



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

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Abstract

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Keywords

African Americans; renal disease; risk perceptions; disease awareness; sociocultural influences; Common Sense Model

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ABSTRACT

African Americans are disproportionately at risk for renal disease, especially those with type 2 diabetes (McDonough et al., 2011). Despite this disease disparity, the literature lacks research on renal disease awareness and risk perceptions among African Americans with type 2 diabetes. Therefore, a literature review guided by the Common Sense Model was conducted 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. The literature identified an overall lack of knowledge about renal disease risk factors, inaccurate risk perceptions, and a low concern for renal disease among African Americans. Numerous sociocultural factors were identified that could be influential to African Americans' renal disease awareness and risk perceptions, and these can be used to guide future care and policy.

Keywords: African Americans; renal disease; risk perceptions; disease awareness; sociocultural influences; Common Sense Model

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 (Howard Leventhal, Leventhal, & Contrada, 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.'s (2011) 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 (Howard Leventhal, Leventhal, & Breland, 2011; Howard 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

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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.

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 (Howard 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 1 illustrates the components of the model used to guide this review.

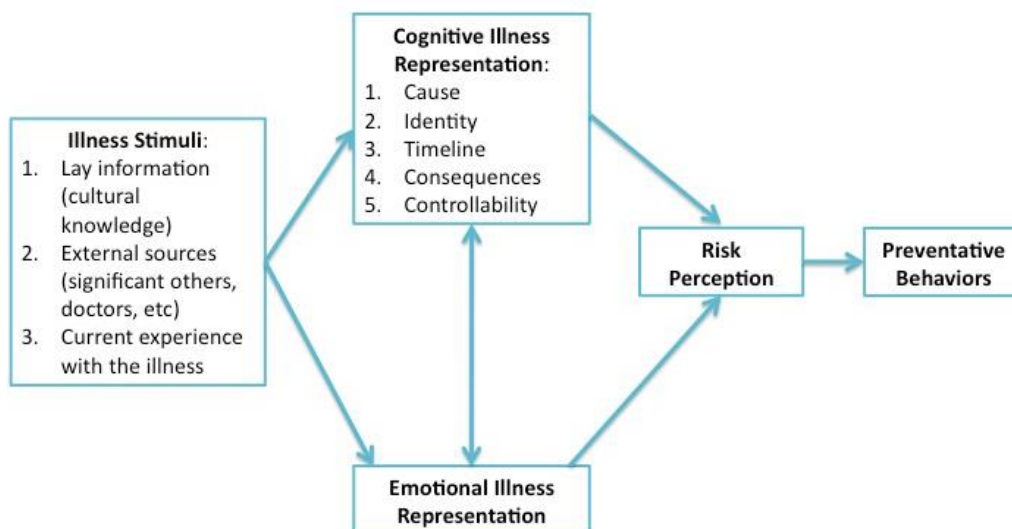


Figure 1:
CSM modified to study risk perceptions

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; H. Leventhal, Brissette, & Leventhal, 2003; Howard Leventhal et al., 1998). These emotional representations are part of the

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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.

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 2), 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.

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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 2), 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.

