor further. According to the U.S. Department of Education, in 2010, 89.6% of African Americans held a high school degree or equivalent and 19.4% held a bachelor’s degree compared to 94.5% and 38.6% of whites (Aud et al., 2011). These educational differences have been related to limited access to resources and infrastructure issues in urban schools as compared to suburban environments (Belgrave & Allison, 2010), which may be a product of residential segregation. Although residential segregation has declined overall, African Americans remain the most segregated group in the U.S., and even the most affluent African Americans experience higher levels of residential segregation than the poorest Latinos and Asians (Belgrave & Allison, 2010; D. R. Williams & Jackson, 2005). Williams and Jackson (2005) suggest that the elimination of residential segregation would completely erase not only black-white differences in earnings, but also in high school graduation rates. Research has also shown that institutional racism plays a significant role in educational attainment differences as well. Differences in teacher expectations of students, disciplinary action, opportunities for advanced learning, lack of cultural competence of standardized tests and differential support of students have been noted by African American students (Belgrave & Allison, 2010). Limited health literacy and lack of insurance may also be linked to this educational disparity among African Americans. Therefore, although lower educational attainment
and limited health literacy were identified as sociocultural factors under lay information, there are clearly other socioeconomic disparities that may be contributing to these issues as well, which may influence future interventions aimed at correcting inaccurate risk perceptions.

Next, this literature also displayed the prevalence of weight optimism in the African American community, suggesting it may be influential to disease knowledge and risk perceptions. Other research has also demonstrated weight optimism and inaccurate weight perceptions in the African American community. Compared to 52% of white Americans, almost 64% of African Americans in the U.S. are overweight, and 25% are obese compared to 18% of whites (E. A. Walker et al., 2010); but, in general, African Americans are more likely to accept obesity as the norm (Gavin & Wright, 2007). Burroughs et al. (2008) found that 56% of African Americans compared to 34% of Mexican Americans who described themselves as “slightly” overweight were actually classified as obese based on their BMI. The weight misconceptions of African Americans likely reflect the greater social acceptance of excess weight in this culture and lower rates of body dissatisfaction (Burroughs et al., 2008; Kirkendoll et al., 2010).

Even though obesity is more prevalent and acceptable among African Americans, social disparities such as food deserts and residential segregation may also have a strong influence. The concept ‘food desert’ was coined in the early 1990’s and has since been defined and measured in different ways by various researchers; however, in general, food deserts refer to low-income, minority neighborhoods in which residents are unable to buy affordable, healthy food, usually due to the absence of a local supermarket (R. E. Walker, Keane, & Burke, 2010). Poor supermarket access frequently leads to increased exposure to “empty calorie” foods, such as those available at convenience stores and fast food restaurants, which are more prevalent in low-income
neighborhoods (R. E. Walker et al., 2010). A literature review was conducted on food deserts and found that on a national level, the lowest income areas had about 30% fewer supermarkets than the highest income areas, however in Philadelphia, the highest income areas had 156% more supermarkets, displaying the vast range of access (R. E. Walker et al., 2010). Secondly, in low-income areas, smaller stores are more prominent, and these smaller stores usually have higher prices related to high crime in the area, poorer quality of food, and smaller quantities (R. E. Walker et al., 2010). The third important theme was that residents in low-income areas were more likely to have to travel farther distances to obtain the same resources, and a significant number of residents lacked transportation resources (R. E. Walker et al., 2010). Generally, people are going to make food choices based on the options available in their immediate neighborhood, especially when transportation is a barrier (R. E. Walker et al., 2010).

Lack of physical activity is another lifestyle factor that has been touted as an ‘obesity-inducing’ behavior among African Americans (Das, 2013). Research shows that only 21.6% of African American adults in the U.S. participate in regular and sustained activity (E. A. Walker et al., 2010). Maillet et al. (1996) found that focus group participants identified the following barriers to exercise: physical inability due to peripheral nephropathy or degenerative joint disease, a dangerous walking environment, and lack of a partner to walk with. Therefore, suboptimal living conditions exacerbated by residential segregation can impact physical activity because of the lack of safety. Another barrier to physical activity noted in the literature is the multi-caretaker role that many African American women assume. Samuel-Hodge et al. (2000) found that women with diabetes were often caring for homebound parents, adult children or grandchildren and that was a barrier to self-management, particularly physical activity, due to added stress, pressure and fatigue. Therefore, even though the statistics show
that African Americans are less active, and this is a proven risk for obesity, the underlying social reasons for this inactivity must be considered. In summary, weight optimism was determined to be a sociocultural influence on disease knowledge and risk perceptions, however this is deeply seeded among cultural disparities that may not easily be addressed with behavioral interventions.

Relationship with primary care provider was identified as an external source, and discussion of renal disease with a medical professional was identified as current experience under the illness stimuli component. Since this literature illustrated that communication with a primary care provider could influence disease knowledge and risk perceptions, it is important to discuss the health care disparities in the African American community. Evans et al. (2011) showed that whites are more likely to have a private physician, whereas insured and uninsured African Americans are more likely to use a regular health clinic or emergency department for their usual source of care (Evans et al., 2011). In one study, the odds of African American participants having a primary care physician were 0.60 compared to non-Hispanic white participants (95% CI = 0.50-0.72), and the odds of using the emergency room were 1.91 (95% CI = 1.65-2.20) (Ontiveros, Black, Jakobi, & Goodwin, 1999). These statistics show that African Americans are less likely to receive care from a primary care provider, and communication with primary care providers has been shown to positively influence risk perceptions.

Institutional racism has also been shown to play an influential role in African Americans’ relationships with primary care providers, and must be considered. Belgrave & Allison (2010) stressed that attitudes and practices of health providers and institutional policies provide significant evidence of institutional racism. In one study, medical visits were analyzed to compare the quality of communication with a physician
between African American and white patients (Johnson, Roter, Powe, & Cooper, 2004). The results showed that physicians engaged in 33% less patient-centered communication and were 22% more verbally dominant with African American patients (Johnson et al., 2004). Another study reported the following findings, all statistically significant, in regards to perceived racism in health care settings: 67.5% of African Americans felt doctors treat African Americans and whites the same, compared to 86.8% of whites; 30% of African Americans felt racial discrimination in a doctor’s office is common, compared to 7.3% of whites; 78.6% of African Americans felt equal care was received in most hospitals compared to 88.1% of whites (LaVeist, Nickerson, & Bowie, 2000). Perceived racism within health care settings was reaffirmed when examining results from focus group studies with all-African American participants. Some participants voiced concerns that they felt some diseases, especially those prevalent among African Americans, were used to financially benefit companies, such as pharmaceutical companies, and this led to physician distrust in most participants (Kirkendoll et al., 2010). One participant even stated, “Doctors tell all Black people over 40 or 50 that they have high blood pressure. I think that it’s just a trend.” (Kirkendoll et al., 2010, p. 108). Another focus group study found that distrust in the health care system was based on personal and family experiences and all groups mentioned that the Tuskegee experiment had a significant influence on their distrust (Peters, Aroian, & Flack, 2006). Participants admitted that their distrust also affected health behaviors of their children and grandchildren and one participant stated, “All of them [older folks] not wanting to go to the doctor because of how they’ve been done along the lines, they pass that along…” (Peters et al., 2006, p. 7). These findings all support the notion of perceived institutional racism within health care, which can be influential to African American patients’ relationships with providers, thereby influencing risk perceptions and disease
knowledge, making interventions aimed at improving relationships with providers challenging on the surface level.

Regarding emotional illness representations, one study in this literature search found that stress was a significant predictor of underestimation of risk among participants, and stress as a social disparity has been studied extensively in the African American community. One author recently studied an interesting concept called “weathering” (Das, 2013). Das (2013) noted that literature frequently blames obesity (conceived as the result of unhealthy behaviors and poor social control), risky behaviors (such as smoking), and inactivity for poor metabolic outcomes, especially in African Americans, suggesting an implicit “culture of irresponsibility.” However, he suggests that metabolic pathologies may also be a result of older African American men’s greater stress-induced “weathering,” defined as “the cumulative health impact of black individuals’ repeated experiences with social, economic, or political exclusion” (Das, 2013, p. 76). Das (2013) suggests that “weathering” results in high-effort coping and may potentially induce morbidity through both direct measures and also indirectly through unhealthy behaviors. He found that older black men were no more likely than white participants to smoke, were less likely to consume alcohol, less likely to be obese, but more likely to be inactive (Das, 2013). However, black men were more likely to have chronic inflammation, and it was the only mediator significantly associated with black-white differentials in blood-sugar control, hemoglobin A1C, blood pressure, and heart rate, three of which are proven renal disease risk factors (Das, 2013). In summary, this study exemplifies the long-term effects of chronic stress from racism on renal disease risk in African American men, and shows it may even be more influential on the development of risk factors than lifestyle choices, which can be influential in future intervention research.
When focusing on the cognitive illness representation component, the three domains we were able to categorize findings under from this literature were cause, consequences, and controllability. However, no studies were found that specifically used the CSM to study the domains of renal disease cognitive representations, and the findings categorized under these three domains were very limited. To date, the CSM has only been used to study representations of renal disease in patients already diagnosed with renal disease. The literature includes studies exploring the association of renal disease representations with the following: survival among patients with ESRD, depressive symptoms in hemodialysis patients, fluid non-adherence in hemodialysis patients, self-care behaviors in ESRD patients, and quality of life in ESRD patients (Chilcot et al., 2011; Chilcot et al., 2010; Covic et al., 2004; Fowler & Baas, 2006; Griva et al., 2009; O’Connor et al., 2008; Parfeni et al., 2013; van Dijk et al., 2009). However, the literature lacks studies that measure renal disease representations in patients at risk for the disease, which would be beneficial in determining how renal disease representations, incorporating all five domains, are related to risk perceptions, especially in a high-risk group such as African Americans.

Overall, the findings illustrated an apparent lack of perceived susceptibility to renal disease and a low concern for kidney disease despite the presence of renal disease risk factors. Renal disease risk factor knowledge also appears to be lacking in the African American population, even though those with the presence of risk factors have a slightly higher knowledge level compared to African Americans who do not have diabetes or risk factors present. These findings are very concerning for this population, and support Calvin et al.’s (2011) identification of an urgent need to increase perception of risk for diabetes complications, especially ESRD, in this high-risk population. This literature search indicates the importance of studying renal disease awareness and risk
perceptions in the African American community in greater detail in terms of the illness stimuli and illness representations that inform risk perceptions. This may lead to a better understanding of the reasoning behind the significant lack of awareness and inaccurate risk perceptions and potentially warrant future interventions to increase awareness and correct inaccurate risk perceptions.

Further research focused on determining what modifiable sociocultural factors influence renal disease representations directly and exploring prevalent renal disease representations among African American participants is warranted based on these findings. Once modifiable sociocultural factors influential to renal disease awareness and risk perceptions, prevalent renal disease beliefs under cognitive illness representations, and associated emotional illness representations are better understood, appropriate interventions can be developed to improve awareness and inaccurate risk perceptions in this population.

2.6 Limitations

There were significant findings from this literature review; however it is important to note the limitations as well. First, there was limited available research to synthesize, especially specific to ESRD risk awareness and perceptions among African Americans. Also, there was no existing literature that used the CSM to study renal disease risk perceptions among participants not yet diagnosed with this disease. This is a limitation because it made synthesis and generalizations difficult. However, this lack of current research illustrates gaps for future research needs. Secondly, the different study designs used in both searches, including qualitative focus groups, in-depth interviews, qualitative and quantitative questionnaires, and random telephone surveys, made synthesis of the results more difficult. Despite differing approaches, the results of the studies were fairly consistent. Finally, all of the studies included in this search were
cross-sectional studies. Longitudinal studies would be very beneficial to evaluate when looking at this topic, in order to examine how renal disease awareness and risk perceptions change over time, especially in the context of chronic disease trajectories such as diabetes.

2.7 Conclusion

From a clinical and public health standpoint, the findings from this literature review are important to improve patient care. It is apparent that African Americans at risk for renal disease are often unaware of their risk and hold inaccurate risk perceptions. More importantly, there is an overall lack of concern for renal disease in this population, based on these findings. In a clinical practice setting, it is important to educate patients on their risk for renal disease, especially those with risk factors already present, namely T2D. It is also important to discuss renal disease in general with patients and clearly identify the most prominent risk factors, disease progression and treatment options in order to improve disease understanding and hopefully raise concern and use of preventive measures. This literature showed that communication with health care providers was influential in chronic disease knowledge and awareness, and can be key to improving the current lack of knowledge, awareness and inaccurate risk perceptions of this life-threatening disease. However, providers must first establish trust with their patients and break the mistrust barrier that often exists, due to underlying social issues mentioned above.

From a practice perspective, once we better understand risk perceptions in this population, we can work on correcting inaccurate risk perceptions in health care settings, which can potentially lead to positive behavior change. “Theoretically, one is more likely to participate in diabetes self-care if the perceived risk of developing
complications is high” (Calvin et al., 2011, p. 690). This is a powerful quote, displaying the practice implications of this research. From the general research on renal disease risk perceptions, it is apparent African Americans, even those with T2D, underestimate their renal disease risk. Therefore, once we better understand renal disease risk perceptions in this population, we can work to correct any inaccuracies, which in turn should lead to improved diabetes self-care, control of comorbidities such as hypertension, and ultimately a decreased renal disease risk.

The findings from this literature review inform future research as well. They demonstrate the need for more specific research focused on renal disease awareness and risk perceptions in African Americans with diabetes through more in-depth study. Once this is better understood, interventions can be developed with the purpose of increasing awareness and correcting inaccurate risk perceptions, and the sociocultural influences identified in this literature review and future research can be used to guide interventions.
3. Renal Disease Risk Perceptions Among African-American Women with Type 2 Diabetes

3.1 Introduction

In the US, African Americans are disproportionately burdened by diabetes and also end stage renal disease (ESRD), a complication of diabetes. Compared to their white counterparts, African Americans are 1.8 times more likely to develop type 2 diabetes (T2D), and 4 times more likely to develop ESRD (Calvin et al., 2011; USRDS, 2014). In 2012, the prevalence rate for diabetic ESRD for white Americans was 536.5 per million, and for African Americans it was 2,135.9 per million (USRDS, 2014). The earliest sign of diabetic renal disease, microalbuminuria, may be present in patients even at the time of T2D diagnosis since the actual onset of T2D may precede its clinical diagnosis by many years (Calvin et al., 2011; Deshpande, Harris-Hayes, & Schootman, 2008). Compared to white Americans, African Americans exhibit microalbuminuria much earlier in the course of T2D; in fact, 20-25% of African Americans exhibited microalbuminuria less than a year after the diagnosis of T2D in two studies (Calvin et al., 2011; Goldschmid et al., 1995; Thaler et al., 1998). Therefore, not only are African Americans with T2D at an elevated risk for ESRD, they are also at an elevated risk for earlier disease onset.

Despite the high prevalence in this minority group, the research to date shows that African Americans have a poor understanding of renal disease and associated risk factors, and they underestimate their risk. Several studies have found that African Americans lacked awareness of renal disease and did not see it as a significant health problem (Boulware et al., 2009; Calvin et al., 2011; Jurkovitz et al., 2005; Waterman et al., 2008). In one study, African Americans with T2D ranked ESRD below all other complications except amputation in a risk comparison (Calvin et al., 2011).
African-American women have been found to be more likely to develop ESRD as a result of diabetes than African-American men (Crook & Patel, 2004; Crook et al., 2003; Samuel-Hodge et al., 2000). In one large study, diabetes accounted for 50.5% of ESRD cases among African-American women and only 17.6% of ESRD cases among African-American men; comparatively, 48.1% of African-American men had developed ESRD as a result of hypertension (HTN) (Crook et al., 2001). Similarly, the US Renal Data System reported that among African-American women, the primary cause of ESRD is diabetes (40.12%), whereas among African-American men, the primary cause of ESRD is HTN (40.29%) (USRDS, 2014). These results demonstrate that African-American men are more at risk for ESRD secondary to HTN, whereas African-American women are more at risk for ESRD secondary to diabetes.

The disparities in rates of diabetic ESRD are often attributed to poor glycemic control in African-American women. Two studies found that 47%-50% of African-American women had poor glucose control compared to 36.5%-41% of African-American men, 36.2%-38% of white men, and 29%-35.5% of white women (Harris et al., 1999; Weatherspoon et al., 1994). The following barriers to glucose control have been identified among African-American women: stress, social demands, the multi-caregiver role, embarrassment, and financial burden (Balukonis, Melkus, & Chyun, 2008; Cagle, Appel, Skelly, & Carter-Edwards, 2002; Carthron, Johnson, Hubbart, Strickland, & Nance, 2010; Chlebowy, Hood, & LaJoie, 2013; Samuel-Hodge et al., 2000; Samuel-Hodge, Skelly, Headen, & Carter-Edwards, 2005).

Although the disproportionate risk for ESRD in African-American women with T2D has often been attributed to poor glucose control in response to cultural barriers, one study found that only 44% of the excess risk of renal disease among African Americans compared to whites could be explained by sociodemographic, lifestyle, and
clinical factors (Tarver-Carr et al., 2002). Therefore, other factors influencing this disparate risk need to be explored, and risk perceptions have been shown to have a strong influence on preventative behaviors, which may play a role in excess risk among this high-risk population. Research has shown that when perceived risk of developing complications is high, people are more likely to engage in diabetes self-management (van der Pligt, 1998; E. A. Walker et al., 2007). Therefore, Calvin et al. (2011) conducted a quantitative study to explore patients’ personal illness perceptions, well-being, and beliefs concerning their perceptions of risk for diabetes complications, in order to determine if excess risk among African Americans with T2D could be explained by personal factors. They concluded that perceptions of risk for diabetes complications was low, particularly ESRD, yet only 19% of the variation in risk perception was explained by perceived diabetes consequences and well-being (Calvin et al., 2011). However, this quantitative study did not focus solely on African-American women, and the authors stressed the need to explore patients’ perceptions of risk for diabetes complications using a qualitative approach, to better understand why perceptions of risk were so low. Therefore, if we could gain an in-depth understanding of renal disease risk perceptions among high-risk African-American women with T2D, future interventions could be aimed at addressing risk perceptions, with an ultimate goal of influencing behavior to modify risk. Also, from a clinical practice standpoint, an in-depth understanding of renal disease risk perceptions among high-risk African-American women with T2D could be beneficial to guide self-management education and patient counseling to influence behaviors and decrease risk in this population.

Therefore, the aim of this qualitative descriptive study was to explore and describe the renal disease representations, perceptions of individual renal disease risk, and factors influencing representations and risk perceptions in African-American
women with T2D. The research questions for this study were: 1) How do African-American women with T2D perceive their individual risk for renal disease? 2) How do African-American women with T2D perceive their risk for renal disease relative to other complications of diabetes (i.e., heart disease, stroke, retinopathy, and neuropathy)? 3) How do African-American women with T2D describe their cognitive renal disease representations through the five domains of illness representations: symptoms, cause, timeline, consequences, and controllability? 4) What has influenced the development of these representations? 5) What emotional representations of renal disease do African-American women with T2D portray?

3.1.1 Theoretical Framework

Perceptions of risk have been the foundation of health behavior theories for years and are integral to theories such as the Health Belief Model (HBM) (Wang et al., 2009). The HBM was developed by social psychologists in the 1950’s and postulates that health behavior is a function of perceived susceptibility and severity of the disease, perceived benefits, perceived barriers, and perceived self-efficacy (Champion & Skinner, 2008; Diefenbach & Leventhal, 1996; Janz & Becker, 1984). However, a meta-analysis found that although the model dimensions significantly influenced behavior, the variance in behavior accounted for by these dimensions was small (<10%) (Harrison, Mullen, & Green, 1992). Also, in diabetes, the model has provided inconsistent results between the dimensions and self-management behaviors, and it has been suggested this is due to the absence of emotional responses to illness in this model (Harvey & Lawson, 2009). The HBM is a strictly cognitive-based model and does not consider an emotional component of behavior (Champion & Skinner, 2008). Emotions such as fear and anxiety are well-established as influential in health behavior and responses to health risks (Cameron, 2003; Champion & Skinner, 2008). Therefore, emotional responses are an important
concept to incorporate when studying risk perceptions and behavior. Also, the HBM only includes perceived severity of an illness and fails to incorporate an individual’s complete illness representation, which has also been shown to impact risk perceptions and influence behavior. In this study, the aim was to explore and describe how African-American women with T2D arrive at and conceptualize individual risk perceptions, which in turn can influence behaviors.

