

RISK PERCEPTION OF DEVELOPING DIABETES COMPLICATIONS AMONG
AFRICAN AMERICAN WOMEN WITH TYPE 2 DIABETES

by

Judith Muhonja Ochieng

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SIGNED: Judith Muhonja Ochieng

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ABSTRACT

Background: African American (AA) women have a disproportionately higher prevalence of Type 2 Diabetes Mellitus (T2DM) and its related complications than Hispanics and non-Hispanic white women. Cultural practices, stigmatization, discrimination, socio-economic status, historical experiences and geographical locations have all been proposed as factors that influence the prevalence of T2DM in AA women. However, no study has explored how AA women with T2DM perceive their risk of developing diabetes complications, and how their risk perceptions impact their diabetes self-management.

Purpose: The purpose of this study was to describe the perceptions that AA women diagnosed with T2DM have of their risks of developing DM complications, how their perceived risk of diabetes complications influences their DM self-management, and how the socio-cultural and economic contexts in which DM management occurs influences AA women's DM self-management behaviors.

Method: A qualitative descriptive study was used to provide a comprehensive description of the perception of risk for developing diabetes complications among AA women with T2DM. A purposive sample of 10 AA women with T2DM was selected for the study.

Findings: Findings revealed that the risk perception for developing DM complications influenced DM self-management among AA women with T2DM. Sociocultural and economic factors were also found to influence DM self-management among AA women with T2DM.

Conclusion: This study revealed numerous factors that were associated with development of diabetes complications among AA with T2DM. However, risk perception stood out to be associated with all the factors.

CHAPTER I: RESEARCH PROBLEM

Diabetes is a serious chronic disease that has reached epidemic proportions in the United States of America (US) (Centers for Disease Control and Prevention [CDC], 2014). In 2012, 29.1 million Americans (9.3%) were estimated to have diabetes, although nearly 30% or 8.1 million were undiagnosed (American Diabetes Association, Statistics [ADA], 2014d). The number of Americans with diabetes continues to grow. In 2010, 25.8 million (8.3%) were estimated to have diabetes; of these, 7 million had not been formally diagnosed. The prevalence rate of diabetes in the US among adults age 20 and older in 2012 was 12.3% compared to 11.3% in 2010. The risk factors for the prevalence of diabetes are age, race, and ethnicity. In the US, the prevalence of diabetes among seniors aged 65 years and above is 25.9% or 11.8 million. Among racial and ethnic groups, American Indians/Alaska Native individuals have the highest prevalence (15.9%) followed by Non-Hispanic blacks individuals (13.2%). These rates are more than twice that of 7.6% for Non-Hispanic white (NHW) individuals (Centers for Disease Control and Prevention [CDC], 2011).

Diabetes is ranked as the seventh leading cause of death in the US (ADA, 2014d) and results in significant morbidity and mortality, and is an economic burden of more than \$245 billion annually in the US (Kirkman et al., 2012). Among the older adult population (65 years and above) diabetes is responsible for acute and chronic microvascular and cardiovascular complications (Kirkman et al., 2012). Diabetes is the leading cause of kidney failure; and increases the risk for blindness, heart disease, and stroke (Kirkman et al., 2012).

AAs experience higher diabetes health disparities than their NHW counterparts, and are more likely to be diagnosed with diabetes than NHW individuals (Molina, Lehavot, Beadnell, &

Simoni, 2014). *Healthy People 2020* defines health disparity as differences in health distribution related to factors such as race, social, economic, or environment of a disadvantaged population (<http://www.healthypeople.gov/2020>). AA individuals are therefore more likely to suffer from diabetes related complications than Hispanic and NHW individuals in the US (Molina, Lehavot, Beadnell, & Simoni, 2014). Rates of end-stage renal disease, amputation and death among AA individuals are more than twice that of NHW individuals (United States Department of Health & Human Services, 2014; Molina, Lehavot, Beadnell, & Simoni, 2014). AA have been noted to have poorer health behaviors and likely to suffer from diabetes and diabetes complications more than Hispanic and NHW individuals (Molina, Lehavot, Beadnell, & Simoni, 2014; Chow, Foster, Gonzalez, & McIver, 2012). For example, AA adults are almost 70% more likely to be diagnosed with diabetes than NHW adults, 2.7 times more likely to start treatment on diabetes related end-stage renal disease, and 2.2 times likely to die from diabetes than NHW individuals (United States Department of Health & Human Services, 2014; Chow, Foster, Gonzalez, & McIver, 2012).