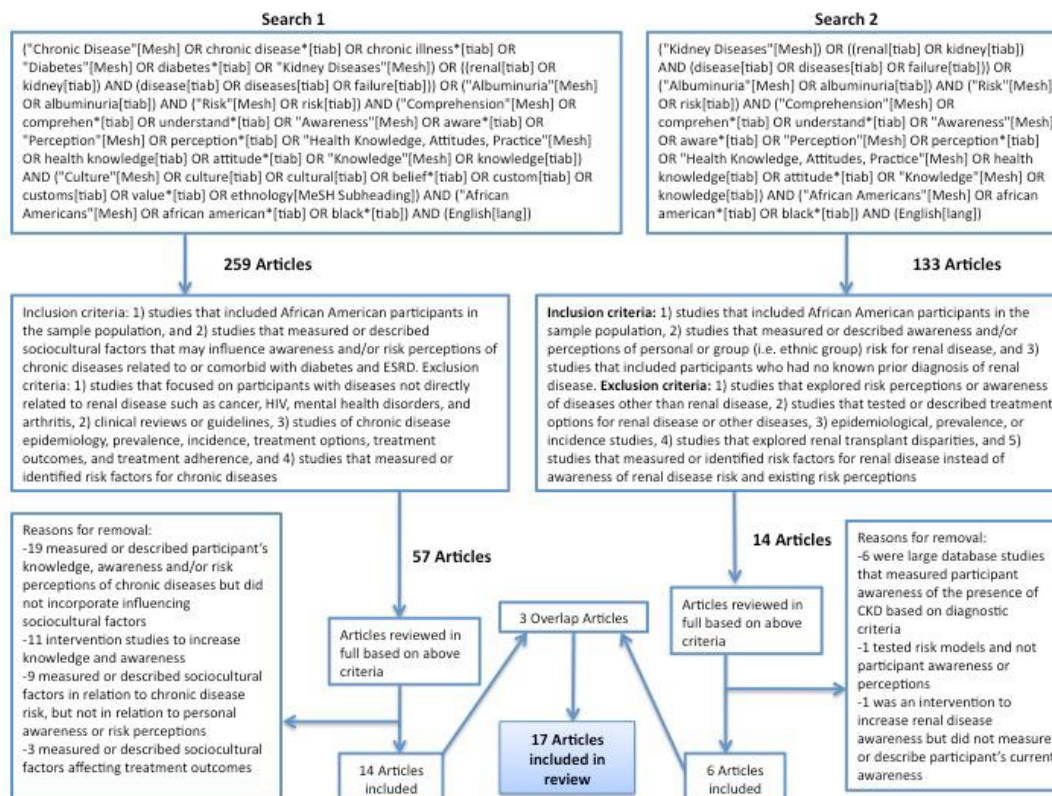


Figure 2: Flow diagram of literature searches

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 2. 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

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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 1). This matrix was then used to examine the study characteristics and to identify CSM themes and sub themes across the studies.

Table 1: Matrix of final articles

Year	Author(s)	Sample Size & Demographics	Clinical Characteristics of Sample	Study Purpose	Study Design & Measures	CSM Theme(s)	Sub-theme(s)
2012	Giardina, E.V. et al.	681 (all females), 7.3% 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 Measures: 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	Describe the perceived risk for diabetes complications (including ESRD) among African Americans with T2D and to explore inter-relationships	Design: Cross-sectional, exploratory, descriptive, correlational Measures: Risk Perception Survey-DM, Well-being Questionnaire, IPQ-R, & physiologic measures including serum A1C, urine microalbumin, and BP	Illness Stimuli -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 characteristic	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,	Illness Stimuli -Lay information	-Limited health literacy

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				s in patients with ESRD	depression via Patient Health Questionnaire 9, symptom burden via Dialysis Symptom Index, and Rapid Estimate of Adult Health Literacy in Medicine (REALM)		
2010	Jennette, C.E. et al.	201, 74% AA	Rural community members	To assess community perceptions of kidney disease, barriers to health care and strategies for raising awareness	Design: Cross-sectional, focus group study based on the grounded theory approach Measure: Pilot-tested scripted discussion guide	Illness Stimuli -External sources -Current experience with the illness Cognitive Illness Rep -Cause -Consequences	-Relationship with PCP -Relationship with someone diagnosed with renal disease -Poor renal disease risk factor knowledge -Difficulty of life on dialysis
2010	McKenzie, C. & Skelly, A.H.	6 (all females), 100% AA	Females with self-reported type 2 diabetes > 1 year	To explore AA women with T2D's perceptions of heart disease risk	Design: 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 Measures: In-depth, pilot-tested semi-structured interviews in-person with 2 women from each stratification group	Illness Stimuli -External sources	-Relationship with PCP -Faith
2010	Tan, A.U., Hoffman, B., & Rosas, S.E.	229, 33.6% AA	Diagnosis of CKD, stage 3 or 4	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	Design: Cross-sectional, exploratory, descriptive Measures: A questionnaire based on a literature search of past knowledge assessment studies & self-reported BP, glucose, and creatinine levels	Illness Stimuli -Lay information	-Lower education level -Smoking status
2009	Ayotte, B.J., Trivedi, R., & Bosworth, H.B.	1177, 46% AA	Patients with a diagnosis of HTN who had filled a prescription for HTN medication in the past	To extend previous research on racial differences in HTN knowledge	Design: Cross-sectional, descriptive, secondary analysis from 2 RCTs that were conducted to improve BP control Measures: Demographic data from RCTs & a HTN item response	Illness Stimuli -Lay information	-Lower education level