At this step of research, the Common Sense Model of illness representation (CSM) was a better fitting model to use to explore this under-researched topic. The CSM, developed by Leventhal et al. (1998), was used as the theoretical framework in Calvin et al.’s (2011) study and guided this study as well. The CSM is a dynamic systems model of the processes involved in common-sense management of health threats in everyday life (Leventhal et al., 2011). The model suggests that illness representations form individuals’ common-sense definitions of health threats, and these in turn influence behavior (Leventhal et al., 1998). Illness representations are very personal and may differ widely depending on experience and culture, leading to different responses to the same health threat (Rees et al., 2001).

Cognitive illness representations are the focus of the model, and they encompass the following five content domains: cause, identity, timeline, consequences, and controllability (Leventhal et al., 1998). Initially, most of the research conducted using the CSM focused on the five domains as predictors of behavior and was conducted with individuals already diagnosed with the target illness (Cameron, 2003). However, Cameron (2003) suggested that the CSM has key features that can be used to explore risk perceptions and noted that the five cognitive illness representation domains could influence development of risk perceptions. Information in these five domains may influence people’s perceptions of risk, shape how they express perceptions of risk, and
affect the relationship of perceived risk to behavior (Kelly et al., 2005). Hence, many authors have adapted the CSM to incorporate risk perceptions and study how illness representations influence perceptions of risk for various illnesses (Figure 5). Calvin et al. (2011) found that risk perceptions of diabetes complications were positively and significantly associated with participants’ perceptions of negative consequences (r=.292), symptoms (r=.251), and negative emotions (r=.325) of diabetes among African Americans already diagnosed with diabetes. That is, the more perceived negative consequences, the more symptoms, and the more negative emotions one associated with diabetes, the higher one’s risk perception for complications from the disease (Calvin et al., 2011).

Cognitive illness representations are a significant component of the overall illness representation; however, it is important to incorporate the emotional component as well when describing illness representations in regard to renal disease, as was evident in Calvin et al.’s findings (2011). The CSM posits that health threats generate not only a cognitive representation of the threat, but also emotional states such as fear and distress, described as the emotional illness representation (Leventhal et al., 2003). The emotional illness representation is defined as the regulation of emotional reactions to a health threat, which can be shaped by and influence both the cognitive illness representation and also risk perceptions (Cameron, 2003; Hagger, 2003; Leventhal et al., 2003; Leventhal et al., 1998). As Cameron (2003) notes, there is extensive research that has established the influence of anxiety on responses to health risks. For example, anxiety can lead to the development of more detailed and extensive risk perceptions by promoting reflection of threat-related information over time and enhancing vigilance in processing risk information (Cameron, 2003). As mentioned previously, Calvin et al. (2011) found the more negative emotions participants attributed to their diabetes, the more accurate their
risk perceptions of complications. According to the CSM, these emotional representations are part of the overall illness representation and could provide valuable insight to understanding risk perceptions of renal disease in this population.

Also according to the CSM, both cognitive and emotional representations activate behaviors adopted in response to the illness, and these are termed ‘coping procedures’ (Hagger, 2003; Leventhal et al., 1980). Coping procedures can be cognitive or behavioral and are actions taken (or not taken) to improve health and to prevent, treat, or recuperate from a specified illness (Leventhal et al., 1998). According to a meta-analysis of the CSM, some emergent coping procedures included avoidance/denial, cognitive reappraisal, expressing emotion, problem-focused coping, and seeking social support (Hagger, 2003). Individuals choose coping procedures in response to their perceived representation of an illness, and the model implies the relationship is causal, or the effect on coping procedures is in proportion to the perceived severity of the illness (Hagger, 2003; Reynolds & Alonzo, 2000). Finally, the CSM proposes that coping procedures influence health outcomes (Leventhal et al., 1980).

Both cognitive and emotional illness representations are shaped by three basic sources of information, known as illness stimuli, according to the CSM (Hagger, 2003; Leventhal et al., 1980; Leventhal, Nerenz, & Steele, 1984; Reynolds & Alonzo, 2000). The first source, known as ‘lay’ information, includes general information that an individual has already assimilated from cultural knowledge, practices, previous communication, and media sources (Hagger, 2003; Leventhal et al., 1980; Leventhal et al., 1984; Reynolds & Alonzo, 2000). The second illness stimulus involves external sources, or information gained from interaction with sources in the external social environment, including significant others, family, friends, and health care providers (Hagger, 2003; Leventhal et al., 1980; Leventhal et al., 1984; Reynolds & Alonzo, 2000). The third illness stimulus is
current experience and includes an individual’s current experience with the illness, which includes bodily symptoms and sensations, memories of past symptoms, and illness experiences (Hagger, 2003; Leventhal et al., 1980; Leventhal et al., 1984; Reynolds & Alonzo, 2000). Information from all three of these sources contributes to an individual’s forming an illness representation of a specified illness or making sense of that illness (Hagger, 2003; Leventhal et al., 1980; Leventhal et al., 1984; Reynolds & Alonzo, 2000).

To date, the CSM has only been used to study representations of renal disease in participants already diagnosed with renal disease, not in participants at risk. Studies have explored the association of renal disease representations with all of the following: self-care behaviors in ESRD patients, fluid non-adherence in hemodialysis patients, depressive symptoms in hemodialysis patients, survival among patients with ESRD, and quality of life in ESRD patients (Chilcot et al., 2011; Chilcot et al., 2010; Covic et al., 2004; Fowler & Baas, 2006; Griva et al., 2009; O’Connor et al., 2008; Parfeni et al., 2013; van Dijk et al., 2009). This literature concluded that among participants with ESRD, renal disease representations were related to mood symptoms, quality of life, well-being, therapy choice, and self-care behaviors, including fluid adherence, diet, and medication (Chilcot et al., 2011; Chilcot et al., 2010; Covic et al., 2004; Fowler & Baas, 2006; Griva et al., 2009; O’Connor et al., 2008). Two of these studies suggested that ESRD outcomes might be significantly improved by changes in patients’ renal disease beliefs, as measured by both cognitive and emotional illness representations (Parfeni et al., 2013; van Dijk et al., 2009). However, the literature lacks studies that explored renal disease representations in patients at risk for the disease, which would be beneficial to determine how renal disease representations are related to risk perceptions, especially in a high-risk group such as African-American women with T2D.
The studies that have used the CSM to understand risk perceptions of other diseases have produced findings of considerable significance. The CSM has been used to explore and describe risk perceptions in participants with BRCA1/2 mutations (Kelly et al., 2005), in participants at risk for venous thrombosis (Kaptein et al., 2007), and most relevant to this study, in African-American participants with T2D at risk for diabetic complications, including ESRD (Calvin et al., 2011). All three of these studies found that illness representations influenced risk perceptions for the specified diseases. Another study that used the CSM to examine breast cancer risk found that personal experience had an important impact on risk perceptions, illness representations, and decision-making, hence the importance of studying illness stimuli presented in the CSM (Rees et al., 2001). Kelly et al. (2005) noted that the CSM is a good model to use to examine risk perceptions because information in these five domains may influence peoples’ perceptions of risk, shape how they express perceptions of risk, and affect the relationship of perceived risk to behavior.

Building on this literature, the CSM was used to guide the development of the research questions for this study and to explore and describe renal disease representations, perceptions of individual renal disease risk, and factors influencing representations and risk perceptions in African-American women with T2D (Figure 5). An interview guide was developed for this study based on the CSM components for this qualitative study. Open-ended questions were designed to encourage patients to elaborate on their common sense ideas about renal disease. An in-depth qualitative analysis allowed us to understand better renal disease representations in African-American women with T2D and also explore if these representations were related to risk perceptions in this population.
3.1.2 Background and Significance/Literature Review

Little research has focused on individuals’ renal disease representations and perceived risk of renal disease, and no studies have focused on these concepts solely in African-American women with diabetes, a very high-risk group. The few studies that have examined individual renal disease risk perceptions suggested that many people were unaware of their renal disease risk, even in the presence of risk factors (Boulware et al., 2009; Calvin et al., 2011; Jennette et al., 2010; Jurkovitz et al., 2005; Waterman et al., 2008). In fact, large-scale database research supports a conclusion that a significant number of people with varying stages of renal disease are unaware of disease presence
Three community-based studies reported that almost half of African-American participants had at least one risk factor for kidney disease, and a number of them had diagnosed diabetes; however, the majority of participants in all three studies did not perceive themselves at high risk for kidney disease (Boulware et al., 2009; Jurkovitz et al., 2005; Waterman et al., 2008). Even though Jurkovitz et al. (2005) found that African-American participants were six times as likely as non-black participants to report a family history of ESRD, only 30.3% reported that it was likely that individuals like themselves would develop kidney disease. Similarly, Boulware et al. (2009) found that only 20% of participants from a predominantly African-American sample reported themselves “very likely” to develop kidney disease. Waterman et al. (2008) reported that 23.5% of African-American participants had been screened for kidney disease in the past year, yet only 2.8% reported that chronic kidney disease was a top health concern. Although Boulware et al. (2009) reported that 33% of participants were “very concerned” about kidney disease, this was reported as the least concerning illness compared to cancer, vision problems, heart failure, and stroke.

Calvin et al. (2011) conducted the single study in African Americans with T2D and explored perceptions of risk for various complications of diabetes, including ESRD. Physiologic measures showed that a majority of participants had hemoglobin A1C (HbA1C) levels over 7% and HTN, and almost a third already had microalbuminuria, the earliest diagnostic criterion for diabetic kidney disease. However, even in the presence of microalbuminuria and other risk factors, participants’ perceived risk of ESRD was low; only 23.8% of participants felt they were at high risk for ESRD (Calvin et al., 2011). In addition, they ranked ESRD below all other complications except
amputation in a risk comparison (Calvin et al., 2011). Since this study was quantitative and did not explore how participants arrived at their risk perceptions, Calvin et al. (2011) pointed to a need for qualitative research to gain a more in-depth understanding of why there was such a low perception of risk for diabetes complications, including ESRD, and in turn facilitate interventions aimed at addressing these perceptions.

In a single qualitative study, focus groups were used to explore perspectives on kidney disease in a predominantly African-American community sample, but the study focused on understanding of kidney disease and risk factors, barriers to health care and strategies for raising awareness, and did not evaluate individual risk perceptions (Jennette et al., 2010). Most of the focus groups contained at least one participant with a family member or friend with ESRD, and participants stated that alcohol, soda, obesity, diet, and urination problems were risk factors for developing chronic kidney disease; however, participants did not recognize diabetes, HTN, or family history as risk factors (Jennette et al., 2010). Also, each group mentioned that, when thinking of kidney disease, dialysis came to mind as a negative, life-altering treatment that was stressful on patients and families (Jennette et al., 2010).

Finally, large database studies have shown that a significant number of Americans who exhibit the diagnostic criteria for chronic kidney disease lack even an awareness of the disease. The overall chronic kidney disease prevalence ranged from 12%-47%; however, only 2%-19% of participants were aware of this impairment (Coresh et al., 2005; McGill et al., 2004; Vassalotti et al., 2010; A. Whaley-Connell et al., 2009). Significantly, awareness was lowest in African Americans (6%) (Vassalotti et al., 2010) and women (3%) (Coresh et al., 2005).

In summary, only four studies were found that specifically examined renal disease risk perceptions among African Americans, and only one of those included a
sample comprised completely of participants with T2D. However, all of these studies concluded that African Americans lack a general understanding of renal disease and underestimate their risk, even in the presence of risk factors. In addition, large database studies have shown that even people in various stages of renal disease are unaware of its presence, and African Americans and women exhibited the lowest awareness. There is no research available that examines renal disease risk perceptions solely in African-American women with T2D, although they are the highest risk group for disease prevalence, and no research that examines how participants arrived at their renal disease risk perceptions. An in-depth understanding of renal disease risk perceptions among high-risk people, such as African-American women with T2D, is needed in order to develop interventions and clinical approaches to increase awareness and address inaccurate risk perceptions, with a goal of influencing behaviors aimed at disease prevention.

3.2 Methods

3.2.1 Design

A qualitative descriptive design (Sandelowski, 2000) was used to explore and describe perceptions of individual renal disease risk, renal disease representations, and factors influencing risk perceptions and representations in a sample of African-American women with T2D.

3.2.2 Sample

Eligible subjects were African-American women with self-reported T2D, without self-reported renal disease or other complications of diabetes including heart disease, stroke, retinopathy, and neuropathy, who were 21 years of age or older, and were able to speak, read, and comprehend English. The algorithm in Appendix A was used to determine study eligibility. Women with self-reported complications of diabetes were
excluded because the presence of T2D complications may influence women’s renal disease risk perceptions and representations and also their complication risk comparisons. Also, these criteria were established in order to capture women early in the trajectory of diagnosed T2D, in an attempt to avoid the presence of microalbuminuria, the earliest sign of renal disease, which could also impact risk perceptions and representations.

Purposive sampling was used which begins with volunteer participants, but allows the researcher to select participants based on personal judgment as to who will be the most informative for the study purpose (Polit, 2008). Maximum variation sampling, a specific form of purposive sampling in which the PI attempts to represent a wide range of experiences, was used to explore both unique and common findings in the target population (Sandelowski, 2000). The PI recruited from a wide range of settings, and individualized recruitment strategies at locations that were underrepresented in the early study stages ensured maximum variation sampling. Participants were recruited using the strategies and plans identified in Section 3.3.4.

The recruitment goal was 30 participants; however, the PI enrolled participants until data saturation was reached at 21 participants. Data saturation occurs when no new themes are emerging from the data and redundancy occurs (Jeanfreau & Jack, 2010). Data saturation has been defined as “data adequacy;” however, there are no adequacy tests or published guidelines that estimate the required sample size to reach saturation (Morse, 1995). Guest, Bunce, and Johnson (2006) conducted an exploratory study and determined that 12 participants were required for data saturation on their topic, but they reported that previous authors have suggested anywhere from five to 36 participants when determining qualitative sample sizes. Therefore, an estimated sample size of 30 women was selected for this study; however, the PI and her two consulting
mentors agreed data saturation was reached once 21 women were enrolled. These three researchers agreed that there was redundancy in themes and no new themes would likely emerge through further data collection by reviewing transcripts.

### 3.2.3 Settings

The Institutional Review Board of Duke University Medical Center approved the study and it was conducted in North Carolina (NC). NC ranked 13th in diabetes prevalence in 2009, and the highest prevalence of cases in the state was among African Americans (15.6%) (DHHS, 2010). In NC in 2011, the point prevalence rate of ESRD secondary to diabetes among African-American women was 2,066.5 (per million population), up from 2,013.3 in 2010 (USRDS, 2014). Comparatively, the NC 2011 point prevalence rate of ESRD secondary to diabetes among White women was 336.1 (per million population), a decrease from 341.6 in 2010 (USRDS, 2014).

The initial recruitment plan included the following locations: the Duke Endocrine Clinic, a research-intensive clinic that treats patients with poorly controlled T2D; Duke Family Medicine, a primary care practice that provides diabetes management and serves a large number of African Americans; churches in Wake County, NC, and surrounding areas with predominately African-American congregations; DukeList, a free classifieds marketplace for the Duke community; and Craigslist. Only one woman was recruited from Duke Endocrine Clinic despite on-going contact between the PI and clinic providers. This could be due to the large number of research studies that attempt to recruit participants from this location. No participants were recruited from Duke Family Medicine. The PI contacted two providers from this location, and although the providers agreed to refer potential participants, this setting did not allow fliers to be hung in the waiting room due to clinic policy. The majority of enrolled participants (13 women, 61.9%) were recruited from four area churches, and nine of those women were
recruited from one rural church outside of Wake County, in a town called Cameron, NC, with a reported population of 285 in 2010 (Bureau, 2010). Kennedy et al. (2011) found that the most effective strategy for recruitment of African-American study participants was hand-distributed letters and fliers at various churches. The literature highlighted that working through community-based organizations, namely churches, was an effective recruitment strategy used to increase involvement of African-American participants (Yancey, Ortega, & Kumanyika, 2006). No participants were recruited from the ad on DukeList, and two women were recruited through the same ad on Craigslist. Research has shown that recruitment through Craigslist required minimal effort, was low cost, provided widespread distribution to a diverse population, and was effective in recruiting younger participants and women for qualitative research (Arab et al., 2010; Ramo, Hall, & Prochaska, 2010; Worthen, 2013). Finally, five women were recruited via snowball sampling. This type of sampling involves asking early participants to make referrals to other potential participants and may be more cost-effective, practical, and aid in establishing trust with the referred participants (Polit, 2008). Snowball sampling was found to be an effective recruitment strategy among African American participants in a systematic review focused on strategies to recruit minority populations (Ibrahim & Sidani, 2014).

3.2.4 Recruitment Procedures

Healthcare providers and staff at the Duke Endocrine Clinic and Duke Family Medicine were informed of the study purpose and sampling plan. The PI described the study to providers from both clinics and also front office staff at the Duke Endocrine Clinic and emailed fliers and detailed study information to providers from both clinics so they would have extra copies and the PI’s email address and contact information. Providers at both locations were very interested in the study and responsive. Providers
were asked to approach potential study participants and inform them about the study and offer them the IRB-approved flier that included the PI’s contact information. The PI also obtained permission to place IRB-approved fliers in the waiting room at the Duke Endocrine Clinic.

In order to reach potential participants in predominantly African-American churches in the Wake County area, the PI, a healthcare provider in Wake County, approached patients, current coworkers, and former coworkers who were congregation members of local churches, or had connections to local churches, and asked for their assistance in obtaining contact information for lay church leaders. The PI then met with, emailed or called lay church leaders to inform them of the study purpose and sampling plan and asked them for permission to post IRB-approved study fliers on church bulletin boards for self-referral of participants. The PI also asked congregation members to approach potential participants for referral and offer them fliers. The PI collaborated with a lay church leader from one church and set up a weekend information session to present the study purpose and inclusion criteria to church members. Nine women were recruited and enrolled from this church presentation. According to research on effective recruitment and retention of minority participants, a common approach to alleviating barriers and establishing trust was community involvement, particularly in the form of using a lay outreach worker from the targeted population (Yancey et al., 2006). The PI also encouraged early participants to refer women through snowball sampling and provided extra fliers as requested. Some major advantages of snowball sampling include less time screening people to determine if they are appropriate for the study, cost-effectiveness, and smoother establishment of a trusting relationship due to referral from a previous participant (Polit, 2008).
Finally, the PI posted ads on DukeList and Craigslist under “volunteer opportunities” with IRB approval. The ads were identical and described the study in detail and included the inclusion criteria and the PI’s contact information, including an email address. Both of these ads were renewed once throughout the recruitment period due to time frame limitations on posts.

Women who met the inclusion criteria and were willing to participate were asked to contact the PI, who determined study eligibility. The PI followed a phone script with prospective participants when they contacted her over the phone (Appendix B) and none of these responses were recorded. Potential participants who initially emailed the PI were contacted via telephone so the PI could determine eligibility via the phone script. The PI determined eligibility of the women recruited from the church presentation in-person in a private location as they approached her after the presentation. Women who were still interested in the study after the phone screening or in-person screening and study description were asked to meet in a private location that was convenient to them to obtain informed consent, including permission to audio record the interview. All of the women enrolled from the church presentation were interviewed in the church, in a private area. Other locations women chose to conduct the interview included their home, their workplace, fast food locations, and the mall. Each participant was offered a $30 gift card as compensation for participation upon completion of the interview.

3.2.5 Consent

During initial telephone contact with each prospective participant, the PI explained the study in detail, including the study purpose, benefits and risks, the demographic data collection tool, and the interview. Each woman was advised that her participation was completely voluntary and was also advised that her information
would be kept confidential and only shared with the PI's mentors, and that her digitally recorded interview would be destroyed after data analysis was complete. If the woman agreed to proceed with the study at that point, the PI set up a convenient time and location to meet her, in her home, at her workplace, or at a local community based location. At the in-person meeting, the PI explained the study in detail again and reviewed the consent form with the woman, asking if she had any questions before obtaining informed consent. Once informed consent had been obtained, the PI proceeded with data collection via the demographic data form and then the open-ended interview. The Institutional Review Board of Duke University Medical Center approved the consent form.