Overview of Diabetes

Diabetes mellitus (DM) is a group of chronic metabolic disorders that are characterized by hyperglycemia (Anuradha, Saraswati, Kumar, & Rani, 2014). DM is a chronic disease caused by one or more of the following factors: a) impaired insulin secretion; b) inappropriate hepatic glucose production; or c) peripheral insulin receptor insensitivity (Huether & McCance, 2011; Shrivastava, Shrivastava, & Ramasamy, 2013). Genetic factors are significant in the development of diabetes and its complications. The onset of T2DM is accelerated by other factors including obesity, sedentary lifestyle, hyperlipidemia, and hypertension.

Types of Diabetes and Symptoms

There are three major types of diabetes, Type 1, Type 2, and gestational diabetes (GD) (Huether & McCance, 2011; Anuradha et al., 2014). Diabetes Type 1 is an autoimmune disorder characterized by insulin deficiency. People with Type 1 diabetes are insulin dependent because their bodies attack and destroy insulin-producing cells and hence their pancreases cannot produce any insulin (Huether & McCance, 2011). GD is a metabolic disorder pregnant women develop during pregnancy due to insufficient insulin production. GD places women at risk for developing T2DM. Reported rates of GD in pregnancies range from 2-10%. In the US, it is estimated that 5-10% of women who have GD during their pregnancies develop T2DM after pregnancy and have a 35-60% chance of developing T2DM in the next 10 to 20 years of their lives (CDC, 2011).

This study focused on participants with T2DM. T2DM is the most common type of diabetes and is characterized by insulin resistance and/or insufficient production of insulin (ADA, 2014b). T2DM commonly develops in older and middle age adults, though there are some cases among younger people (ADA, 2014a). While the cause or causes of T2DM are not completely understood, obesity and lack of physical activity are thought to be major risk factors (ADA, 2014b). Symptoms for T2DM tend to develop slowly and can sometimes be confused with signs of aging. The most common symptoms are fatigue, slow wound healing, blurred vision, and frequent infections such as vaginitis (ADA, 2014d). Due to the nature of T2DM symptom development, most people are diagnosed with T2DM when they go for routine medical screening or appointments. The reason is that T2DM is often asymptomatic until late in its course (ADA, 2014d). The majority of people with T2DM are obese, and acanthosis nigricans (AN) may be present in those who are of Native American, African American, or of people of

Hispanic descent (ADA, 2014c). AN is a skin disorder in which there is darker, thick, velvety skin in body folds and creases. AN has a gradual onset, appears in the armpits, groin and neck folds, and over the joints of the fingers and toes (Huether & McCance, 2011).

There are three recommended tests to diagnosis T2DM. These tests include hemoglobin A1C (A1C), fasting blood glucose (FBG), and a two-hour oral glucose tolerance test (OGTT). The hemoglobin A1C is the easiest to obtain, as it does not require fasting. While points of service finger stick tests are available, they should not be used to diagnose T2DM because they are not accurate enough, but can be used in the office to determine if blood glucose is high (National Diabetes Information Clearinghouse, 2014). If an individual is symptomatic, a random glucose level equal to or greater than 200mg/dl can be used to confirm diabetes diagnosis (ADA, 2014b). The A1C estimates the level of glycemic control over the previous three months (ADA, 2014b). An A1C greater than 6.9 is diagnostic for diabetes and a level between 5.5 - 6% indicate high risk for developing diabetes (pre-diabetes). The benefit of performing the A1C test is that the individual does not need to fast before the test (ADA, 2014b). Fasting blood glucose levels > 126mg/dl or two-hour OGTT > 200mg/dl are also diagnostic for diabetes (ADA (2014b). While the two-hour OGTT has been the gold standard for diagnosing diabetes, it is the most costly and time consuming of the three diagnostic tests (ADA, 2014b).

Diabetes Complications

Due to its progressive nature, T2DM affects the whole body, resulting in large vessel problems that may lead to cardiovascular problems/myocardial infarction, stroke (macrovascular complications); and small vessels problems that may result in complications such as peripheral/diabetic neuropathy, retinopathy, and nephropathy (microvascular complications)

(ADA, 2014b; Huether & McCance, 2011). Some of these complications may range from moderate to severe and can result in loss of limbs through amputation, end-stage renal failure, cardiovascular problems, stroke and/or death. (Anuradha et al., 2014).