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			year		questionnaire		
2009	Boulware, L.E. et al.	195, 63% AA	HTN diagnosis	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	Design: Cross-sectional, descriptive, secondary analysis of patients enrolled in an RCT (The Patient-Physician Partnership to Improve High BP Adherence) 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 & concern	Illness Stimuli -Lay information -Current experience with the illness Emotional Illness Rep Risk Perceptions	-Limited health literacy -Evidence of renal disease risk factors -Low concern for renal disease -Low perceived susceptibility to renal disease
2008	Burroughs, V.J. et al.	1063, 50.5% AA	Self-described overweight AA or Hispanic adults	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	Design: Cross-sectional, exploratory, descriptive Measures: Telephone survey, self-reported height and weight (to calculate BMI)	Illness Stimuli -Lay information	-Weight status and weight optimism
2008	Pace, R. et al.	127, 100% AA	African Americans with a history of high blood pressure or high cholesterol (smokers and drinkers excluded)	To determine the relationship of knowledge of CVD, HTN, obesity, and dietary intake to demographics and examine the relationship between dietary behaviors and dietary knowledge in	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	Illness Stimuli -Lay information	-Lower education level

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				rural AA adults			
2008	Waterman, A.D. et al.	2,017, 100% AA	Random sample	To examine African Americans' awareness and attitudes about kidney disease	Design: Cross-sectional, exploratory, descriptive Measure: A pre-tested survey assessing knowledge and attitudes about kidney disease among AAs via random-digit dialing	Illness Stimuli -Lay information -Current experience with the illness Cognitive Illness Rep -Cause -Controllability Emotional Illness Rep Risk Perceptions	-Lower education level -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
2007	Burnet, D.L. et al.	67 focus group participants, 100% AA 9 interview participants, race not disclosed	Families with a 9-13 year old child in the self-reported 85 th weight percentile or above	To assess beliefs and practices re: nutrition and weight among overweight AA youth and their parents	Design: Cross-sectional, exploratory, descriptive Measure: Semi-structured focus group interviews conducted by community leaders	Illness Stimuli -Lay information -External sources	-Weight status and weight optimism -Relationship with PCP
2006	Brezo, J. et al.	37, 100% AA	African Americans who were either outpatients or their friends/relatives in a family health clinic, no specific clinical condition required	To investigate possible associations between ethnic identity and health attitudes towards type 2 diabetes	Design: Cross-sectional, exploratory, descriptive, correlational Measure: an expert-evaluated questionnaire (one version for participants with T2D and another for those without)	Illness Stimuli -Lay information	-Ethnic identity
2006	Skelly, A.H. et al.	42, 100% AA	African Americans without diagnosed diabetes who meet the US standards for	To explore how African Americans view diabetes and their explanatory models of diabetes	Design: Cross-sectional, exploratory, descriptive Measure: In-depth semi-structured interview guide	Illness Stimuli -Lay information -External sources	-Weight status and weight optimism -Faith

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			working poor				
2005	DeSalvo, K.B. et al.	128 (all females), 100% AA	African American females presenting for care at an urban community clinic (sample taken from a larger RCT sample)	To determine whether high-risk AA women accurately perceive their risk for heart disease and explore personal characteristics associated with under-estimation of risk	Design: Cross-sectional, exploratory, descriptive, secondary analysis of a larger RCT Measures: A multipart survey measuring demographic, socioeconomic, medical history, and psychosocial variables, a single question to measure perceived risk for cardiac disease, and medical chart review (to obtain weight)	Emotional Illness Rep	-Stress
2005	Jurkowitz, C., Hylton, T.N., McClellan, W.M.	402, 20.1% AA	Random sample	To estimate the prevalence of family history of kidney disease and perceptions of risk for kidney disease in the general Georgia population and examine if AAs are more likely to have a family member with kidney disease and more likely to perceive themselves at great risk for the disease as a result, compared to whites	Design: Cross-sectional, exploratory, descriptive Measure: A random probability phone survey	Illness Stimuli -Current experience with the illness Risk Perceptions	-Evidence of renal disease risk factors -Relationship with someone diagnosed with renal disease -Low perceived susceptibility to renal disease

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AA = African American; CVD = cardiovascular disease; BP = blood pressure; ESRD = end stage renal disease; T2D = type 2 diabetes; DM = diabetes mellitus; IPQ-R = Illness Perception Questionnaire, Revised; RCT = randomized controlled trial; PCP = primary care practitioner; CKD = chronic kidney disease; HTN = hypertension; BMI = body mass index

RESULTS

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. 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.