3.2.6 Data Collection Methods

3.2.6.1 Subject characteristics

Each participant was asked to complete a demographic data form prior to the interview that asked the following: age (years), income (categorical range), time since diagnosis of T2D, co-morbidities, living arrangements, marital status, educational level, primary care provider (yes/no), date of last hemoglobin A1C (HbA1C) or metabolic assessment (if known), and presence of microalbuminuria (if known) (Appendix C). This demographic data was used to describe the study sample and to look for patterns in demographic characteristics.

3.2.6.2 Open-ended interviews

Data was collected via open-ended interviews. All interviews were conducted by the PI and scheduled based on participant preference, face to face at a convenient location and time. Interviews lasted approximately 60 minutes to avoid burden to the participants. The interviews conducted with the first five enrolled subjects were considered pilot interviews in order to conduct a validity assessment of the proposed
interview guide. According to Polit (2008), it is beneficial to get preliminary feedback on measures from a small number of people, and one approach is to pre-test the measure with a sample of people drawn from the target population. Cognitive questioning, which incorporates simple questions to determine how participants processed the words and ideas presented to them in the questions (Polit, 2008) was conducted after each of the first five interviews. The following questions were asked: Did you understand the wording and meaning of each question and, if not, which questions were not clear? Were there any questions that confused you and, if so, which words or parts were confusing? Was there anything else you wish I had asked? (Polit, 2008). The first five women enrolled reported that they understood the meaning of each question, were not confused about any of the questions, and could not think of any added questions. Therefore, the questions were deemed valid, the same set of questions was used with the remainder of the participants, and the interviews from these five participants were incorporated into the overall study data and findings.

The interviews were semi-structured, and the interview guide (Appendix D) was used as a template. However, the order of questions was altered in some interviews according to participant responses to facilitate the flow of conversation, and extra probing questions were incorporated when responses were not detailed or elicited further questions (Polit, 2008). In order to avoid jumping directly into questions and to establish trust, the PI began each interview asking the woman to tell her about her course of diabetes (i.e., when was she diagnosed and what has transpired since then). This allowed the PI to have an interactive discussion with each woman at the beginning and allowed each woman to open up and tell her story before more structured questions were asked from the interview guide (Polit, 2008).
Question 1 elicited how likely the woman felt she was to develop renal disease. This question addressed research question 1 and incorporated risk perceptions from the CSM. This question was open-ended in order to elicit various degrees or descriptions of risk from the women, although most of the women requested options, and a Likert scale was offered ranging from not likely to very likely. Question 2 addressed research question 2, incorporated a comparative analysis of various diabetes complications, and was assessed with note cards. Each note card listed one complication of T2D, and each woman was asked to rank the complications in order of her perceived personal risk. This provided a comparative view of risk and was conducted in this manner so that participants were not required to acknowledge various complications. Question 3 assessed each woman’s cognitive renal disease representation by asking questions on beliefs within each of the five domains proposed by the CSM. This question addressed research question 3. The domains were simplified to lay language to enhance participant understanding, and open-ended probes were used if a woman provided vague responses to elicit more discussion. Question 4 was used to answer research question 4 and explored illness stimuli from the CSM, asking the women to explain how they arrived at their renal disease representations. Probes were frequently used after this question, because many women did not report primary illness stimuli noted in the literature, namely healthcare providers and media sources. Finally, question 5 addressed research question 5, and was intended to elicit the woman’s emotional representation of renal disease; however, emotions verbalized or portrayed by the women throughout the interviews were also accounted for to describe this component of the CSM.

The risks to participants in this study were minimal; however, some of the questions may have made the women feel uncomfortable. Each woman was reassured she could refuse to answer any of the questions and could take a break at any time.
during the interview. Each woman was also informed that she could stop participation in the study at any time. Each interview was limited to approximately 60 minutes in order to decrease interview burden.

### 3.2.7 Data Preparation

All interviews were audio-recorded using a digital recorder with participant permission. Upon completion of each interview, the PI thanked the participant and asked permission to follow up with her in order to establish study rigor through member checking (Polit, 2008). A professional transcriptionist transcribed all interviews verbatim, and, to ensure accuracy, the PI checked all of the transcribed interviews against the recordings (Polit, 2008). Each participant was assigned a study ID number to ensure confidentiality, and all transcribed interview data were stored on a secure SED drive on the Duke University server developed solely for this study. The only people who had access to this drive were the study PI and the PI’s mentors. Recordings were destroyed after data analysis was complete. The PI compiled the demographic data from all participants in a single Excel spreadsheet, and it was double-checked for accuracy and is stored on the secure SED drive as well. Means and standard deviations of interval-based variables were calculated via the function feature in Excel. All signed consent forms, demographic data forms, and interview notes are stored in a locked cabinet in the locked PhD student suite at Duke University School of Nursing.

### 3.2.8 Data Analysis

Data collection and data analysis occurred simultaneously, which is common in qualitative studies, allowing for constant comparative analysis of the data (Polit, 2008; Sandelowski, 2000; Thorne, 2000). Qualitative content analysis was used to analyze the data, a dynamic form of analysis aimed at summarizing the informational content of the data (Sandelowski, 2000). This type of analysis is data-derived so that codes are
generated from the data, in contrast to quantitative content analysis which includes application of pre-existing codes to the data (Sandelowski, 2000). According to Sandelowski (2000), in qualitative content analysis, the research may begin with a pre-existing coding system; however, that is always modified or may even be completely discarded during the data analysis process to ensure the best fit. Hence, the literature to date on renal disease risk perceptions and the CSM were used to establish a pre-existing coding scheme; however, coding was not limited to these a priori codes and included development of new codes and themes within the CSM. The coding guide with definitions is presented in Appendix E.

First, the PI manually read each transcribed interview several times to gain an overall sense of the views expressed by each woman. Then, the PI used a manual color-coded system to highlight responses in each interview pertaining to each component of the CSM, as defined in the a priori coding scheme. For example, responses that the PI felt pertained to renal disease risk perceptions were highlighted in pink, and responses that the PI felt pertained to emotional renal disease representations were highlighted in yellow. This coding scheme is described in Appendix F. Conceptual files were used to manage the codes pertaining to the CSM. In this manual approach to data analysis, a physical file folder is created for each code, and all material related to that code is inserted into the file (Polit, 2008). The physical file folders were then reviewed to establish themes and sub-themes within each component of the CSM.

The PI manually notated codes that arose in the interviews that were not defined in the a priori coding scheme in the margins of each interview. These codes were compared among interviews for similarities and differences. When similarities were observed, new codes and themes were created. These included unexpected subthemes under codes within the CSM, creation of a new category of illness stimuli, and
exploration of a component of the CSM that the PI did not initially intend to study. The new codes and themes are defined in Appendix E. Vivid quotes were extracted from the transcripts to support the themes.

Member checking and peer debriefing were conducted to establish rigor. Member checking occurs when the researcher provides feedback to participants on the analysis of emerging interpretations and obtains participants’ reactions (Polit, 2008). The PI selected four participants (20%) for member checks. All four participants were in agreement with the PI on the general interpretations discussed. Peer debriefing involves reviewing and exploring various aspects of the study with peers experienced in qualitative methods, the phenomenon being studied, or both (Polit, 2008). One of the PI’s mentors, Dr. Allison Vorderstrasse, has had significant research experience with African-American women with T2D; another mentor, Dr. Julie Barroso, is an expert in qualitative methods. Both of these mentors individually read and coded five random interviews along with the PI, and the three researchers discussed the themes they derived from the selected interviews in a conference call. All three researchers were in agreement on the overarching themes present in this sub-set of interviews and were in concordance with development of a new theme within the timeline domain of cognitive illness representations. One mentor also read 20% of the remaining interviews to ensure agreement on codes and themes and met with the PI weekly throughout data analysis to collaborate and discuss data analysis. All of the new themes that arose outside of the a priori coding scheme were discussed at length in these meetings, and there was agreement regarding these themes.
3.3 Results

3.3.1 Sample demographics

Twenty-one women contacted the PI and were screened, and, based on screening responses, all 21 were eligible for participation and enrolled. Although the majority of women enrolled were recruited from churches, and nine women were recruited from a single church, variability of demographic characteristics was evident. The age range of the women enrolled in the study was 29-68 years, with a mean age of 50.7 (SD=9.8) years. The average time since diagnosis of T2D was 10.9 (SD=8.7) years, and the self-reported mean HbA1C was 7.58% (SD=.02). The majority of women had co-morbidities, including HTN and hyperlipidemia. A vast majority of the women reported they had a primary care physician and insurance. The self-reported demographic information is summarized in Table 3. Within the results, “kidney disease” was used in reference to “renal disease,” the way it was presented throughout the interviews for the use of lay language.
Table 3: Sample Characteristics

<table>
<thead>
<tr>
<th>Demographic Factor</th>
<th>Range/Categorical Responses</th>
<th>Mean/Frequency</th>
<th>n = Number of women who responded to question (of 21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>29-68 years</td>
<td>50.7 years</td>
<td>21</td>
</tr>
<tr>
<td>Length of T2D Diagnosis</td>
<td>1 month-30 years</td>
<td>10.71 years</td>
<td>21</td>
</tr>
<tr>
<td>Self-reported HgbA1C (most recent)</td>
<td>6.1-12%</td>
<td>7.58%</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>8 were unsure</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td>Less than $24,999</td>
<td></td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>$25,000-$49,999</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>$50,000-$99,999</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>$100,000 or more</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>8 (38.10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 (28.57%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 (28.57%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-morbidities</td>
<td>High blood pressure</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>High cholesterol</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Heart disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Liver disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 (57.14%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>14 (66.67%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 (19.05%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Arrangements</td>
<td>Alone</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>With significant other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>With family member/friend</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>In assisted living</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 (19.05%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9 (42.86%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>8 (38.10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Living with a partner</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Single, never married</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10 (47.62%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 (4.76%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (14.29%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 (33.33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highest level of education</td>
<td>12th grade or less</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>High school diploma</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some college, no degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Associate or technical degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bachelor's degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Graduate/professional degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (14.29%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (14.29%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 (33.33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 (23.80%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 (9.52%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 (4.76%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary Care Provider?</td>
<td>Yes</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20 (95.24%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 (4.76%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been told you have</td>
<td>Yes</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>microalbuminuria, or protein in</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your urine?</td>
<td>Unsere</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 (33.33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 (57.14%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 (9.52%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.3.2 Risk Perceptions

3.3.2.1 Low perceived susceptibility to kidney disease

Five women reported they felt “very unlikely” to develop kidney disease, and seven reported they felt “not likely;” therefore, a majority of the women (57.1%) felt they were unlikely to develop kidney disease. Conversely, four women felt “likely,” three felt “very likely,” and two women reported they were unsure of their likelihood; therefore, a third of the women perceived they were likely to develop kidney disease. Most of the women who perceived their risk as unlikely felt they were staying on top of things and controlling their diabetes, including their blood glucose and HbA1C levels, although one of them stated she had not been to the doctor in a year and does not have a glucometer due to lack of insurance, and another woman reported she is “past due” for a HbA1C check. Two women also noted that they felt unlikely because they drink a lot of water daily to “protect their kidneys.” Two other women felt they were unlikely since healthcare providers communicated their “kidney labs currently looked good.”

Among the four women that felt likely to develop kidney disease, three attributed this perception to lack of diabetes control, and one of these women turned the focus to healthcare providers by noting, “It is hard for them to control my diabetes.” Among the three women who felt very likely to develop kidney disease, one reported she felt this way because she is on insulin; another woman explained she felt at very high risk because her diabetes is not well controlled at this point (HbA1C reported at 12%), and the third woman explained she was referred to a nephrologist last year due to her lab work, but she had not returned for a follow-up yet.

3.3.2.2 Kidney disease ranked low in comparison of complications
When ranking diabetes complications from most perceived risk to least, eleven women (52.4%) ranked kidney disease last; two women ranked kidney disease second to last; and four ranked it in the middle, as #3. Therefore, 81% of the women ranked kidney disease in the bottom three when ranking complications for which they felt most at risk. One woman stressed, “I guess I feel like, you know, when you are overweight mostly they stress about your heart, your heart, your heart. They do not necessarily talk a lot about your kidneys.” Another woman noted, “Possibly I think it is at the bottom because again, I really do not know anything about kidney disease, have not really been told anything about it. I have not really did any research about kidney disease. And I do not recall reading anything about it being on the list for diabetics.”

Ten women ranked neuropathy first, and retinopathy and stroke followed with four #1 rankings each. Most of the women that ranked neuropathy first reported they were experiencing some current symptoms associated with it. Of the four women who chose retinopathy as #1, two of them reported some early signs and noted they were being followed closely for it. Out of the four women who ranked stroke as #1, two of them had had strokes themselves, although they both reported they occurred before they were diagnosed with T2D, and the other two had immediate family members that had experienced strokes. Overall, 12 women disclosed they had a personal, family, or close friend connection to strokes that had resonated with them and impacted their rankings. Finally, heart disease was ranked as #1 from two women who reported comorbidities including HTN and hyperlipidemia, respectively.

3.3.3 Cognitive Illness Representations

3.3.3.1 Identity (Symptoms)

The women’s cognitive representations of kidney disease are summarized in Table 4. The perceived symptoms of kidney disease mentioned most frequently were
urination problems. Almost half of the women (47.6%) believed decreased urination was a symptom, whereas six women believed frequent urination was a symptom. The next most common symptoms mentioned were swelling or bloating (23.8%), back pain (14.3%), kidney stones (9.5%), and high creatinine level (9.5%). Another two women mentioned toxins by noting “issues with toxins” and problems “with all the stuff that needs to be filtered out of your body.” Protein in the urine, high sugars all of the time, side pain, and pressure were each mentioned by one woman only. Three women (14.3%) responded that they did not know what the symptoms were.

3.3.3.2 Causes

A majority of the women did mention diabetes (12 women, 57%) was a cause; however, a number of these women added that participation in this study made them more aware of that. However, only three women mentioned elevated blood sugars or HbA1C were influential. The next most common cause mentioned was HTN (19%), followed by family history or genetic factors (14.3%). Five women reported they had an immediate family history of kidney disease, and four an extended family history; however, only two of the women with an immediate family history mentioned family history as a cause. Two women mentioned lupus could cause kidney disease, and one woman added cancer. Regarding diet, not eating right, not drinking enough fluid, consuming too much alcohol, and drinking soda were each mentioned twice as perceived causes. Drug use, urine backed up in the kidneys, and “too much stuff attacking the kidneys” were each mentioned once. Finally, four women (19%) replied they did not know any causes of kidney disease.

3.3.3.3 Timeline

A vast majority of the women (71%) thought that kidney disease develops gradually, and most of those women clarified they meant over years when probed.
However, three women noted that, although they believed it was a gradual process, people often ignore it or do not take action in the beginning, and therefore it seems to come on quickly at the end. For example, “I do think it starts off kind of slow and then gets worse, but they just do not take action on it.” And another woman stated, “I think it hits people quickly only because it is ignored in the beginning…you know, because we did so much damage on the front end…when we are younger, we are not going to the doctor, taking our health in consideration as we should.” Three women reported they felt it follows a different course for each person, and this variability was attributed to how people take care of themselves. Only one woman reported she felt it had a rapid onset, noting, “You know, you need your kidneys to function, and that is an everyday 24-hour thing, so if they start going bad then I think you may feel it pretty quickly.” One woman specifically felt it was inevitable and stated, “It is going to come,” although she added she felt it would not come on as quickly if you do what the doctors ask you to do. Finally, one woman admitted she was not sure, noting, “I was scared of what I may find out.”

### 3.3.3.1 Perceived temporal order of diabetes complications

A subtheme that arose under timeline was a perceived temporal order of diabetes complications. A number of women suggested that they felt kidney disease was a late complication of diabetes when rationalizing why they ranked kidney disease towards the bottom of the five complications. For example, one woman stated, “I usually think that that [kidney disease] is probably, to me, the last stages of what I have seen people go through.” Another woman stated that she ranked retinopathy above kidney disease because “I figure that if my levels continue to increase that it might start to affect, you know, smaller organs and things of that nature before it went to larger ones.” A third woman mentioned that she felt she was doing fairly well because “most people that has had it [diabetes] this long [20 years] are on dialysis.” Admittedly, a few of the
women felt kidney disease developed later in the disease process because their doctors had not talked to them much about it or brushed it off. Therefore, these women seemed to perceive kidney disease as a late complication of diabetes and were not concerned about it at this time.

3.3.3.4 Consequences

A majority of the women (76.2%) related their perceived consequences of kidney disease directly to dialysis. One woman stressed, “It could be pretty devastating, especially when they get to the point where they have to go on dialysis...It is rough.” The following were the most commonly mentioned consequences of dialysis: tiredness and/or weakness (38.1%); interference with work (23.8%); more dependence on others (19%), especially for transportation to and from treatments; and decreased ability to travel (14.3%). For example, one woman stated, “My mother-in-law, now she used to be a worker. And so once she got on dialysis, like everything just stopped...She come home from dialysis, and she just zonked out. She just was.” Another woman poignantly discussed the travel consequences by stating, “You cannot go nowhere. You cannot really travel, you know. You just surviving.”

Regarding daily life consequences, the following were the most common responses: dietary changes, medications, and exercise (each mentioned by 33.3% of the women), and watching fluids and physical appearance changes (both 9.5%). Regarding fluid intake, one woman noted, “All I know from what I have heard is that if a person has kidney problems they have to really watch their fluid intake. That is the only thing I can remember now. They cannot drink a certain- they have to drink less.” Two women perceived using the restroom more often was a consequence, whereas two others reported kidney disease results in the inability to urinate. Some other things that were mentioned individually included depression, pain, soreness at the access site, smelling...
like urine, decreased appetite, and vomiting. One woman also noted the risk for depression once on dialysis by stating, “So, it is your whole day you are sitting there and then not being able to use the bathroom... And I can see how people get depressed.”

### 3.3.3.5 Controllability

Eight women (38.1%) perceived kidney disease was controllable without mentioning any specific ways to control it, whereas six other women (28.6%) felt it was controllable under certain circumstances. These women felt it was controllable with lifestyle changes, by staying healthy and/or with education. For example, one woman noted, “To control it is, you know, just make sure that you are doing things to keep your kidneys healthy. So, like me as a diabetic, you know, monitoring my glucose levels. I even think that exercising, because if you are having hypertension and if you are able to exercise and, you know, keep the body strong as a whole, then I think that it will help to heal what was broken.” Regarding education, one woman noted, “I think it definitely can be controlled if you are educated about it, you know what it is, and you know the things to do to prevent it.” One other woman reported she felt it depended on the person, and one was unsure, noting, “You know, I do not know what makes it tick or what happens with it.” Four women felt it was uncontrollable.

Eight women (38.1%) also felt kidney disease was curable with a transplant. One woman answered, “Yes, with a transplant. That is the only thing that can cure it.” Five other women reported it was curable without mentioning transplants, and one of these women explained, “I do believe it can be cured, and the reason why, because with modern medicine, with the change of lifestyle, I believe that there can be cures where people who have been on dialysis can literally come off of dialysis, that their kidneys can heal.” Four other women admitted they were unsure if it was curable, with one saying, “So when you hear that end-stage renal it is kind of frightening because it means
I am in the end, bottom line, last results…Do you ever come back from that?” Three other women believed it is not curable, with one stating, “I would like to hope so. I would like to hope so. But evidently not because I see so many people that has gone on dialysis.”