AA women have a high prevalence of developing diabetes complications such as kidney disease, amputations, cardiovascular disease and stroke. AA women with T2DM are 1.5 to 2.5 times more likely to lose their limbs in amputation due to diabetes complications than other ethnic groups (Omolafe, Mouttapa, McMahan, & Tangasri, 2010). In 2010, it was estimated that 10.1% of adults living in Pinal County had diabetes (Health Communities Institute, 2015).

Treatment

The common treatment for T2DM includes medication and lifestyle modifications including daily exercise, medical nutrition therapy and self-blood glucose monitoring. Medication for those with T2DM includes oral hypoglycemic agents such as metformin and glipizide, although basal insulin is increasingly being used (ADA, 2014c). However, individuals' participation in their own care can make a dramatic impact on the progression of diabetes and diabetes complications (Anuradha et al., 2014; Shrivastava et al., 2013).

Diabetes self-management. There is no universal agreed upon definition of self-management. Different disciplines (psychology, nursing or health promotion, medical) have different definitions specific to their disciplines (Cummings, 2013). American Association of Diabetes Educators (AADE) outlines seven essential self-management behaviors necessary to achieve desired diabetes management outcomes (AADE, 2010). The behaviors include healthful eating, being active, monitoring blood glucose level, taking medication, problem solving, reducing risks, and healthy coping (AADE, 2010). Diabetes self-management is critical in

decreasing mortality and morbidity, which lowers health care costs (Funnell et al., 2011).

Diabetes self-management improves glycemic control and delay onset of microvascular and macrovascular complications (Vincent, McEwen, & Pasvogel, 2008; Shrivastava et al., 2013).

The main goal of diabetes self-management is to control blood glucose, achieve low glycemic control, minimize, and/or delay diabetes complications (Shrivastava et al., 2013; Skelly, Carison, Leeman, Steward, & Burns, 2010).

AA women with T2DM have not understood the concept of diabetes self-management (Lynch, Fernandez, Lighthouse, Mendenhall, & Jacobs, 2012). AA women with T2DM have a limited understanding of diabetes self-management such as taking medication, dieting, and exercising (Lynch et al., 2012). AA women are inconsistent in complying with evidence-based recommendations for diabetes self-management (Lynch et al., 2012). Evidence-based practice mandates that people with diabetes should perform moderate to vigorous physical activities for 150 minutes per week to achieve the desired outcome (Lynch et al., 2012).

As a minority group, AA women with T2DM share the same risk factors with American Indian individuals, Alaskan Native individuals and Hispanic individuals. Apart from lower socioeconomic status, other factors such as race or ethnicity, geographical location, access to care, environment and cultural practices, among others contribute to worsening their diabetes self-management and its complications (Lynch et al., 2012). AA individuals' cultural beliefs and practices such as food preparation, spirituality, emotional coping styles, competing care for self and family members, and the multi-caregiver roles all pose challenges for AA women who have T2DM to perform diabetes self-management (Skelly et al., 2009). These factors are further described in Chapter 2.

Risk Perception

Risk is generally defined as the likelihood that an individual or a group of people will experience the effects of a danger, or the chances of being affected by a disease (Calvin et al., 2011). Like other social factors, risk is subjective; it depends on people's experiences within socio-cultural and socio-economic contexts (Calvin et al., 2011). Risk perception may therefore be defined as the way a person or a group of individuals make judgments regarding the seriousness, extent, or severity of a threatening situation and its probability of occurrence (Allen, Purcell, Szanton, & Dennison, 2010).

In healthcare, risk perception is the way an individual or a group of people regards the potential dangers and the possibility of developing complications from a disease and the need to seek health care services (Calvin et al., 2011; Allen, et al., 2010). Risk perception is the ability to recognize negative consequences that may arise from certain behavior or failure to do something (National Safety Council, 2014). Risk perception is therefore influenced by a number of factors including culture and belief systems, past experiences, knowledge of the disease, and age, among other factors. Risk perception determines the likelihood of a person or a group of people seeking health care services to counter the potential threats of a disease. This likelihood of seeking health care services is further complicated by the extent to which a person or a group perceives the availability of resources at their disposal. Risk perception can therefore be considered a major factor that determines health, since it determines people's health care-seeking behavior. Research indicates that people commonly believe that they are at a lower risk of anything negative than their peers, thereby underestimating their susceptibility to unfavorable health incidences (Allen et al., 2010).