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 and is outlined in Table 2.

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.

Lower education level

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; 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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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 (Table 2).

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; Howard Leventhal et al., 2011). Poor renal disease risk factor knowledge was the single sub-theme found under the domain of cause.

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.

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.

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 (Jennette et al., 2010). 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.

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.

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.

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 (Table 2).

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.

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.

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 (Table 2).

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; Jurkowitz et al., 2005; Waterman et al., 2008). 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; Jurkowitz 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)". Jurkowitz 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; (Jurkowitz 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.

Table 2: Findings within the CSM categories

Illness Stimuli		
Lay Information (sociocultural influences)	External Sources	Current Experience with Illness
Lower education level	Relationship with primary care provider	Evidence of renal disease risk factors
Limited health literacy	Faith	Discussion of renal disease with medical professionals
Weight status and weight optimism		Relationship with someone with renal disease
Smoking status		
Lack of insurance		
Ethnic identity		
Cognitive Illness Representations		
Causes	Consequences	Controllability
Poor renal disease risk factor knowledge	Difficulty of life on dialysis	Preventable and treatable disease beliefs
Emotional Illness Representations		
Low concern for renal disease	Stress	
Risk Perceptions		
Low perceived susceptibility to renal disease		

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.

Illness Stimuli

Multiple sociocultural factors were identified as illness stimuli in this review 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.

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; 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, Stevens, & Persaud, 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). 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-caregiver 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.

External sources and current experience with renal disease

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). 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. 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). 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). 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.

Cognitive Illness Representations

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, Wellsted, Davenport, & Farrington, 2011; Chilcot, Wellsted, & Farrington, 2010; Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & 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, incorporating all five domains, are related to risk perceptions, especially in a high-risk group such as African Americans.

Emotional Illness Representations

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; 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.

Risk Perceptions

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 review 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.

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.

CONCLUSION

Important research implications arose from this literature review. First and foremost, the review displayed a general gap in the literature on renal disease risk perceptions and representations among African Americans, particularly among those with T2D, a very high-risk group. Since African Americans with T2D are at such a disparate risk for renal disease development, it is imperative that further research is conducted to explore their perceptions of risk for renal disease more in-depth. This knowledge could be an important component to develop interventions to improve risk perceptions and disease representations and eventually decrease risk. Secondly, this review provided insight into various sociocultural influences that could be influential to chronic disease risk perceptions and representations, including renal disease. Research aimed at exploring these sociocultural influences in regards to renal disease should be conducted to better understand their specific influence on risk perceptions and representations. Also, interventions focused on the aforementioned sociocultural influences could be developed in an effort improve risk perceptions and representations, although this may involve some public policy interventions due to the influence of social issues discussed previously.

The findings from this literature review also have significant clinical relevance. The review showed 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. “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). 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 provide culturally competent care, due to underlying social issues mentioned above.

From a social perspective, African Americans often face social barriers such as residential segregation, food deserts, and institutional racism, which may play a role in the sociocultural influences found in the literature and suggest the need for public policy interventions. Although these social issues appear overwhelming and cannot easily be eliminated, interventions can be developed to begin to address some areas. First, education programs for healthcare professionals could develop and incorporate mandatory culturally competent care courses in an attempt to decrease the perceived racism reported in healthcare facilities and increase trust among minority patients and providers. Secondly, healthcare facilities could hire a patient liaison that is trained in health literacy and acts as an advocate for patients and follows up with patients after they see their provider, allowing them to express their concerns and ask questions and receive clarification. Finally, community programs could be developed in suburban and rural areas aimed at educating residents on chronic disease and prevention, and offer preventative resources, such as walking groups in safe areas to increase physical activity and farmer's markets with fresh fruit and vegetables on specified days on the month. In summary, improving representations of renal disease and risk perceptions, especially among high-risk people, is imperative in order to increase disease prevention and this literature review showed that the lack of knowledge and inaccurate risk perceptions are very concerning and should be addressed in various ways.

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