Table 4: Cognitive illness representation results

<table>
<thead>
<tr>
<th>Identity (Symptoms)</th>
<th>Causes</th>
<th>Timeline</th>
<th>Consequences</th>
<th>Controllability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased urination/ frequen urination (47.6%)</td>
<td>Diabetes (57%)</td>
<td>Gradual (71%)</td>
<td>Related to dialysis (76.2%)</td>
<td>Controllable (66.7%)</td>
</tr>
<tr>
<td>Swelling/bloating (23.8%)</td>
<td>HTN (19%)</td>
<td>Different course for everyone (14.3%)</td>
<td>-Tiredness/weakness (38.1%)</td>
<td>Uncontrollable (19%)</td>
</tr>
<tr>
<td>Back pain (14.3%)</td>
<td>Family history/ genetic factors (14.3%)</td>
<td>Rapid onset (4.8%)</td>
<td>-Interference with work (23.8%)</td>
<td>Curable with transplant (38.1%)</td>
</tr>
<tr>
<td>Kidney stones (9.5%)</td>
<td>Lupus (9.5%)</td>
<td>Inevitable (4.8%)</td>
<td>-Dependence on others (19%)</td>
<td>Curable without mention of transplant (23.8%)</td>
</tr>
<tr>
<td>Elevated creatinine level (9.5%)</td>
<td>Dietary: not eating right, not drinking enough fluid, consuming too much alcohol, drinking too much soda (each 9.5%)</td>
<td>-Perceived temporal order of diabetes complications</td>
<td>-Decreased ability to travel (14.3%)</td>
<td></td>
</tr>
<tr>
<td>Problems with toxins (9.5%)</td>
<td></td>
<td></td>
<td>Dietary changes, medications, exercise (each 33.3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Watching fluids, physical appearance changes (both 9.5%)</td>
<td></td>
</tr>
<tr>
<td>Unsure (14.3%)</td>
<td>Unsure (19%)</td>
<td>Unsure (4.8%)</td>
<td>Unsure (4.8%)</td>
<td>Unsure (19%)</td>
</tr>
</tbody>
</table>

3.3.3.6 General lack of kidney disease knowledge

A number of women addressed their lack of kidney disease knowledge throughout the interviews. One woman reported she never really even thought about
kidney disease, while another explained why she brought it up with her doctor recently, “I said because I do not know nothing about it, and I got all these things going on with me.” One woman noted she really has not had a reason to research it, while another said she had never read anything about it because she “was scared” of what she might find out. Two other women suggested they have taken it upon themselves to learn about kidney disease and be their own advocates. One of them discussed how she wished she had been educated earlier on kidney disease:

I think that even for myself with having higher numbers in my albumin and creatinine levels…I think if I was educated about what was going on with my body and how to prevent it and the importance of certain things like my Lisinopril. Like, if I knew the importance of it, then I think I would have been able to not be where I am right now.

3.3.4 Emotional Illness Representations

3.3.4.1 Fear

There were ten women (47.6%) who mentioned feeling scared, and similarly six women (28.6%) who mentioned fear when the women were asked what emotions or feelings came to mind when they thought about kidney disease and their feelings were expressed throughout the interviews. One woman stated, “You know, it is scary enough that if you can prevent it, you should.” Another woman simply professed, “I think other than cancer, I think it is the most feared disease that you can have.” Eight women related their emotions and feelings to their perceptions of dialysis. Some poignant examples of this are displayed in Table 5.

3.3.4.2 Sad or depressed feelings

Five women (23.8%) reported they felt sad when thinking about kidney disease, while two women (9.5%) reported it was depressing to think about, and one other
woman noted she felt heartbroken and another that she would feel like her life was over (Table 5).

3.3.4.3 Other feelings

Anger and concern were each expressed by two women (9.5%) (Table 5). One woman related the associated anger to a friend and compared it to the grief process by stating, “Sometimes, using the lady, the friend that I had, had it because it changed her life so drastically. Because, she went from being angry to dealing with it, to getting angry because she could not go places, could not do things that she had done in the past...As if she was going through the grief stages.” Some other feelings that were mentioned individually were devastation, frustration over lack of knowledge, and happiness and hope, both related to the possibility of a transplant.

Table 5: Emotional illness representation findings

<table>
<thead>
<tr>
<th>Fear or feeling scared (76.2%)</th>
<th>&quot;That I do not want to have it. Because I do not want to go on dialysis. I see my brother-in-law on dialysis. I actually went in there and looked at him on dialysis and that is scary.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&quot;Wow. I am like wow. I need to do what I need to do so I do not have to go down that path...I do not want to have to go to dialysis...Well, like I said a little fear because I know sometimes people die from it so ...And then, you know, have complications with the shunts and stuff because that was one of the things with him [a friend]. They did the first surgery and it closed up and they had to go back in and do another one...So I am like wow, I do not want to have to go through that.&quot;</td>
</tr>
<tr>
<td></td>
<td>I had an aunt to go [on dialysis], and that is the only reason why I am on insulin because she always would tell me, she is dead now, that 'I think if the doctor would have put me on insulin I would not be on that.' She liked to shift the blame but some of it is our fault. But, she would always say that so I actually went and requested to my doctor that I be on insulin because my sugar numbers were just so...I had taken her to dialysis a couple times and honey that scared me enough.</td>
</tr>
<tr>
<td>Sad or depressing feelings (42.9%)</td>
<td>&quot;I feel sad. Only because, again, I think of it as, you know, no recovery. I just never really seen anybody go on [dialysis], and like cancer, you go into remission, and there probably is people that do, but I never seen them.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;Just if I think about it long I lose it. You feel like your life is over. I would.&quot;</td>
</tr>
<tr>
<td>Anger (9.5%)</td>
<td>&quot;She [a friend] went from being angry to dealing with it, to getting angry because she could not go places.&quot;</td>
</tr>
<tr>
<td>Concern (9.5%)</td>
<td>&quot;I am really concerned about kidney disease...Because you know, I just have heard of a lot of people being on dialysis and stuff like that...But, you know, and it comes from diabetes&quot;</td>
</tr>
</tbody>
</table>
3.3.4.4 Low concern for kidney disease comparatively

Overall, the women reported more concern for the other four complications included in the ranking comparison, and this was frequently related to personal experiences and family history. When the women were asked which of the five complications they were most concerned about, five women admitted stroke was the most concerning complication to them, and most of them attributed this to their personal experiences or friends or family who have suffered from the consequences of strokes. One woman cited the morbidity associated with strokes explaining, “Because then I will not be able to maintain life with my kids. Even though the next one would be the kidney because of the dialysis and stuff, but I think stroke would really get me more than anything.” Five women stated heart disease was the most concerning to them, attributing this concern to a family history and the associated mortality. Five women also reported retinopathy as the most concerning, and most of these women reported fear of losing their vision, with one noting, “I have to see.” Only three women reported kidney disease carried the most concern of the five, and all of these women attributed this concern to dialysis: “Because, you know, if it gets worse, I could be on dialysis.” One woman openly stated all five of them concerned her equally, stressing, “Because you do not want to go on dialysis, you do not want to have a stroke. You do not want to have a heart attack. And you do not want to lose your vision. So all of them.”

3.3.5 Illness Stimuli

3.3.5.1 Lay information (media sources and cultural knowledge)

Only six women (28.6%) reported they have learned about kidney disease from Internet sources. Google was the most mentioned site followed by WebMD, The Mayo Clinic, and Health Med. One of these woman reported the Internet was where she had learned the most and stated, “For me, the Internet. I search stuff…Internet is the first
thing you go to to figure out what is going on.” Conversely, when probed about the Internet, another woman reported, “That is amazing because that is about the only thing I have never Googled, kidney disease.” Five women (23.8%) mentioned they learned some things about kidney disease from television, including commercials, The Learning Channel, “The Doctors” and “Dr Oz,” and one woman mentioned watching a documentary on dialysis. This woman noted, “I did not understand what they did with dialysis…until I saw the documentary.” Finally, four women (19%) mentioned pamphlets or brochures as sources, mainly pamphlets at the doctors’ office.

This category of illness stimuli also incorporates cultural knowledge, which came up a few times in the interviews. For example, a number of women called diabetes “sugar” throughout the interviews, which could be influential to disease knowledge and impact risk perceptions of complications. Also, three women expressed their risk perceptions were related to their faith by insinuating they did not want kidney disease, but it was in God’s hands. There were limited references to cultural knowledge among the women in the interviews, although a few sociocultural factors were mentioned as influential to kidney disease knowledge and preventative behaviors. For example, among three women a lack of disease knowledge and poor glucose monitoring was attributed to the multi-caregiver role, especially in conjunction with holding a full-time job. Also, two women admitted that they had not heard a lot about kidney disease from their healthcare providers because they lacked insurance coverage, and when they were able to make appointments the focus was always on glucose control, obtaining medications and supplies, and control of the current situation. One of these women noted she had signed up for a program to help with her doctor’s visits, but it would not cover her supplies and medicine. However, she suggested she had family members and a friend at church that helped her with lancets and supplies. This woman also admitted
that financial concerns prohibit her from getting to the doctor often, and although she was aware of some free programs, they were far away. The other woman lacking health insurance noted she has not been to the doctor in a year and does not own a glucometer, yet feels her diabetes is under control.

3.3.5.2 External sources

3.3.5.2.1 Family and friends

A majority of women reported learning about kidney disease and dialysis from family members and friends who had experienced it; however, almost all of these women conveyed that they did not discuss the disease or dialysis process with these sources but gained insight from observation. Seven women (33.3%) reported they had close family members (a parent, sibling or grandparent) with varying stages of kidney disease, and three of those family members were on dialysis. Out of these women, only one of them stated she had actually spoken to her family member about the disease, yet it was minimal. She noted, “He [grandfather] used to be on dialysis as well and kind of touched on it a little bit before he died.” The remaining six women suggested they learned from watching their family members struggle with the disease. For example, one woman mentioned she learned about the symptoms of kidney disease from her father; however, she admitted she did not really know him and had not met him until about a year ago, but “remembered he needed to go and be dialyzed, and his face was like….so his face sometimes would swell up so huge because he was not compliant.” One other woman mentioned her brother was recently diagnosed with early kidney disease, and she had read about it on his discharge summary and researched it for him. She admitted she had learned more about the disease from her brother’s recent diagnosis than from her father who had kidney disease; although she had been his caregiver, she “did not really pay it too much attention… just figured, you now, dad had diabetes for as long as I had known him and these are just things that...”
Another seven women (33.3%) noted they had learned about kidney disease from extended family members with the disease, including aunts, cousins, and adopted family members, some of whom were also on dialysis and one who had received a transplant. Similarly, these women also reported their knowledge was mainly gained from observation of the family members, including giving rides to family members with the disease. One woman who had a cousin on dialysis admitted she had not said much about the process “except for being tired.” Another woman cited distant family knowledge by noting, “I know some people. One of my, well, I call her cousin auntie, but she had it, but she died. That is from hearsay.”

There were also eight women (38.1%) who mentioned they learned about kidney disease from friends. One of these women mentioned a friend who had just had a shunt placed for dialysis and stated, “But we really have not really talked about the causes or what really caused it to happen. I mean, I think I have asked him several times, but we never really got into it but, so just knowing him.” Another woman discussed learning about the disease from helping her girlfriend pick her aunt up from dialysis, but when asked if she ever talked to her about the disease process, she admitted, “No, and my girlfriend, you know, I do not think she knows a whole lot.” Another woman noted she has a Facebook friend whose child was diagnosed with kidney disease, and she reads when the mother “chronicles it on Facebook.” Conversely, there was one woman who noted she had learned a lot about kidney disease and dialysis by talking to others and asking questions. She stated, “I learn more through talking to people about it than going on the Internet and getting their version. Because I want to know the real thing.”

3.3.5.2.2 Healthcare providers

The majority of women had not learned about kidney disease from their healthcare providers, nor were providers their main information source. A majority of the women (57.1%) did not mention healthcare providers as a source of knowledge; the
interviewer probed further, and Table 6 summarizes the responses. In total, 61.9% of the women acknowledged kidney disease was mentioned, but never discussed in-depth. The majority of these women reported hearing things related to kidney disease from their doctors, mainly about labs and protein in their urine, but affirmed that their providers never discussed the relationship to kidney disease. One women added that “doctors do not have time for that” when discussing her lack of understanding of lab values. Five women (23.8%) reported they had not had any direct communication about kidney disease with their doctors. Conversely, 14.3% of the women reported they have discussed kidney disease with their doctors; however, one of them just recently had a conversation about kidney disease with her doctor for the first time in relationship to a lab draw, another women reported she initiates the discussions herself, and the third woman reported that healthcare providers were a main source of knowledge, noting, “Well, my primary care doctor – she talks to me a lot about stuff, the kidneys and dialysis. She is trying to keep me healthy.”

3.3.5.2.2.1 Provider control
Six women (28.6%) made comments that suggested that they relied on healthcare providers to keep their kidneys healthy, instead of exhibiting autonomy in regards to kidney disease prevention, suggesting a subtheme of provider control. One woman reported, “They keep a check on it. They said everything is fine.” Another woman said, “They really have not sat me down because she said we do not need to worry about that bridge until we get to it.” Another woman claimed, “I feel like all of the doctors are working together to make sure I do not have it.” And another woman reported the doctors have not discussed kidney disease with her much because “it is hard for them to control my diabetes.” A third woman claimed her primary care doctor talks to her about kidney-related topics, and noted, “She is trying to keep me healthy.” Conversely, there
was one woman in the study that insinuated she works with the doctors to stay on top of everything.

Table 6: Findings under illness stimuli: healthcare providers

<table>
<thead>
<tr>
<th>Healthcare Providers</th>
<th>Statement Examples</th>
</tr>
</thead>
</table>
| 61.9% of women reported kidney disease had been “mentioned” | “Well yes. I mean, whenever I get my results back from my tests he will say you know, your kidney looks good and, but that’s about it. He does not really go into it. I guess as long as they look good.”  
“’They say you are having some protein spill over in your urine. Well, I really did not know what that meant, but I realize that, you know, after studying, that it meant that my kidneys were not functioning properly…But, in that, I had no idea what my microalbumin and creatinine levels were, and they were even elevated for the last three years, like majorly elevated.” |
| 23.8% of women reported no discussion at all | “Not even from my doctor. No. They talk about your eyes, your feet, your A1Cs.”  
“Actually, it is just so ironic. My doctor, I do not think she has ever really spoken of kidney disease…But, I have always spilled protein in my urine…No one would ever say directly or indirectly what the relationship was.”  
“Usually like when I go to the doctor, not that they tell me about it, maybe because mine is kind of controlled, but there is always like stuff on the wall.” |
| 14.3% of women reported in-depth discussions | “I talk to my doctors. Any of my doctors I can talk to about any subject and if something worries me about diabetes or about kidneys I will talk to them. I make them explain it to me.”  
“Well, my primary care doctor. She talks to me a lot about stuff, the kidneys and dialysis. She is trying to keep me healthy.” |

3.3.5.2.3 Workplace experience

Finally, in the context of external sources, there were three women (14.3%) who mentioned they had learned about kidney disease, particularly dialysis, from their workplace experiences. One woman stated she used to be a disability insurance claims adjustor and reviewed claims from people filing for disability when they were starting dialysis. Another woman said she had been to the dialysis unit at her workplace and saw the process firsthand, while the third woman also sees dialysis patients come and go at her current workplace, and she also noted she once worked at a dialysis center.
3.3.5.3 Current experience with the illness

Since this study was conducted with women only at risk for kidney disease, there was limited current experience with the illness; however, four women (19%) had been to a nephrologist, seven (33.3%) reported they had been told they had microalbuminuria, or protein in their urine, and three (14.3%) reported other possible disease symptoms during the interview. Three of the women who had been referred to a nephrologist reported they had been referred years ago by their primary care physicians but had not returned, mainly because of improved lab work. Conversely, the fourth woman had been to a nephrologist in the past year because her doctor told her that her protein in her urine was high, and her creatinine was “borderline.” She reported she had not been back to see him but is due to go very soon, and he put her on a blood pressure medication. She noted that he did not explain much to her, and she is scared to learn much about it. Out of these four women, two of them ranked kidney disease as #5 out of the diabetes complications, one ranked it #3, and the woman who had most recently been to the nephrologist ranked it #1. However, she was the only one of these four women who also reported she did not check her blood glucose as ordered.

Four women with self-reported microalbuminuria reported that they had discussed it with their primary care physicians, yet at varying lengths; however, the other women did not mention the finding or noted it was not discussed in the healthcare setting. Three women noted possible symptoms that they were currently experiencing, although they all were unsure if they were of concern. One of these woman stated, “Well, I do not think I am anywhere near kidney failure because I am in the bathroom maybe every 10 minutes.” The second woman similarly said she urinates “too much” and “stays in the bathroom.” The third woman reported she was unsure if her symptoms were related to kidney disease and questioned, “I think I go to the bathroom
all of the time. And, you know, my bladder feels like it is full. I do not know if that has anything to do with my kidneys. But it feels like I have to go, but I go, and it is just like two drops. But I drink a lot of water.”

3.3.6 Coping Procedures

3.3.6.1 Denial

Although this study did not include specific questions in regard to coping procedures in order to focus on obtaining an in-depth understanding of the women’s illness representations and their impact on risk perceptions, many important coping procedures arose during the interviews. Denial or avoidance was a cognitive coping procedure implied or directly mentioned by at least a third of the women. When assessing cognitive representations, a few women mentioned that they had never searched kidney disease or asked their physician about it because they were afraid of what they may find out. In regard to complications, one woman admitted she was “in denial of things to come” and did not take complications seriously enough. Yet another woman admitted she was in denial of her diabetes diagnosis and had cancelled her last 10 appointments, and, when asked about kidney disease, reported “I am not going to claim it.” Along the same lines, when asked about her perceived risk for kidney disease, another woman responded, “I do not want to talk about it – thank you, Jesus. I do not want it.” Finally, one woman attempted to sum up her feelings on the overwhelming denial she has observed among her peers by reporting, “I do not think you can find too many diabetics that have not heard of kidney disease. But to know how it come about and what they can do to try to prevent it from being full blown, I do not think they are educated enough…. Well, and I think people do not want to know, so they do not ask the questions. So when they go to the doctor, they go get their A1C levels done, or whatever done, when the doctor finish, they gone. But that is just not me…It is a great
need to educate young people even more so than us older people because they do not understand it, and they do not believe it. They do not want to know because, if they do not know, they think it will not happen. But that is sad because they do not understand that, if their diabetes continue to get high, and their A1C level continue to be high, that alone can cause kidney problems. They do not understand it, so they do not deal with it.... They do not want to hear it. But when they get to the stage they go on dialysis, then they going to wish they had.”

3.3.6.2 Poor adherence to blood glucose monitoring

Poor adherence to blood glucose monitoring was the primary behavioral coping procedure evident among the women. Remarkably, eleven women (52.4%) admitted they do not check their blood glucose as prescribed. One woman stated, “Well, do not tell him [her doctor], but I take it once a day.” Another woman admitted, “I am ashamed to say. I don’t take it as regular as I should. I am going to have to get better at it.” Another woman admitted she only checks it about once a week, and yet another noted that she “will check it when I feel like my levels are off.” One woman admitted she does not check it at all because she does “not even have a monitor anymore.” This woman was struggling with lack of insurance coverage. There were a few other reasons mentioned, including one woman who noted, “I just feel like as long as I am doing what I am supposed to do that it is okay…. But that is not, you know, that is just me thinking…. I hate sticking my finger…. You know, look at the risk that I am putting myself at by not checking them.” Another woman attributed it to her busy schedule, reporting, “I do not, only because it is just so hard for me to balance it…with my busy schedule, home schedule, and it is just so hard…. I have two children and an adopted child that...soccer practice, tennis practice, riding back and forth.” Out of these eleven women, four of them could not remember their last HbA1C, while two of them reported
double digit HbA1C levels, two reported 8%, and three of them reported having an HbA1C below 7%.

3.3.6.3 Insulin fear

Eight women (38.1%) reported that they were on insulin. One of these women was on an insulin pump, while the rest were on injections. Three women who were not on insulin expressed a fear of being put on insulin. One of these women noted that she had cancelled her last 10 appointments and when asked why, she responded, “I do not want to go on insulin and have to deal with all of that.” On the other hand, the two other women insinuated that this fear led to positive behavior changes, including glucose control, dietary improvements, and exercise. One of these woman poignantly stated, “You know my doctor was talking, if you do not get them down, we are going to have to put you on insulin…. It totally scared me. Oh, my God, I am like, no, we are not doing insulin…. She scared me. She scared me.”