Undoubtedly, this phenomenon applies to AA individuals in general and to AA women with T2DM in particular. Statistics from *Healthy People 2010* show that AAs, in general, do not consistently seek required early routine screening and preventive healthcare (Allen et al., 2010). This behavior could be partly explained by the way that AAs in general perceive their risks for developing disease and disease complications. In theory, people are more likely to engage in disease treatment and health promotion behaviors if they perceive that the risk of developing complications is high (Calvin et al., 2011). The concept of risk perception as it pertains to this research study will be discussed in detail in Chapter 2.

Personal Experience with AA Women

During my clinical residency at a community health center, I noticed that some AA women patients with T2DM never wanted to admit that they had diabetes, or even address the issues to do with diabetes such as self-management. According to the policy and procedures of the community health center, patients with chronic diseases who had not followed up with their primary care providers had to have these chronic diseases addressed irrespective of what brought them in. However, a number of AA women with T2DM would shy away from discussing their diabetes and say that, “that is not what brought me in today.” It was also noticed that some of them had lapsed/missed visits for their diabetes checks and still did not want to address it. Out of curiosity, I asked one of the AA women with T2DM why she did not want to talk about her diabetes and she told me that she did not want to talk about it because she didn’t feel sick.

Another patient, through an annual screening, was found to have diabetes. She was presented to me to provide education on diabetes, discuss treatment options, and initiate therapy. When I brought up the issue, the patient was very upset. She said, “I don’t have diabetes” and

refused to discuss the issue or any kind of therapy including counseling or medication. In her response, the patient stated that she was not diabetic and blamed her provider for not helping her lose weight. She stated that she had asked the provider to help her lose weight and the provider refused. During discussion with my preceptor, I learned that the patient had asked to be given medication to help her lose weight. However, her provider informed her that due to her history of hypertension, he could not prescribe a stimulant. She was offered diet counseling and an exercise regimen to help her to not only lose weight but to also control her blood pressure.

In another encounter, during one of my health fair activities in the community, I had a chance to speak to a few AA women, among whom some had diabetes and some had a family history of diabetes. As I was doing blood glucose checks, I had one AA woman whose blood glucose was high. When asked if she had diabetes, she stated that a provider told her that she was diabetic but she had not gone back to the provider and was not taking any medication. She reported that she did not have diabetes; however some of her family members have diabetes and she does not want to have it. She said, “Jesus is my doctor, I don’t have diabetes, praise God.”

From this experience, I learned that AA women’s notion or concept of DM, as a disease is incongruent with AA women’s actual experiences. A number of AA women with T2DM would remain in denial during their initial diagnosis and would not be willing to discuss the issue and begin therapy. Even those who had a known history of diabetes were sometimes reluctant to discuss their diabetes issues with their providers, especially if it was not the primary reason for their visit. Apparently, a number of AA women with T2DM may not understand their risk of developing diabetes complications resulting from poor diabetes self-management.

Statement of the Problem

As reported in the introduction section of this chapter, the prevalence of diabetes in the US is higher among minorities than in NHW individuals. The minority groups in the US therefore suffer disproportionately higher incidences of diabetes and diabetes complications. Statistics indicate that American Indians and Alaskan Natives have the highest prevalence of diabetes, followed by African Americans, Hispanics, Asian Americans, and non-Hispanic whites respectively (ADA, 2014c). Consequently, the minority groups, especially African Americans and Mexican Americans are also two times more likely to be diagnosed with T2DM and suffer diabetes complications than NHW individuals (Lynch et al., 2012). The high incidence of T2DM among minority groups in the US is attributed to the fact that people with a lower socioeconomic status are less likely to engage in the recommended diabetes self-management practices that help to achieve glycemic control (Lynch et al., 2012). Characteristically, minorities in the US suffer scarcity of resources necessary for diabetes care and have limited knowledge and understanding of diabetes self-management. The limited resources available to AA women with T2DM coupled with their lack of diabetes knowledge lead to poor diabetes self-management that increases their chances of developing diabetes complications (Lynch et al., 2012).

The population under study in this research is AA women with T2DM, living in rural communities in Arizona. AA women with diabetes tend to have more co-morbidity related to diabetes such as obesity and hypertension as compared to NHW women. AA women with T2DM are more likely to develop DM related complications such as renal failure, peripheral neuropathy, cardiovascular disease, and stroke than NHW women (Murrock et al., 2013).