3.3.6.4 Other behaviors

Some other behavioral coping procedures that were brought up throughout the conversations hindered prevention of kidney disease. For example, one woman admitted that she has poor health behaviors overall and is not accepting her diabetes. She admitted that she smokes, has not been taking her diabetes medication, does not check her blood glucose, and has not been to the doctor in two years, and her last HbA1C was 8%. She explains her view in detail below:

I am scared to do it [check her BG] because I was not doing what I was supposed to do. Which now, I even saw a psychologist to see why mentally…I do not know what it is. I thought, you know, I have a lot of issues, and I thought after speaking to the doctor that maybe it was, I know, I do not know, but thought it was maybe like an inadvertently suicide type of thing… But once I started
speaking to her – I am, like, is this some type of way of unconsciously…not caring what happened because of all the situations in my life. So, she talked to me and said, well, just do one step at a time. And then I stopped seeing her.

When asked about her next primary care appointment, she stated, “We will see if I cancel it. I have cancelled at least 10 appointments. I do not want to go on insulin and have to deal with all that…And I just do not want to hear what I should do because I know. I know what I should do, but I just cannot get that. I cannot push myself into second gear to…to get over that hump and accept it. I have the pills. I walk around with them…. Maybe I am not accepting it; it does not make sense.”

On the flip side, numerous women spoke about current health behaviors that are preventative in nature. A number of women noted they have changed their diets since being diagnosed with diabetes and started exercising, although a quarter of the women were observed drinking soda or eating sweets during the interview. Many women noted that they have started walking as exercise, although a number of them mentioned arthritis has been a hindrance to high impact exercise. One woman mentioned she recently took up Zumba and another biking. One woman mentioned the importance of weight reduction, by stating, “My diabetes, as it was told to me, is mainly weight induced. So, I mainly have been on keeping my weight down to keep my A1C down.” A few women mentioned throughout the interviews that they believed drinking a lot of water was important for kidney protection. One woman noted, “I know the most important thing is to keep my kidneys flushed, so I have to drink more water,” while another one added, “I try to do my eight glasses of water a day.” A few women did mention that they understood that monitoring their blood glucose levels was important for prevention. One insightful woman mentioned that she is now taking a kidney protective medication, Lisinopril; however, she was unaware it was for kidney
protection until she researched it on her own and had not taken it for years prior to that because she did not have high blood pressure. Other preventive behaviors mentioned were not missing medical appointments, eating out less, and eating more salads.

3.4 Discussion

The primary aim of this study was to explore and describe renal disease risk perceptions among African-American women with T2D and to explore the role of cognitive and emotional illness representations and illness stimuli in shaping risk perceptions. A majority of the women felt they were unlikely to develop renal disease and ranked renal disease below the other complications of T2D, although they comprised a very high-risk group. While research on renal disease risk perceptions among African-American women with T2D is lacking, the studies to date have illustrated that African Americans overall and African Americans with T2D also exhibited low perceived susceptibility to renal disease, even in the presence of risk factors (Boulware et al., 2009; Calvin et al., 2011; Jurkovitz et al., 2005; Waterman et al., 2008). One of these studies also found that African Americans with T2D ranked renal disease below all other complications except amputation in a risk comparison (Calvin et al., 2011). The study also revealed an overall lack of concern for renal disease, especially in comparison to other complications of diabetes, which echoes the literature as well (Boulware et al., 2009; Waterman et al., 2008). The women in this study held more concern for complications with which they had a personal or family experience, which was not found in the other research on renal disease risk perceptions.

When cognitive renal disease representations were explored, the women displayed an overall lack of general renal disease knowledge, which influenced risk perceptions. The revised CSM, based on these study findings, is presented in figure 6. The domains of identity (symptoms) and timeline had the most direct influence on the
women’s risk perceptions, whereas the domain of consequences exhibited an indirect influence. The women who did acknowledge symptoms almost unanimously described end-stage disease symptoms, and none of them acknowledged the different stages of renal disease, even though they believed it was a progressive disease. Chronic renal disease is classified in five stages; albuminuria is the earliest manifestation of chronic renal disease due to diabetes, yet symptoms are nonspecific and uncommon until late stages (Levey et al., 2011; Levey et al., 2005). Only one woman mentioned protein in the urine was a symptom, although seven women reported that they had been told they had albuminuria. Therefore, most of the women were not currently experiencing perceived renal disease symptoms, which impacted risk perceptions. In addition, most of the women equated renal disease directly with end-stage renal disease and dialysis, not recognizing the earlier stages, leading to perceptions that they were “far off” from the disease. A temporal order of diabetes complications was also presumed, and renal disease was perceived to fall at the end, which impacted risk perceptions, especially in comparison to other complications for which many of them were symptomatic. Therefore, a lack of understanding of renal disease symptoms and stages, an end-stage identity, and a perceived temporal order of diabetes complications directly and negatively impacted risk perceptions.
Indirectly, the women’s perceived consequences of renal disease impacted their risk perceptions. A majority of them described perceived consequences they had observed in family members and friends in relation to dialysis. Although they admitted a lack of communication about the consequences, they identified them as severe, overwhelming and frightful. A focus group study also reported that participants who had lived the dialysis experience through others felt it was negative and life-altering and placed stress on patients and family members (Jennette et al., 2010). These reported consequences of dialysis were portrayed very negatively and led most women to
identify renal disease in this late stage, which brought out a lot of emotions and denial and avoidance in the women, in turn negatively impacting risk perceptions.

The women’s emotional responses to renal disease were heavily laden with fear and were mainly influenced by personal relationships with people with the disease, most of whom were in end stage disease. In turn, this fear heavily impacted cognitive representations; a number of women admitted they had avoided researching renal disease or talked to healthcare providers about it because of their fear of it, and without accurate disease knowledge, most women were unable to form accurate risk perceptions. The emotions expressed also triggered the cognitive coping procedures of denial and “not claiming,” which impacted risk perceptions.

Denial was one of the main cognitive coping procedures that arose from the interviews and impacted risk perceptions. Prior research has shown that perceived serious consequences and a large number of symptoms were associated with denial, behavioral disengagement, avoidance and wishful thinking (Kemp, Morley, & Anderson, 1999; Rona Moss-Morris, Petrie, & Weinman, 1996). In addition, a meta-analysis of CSM-based research found that when illnesses were perceived to have a lot of symptoms, a chronic timeline, and serious consequences, there was a significant correlation with the coping procedures of denial or avoidance and expressing emotions (coping by venting or expressing emotional reactions to the illness) (Hagger, 2003).

Similarly, our study found that perceived serious consequences and end-stage identity and symptoms of renal disease were often associated with avoidance of disease learning, denial of personal risk, and minimal participation in risk reduction behaviors.

Two women in this study also displayed the cognitive coping procedure of “not claiming.” These women noted they did not want to claim the risk of renal disease, and put it in God’s hands. Two focus group studies with African-American women with
T2D identified the theme “not claiming” and noted that women may fluctuate between denial and not claiming a disease when strong faith is present (McKenzie & Skelly, 2010; Skelly et al., 2006). They reported African-American women expressed religious beliefs about God’s intercession to prevent or cure disease, which may affect the identity the woman forms with a disease, and she may ignore her symptoms or give them over to God (McKenzie & Skelly, 2010; Skelly et al., 2006). One of these studies found that “not claiming” did not seem to affect diabetes self-care behaviors or relate to the absence of preventive behaviors, yet it did appear to impact risk perceptions of coronary heart disease (McKenzie & Skelly, 2010). Conversely, our study found that the two women who reported they were “not claiming” renal disease both exhibited poor glucose control and a lack of preventative behaviors, yet both women ranked renal disease last out of the five complications. One of these women also exhibited diabetes fatalism, along with another woman in the study. Diabetes fatalism has been defined as a complex psychological process involving perceptions of despair, hopelessness, and powerlessness, and is more common in African Americans according to the literature; it has been linked to poorer self-management and diabetes outcomes (R. J. Walker et al., 2012). However, the two women who exhibited diabetes fatalism displayed converse risk perceptions; therefore, this study could not conclude that there was an association between diabetes fatalism and risk perceptions.

The main illness stimulus, or source of information, that was discussed among the women was that of external sources, namely family and friends. A majority of the women admitted they learned about renal disease from family members and friends who had experienced it; however, almost all of the women reported they never spoke to these sources directly about the disease. Rather, they gained knowledge through observations, mainly related to dialysis, which influenced cognitive representations,
mainly identity (symptoms) and consequences and also brought out emotions of fear. A literature review on the experiences of living on dialysis showed that dialysis patients tended to seek more support from clinic staff than family members in order to avoid burdening family members and also showed that they may self-present publicly in a positive way in an attempt appear normal (Polaschek, 2003), which could explain the lack of discussion with family members in this stage.

Less than a third of the women reported they had learned about renal disease from the Internet and even fewer from other media sources. In contrast, Waterman et al. (2008) found that 28.6% of African Americans had read information about renal disease in the past year, and reading about it was the main source of information among participants, although only a small percent had diabetes. A few women mentioned they were afraid of what they may find when probed as to whether they had ever looked up renal disease on the Internet. Women in the interviews did not directly identify cultural knowledge sources, although diabetes was referred to as “sugar” at various times throughout the interviews, which is often referred to as a cultural term and can be influential to disease understanding. For example, one study found that 29% of African Americans labeled their diabetes as “sugar,” and 7% as “sugar-diabetes,” and those participants felt their condition was less serious yet displayed higher glucose levels than those who labeled it “diabetes” (Schorling & Saunders, 2000). A few women also mentioned that the multi-caregiver role, especially in addition to a full-time job, hindered their knowledge of renal disease and also impacted diabetes self-management. Significant research has also found that African-American women with T2D face cultural barriers that affect self-management and control including the multi-caregiver role, social demands, and stress (Balukonis et al., 2008; Cagle et al., 2002; Carthron et al., 2010; Chlebowy et al., 2013; Samuel-Hodge et al., 2000; Samuel-Hodge et al., 2005).
An even smaller number of women had current experience with the illness. Out of the entire group, four women had been referred to a nephrologist in the past, but three of them were informed they did not need follow-up, and one was expected to return soon. All of these women reported they did not learn much about renal disease from those experiences and simply followed their primary care doctor’s suggestions for referral, insinuating provider control. Seven women reported that they had been told they had protein in their urine at one point or another, yet many of them noted that the connection to renal disease had never been explained.

Surprisingly, most of the women admitted they had just heard brief mention of renal disease from their healthcare providers. Of significance, over half of the women had to be probed about healthcare providers, as they were not even mentioned when asked where and from whom they had learned about the disease. This shows that renal disease is not discussed enough in the primary practice setting, similar to a study that reported only 9.1% of African Americans had spoken to their physician about renal disease in the last year, yet those who had were more likely to correctly perceive themselves at increased risk (OR, 1.85; 95% CI, 1.19 to 2.85) (Waterman et al., 2008). Another study found that African-American women with T2D did not believe they were at risk for heart disease unless they were told it specifically by their primary care providers, and being told by their providers that they had heart disease was a greater influence on risk perceptions than being told by the media or anyone else (McKenzie & Skelly, 2010).

Among the women who did admit the disease has been discussed with providers, many noted that the provider had simply said, “Your kidneys look fine” or “We’ll cross that bridge when we get there.” These types of statements support provider control instead of provider support of a patient’s autonomy and can impact risk
perceptions and preventative behaviors. Research has shown that when providers provide patients with diabetes autonomy support and motivation, they are more involved in their care and experience better outcomes in regards to self-management of diabetes, yet when providers maintain control, outcomes are poorer (G. C. Williams, Freedman, & Deci, 1998; G. C. Williams, Lynch, & Glasgow, 2007; G. C. Williams, McGregor, King, Nelson, & Glasgow, 2005; G. C. Williams, McGregor, Zeldman, Freedman, & Deci, 2004; G. C. Williams, McGregor, Zeldman, et al., 2005). One study showed that physicians exhibited lower levels of positive affect, were more verbally dominant, and less patient-centered when communicating with African-American patients compared to white patients (Johnson et al., 2004), alluding that provider control is more evident among African-American patients. Therefore, if providers offered more autonomy support to these women in regard to renal disease prevention, they may become more knowledgeable of the disease and less fearful, and it may promote self-prevention measures instead of denial and avoidance.

In fact, early intervention research that guided the development of the CSM found that participants did not take action (such as getting immunized) towards an illness threat when fear messages alone were provided. Yet fear messages in combination with action plans led to changes in cognitive illness representations which led participants to take action towards the illness threat and decreased feelings of fear (Leventhal et al., 2003). Hence, the overwhelming fear of renal disease expressed by the women in this study was paralyzing, initiating cognitive coping procedures of denial and “not claiming” and lack of renal disease knowledge, which both impacted risk perceptions. However, if that fear were combined with an action plan, such as a provider risk reduction plan, cognitive illness representations could be positively influenced, leading to more accurate risk perceptions and problem-focused coping.
Additionally, research shows that, if that action plan includes provider autonomy support, there is a higher likelihood of improved outcomes.

In summary, the women exhibited a general lack of renal disease knowledge when cognitive illness representations were explored, and this was often attributed to poor communication with healthcare providers, observation of family members and friends with end-stage disease, preoccupation with other current symptoms or complications, and lack of information seeking about the disease due to avoidance or fear. These representations instilled fear and led to low perceived risk of renal disease among the women, frequently halting preventative behaviors. The emotion of fear was overwhelming and did not occur in conjunction with action plans, leading to cognitive coping procedures including denial or avoidance and “not claiming.” In turn, these coping procedures impacted risk perceptions. Research and the CSM both demonstrate that with the addition of action plans, particularly developed in the healthcare setting in conjunction with provider autonomy support, cognitive illness representations can be re-evaluated, and fear may subside, leading to more accurate risk perceptions and problem-focused coping procedures, ultimately impacting renal disease prevalence among this population.

3.5 Study Limitations

Potential limitations need to be considered when interpreting the results of this study. First, the sampling plan may be considered a limitation because it resulted in a self-selected sample of women who volunteered to participate and included a number of participants recruited via snowballing. This type of qualitative sampling may not be representative of the population; it is likely some segment will be under-represented, and snowballing may suggest homogeneity (Polit, 2008). The sampling plan may also be considered a limitation due to the specified geographic region, an area spanning Eastern
NC. However, although nine enrolled women were recruited from one church in a rural NC town, all but one of the other enrolled women were from larger cities in NC, including Durham and Raleigh, incorporating a balance of rural and urban participants. In sum, the women enrolled in this study displayed a wide range of demographic characteristics and heterogeneity. In general, qualitative researchers cannot specify the external validity of findings, but can provide thick descriptions of the data necessary to allow someone interested to reach a conclusion about transferability (Polit, 2008).

Next, the study procedures may be considered a limitation to trustworthiness of the data. In qualitative research, the trustworthiness of the data parallels the standards of reliability and validity in quantitative research and is often referred to as rigor (Polit, 2008). During qualitative data collection, prolonged engagement, or investment of sufficient time collecting the data, allows for an in-depth understanding of the participants’ views and also encourages the development of trust and rapport with participants (Polit, 2008). Since data collection in this study consisted of one-time interviews with each participant only lasting approximately 60 minutes, this can be seen as potentially detrimental to trustworthiness. However, the PI promoted trust throughout the entire study process and provided her contact information to all participants in case they wanted to contact her at a later time to add any further information. Also, member checking was conducted to enhance the trustworthiness of the findings.

Finally, social desirability response bias must be considered as a possible limitation even in interview studies. This bias occurs when participants consistently provide responses that are socially acceptable or congruent with professional expectations (Polit, 2008). Although this bias can be in response to the appearance of the interviewer (Polit, 2008) and the PI was not African American, she was a female and also
dressed in casual street clothes to avoid the “provider presence.” Also, private interview locations, selected by participants, and provisions for anonymity were imposed in an attempt to minimize this bias. Research has found that among interview studies, telephone participants were more likely to present themselves in socially desirable ways than face-to-face participants (Holbrook, Green, & Krosnick, 2003); therefore, the in-person interviews in this study should reduce the bias in the data. Overall, methods were employed to minimize the potential limitations in this study.

3.6 Conclusion

This study showed that among high-risk African-American women with T2D, low perceived susceptibility to renal disease was influenced by perceived beliefs about the symptoms, timeline, consequences of renal disease, and accompanying fear related to the disease. The literature shaping the CSM posits that, in the presence of fear, established action plans can effectively alter an individual’s cognitive illness representation, impact behaviors, and reduce fear (Leventhal et al., 2003). Action plans are goal-directed activities undertaken to reduce fear and danger; individuals actively appraise the efficacy of these plans and incorporate this into their illness representation and shift response from fearful avoidance to self-regulated problem solving (Leventhal et al., 2003). Therefore, future intervention research aimed at improving renal disease risk perceptions in this population should include individualized goal-directed action plans to determine the impact on risk perceptions and coping procedures.

Ultimately, limited communication of the disease with family and friends on dialysis and with providers in the healthcare setting shaped the women’s perceived beliefs about renal disease. From a clinical standpoint, these findings stress the need for improved communication of renal disease and goal-directed action plans in the healthcare setting. However, healthcare providers must first recognize patients at an
elevated risk for renal disease. Research shows that not only do primary care providers often overlook family history and African-American race as renal disease risk factors, they recognize chronic renal disease less frequently in the practice setting than family physicians, general internists, and nephrologists (Boulware, Troll, Jaar, Myers, & Powe, 2006; Lea, McClellan, Melcher, Gladstone, & Hostetter, 2006). Therefore, interventions aimed at improving renal disease knowledge and early recognition with primary care providers may be an important first step to improve renal disease knowledge and risk perceptions.

Evident from this study, healthcare providers tend to focus on the immediate needs of patients with diabetes, for example, controlling blood glucose, and fail to discuss long-term implications, such as renal disease. Although blood glucose control is of utmost importance to prevent complications such as renal disease, a lack of knowledge of this among patients has shown to be detrimental to risk perceptions and coping procedures. Therefore, the findings from this study add to the urgent need for targeted renal disease education among healthcare providers. If providers are knowledgeable enough to recognize patients at high-risk for renal disease, simple goal-directed action plans in combination with provider autonomy support could successfully improve risk perceptions, elicit preventative behaviors and ultimately decrease disease risk in this disparate population.

4.1 Introduction

Diabetes mellitus affects minority populations at a disproportionate rate in the United States, and African Americans are twice as likely to develop diabetes than white Americans (E. A. Walker et al., 2010). African Americans with diabetes also experience more diabetic complications, disability from the disease, and higher rates of mortality than other individuals (E. A. Walker et al., 2010). African-American women are one of the highest risk groups regarding disease prevalence, and experience increased rates of diabetic complications, such as cardiovascular disease, neuropathy, retinopathy, and nephropathy (Samuel-Hodge et al., 2000).

One complication, diabetic nephropathy, is the most common cause of end-stage renal disease (ESRD), accounting for 45% of all ESRD cases (Hung et al., 2012; McDonough et al., 2011). Specifically, one study revealed that diabetic nephropathy was the cause of ESRD in only 17.6% of African-American men, but the cause of ESRD in 50.5% of African-American women (Crook & Patel, 2004). In comparison, hypertension (HTN) was the cause of ESRD in 48.1% of African-American men (Crook & Patel, 2004). These findings parallel the 2012 United States Renal Data System statistics that reported the primary cause of ESRD among African-American women was diabetic nephropathy (40% of cases), while the primary cause among African-American men was HTN (40% of cases) (USRDS, 2014). These findings exemplify the disparate risk of ESRD secondary to diabetes among African-American women.

Among African-American women, the disparities in rates of diabetic complications, including diabetic nephropathy, have often been attributed to poor
glycemic control (hemoglobin A1C levels > 8%). Forty-seven percent to 50% of African-American women exhibited poor glucose control in two studies, compared to 36.5%-41% of African-American men, 36.2%-38% of white men, and 29%-35.5% of white women (Harris et al., 1999; Weatherspoon et al., 1994). Various studies have explored cultural barriers to metabolic control among African-American women and found that the cultural multi-caregiver role may be influential (Balukonis et al., 2008; Cagle et al., 2002; Carthron et al., 2010; Samuel-Hodge et al., 2000; Samuel-Hodge et al., 2005). In fact, African-American women in the multi-caregiver role voiced that this role added stress and pressure and often made their diabetes go “out of control” (Samuel-Hodge et al., 2000). D’Eramo Melkus et al. (2010) also noted that recent research has shown that multiple caregiver responsibilities, social and role demands, and stressful life events interfere with diabetes self-management for women, and the main goal of self-management is glucose control.