As a minority population, AAs are at higher risk for developing diabetes and complications from diabetes not only due to genetic factors, but also due to socio-economic and geographical factors (Murrock et al., 2013; Omolafe et al., 2010). Self-management of diabetes is crucial to treating diabetes but culture, risk perception, socioeconomic status, and literacy level impact self-management behaviors (US Census Bureau, 2012; Braveman, 2011; Seligsoshare, 2010). These concepts are discussed in detail in Chapter 2.

Although all these concepts among others, impact self-management behaviors, the current study focuses on the major knowledge gap related to risk perception for developing diabetes complications, among AA women with T2DM, how their risk perception influences their diabetes self-management, and how the sociocultural and economic factors influences their diabetes (DM) self-management behaviors.

Research Purpose Statement

The purpose of this study was to describe the perceptions that AA women diagnosed with T2DM have of their risks of developing DM complications, how their perceived severity of risk for developing diabetes complications influence their DM self-management, and how the socio-cultural and economic contexts in which DM management occurs influences AA women's DM self-management behaviors.

Specific Aims

The aims of this qualitative descriptive research with AA women diagnosed with T2DM are to:

- I. Describe their perceived risk for developing DM complications.
- II. Describe how their level of perceived risk for developing DM complications influences their diabetes self-management behaviors.

- III. Identify and describe the socio-cultural and economic contexts in which DM self-management occurs.

Research Questions

This qualitative descriptive study is designed to answer the following questions related to risk perception for developing DM complications among AA women with T2DM:

- I. What is the perceived risk among AA women with T2DM of developing diabetes-related complications?
- II. How does the level of perceived risk of developing diabetes-related complications influence DM self-management among AA women with T2DM?
- III. How do sociocultural and economic factors influence DM self-management among AA women with T2DM?

Significance and Implications of the Study for Clinical Practice, Research, and Policy

Practice Implications

The focus of this study is on perceived risk for developing DM complications among AA women with T2DM, and how AA women's perceived risk affect their DM self-management in a socio-cultural context within which their care takes place. Given the study focus, the findings will equip health care providers with valuable knowledge useful in developing population-specific interventions to address the needs of AA women with T2DM. Understanding how this population perceives their risks of developing DM complications is essential for tailoring care and quality patient education based on their perceived risks. Patient-centered care recognizes that listening to patient's needs, and understanding of patient's values and preferences are critical in providing quality patient care (Epstein & Street, 2011). This research study findings will help

providers understand how AA women with T2DM perceive their risks of developing DM complications, and how their perceived risk influences DM self-management. Knowledge gained from these findings may lead to the development of strategies to support diabetes self-management education specific to AA women with T2DM. These educational strategies may encourage AA women to take an active role in DM self-management behaviors. When people understand the cause of their illness, complications, options of treatment available to them, and how they can be involved in their care, gives them a sense of control, hence they take responsibility and feel empowered to participate in their own care (Askham, Coulter, & Parsons, 2008).

The findings in this study will also inform the nursing profession and health care providers in general of AA women's socio-cultural and economic contexts that may influence their risk perception of developing DM complications. This may help the providers develop education material that may enhance knowledge on T2DM among AA women with T2DM. For example understanding the economic context in which AA women with T2DM are managing their disease may trigger the providers to look for patient assistance programs to help AA women with T2DM pay for medication. For instance, if someone is not able to pay for insulin or oral medication, Wal-Mart has some patient assistance programs that can help out, but can only assist if the provider requests for the assistance. This may improve the health outcome of someone who was struggling with managing her diabetes due to lack of medication. The research findings may therefore help healthcare providers to develop socio-cultural appropriate and individualized approaches for providing quality care for AA women with T2DM, to improve their health outcomes.

Socio-cultural context may influence patients' disease management and healthcare needs in ways that providers may not be aware of (Epstein & Street, 2011). Providers should therefore be able to invite patients to participate in their care, by explaining the disease process to the patients and making every visit interactive based on the patients' healthcare needs as defined by their socio-cultural contexts. In summary, this research may help identify the needs of AA women with T2DM, their risk perceptions for developing DM complications, and how their perceived risk for developing diabetes complications influences DM self-management behavior within their socio-cultural context. The findings will inform healthcare industry on strategies that needs to be developed to support diabetes education among AA women with T2DM.