The Common Sense Model of illness representations (CSM) is a parallel-processing model that purports that cultural sources are one of the sources that influence an individual’s development of representations of a specified illness and those representations impact health outcomes (Hagger, 2003; Leventhal et al., 1998). However, there is minimal research focused on culturally based interventions to improve renal disease risk outcomes, although this disparity among African-American women is often attributed to cultural influences. Existing cultural interventions aimed at improving diabetes-related outcomes with ethnic minority groups have resulted in improved psychological and physiological outcomes (S. A. Brown, Garcia, & Winchell, 2002; D’Eramo Melkus et al., 2010; D’Eramo-Melkus et al., 2004; Leeman, Skelly, Burns, Carlson, & Soward, 2008; Melkus et al., 2001; Utz et al., 2008). The extant literature also lacks coping-skills training interventions aimed at improving renal disease risk
outcomes; although the CSM posits that coping behaviors mediate the effect of individual illness representations on health outcomes (Hagger, 2003; Leventhal et al., 1998).

In order to curtail development of ESRD in African-American women with T2D, it is imperative to explore the presence of renal disease risk factors in this population and determine if interventions, namely cultural-based coping-skills interventions, could minimize risk, especially among those women most at risk. Research has shown that the following risk factors were the most significant for development of renal disease: African American race, hypertension, poor glucose control (measured by elevated hemoglobin A1C levels or fasting glucose), elevated body mass index (BMI), older age, male sex, hyperlipidemia, genetic mutations, and family history (Bostrom et al., 2009; L. J. Brown, Clark, Armstrong, Liping, & Dunbar, 2010; Colhoun et al., 2001; Cummings, Larsen, Doherty, Lea, & Holbert, 2011; Hsu, Iribarren, McCulloch, Darbinian, & Go, 2009; Johnson-Spruill & Riegel, 2008; Jurkovitz et al., 2005; Kramer et al., 2005; Leak et al., 2010; Ravid, Brosh, Ravid-Safran, Levy, & Rachmani, 1998; Retnakaran et al., 2006; Sacks et al., 2014; Schelling et al., 2008; A. T. Whaley-Connell et al., 2008). A prior study reported that total cholesterol, mean blood pressure, and hemoglobin A1C (HbA1C) were the main factors associated with renal function decline among patients with T2D, but more importantly found that when all three of these values were higher than the 50th percentile, the odds ratio for microalbuminuria, the earliest indicator of renal disease, was 43 (95% CI: 25-106) (Ravid et al., 1998). However, there is minimal research on the prevalence of these risk factors among African-American women with T2D and none on clustering or categorization of risk groups in this population. There is also a lack of research on culturally relevant coping-skills training interventions to decrease renal disease risk among African-American women with T2D. Therefore, the purpose of this
secondary analysis is to explore and describe the prevalence of renal disease risk factors and the categorization of renal disease risk groups among African-American women with T2D who participated in a self-management and coping skills training intervention; and also explore and describe the change in renal disease risk factors within and between risk groups, determining if participation in a culturally relevant coping-skills training intervention decreased renal disease risk. The research questions for this study are:

1. What are the most prevalent renal disease risk factors in a sample of African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention?

2. How are renal disease risk groups categorized within this sample of African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention?

3. How do renal disease risk factors change over time within risk groups comprised of African-American women with T2D who participated in a culturally relevant self-management and coping skills training intervention?

4. Is the culturally relevant self-management and coping skills training intervention more effective in reducing risk for a certain risk group than another over time?

4.2 Methods

4.2.1 Design

This study is a secondary analysis of data from a longitudinal intervention study entitled Self-Care Intervention for Black Women with Type 2 Diabetes (R01NR05341-01A1; PI: D’Eramo Melkus(D’Eramo Melkus et al., 2010). In the intervention study, participants were randomized to either an experimental group who received a culturally relevant,
cognitive-behavioral diabetes self-management and coping skills training intervention, or a conventional care group who received conventional group diabetes education followed by group question-and-answer sessions (D’Eramo Melkus et al., 2010). The intervention was delivered by nurses, dieticians, and psychologists to groups of participants. Both groups also received diabetes care visits in a primary care setting provided by nurse practitioners every three months. The intervention study period lasted 12 months, with a 24-month follow-up visit. In the primary study, four physiological measures were collected that are also known renal disease risk factors: blood pressure (hypertension), HbA1C (elevated glucose levels), BMI (obesity), and triglycerides (hyperlipidemia). The full study procedures for the parent intervention study have been published elsewhere (D’Eramo Melkus et al., 2010).

4.2.2 Sample

The sample for this secondary analysis included all of the participants from the primary intervention study. The intervention study sample consisted of 109 African-American women with T2D, recruited from a primary care center in an urban southern New England community. The following describes the inclusion criteria for study enrollment: African-American women between the ages of 21 and 65, diagnosis of T2D confirmed by C-peptide assay, not on insulin, BMI < 37, receiving diabetes care from a primary provider, not pregnant or lactating, and able to read and speak English (D’Eramo Melkus et al., 2010). Out of the 109 women, 57 were randomly assigned to the conventional care group, and 52 to the experimental group. At baseline, both groups of women were similar with the exception of significantly higher levels of somatic anxiety in the intervention group (D’Eramo Melkus et al., 2010). The women exhibited poor diabetes control; over 60% of the sample had HbA1C levels greater than 7% (D’Eramo Melkus et al., 2010).
4.2.3 Measures

4.2.3.1 Demographic variables

Demographic variables of each risk group were examined and compared since this secondary analysis categorized the control and intervention groups further into risk groups. The primary study collected baseline demographic data via a demographic data and health history form, including age, ethnicity, education, employment, annual income, living arrangements, duration of T2D, comorbid conditions, and lifestyle behaviors (D’Eramo Melkus et al., 2010).

4.2.3.2 Physiological variables

This secondary analysis focused on four physiological renal disease risk variables that were measured in the intervention study: systolic and diastolic blood pressure (as a measure of hypertension), HbA1C (as a measure of glucose control), BMI (as a measure of obesity), and triglyceride levels (as a measure of hyperlipidemia). This secondary analysis examined the prevalence of these renal disease risk factors among participants at baseline, the clustering of participants into risk groups and categorization of risk groups based on these risk factors, and also the change in these risk factors over time within and between risk groups. These clinical variables were measured at baseline, 3, 6, 9, 12, and 24 months. For the secondary analysis of renal disease risk factor prevalence, a dichotomous variable was established for each factor, determined by professional guidelines and scientific literature, to determine the presence or absence of the renal disease risk factor. These dichotomous variables are defined in Table 7.
Blood pressure was measured with the appropriate sized cuff for each participant using a mercury manometer meeting issued standards and was recorded as the average of two readings separated by 5 minutes in order to obtain more accurate results (D’Eramo Melkus et al., 2010). HbA1c is an established measure of the previous 3 months of glucose control in patients with diabetes and was obtained from a sample of venous blood using the Glyc-affin Ghd column method (D’Eramo Melkus et al., 2010).

The baseline measures of weight and height were obtained for calculation of BMI (D’Eramo Melkus et al., 2010). Each participant’s weight was measured via a standard balance beam scale and was recorded in pounds (to the nearest quarter) (D’Eramo Melkus et al., 2010). BMI values were mathematically calculated using the standard formula of weight (converted to kilograms) divided by height (converted to meters squared). Serum triglyceride levels were obtained via a cardiovascular lipid profile (D’Eramo Melkus et al., 2010).

### Table 7: Study variables and levels defining risk

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measure Description</th>
<th>Levels Defining Risk</th>
<th>Resource</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>Systolic &amp; diastolic blood pressure</td>
<td>Systolic BP ≥140 mmHg OR diastolic BP ≥80 mmHg</td>
<td>American Diabetes Association Guidelines (2013) (ADA, 2013: “Standards of medical care in diabetes--2013,” 2013)</td>
</tr>
<tr>
<td>Obesity</td>
<td>BMI</td>
<td>Ideal: 18.5-24.9 Overweight: 25-29.9 Obese: ≥ 30</td>
<td>American Heart Association (2013) (Jensen et al., 2013)</td>
</tr>
</tbody>
</table>
4.2.4 Data Analysis

Descriptive statistics (frequencies and percents) were used to determine the prevalence of the four renal disease risk factors among the participants at baseline. Then, cluster analysis was used to place the women into groups. Cluster analysis is a statistical classification technique that makes quantitative comparisons of multiple characteristics of individuals in a population and is used to determine whether they fall into different groups (Jain, 2010). First, hierarchical clustering, agglomerative mode, was used to determine the appropriate number of clusters to divide the women into; this clustering algorithm starts with each data point in its own cluster and merges the most similar pair of clusters successively to form a cluster hierarchy (Jain, 2010). Once the appropriate number of clusters was determined, these clusters were analyzed via a k-means cluster analysis. A k-means cluster analysis requires specification of the number of clusters intended, which was determined by the hierarchical analysis. The k-means algorithm then separates clusters so the squared error between the empirical mean of a cluster and the points in the cluster is minimized (Jain, 2010). This analysis provided a means of categorizing the clusters as risk groups. Then the women were categorized manually into four groups based on intervention group and risk cluster. To determine whether these groups were equivalent, baseline data was compared between the four groups using ANOVA and Kruskal Wallis analyses. Once the risk groups were categorized, mixed modeling was conducted to determine change in renal disease risk factors over time within and between risk groups. All statistical analyses were conducted using IBM SPSS Statistics version 22 on a Mac computer.
4.3 Results

Table 8 describes the frequency of each of the four renal disease risk factors among the women at baseline. A majority of the women had an HbA1C level greater than or equal to 7% (62.39%) and were obese (75.93%).

Table 8: Renal disease risk factors at baseline (N=109). Frequencies do not total 109 for all variables due to missing data

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Levels</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>BP &lt; 140/80 mmHg</td>
<td>60</td>
<td>56.07</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Systolic BP ≥ 140 mmHg OR diastolic BP ≥ 80 mmHg</td>
<td>47</td>
<td>43.93</td>
<td>107</td>
</tr>
<tr>
<td>Glucose control</td>
<td>HbA1C &lt; 7%</td>
<td>41</td>
<td>37.61</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>HbA1C ≥ 7%</td>
<td>68</td>
<td>62.39</td>
<td>109</td>
</tr>
<tr>
<td>Obesity</td>
<td>Ideal: BMI 18.5-24.9</td>
<td>5</td>
<td>4.63</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Overweight: BMI 25-29.9</td>
<td>21</td>
<td>19.44</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Obese: BMI ≥ 30</td>
<td>82</td>
<td>75.93</td>
<td>108</td>
</tr>
<tr>
<td>Hyperlipidemia</td>
<td>Triglycerides &lt; 150 mg/dL</td>
<td>79</td>
<td>72.48</td>
<td>79</td>
</tr>
<tr>
<td></td>
<td>Triglycerides ≥ 150 mg/dL</td>
<td>30</td>
<td>27.52</td>
<td>109</td>
</tr>
</tbody>
</table>

According to a hierarchical cluster analysis, two clusters would provide the best fit statistically based on these four renal disease risk factors at baseline. Therefore, a k-means cluster analysis was conducted to divide all the women into two clusters, or risk groups, based on these four risk factors. These risk groups were categorized as low-risk and high-risk based on significant differences in triglyceride and HbA1C levels at baseline, as evidenced in Table 9. Although the two risk clusters only significantly differed on these two renal disease risk factors, changes in all four risk factors were analyzed. The women were then categorized manually into four groups based on intervention group and risk cluster, and these intervention cluster groups were analyzed along with clusters using mixed models (G1C1: control group, low-risk cluster; G1C2:
control group, high-risk cluster; G2C1: intervention group, low-risk cluster; and G2C2: intervention group, high-risk cluster) (Table 10).

**Table 9: Final cluster centers**

<table>
<thead>
<tr>
<th>Cluster</th>
<th>1: Low Risk (82 women)</th>
<th>2: High Risk (24 women)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic Blood Pressure</td>
<td>133</td>
<td>135</td>
</tr>
<tr>
<td>Diastolic Blood Pressure</td>
<td>75</td>
<td>78</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>97</td>
<td>251</td>
</tr>
<tr>
<td>BMI</td>
<td>34.79</td>
<td>35</td>
</tr>
<tr>
<td>Hemoglobin A1C</td>
<td>7.64</td>
<td>9.17</td>
</tr>
</tbody>
</table>

**Table 10: Baseline intervention cluster group frequencies**

<table>
<thead>
<tr>
<th>Intervention Cluster Groups</th>
<th>Baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Valid</strong></td>
<td></td>
</tr>
<tr>
<td>G1C1: Control, Low-risk</td>
<td>42 (38.5)</td>
</tr>
<tr>
<td>G1C2: Control, High-Risk</td>
<td>14 (12.8)</td>
</tr>
<tr>
<td>G2C1: Intervention, Low-risk</td>
<td>39 (35.8)</td>
</tr>
<tr>
<td>G2C2: Intervention, High-risk</td>
<td>10 (9.2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>105 (96.3)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td></td>
</tr>
<tr>
<td>System</td>
<td>4 (3.7)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>109 (100)</td>
</tr>
</tbody>
</table>
At each time point, the women from the parent study that did not have data on all four risk factors were excluded from an intervention cluster group. At baseline, all four groups were similar based on demographic characteristics, with the exception of employment status. The intervention, high-risk cluster group had significantly fewer women employed full-time, and significantly more homemakers.

Mixed modeling revealed an overall significant decline over time in systolic blood pressure (SBP) ($F(1,102.88)=8.85$, $p=.004$). Mean SBP in the high-risk cluster declined from 135mmHg (SD=21.67) to 131mmHg (SD=12.56) over the study period (Figure 7), with a more prominent decline in the control, high-risk cluster group (136mmHg to 130mmHg) than the intervention, high-risk cluster group (134mmHg to 133mmHg) (Figure 8, Table 11). Mean SBP declined in both of the low-risk cluster groups as well, by 5mmHg in the intervention, low-risk cluster group and by 2mmHg in the control, low-risk cluster group.

Figure 7: Mean SBP among clusters over time
Figure 8: Mean SBP among intervention cluster groups over time

Table 11: Mean SBP among intervention cluster groups at all time points

<table>
<thead>
<tr>
<th>Intervention Cluster Groups</th>
<th>Mean Systolic BP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td>G1C1: Control, Low-risk</td>
<td>134</td>
</tr>
<tr>
<td>G1C2: Control, High-Risk</td>
<td>136</td>
</tr>
<tr>
<td>G2C1: Intervention, Low-risk</td>
<td>132</td>
</tr>
<tr>
<td>G2C2: Intervention, High-risk</td>
<td>134</td>
</tr>
</tbody>
</table>

There was also an overall significant decline in triglycerides over time (F(1,3.48)=12.05, p=.032). Although mean triglycerides declined within the high-risk...
cluster from 251mg/dL (SD=76.81) to 186mg/dL (SD=98), they increased within the low-risk cluster from 97mg/dL (SD=32.75) to 119mg/dL (SD=75.5) (Figure 9). Mean triglycerides increased in both low-risk cluster groups and decreased in both high-risk cluster groups, most notably in the control, high-risk cluster group from 251mg/dL (SD=72.65) to 149mg/dL (SD=29.55) (Figure 10, Table 12). There was a significant difference in triglyceride levels between the two clusters of women in general ($F(1, 70.16) = 233.54, p < .001$) and between the two clusters of women over time ($F(1, 6.12), p < .05$), but not between the intervention cluster groups over time ($F(1, 6.18) = .02, p = .892$) (Figures 9 & 10).

![Figure 9: Mean triglycerides among clusters over time](image)

Figure 9: Mean triglycerides among clusters over time
Figure 10: Mean triglycerides among intervention cluster groups over time

Table 12: Mean triglycerides among intervention cluster groups at all time points

<table>
<thead>
<tr>
<th>Intervention Cluster Groups</th>
<th>Mean Triglycerides</th>
<th>Diff</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1C1: Control, Low-risk</td>
<td>99  113  107  111  107  104</td>
<td>+5</td>
</tr>
<tr>
<td>G1C2: Control, High-Risk</td>
<td>251  185  192  147  148  149</td>
<td>-102</td>
</tr>
<tr>
<td>G2C1: Intervention, Low-risk</td>
<td>95   94   85   97   105  140</td>
<td>+45</td>
</tr>
<tr>
<td>G2C2: Intervention, High-risk</td>
<td>251  229  167  176  106  222</td>
<td>-29</td>
</tr>
</tbody>
</table>
Finally, mixed modeling also revealed an overall significant decline in HbA1C over time (F(1,256.26)=32.07, p=.000). Mean HbA1C declined in the high-risk cluster from 9.18% (SD=2.45) to 7.31% (SD=1.83) compared to a decline in the low-risk cluster from 7.64% (SD=2.32) to 7.51% (SD=2.64) (Figure 11). A decline was also evident in each of the intervention cluster groups, most notably in the control, high-risk cluster group from 9.02% (SD=2.35) to 6.93% (SD=1.27) (Figure 12, Table 13). The intervention, high-risk cluster group experienced a decline of 1.68%, and the intervention, low-risk cluster group reported an overall decline of 0.24%.

Figure 11: Mean HbA1C levels among clusters over time
Figure 12: Mean HbA1C levels among intervention cluster groups over time

Table 13: Mean HbA1C levels among intervention cluster groups at all time points

<table>
<thead>
<tr>
<th>Intervention Cluster Groups</th>
<th>Mean HbA1C</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Diff</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1C1: Control, Low-risk</td>
<td>8.06%</td>
<td>6.24%</td>
<td>7.15%</td>
<td>7.38%</td>
<td>6.95%</td>
<td>7.99%</td>
<td>-0.07%</td>
</tr>
<tr>
<td>G1C2: Control, High-Risk</td>
<td>9.03%</td>
<td>5.47%</td>
<td>6.23%</td>
<td>7.33%</td>
<td>6.99%</td>
<td>6.93%</td>
<td>-2.10%</td>
</tr>
<tr>
<td>G2C1: Intervention, Low-risk</td>
<td>7.23%</td>
<td>6.93%</td>
<td>6.33%</td>
<td>7.21%</td>
<td>7.09%</td>
<td>6.99%</td>
<td>-0.24%</td>
</tr>
<tr>
<td>G2C2: Intervention, High-risk</td>
<td>9.38%</td>
<td>7.56%</td>
<td>7.73%</td>
<td>8.64%</td>
<td>8.54%</td>
<td>7.70%</td>
<td>-1.68%</td>
</tr>
</tbody>
</table>
4.4 Discussion

The primary aim of this secondary analysis was to categorize all of the women who participated in a culturally relevant diabetes self-management and coping skills training intervention study into renal disease risk groups and determine if risk factors changed over time within these risk groups. The findings were intended to explore whether the intervention had differential effects by risk group as well. The clinical goal was to determine if a culturally relevant coping skills training intervention aimed at improving diabetes self-management would effectively improve renal disease risk outcomes in African-American women with T2D at high-risk for renal disease, with an ultimate aim to curtail renal disease prevalence in this disparate population.

Poor glucose control and obesity were prominent in this sample of women. A number of studies have also found that African Americans in general exhibited poor glucose control compared to their white counterparts (Betancourt, Degnan, & Long, 2013; Kirk et al., 2006), and more specifically that African-American women with T2D exhibited significantly worse control compared to white women and African-American and white men (Harris et al., 1999; Wagner, Tennen, Feinn, & Finan, 2013; Weatherspoon et al., 1994). Although the prevalence of obesity among participants (75.93%) was much higher than the reported prevalence among the general population of African-American women (58.5%), it was lower than the prevalence of obesity reported among African-American women at risk for renal disease in another study (90.5%) (L. J. Brown et al., 2010; Flegal, Carroll, Kit, & Ogden, 2012), which could be explained by the inclusion criteria of a BMI < 37. Regarding other renal disease risk factors, hypertension was present in about 44% of the sample and hypertriglyceridemia in only about 28%; however the mean baseline triglyceride level among the high-risk cluster of women was
251 mg/dL. Research has shown that increased HbA1C levels (p<0.01), mean arterial pressure (p<0.01), triglyceride levels (p<0.01) and BMI (p=0.0156) were all independent predictors of renal disease among African Americans newly diagnosed with T2D (Kohler, McClellan, Ziemer, Kleinbaum, & Boring, 2000). In addition, Ravid et al. (1998) found that among patients with T2D, when total cholesterol, mean blood pressure, and HbA1C are all higher than the 50th percentile, the odds ratio for microalbuminuria was exceptionally elevated, indicating the importance of analyzing risk clusters.

The clusters developed via cluster analysis were categorized as low-risk and high-risk based on mean values for each risk factor at baseline, namely the significantly different triglyceride and HbA1C levels. Categorizing women into risk groups allowed us to determine which of the women were at the highest risk for renal disease in order to explore if renal disease risk outcomes improved in this group, and if so, if they could be attributed to the intervention, which was accomplished by further dividing the women into four intervention cluster groups. The low number of women in the high-risk cluster may have been related to their relatively short duration of diabetes, since African-American women with T2D who were on insulin and had a BMI ≥ 37 were excluded from the intervention study. Although the low-risk cluster had significantly more women in it, the high-risk cluster displayed significantly higher mean triglyceride and HbA1C levels, primary risk factors for renal disease. Research has shown that elevated triglycerides were significant independent predictors of renal impairment among people with T2D, even after adjustments were made for elevated HbA1C, and one of these studies was comprised of an all-African American sample (Colhoun et al., 2001; Kohler et al., 2000; Retnakaran et al., 2006; Sacks et al., 2014). A number of studies have also established that elevated HbA1C levels were a significant independent risk factor for
renal disease (Crook & Patel, 2006; Cummings et al., 2011; Kohler et al., 2000; Parving et al., 2006; Ravid et al., 1998).

Through mixed modeling, we found that there was a significant decline in SBP over time, although the mean decline within each cluster was minimal (4mmHg in the high-risk cluster and 3mmHg in the low-risk cluster). However, this decline could not be attributed to the intervention because the control, high-risk cluster group experienced the greatest overall decline out of the four intervention cluster groups (6mmHg). Although the intervention, high-risk group ended with the highest mean SBP, the intervention, low-risk cluster group displayed a mean SBP lower than both control groups at 24 months, but these differences were not significant. Similarly, a number of T2D self-management intervention studies have failed to establish a significant difference in SBP between the intervention and control group, and only very few have reported decreases in SBP at all, albeit small and insignificant decreases, similar to our findings (3-4 mmHg), however none of these studies broke down participants into risk groups (Norris, Engelgau, & Narayan, 2001; Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012).

There was also a significant decline in mean triglycerides over time. Although mean triglycerides increased in both low-risk groups, they declined extensively in both high-risk groups, most notably up to 12 months. Mean triglycerides in the intervention, high-risk cluster group dropped to 106mg/dL at 12 months, which was lower than the control, high-risk cluster group’s mean of 148mg/dL and also below the clinical high-risk cutoff of 150mg/dL, displaying the effectiveness of the intervention in this cluster group at 12 months. However, mean triglycerides in the intervention, high-risk cluster group then increased to 222mg/dL at the 24-month follow-up, indicating the intervention did not result in long-term improvements. These findings could be
explained by the intervention ending at 12 months and the long follow-up period post intervention, with no interaction during the 12 month to 24 month time frame. A review of T2D self-management intervention studies concluded that length of follow-up after completion of an intervention greatly affected outcomes and stressed that a follow-up period ≤ 6 months was most effective (Norris et al., 2001). The control, high-risk cluster group exhibited an overall mean decline from 251mg/dL to 149mg/dL, which is also below the high-risk cutoff. The control group attended community educational group sessions for the first 10 weeks and also were followed by a NP every 3 months for 12 months to receive equal attention which could explain this outcome (D’Eramo Melkus et al., 2010). A systematic review that focused solely on interventions to improve diabetes care in socially disadvantaged populations, including many that had all-African American samples, found that positive effects were commonly associated with the use of community educators or lay people leading the intervention (Glazier, Bajcar, Kennie, & Willson, 2006), indicating the community focus in the classes attended by the control group may have influenced outcomes in this subgroup. Systematic reviews of other T2D self-management intervention studies have demonstrated that group differences in triglycerides were typically not found; one study confirmed reduction in the control group at 12 weeks, another reported a reduction in the intervention group at 12 months, and yet another confirmed reduction in both groups overall; however none of these studies broke down the results by risk groups either (Norris et al., 2001; Steinsbekk et al., 2012).

A significant decline over time in mean HbA1C was also revealed, with a decline in both the low-risk and high-risk clusters. The high-risk cluster ended the study with a lower mean HbA1c than the low-risk cluster (7.31% compared to 7.51%). When the improvements were analyzed within intervention cluster groups, the intervention, high-
risk cluster group declined from 9.38% to 7.7%, and the control, high-risk cluster group declined from 9.03% to 6.93%, which is below the clinical high-risk cutoff of 7%, insinuating again that conventional care may have been effective as well as the intervention among high-risk women. Notably, the high-risk cluster portrayed lower mean HbA1C values than the low-risk cluster at both 3 and 6 months due to the drastic decline in the control, high-risk cluster from baseline to 3 months. Although this group did not receive an intensive intervention, the community-based education may have been enough to improve HbA1C levels, similar to triglycerides. A large number of T2D self-management intervention studies have also recognized improvements in glycemic control, yet many did not find group differences between the intervention and control groups, and again did not evaluate risk clusters (Norris et al., 2001; Steinsbekk et al., 2012).

In summary, the high-risk cluster displayed clinically significant declines in mean SBP, triglycerides and HbA1C, in both the control and intervention groups, and the intervention was more effective in reducing triglycerides and HbA1C levels among high-risk participants than low-risk. The control, high-risk cluster group even ended with triglyceride and HbA1C levels below the clinical high-risk standards, and the intervention, high-risk cluster group dropped their mean triglycerides below high-risk standards at the end of the intervention period, 12 months. The documented relationship between triglycerides and HbA1C could explain these findings. A dietary intervention that significantly decreased triglyceride concentrations by 10.2% also resulted in significantly lower pre-prandial glucose levels (Chandalia et al., 2000). Inversely, another author stressed the primary and essential approach to triglyceride reduction is glycemic control (Goldberg, 2001). Yet another study found that elevated triglycerides, when clustered with abdominal obesity and high blood pressure, were
associated with 9.1 (95% CI: 2.9-28.7) increased odds of elevated A1C in African-Americans with T2D (Okosun, Annor, Dawodu, & Eriksen, 2014). These findings assume a significant correlation between triglyceride levels and HbA1C levels among people with T2D, specifically African-Americans, and explain the findings from this study. Interventions aimed at improving triglyceride levels among African-American women at high risk for renal disease should also have an impact on HbA1C based on the literature.

Although we established significant declines in mean SBP, triglycerides and HbA1C overall, and substantial declines in mean triglycerides and HbA1C in the high-risk cluster, it is important to note that the number of measurements in each group declined over time due to attrition and missing data, which is common in longitudinal studies. This decline was especially evident among the high-risk cluster, which started smaller than the low-risk cluster, as evidenced in Table 9. In summary, these findings regarding important declines in both mean HbA1C and triglycerides, especially within the high-risk cluster, should be interpreted with caution due to the decreased measurements over time and small numbers of measurements in the two high-risk groups at 24 months, but the overall declines are still clinically relevant.

4.5 Limitations

The main limitation of this study was that the high-risk cluster started out with only 24 women and was further broken down into intervention cluster groups, resulting in small group sizes. Similar to other longitudinal studies, the number of available measurements decreased at each time point, further restricting our ability to compare groups. Therefore, the declines in mean triglycerides and HbA1C in the two high-risk groups may have been influenced by the missing data and study completers. The women who completed the study may have varied on characteristics that affected these
clinical outcomes and associated health behaviors or medical management, creating a bias. On the other hand, the ability to detect more statistically significant differences between groups may have been hindered with the small group sizes. When sample sizes are small, the power to detect an effect is lower (Blood, Cabral, Heeren, & Cheng, 2010).

The inclusion criteria of the parent study could also be noted as a limitation. Women were excluded if they were on insulin and had a BMI > 37. Therefore, the women were most likely captured earlier in the diabetes disease process and extremely obese women were excluded. Although it is important to study renal disease risk in this disparate group and establish early prevention of complications, improvements in risk factors may have been more prominent if the sample had included a larger number of higher risk participants.

4.6 Conclusion

In summary, the significant improvements in mean SBP, HbA1C and triglycerides overall show that the study had a clinically significant impact on renal disease risk, especially among high-risk participants, most notably in the control group. The results indicated that African-American women with T2D who are at high-risk for renal disease would benefit from culturally tailored diabetes self-management and coping skills training interventions, however some minor alterations may be beneficial for sustained outcomes, and improvements in other renal disease risk factors. This intervention consisted of intense group sessions for the first 3 months and then tapered off to clinical visits with a NP every three months up to 12 months and included a 12-month post intervention follow-up. Reviews of T2D self-management intervention studies concluded that positive outcomes were frequently observed in interventions that included a longer duration of frequent contact with participants (up to 6 months), individual assessment and feedback, community leaders or lay educators, and a follow-
up period ≤ 6 months post intervention (Glazier et al., 2006; Norris et al., 2001). Therefore, these aspects should be incorporated into future interventions aimed at decreasing renal disease risk among high-risk participants. The success of using community leaders to lead interventions may help explain the improvements noted in the control, high-risk cluster group in this study since they attended community diabetes group sessions for the first 3 months. Although this intervention was already culturally tailored, it may have benefited from the use of lay or community educators as well as group sessions longer than 3 months and a follow-up period less than 12 months post intervention to assess interim sustainability. Finally, since interventions with more individualized assessment and feedback have been shown to be more effective on outcomes among socially disadvantaged participants (Glazier et al., 2006), future interventions could benefit from individualized goal-directed action plans with regular feedback. Goal-directed actions plans have effectively led to self-regulated problem solving and had large effects on health outcomes (Leventhal et al., 2003).

From a clinical standpoint, although classification of all T2D patients as low and high risk may not be conducive, it is important for providers to recognize patients with T2D at high-risk for renal disease and acknowledge, as this study showed, that risk reduction is obtainable. The results from this study proved that all three of these risk factors could be significantly impacted, namely among high-risk participants. Providers also need to be aware of the positive impact of cultural care on renal disease risk factors, as this study exhibited. In summary, this study displays the importance of acknowledging African-American women with T2D at high-risk for renal disease in healthcare settings, which is often overlooked. One study showed that primary care providers often overlooked family history and African-American race as significant risk factors for renal disease (Lea et al., 2006). Once identified, measures can be taken to
address risk factors among this disparately affected population, and aim to decrease their overall renal disease risk.
5. Discussion

5.1 Introduction

The aim of this dissertation was to gain an understanding of the current state of the science in renal disease awareness and risk perceptions in African Americans and to explore and describe renal disease risk perceptions and representations, the presence of risk factors, and effects of a tailored intervention on African-American women with T2D. Three different methods of analysis were employed to address this overall aim. First, due to the high prevalence rates of ESRD among African Americans, exploring and synthesizing the literature on renal disease awareness and existing risk perceptions among African Americans was an important initial step. Since the focus is on a specific at-risk population, it was also important to explore influential sociocultural factors in the literature. The literature review was conducted to enhance our understanding of the general knowledge base and existing risk perceptions of renal disease in the African American community and help guide a qualitative study focused specifically on the high-risk group of African-American women with T2D.

Once the literature on awareness and existing risk perceptions of renal disease in the general African American population was explored and synthesized, a large gap in the understanding of renal disease risk awareness and preceding influences on renal disease representations among African-American women with T2D was identified. Therefore, renal disease representations and risk perceptions were explored qualitatively in this population. Semi-structured interviews were used to gain an in-depth understanding of renal disease risk perceptions and representations and underlying influences among African American women with T2D, filling this gap in the existing literature.
In addition to exploring and describing renal disease risk perceptions among African-American women with T2D, a secondary analysis on the effects of a culturally relevant diabetes self-management training and coping skills intervention on risk groups of African American women with T2D was conducted. To date, there is no existing research that categorizes African-American women with T2D into renal disease risk groups to examine change in risk status over time. By conducting this secondary analysis, we were able to describe the most prevalent renal disease risk factors and also categorize the women into risk groups to determine the effects of the culturally relevant intervention which included coping skills training on renal disease risk outcomes within and between risk groups. This provided guidance for future intervention research.

All three approaches in this dissertation incorporated components from the CSM adapted to study risk perceptions (Cameron, 2003; Leventhal et al., 2003; Leventhal et al., 1980; Leventhal et al., 1984). The findings in this discussion chapter are organized according to the components of the model (Figure 13).
5.2 Risk Perceptions

The literature review revealed that African Americans in general exhibited a low perceived susceptibility to renal disease (Migliore, Barroso, & Vorderstrasse, In press) and similarly, the qualitative study revealed that African-American women with T2D exhibited a low perceived susceptibility to renal disease (Migliore, Barroso, & Vorderstrasse, 2015). These findings were in light of the presence of significant renal disease risk factors. For example, in the literature review, 28% to 66.7% of participants had risk factors for renal disease, while the majority of women in the qualitative study reported elevated hemoglobin A1C levels, high cholesterol or hypertension. Also, both the literature review and qualitative study findings showed that participants ranked
renal disease below all other complications of diabetes except amputations in risk comparisons. Therefore, overall, this dissertation found that even in the presence of significant risk factors, African Americans and African-American woman with T2D exhibited a low perceived susceptibility to renal disease, especially in relation to other complications of diabetes. The factors influencing this low perceived risk are discussed in the following sections.

5.3 Cognitive Illness Representations

The CSM purports that individuals’ cognitive illness representations influence their risk perceptions. Both the literature review and the qualitative study displayed a lack of renal disease knowledge within the five domains of cognitive illness representations among participants. The literature review revealed a lack of knowledge of renal disease causes. A theme in the qualitative study was inaccurate perceptions of renal disease symptoms (identity). The women in this study almost unanimously reported end-stage disease symptoms, identifying renal disease directly with ESRD, and lacked knowledge of disease stages. The women did understand renal disease is a progressive disease; however, they perceived a temporal timeline of diabetes complications with renal disease at the end. The qualitative findings and literature review both identified the theme of perceived negative consequences of renal disease, attributed mainly to dialysis. Of the cognitive representations, the qualitative analysis revealed that the domains of timeline, identity, and consequences were most influential to the development of risk perceptions among African-American women with T2D. These findings are similar to a prior study, which showed that one’s perception of diabetes consequences, symptoms and underlying emotions were associated with perception of risk for diabetes complications (Calvin et al., 2011). In summary, renal disease knowledge and beliefs among African Americans appear to be very influential in
their low perceived susceptibility to renal disease, which is concerning especially among high-risk individuals such as African-American women with T2D.

### 5.4 Emotional Illness Representations

Both the literature review and the qualitative study in this dissertation revealed significant emotions related to renal disease. African Americans exhibited a lack of concern for renal disease, especially in comparison to other chronic illnesses in the literature review and in comparison to other complications of diabetes in the qualitative study. Besides lack of concern, the qualitative findings showed renal disease instilled fear in many women, mainly in response to their perceived negative consequences of renal disease, obtained from observing friends and/or family members in the end-stages of renal disease on dialysis. This fear not only impacted cognitive representations of renal disease since women were afraid to research it or learn more about it, it also lead to coping procedures, namely denial and “not claiming”, which impacted risk perceptions. Intervention research has shown that fear messages alone, without the presence of action plans, most often result in maladaptive coping procedures, which in turn can influence risk perceptions and health outcomes (Leventhal et al., 2003). Therefore, the lack of renal disease concern found in the literature and qualitative findings, and the overwhelming fear expressed by the women appeared to have a considerable influence on risk perceptions. Attempts to reduce fear should be implemented in combination with action plans in order to initiate problem-focused coping procedures and ultimately improve health outcomes by decreasing risk.

### 5.5 Illness Stimuli

According to the CSM, illness representations are guided by information from three basic sources: media (lay public) and culture, external sources, and current experience with the illness (Hagger, 2003; Leventhal et al., 2003). In this dissertation, the
literature review and the qualitative study explored illness stimuli that could be influential to illness representations, while the secondary analysis explored whether an intervention with a cultural basis impacted health outcomes in African-American women with T2D. Both the literature review and the qualitative study found that external sources, namely family, friends, and primary care providers exerted the biggest influence on renal disease representations, albeit predominantly negative. For example, as noted in the literature, the qualitative findings showed that a significant number of participants learned about the disease from family and friends, yet most of these acquaintances were in ESRD and on dialysis, leading to many perceived negative consequences, a perceived end-stage identity, and expressions of fear. According to Leventhal et al. (2003), social influences can have powerful effects on behavior, even when the influences are not from healthcare providers. People gain significant information from spending time with and observing social contacts who are further along in the treatment trajectory, which helps to clarify expectations of the illness; in the adaptation to a chronic illness, this can promote well-being, however, in the context of promoting preventative behaviors, it can lead to overly optimistic appraisals of individual risk (Leventhal et al., 2003).

The literature and qualitative findings also revealed that a majority of women had not learned about renal disease from their healthcare providers, which impacted their representations. Specifically, one study reported that only 9.1% of African Americans had spoken to a physician about renal disease in the past year, although communication of renal disease with a primary care provider improved disease knowledge and risk perceptions (Waterman et al., 2008). A number of participants in both studies had current experience with renal disease including microalbuminuria, the earliest indicator of renal disease, and four women had been referred to a nephrologist
in the qualitative findings. However, as found in the literature, women in the qualitative study overwhelmingly still reported that healthcare providers did not discuss renal disease with them, at least not in depth, and often took control, insinuating the women didn’t have to worry about it right now. This concept of provider control was a theme that arose in the qualitative study and is in opposition to provider autonomy support. Research has shown that provider control is not only more common among African-American patients, but also results in poor outcomes in diabetes care compared to provider autonomy support (Johnson et al., 2004; G. C. Williams et al., 1998; G. C. Williams et al., 2007; G. C. Williams, McGregor, King, et al., 2005; G. C. Williams et al., 2004; G. C. Williams, McGregor, Zeldman, et al., 2005). In summary, both the literature review and the qualitative study showed that the external sources of family, friends and healthcare providers exerted the biggest influence on renal disease representations and in turn risk perceptions.

Experience with competing diabetes complications seemed to have a bigger impact on representations and risk perceptions than experience with renal disease. The literature review and the qualitative study found that participants ranked renal disease below almost all other complications of diabetes in a risk comparison. The qualitative study findings illuminate the rationale for this since participants had experienced symptoms of other complications and/or discussed them with providers more often, influencing them to perceive a temporal order of diabetes complications (timeline), placing renal disease toward the end of the spectrum. Specifically, the qualitative study findings showed that African-American women with T2D held more concern for complications of diabetes that they have experienced personal symptoms of or experienced through family and friends. Therefore, current experience with renal disease symptoms did not have as much of an impact on representations and risk
perceptions as experience with other competing complications due to personal experiences.

The literature review also explored various sociocultural influences on chronic disease illness representations and risk perceptions and found that low educational level and limited health literacy were associated with poorer renal disease knowledge and more inaccurate risk perceptions, while weight optimism and lack of insurance led to more inaccurate risk perceptions and decreased disease knowledge in regard to other chronic illnesses. Similarly, the qualitative study findings revealed that two of the women who reported the highest perceived risk (“very likely”) to develop kidney disease had at least some college education, health insurance and moderate incomes. Only two women in the qualitative study lacked health insurance, and although they exhibited lack of knowledge in some cognitive renal disease domains and both exhibited non-adherence to glucose monitoring, their risk perceptions differed; one perceived her risk as “likely,” while the other “not likely.” Finally, the literature review revealed a sociocultural theme of faith, with a sub-theme of “not claiming” disease risk, also described as handing it over to God, among African-American women. Similarly, the qualitative findings revealed that “not claiming” arose as a coping procedure that impacted risk perceptions, since the women handed their risk over to a higher power. Therefore, significant sociocultural influences that played a role in renal disease risk perceptions arose in both studies.

Since sociocultural factors were found to be influential on renal disease representations and risk perceptions in the literature and qualitative study, an aim of the secondary analysis was to determine if an intervention that had a strong cultural underpinning impacted renal disease risk outcomes in African-American women with T2D, and if so, in which risk groups. It is important to note that risk perceptions and
representations were not assessed in this study; however, access to the dataset allowed us to determine if the intervention had an effect on renal disease risk outcomes in a subset of African-American women with T2D. The analysis demonstrated that there was an overall decline in systolic blood pressure, triglycerides, and HbA1C levels over time, and the intervention resulted in more substantial declines in triglycerides and HbA1C in the high-risk cluster than the low-risk cluster. However, among these three risk factors, the high-risk control cluster displayed the most significant declines overall. These findings indicate that among high-risk participants, the ‘standard of care’ received in the control group exhibited the biggest influence on outcomes. The control group attended weekly hospital-based community group sessions for 10 weeks, and the community aspect may have been influential, although we cannot be certain. They also received diabetes care on a quarterly basis from a nurse practitioner on the study team, which may have impacted their improved outcomes. In summary, we cannot state that the care received by participants in this study impacted renal disease risk perceptions and/or representations; however, these findings provide groundwork for future intervention research aimed at addressing renal disease risk perceptions in order to influence renal disease risk outcomes.

5.6 Coping Procedures

Coping procedures are influenced by illness representations and mediate the effect of representations on health outcomes. They are defined as cognitive and behavioral actions taken (or not taken) to enhance health, and to prevent, treat, and rehabilitate from illness (Hagger, 2003; Leventhal et al., 1998). In this dissertation, although they were not directly assessed, pertinent coping procedures emerged in the qualitative study. Poor adherence to glucose testing was evident in a majority of the women and was the primary behavioral coping procedure that arose. The reasons for
poor adherence were attributed to various factors including sociocultural barriers such as lack of insurance and the multi-caregiver role. However, most of the women who reported poor adherence noted they felt like their diabetes was under control, even if their last reported HbA1C was inconsistent with this belief, portraying the impact of representations and risk perceptions on coping procedures.

Denial and “not claiming” were cognitive coping procedures displayed by a number of women in regard to renal disease. These procedures were elicited mainly during the discussion of emotions with the women, and somewhat during the discussion of consequences. Therefore, the ominous fear and perceived negative consequences of renal disease lead to the coping procedures of denial and “not claiming”. Similarly, authors of a meta-analysis of the CSM found that perceptions of an illness as highly symptomatic, having serious consequences, and a chronic timeline were significantly correlated with expressing emotions and denial/avoidance coping procedures (Hagger, 2003). These three illness domains also were significantly and negatively correlated with health outcomes such as well being, role and social functioning and vitality, demonstrating the relationship between illness cognitions, coping, and outcomes (Hagger, 2003).

In the secondary analysis we aimed to explore and describe whether an intervention with a coping skills training component impacted renal disease risk outcomes in a sample of African-American women with T2D. Although we could not explore the impact of cognitive representations in this analysis, this was a starting point for future intervention development. As previously mentioned, significant declines in systolic blood pressure, triglycerides, and HbA1C levels were evident in both the high-risk control and intervention groups, although the high-risk control group experienced the largest declines. These findings stress the need for future interventions to explore
which specific components received by the groups were influential to improved health outcomes.

5.7 Health Outcomes

Although the secondary analysis was the only chapter in this dissertation that explored health outcomes directly, renal disease risk outcomes were significantly impacted in this study. As previously mentioned, significant improvements were noted in systolic blood pressure, triglycerides, and HbA1C levels over the course of the study. However, since other aspects of the CSM were not incorporated into the parent study, we were unable to establish influencing factors on the improvements in these renal disease risk outcomes. These findings did provide us with pertinent knowledge to move forward with other intervention research. For example, this analysis showed that the high-risk cluster exhibited greater mean declines in all three risk factors than the low-risk cluster, and the high-risk cluster actually ended the study with a lower mean HbA1C than the low-risk cluster, stressing the importance of clinical practice interventions and intervention research in participants at high-risk for renal disease. Second, this analysis showed that the high-risk control group had greater mean declines in all three risk factors than the high-risk intervention group, insinuating that the care received in the control group was as effective, or more effective, than the intervention among high-risk participants. Finally, analyzing data from a longitudinal study allowed us to explore the impacts on attrition and risk outcomes over time. Specifically, the rate of attrition was higher in the high-risk cluster, indicating sociocultural factors or the health demands of this higher risk status may play a role in longitudinal study participation. Also, the high-risk cluster displayed a steady decline in triglyceride levels up until the 12-month mark, when the intervention period ended, and increased at the 24-month follow-up, indicating the importance of more frequent interactions and
ongoing follow-up for outcome sustainability, which have both been established to improve outcomes in diabetes self-management studies (Glazier et al., 2006; Norris et al., 2001).

5.8 Synthesis of Dissertation Findings

Figure 14: Comprehensive findings within CSM components

5.9 Implications for Research

This dissertation points to the need for intervention research among healthcare providers; healthcare providers were not a primary source of renal disease knowledge
and communication of renal disease with providers was lacking. First and foremost, since the literature shows that primary care providers often overlook risk factors for renal disease and sometimes fail to recognize early renal disease in the primary practice setting (Boulware et al., 2006; Lea et al., 2006), a simple risk assessment tool should be developed. An intervention study could be conducted to develop and introduce a renal disease risk assessment tool to be used with all patients with T2D in one primary care practice setting. Comparisons in referrals to nephrologists and renal disease risk outcomes could be made with another primary care practice not using the tool. These findings would be valuable to determine the impact of a simple risk assessment tool in primary practice and could open up lines of communication with providers in regard to renal disease.

Second, an intervention could be developed that incorporates the same risk tool in the primary practice setting as a guide to pinpoint high-risk patients and then introduces a simple action plan to be used with the patients established as high-risk from the tool. Action plans are goal-directed activities undertaken to reduce fear and danger, and have been shown to exert a large effect on performance of health behaviors in many different areas, mainly due to individuals actively appraising the efficacy of the plans and incorporating this into their representations (Leventhal et al., 2003). This intervention study would evaluate the impact and feasibility of individualized, goal-directed action plans in this setting and could improve provider autonomy support, which was lacking in the interviews. In summary, interventions with primary care providers are an important step to improve renal disease knowledge and impact representations, which could be very influential to risk perceptions and outcomes among high-risk patients.
The findings from this dissertation also demonstrate the need for future intervention research focused on African-American women with T2D. The literature review and qualitative study portrayed a very low concern for renal disease and low perceived susceptibility in this population, despite the presence of risk factors. These perceptions were related to cognitive renal disease representations, namely a perceived end-stage identity, perceived severe negative consequences, and a chronic timeline; a perceived temporal timeline of complications; and the emotional illness representation of fear along with the coping procedures of denial and “not claiming” (Figure 14). In order to incorporate more problem-focused coping procedures, the CSM posits that illness representations must be adjusted. However research has shown this is not likely in the presence of fear, unless action plans are initiated (Leventhal et al., 2003; Reynolds & Alonzo, 2000). Therefore, a future intervention study should be developed that incorporates individual, goal-directed action plans with African-American women with T2D at high-risk for renal disease, once the feasibility of a risk assessment tool and action plan is established. This intervention should incorporate goal-directed action plans with frequent feedback and short time frames between renal disease risk measures and explore changes in cognitive and emotional representations, and risk perceptions to determine if these factors impacted outcomes. Interventions to improve diabetes self-management in socially disadvantaged populations have shown to be more effective when frequent individual assessment and feedback is incorporated (Glazier et al., 2006). Finally, since the high-risk control group who received standard community based diabetes education displayed such significant improvements in the secondary analysis, this intervention research may benefit from incorporating lay leaders or community educators to establish trust and recruitment strategies could be aimed at targeting local churches since the qualitative study showed the majority of participants in this
population were recruited from churches. In summary, this dissertation stressed the need for intervention research aimed at targeting renal disease risk perceptions in African-American women with T2D, and although this research could be conducted in the primary care setting once the feasibility of tools is established, research in the community may be more beneficial for this targeted group, as evidenced by previous research and the dissertation findings.

5.10 Implications for Clinical Practice

This dissertation revealed a significant, negative influence of healthcare providers on renal disease risk perceptions, displaying a critical need for improvements in the care of patients at high-risk for renal disease. Overall, providers seemed to focus on immediate diabetes care needs among participants, and dodged discussion of complications, unless women were experiencing specific symptoms. Although time is obviously very limited during healthcare visits, discussion of all possible complications is important, as these findings show. If African-American women better understood the various complications they were at risk for, projection of a temporal timeline of complications could be avoided.

These findings showed providers had not discussed renal disease at length with participants and often exhibited provider control, which has been shown to result in poorer diabetes outcomes than provider autonomy support. First, providers must be educated and encouraged to focus on renal disease and conduct comprehensive risk assessments. Once providers are able to easily distinguish high-risk patients, provider autonomy support and initiation of individualized action plans in primary care practice should ultimately result in improved renal disease risk outcomes, and effectively impact risk outcomes for other complications of diabetes.

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It was also evident from the findings that African Americans, particularly African-American women, who displayed more self-advocacy were more knowledgeable of renal disease and their risk; however existing literature and the literature review findings illustrated that African Americans perceive more racism from providers and lack trust compared to their white counterparts, which often hinders them from discussing important concerns (Johnson et al., 2004; LaVeist et al., 2000). Therefore, providers need to be aware of these cultural barriers and establish trust and initiate difficult discussions with high-risk patients, or refer them to the appropriate resources. For example, many women in the qualitative study reported they had not been to a diabetes educator in many years, if at all. Another clinical practice suggestion would be to refer patients yearly to diabetes educators in order to keep patients educated on complications and risk factors since primary care providers are often strapped for time. Another suggestion is to offer more community educational programs to patients with T2D, such as in church settings which has shown to be beneficial in prior research and this dissertation. In summary, healthcare providers need to be encouraged to conduct comprehensive risk assessments on all patients with T2D, incorporate better education on diabetes complications, and address cultural barriers more readily.
Appendix A: Participant Inclusion/Exclusion Algorithm

African American Woman

- Do you have type 2 diabetes?
  - YES
  - NO

- Have you ever been told you have kidney disease?
  - YES
  - NO

- Have you ever been told you have heart disease?
  - YES
  - NO

- Have you ever been told you have eye problems, such as retinopathy?
  - YES
  - NO

- Have you ever been told you have neuropathy (sensation loss and/or numbness & tingling of hands and/or feet)?
  - YES
  - NO

- Have you ever been told you had a stroke?
  - YES
  - NO

- Are you 21 years of age or older?
  - YES
  - NO

- Are you able to speak, read and comprehend English?
  - YES
  - NO

Eligible

Ineligible
Appendix B: Phone Script to Determine Participant Eligibility

Phone Script: *None of the responses will be recorded.

Hello. My name is Casey. The name of this study is Renal Disease Risk Perceptions in African-American Women with Type 2 Diabetes. The purpose of this study is to explore and describe your understanding of kidney disease, your risk perceptions of various complications of diabetes, and factors influencing your risk perceptions. If you agree to take part in this study, there are no direct medical benefits to you. We hope that in the future the information learned from this study will benefit other people with type 2 diabetes. There are no physical risks associated with this study. Every effort will be made to keep your information confidential, and you will be assigned a number to ensure anonymity, and your responses will only be shared with my research mentors. A professional transcriptionist will transcribe all interviews verbatim, however any names provided in the interviews will not be transcribed. Recordings will be destroyed after data analysis is complete.

I will need to ask you a few short questions to determine your eligibility to participate in this study, and your responses are completely voluntary. No information will be written down or recorded today, nor will it be associated with your name or any other identifier. Do you have any questions before I proceed with the eligibility questions?

Eligibility questions:

1. Have you been told you have type 2 diabetes by a health care provider?
2. Have you been told by a healthcare provider you have kidney disease or any of the following complications of diabetes: heart problems, eye problems such as retinopathy, neuropathy (sensation loss, numbness or tingling in hands or feet), or stroke?
3. Are you 21 years of age or older?
4. Are you able to speak, read, and understand English?

Eligible participants: According to your responses, you are eligible to participate in this study. If you agree to participate in this study, we can proceed by meeting in a private location convenient to you in order to review the consent form and proceed with the questionnaire and interview. This meeting will last approximately 60-90 minutes and will include a simple demographic data questionnaire and an open-ended one-on-one interview asking about your perspectives on kidney disease and other complications of diabetes. Some of the questions I will ask you as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions and you may take a break at any time during the study. You may stop your participation in this study at any time. You will be offered a $30 gift card as compensation for participation upon completion of the interview.

Can you please tell me a convenient time and location for us to meet if you are interested in proceeding? Thank you.

Non-eligible participants: Unfortunately your responses indicate that you do not meet the eligibility requirements for this study. I appreciate your time. Thank you and have a nice day.
Appendix C: Participant Demographic Data Form

**Instructions:** Please answer each item below.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your age in years?</td>
<td>______ years</td>
</tr>
<tr>
<td>What is your annual household income range?</td>
<td>______ Less than $24,999</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ $25,000 to $49,999</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ $50,000 to $99,999</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ $100,000 or more</td>
</tr>
<tr>
<td>How long ago were you diagnosed with type 2 diabetes (in years and months if possible)?</td>
<td>______ years ______ months</td>
</tr>
<tr>
<td>Has your health care provider told you that you have any of the following conditions (check all that apply)?</td>
<td>______ High blood pressure</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ High cholesterol</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Heart disease</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Cancer</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Liver disease</td>
</tr>
<tr>
<td>What are your living arrangements? (Choose one)</td>
<td>______ Alone</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ With a significant other</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ With a family member or friend</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ In assisted living</td>
</tr>
<tr>
<td>What is your marital status? (Choose one)</td>
<td>______ Married</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Living with a partner</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Widowed</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Divorced</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Single, never married</td>
</tr>
<tr>
<td>What is the highest degree or level of education you have completed? (Choose one)</td>
<td>______ 12th grade or less (no diploma)</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ High school diploma</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Some college, no degree</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Associate or technical degree</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Bachelor's degree</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Graduate degree/professional</td>
</tr>
<tr>
<td>Do you have a primary health care provider?</td>
<td>______ Yes</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ No</td>
</tr>
<tr>
<td>When was your last A1C test or metabolic control appointment? Do you remember your last A1C level?</td>
<td>______ months ago</td>
</tr>
<tr>
<td>Do you remember your last A1C level?</td>
<td>______ year(s) ago</td>
</tr>
<tr>
<td>last A1C result: ______</td>
<td>______ don’t remember</td>
</tr>
<tr>
<td>Have you ever been told you have microalbuminuria, or protein in your urine?</td>
<td>______ Yes</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ No</td>
</tr>
<tr>
<td>(Choose one)</td>
<td>______ Unsure</td>
</tr>
</tbody>
</table>
Appendix D: Interview Guide

1. How likely do you feel you are to get kidney disease? Tell me about it.

2. I will show the woman index cards with a complication related to type 2 diabetes listed on each card, including kidney disease, heart disease (described as heart problems), stroke, retinopathy (described as eye problems), and neuropathy (described as numbness, tingling or sensation loss of feet or hand), and ask her to rank these complications in order of how at-risk she thinks she is. I will then ask her to describe to me her understanding of each of the various complications listed on the index cards. I will then ask her to explain which of these complications she is concerned about developing and why.

3. When thinking about kidney disease, as you know it, please answer the following questions:
   - What are the symptoms of kidney disease?
   - What do you believe is the cause of kidney disease?
   - How would you describe the course of kidney disease (timeline)?
   - What do you believe are the impacts of kidney disease on quality of life, and how do you believe it affects people’s functioning or daily activities (consequences)?
   - Do you believe kidney disease is controllable or curable?

4. Where and from whom have you heard about or learned about kidney disease? Have you had any personal experience with kidney disease? Can you think of anything in your life that has influenced your opinion of kidney disease?

5. What emotions, if any, come to mind when you think about kidney disease? This question will also be answered by picking up on any emotions verbalized or portrayed throughout the entire interview process.
## Appendix E: Coding Guide with Definitions (* indicates a new code derived from data analysis)

<table>
<thead>
<tr>
<th>CSM Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Risk Perception</strong></td>
<td>Beliefs on awareness of personal susceptibility to renal disease, interpreted in the light of experience, incorporating risk comparison of complications studied</td>
</tr>
<tr>
<td><strong>Causes</strong></td>
<td>Beliefs about the factors responsible for causing renal disease</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>Beliefs about the label of renal disease and any discussion of renal disease symptoms</td>
</tr>
<tr>
<td><strong>Timeline</strong></td>
<td>Beliefs about the course of renal disease, incorporating speed of development and progression</td>
</tr>
<tr>
<td><strong>Consequences</strong></td>
<td>Beliefs about the impact of renal disease on quality of life and how it affects functionality</td>
</tr>
<tr>
<td><strong>Controllability</strong></td>
<td>Beliefs about whether renal disease can be cured or controlled</td>
</tr>
<tr>
<td><em>General lack of renal disease knowledge</em></td>
<td>Verbalization of a lack of disease knowledge and/or responses exhibiting a lack of knowledge of within the five domains</td>
</tr>
<tr>
<td><strong>Emotional illness representation</strong></td>
<td>Any discussion of emotions or feelings regarding renal disease, or any outward emotions expressed when discussing the disease.</td>
</tr>
<tr>
<td><em>Low concern for kidney disease comparatively</em></td>
<td>When discussing which of the five noted complications carry the most concern, renal disease mentioned less frequently than the other four</td>
</tr>
<tr>
<td><strong>Lay information</strong></td>
<td>Reports that any perceived beliefs of renal disease were learned/incorporated from assimilated lay information, cultural knowledge, or media sources</td>
</tr>
<tr>
<td><strong>External sources</strong></td>
<td>Reports that any perceived beliefs of renal disease were learned/incorporated from significant others, family, friends, or health care providers</td>
</tr>
<tr>
<td><em>Sub-theme: provider control</em></td>
<td>Any reports of healthcare providers being relied upon to keep kidneys healthy or monitor risk for renal disease or carry the burden of disease prevention, i.e. a lack of patient autonomy in regards to preventing renal disease</td>
</tr>
<tr>
<td><em>Workplace experience</em></td>
<td>Reports that any perceived beliefs of renal disease were learned/incorporated from experience in a work setting</td>
</tr>
<tr>
<td><strong>Current experience with the illness</strong></td>
<td>Reports that any perceived beliefs of renal disease were learned/incorporated from current experience with the illness, for example having tests done, such as a urine analysis, to</td>
</tr>
</tbody>
</table>
determine if the disease is present

| *Current experience with other complications | Findings that portray women put more emphasis/focus on other complications of diabetes in which they have symptoms of, which impacts their perceived risk for renal disease |
| *Coping procedures | Cognitive or behavioral actions taken (or not taken) to improve health and to prevent renal disease |
Appendix F: Color-coded CSM Coding Scheme

Renal disease risk perceptions: PINK

Renal disease cognitive representations: ORANGE

Numbered: 1. Identity (symptoms)
          2. Causes
          3. Timeline
          4. Consequences
          5. Controllability

Renal disease emotional representations: YELLOW

Illness Stimuli: GREEN

Numbered: 1. Lay information
          2. External source
          3. Current experience with renal disease
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Biography

Casey Lynn Migliore was born in Salem, Ohio in 1979. She graduated from Kent State University in 2001 with a Bachelor’s of Science in Nursing. In 2006, she graduated from Duke University and Meredith College with a dual Master’s of Science in Nursing Administration and a Master’s in Business Administration. While attending Kent State University, she was inducted into Nursing’s Sigma Theta Tau International Honor Society. Casey entered the PhD program at Duke University’s School of Nursing in 2010. During her time in this program, Casey received a Duke Graduate School Summer Research Fellowship and an American Nephrology Nurse’s Association (ANNA) Research Grant. The ANNA grant funded her main dissertation study. Casey also submitted a manuscript for journal publication and is awaiting publication notification, has another manuscript under review at a journal, presented a poster at the Southern Nursing Research Society conference, and presented her research at two Office of Research Affairs seminars at Duke. She also taught a one-semester online master’s level course in the Duke University School of Nursing during her time in the PhD program and served as the nursing PhD representative for the Graduate Program Student Council for three semesters. Casey has been a member of Sigma Theta Tau since 2001 and ANNA since 2007 and has extensive nursing experience with patients in renal failure, which elicited her research passion in this area.