Research Implications

No research has been done to understand how AA women with T2DM perceive their risk for developing diabetes complications, and how risk perception affects their diabetes self-management. This research will therefore begin to fill the existing knowledge gap by describing the risk perception of developing diabetes complications among AA women with T2DM. How their perception of risk influences their DM self-management behaviors and also by describing the socio-cultural and economic context in which DM self-management behavior occurs as narrated in AA women's own words in a socio-cultural context. The research findings may also enable future researchers to identify other areas of interest in the same topic that will needs to be studied further to improve the health outcomes among AA women with T2DM.

Policy Implications

Diabetes does not only have clinical implications, but also economic and social implications. In the US alone, \$245 billion is spent annually on diabetes and related

comorbidities (ADA, 2014d), which includes \$176 billion for direct medical costs, and \$69 billion in reduced productivity (ADA, 2014d). The findings from this study may contribute information to policy makers that may be used in conjunction with other study findings to develop healthcare programs and policies that may enhance risk awareness and diabetes self-management among AA women with T2DM. The developments of risk awareness programs may help improve diabetes self-management behavior, health outcomes among this population, reduce cost of healthcare, and improve productivity.

Summary

Despite advances in healthcare in the US, diabetes still remains a major health concern in many communities, especially the minority ethnic groups. AA women with T2DM have a higher risk of developing diabetes complications resulting in blindness, amputations, kidney failure, and cardiac problems, among others than other ethnic groups in the US (Omolafe et al., 2010). This research study will describe how AA women with T2DM perceive their risks for developing T2DM complications, the impact of risk perception on diabetes self-management behaviors among AA women with T2DM, and the context of socio-cultural and economic factors on diabetes self-management among AA women with T2DM.

The findings of this research may provide knowledge that will be used by healthcare providers to develop population specific plan of care that will address the health care needs of AA women with T2DM. In addition, the study findings may provide suggestions for further research among AA women with T2DM that will enhance and improve knowledge of diabetes care among this population. Finally, the study findings may also help improve diabetes self-

management among AA women with T2DM by providing necessary knowledge to develop policies that address population specific approach to providing diabetes care and management.

Operational Definition of Terms

African American women: African American women are females of African decent living in the US (Lynch, 2014).

Health Disparity: Health disparity is the unequal health outcome to a greater or lesser extent between populations resulting from an uneven distribution of health care resources and opportunities in society (United States Department of Human & Health Services, 2014). Typically, health disparities are health differences that negatively affect socially disadvantaged or underprivileged populations. By nature, health disparities based on race wealth, religion, education, socioeconomic status and occupation, among other social classifications are avoidable health differences that affect a population (Braveman et al., 2011).

Risk Perception: Risk perception is the way an individual or a group of people regard, consider or understand the likely dangers or gravity of a disease, and the need to seek health services (Sjöberg, Moen, & Rundmo, 2004).

Diabetes Self-Management: There is no universal agreed upon definition of self-management. Different disciplines (psychology, nursing or health promotion, medical) have different definitions specific to their disciplines (Cummings, 2013). Diabetes self-management is individual participation in diabetes care by following a prescribed treatment regimen, and collaborating with a health care provider to minimize and delay the progression and development of complications within a sociocultural context (ADA, n.d.; Shrivastava, et al., 2013).

Rural Area: US Census Bureau considers all population and housing not included in urban as rural irrespective of city or county boundaries (Health Resources & Services Administration, n.d.). According to the White House Office of Management and Budget (OMB), counties are categorized as metropolitan (Metro), and micropolitan (Micro). A Metro area contains 50,000 or more population, and a Micro area contains at least 10,000 (but less than 50,000) population. All counties that are not part of metropolitan or micropolitan are considered rural (HRSA, n.d.).

Type 2 Diabetes (T2DM): T2DM is a metabolic disorder that affects the body's ability to use glucose due to insufficient insulin production or insulin resistance (Huether & McCance, 2011).

Vulnerable Population: Vulnerable population (VP) refers to people who are at risk for poor health outcomes and poor access to healthcare (Aday, 2003).

CHAPTER II: LITERATURE REVIEW

African Americans (AAs) is a term that refers to people of African decent living in the United States of America (Lynch, 2014; Welch, 2003). The word *Blacks* is often used interchangeably with African Americans. However, the term AAs refers to the descendants of Africans who were brought to America in the 18th and 19th century through the slave trade (Welch, 2003). The term *Blacks* refers to the various ethnic groups who have migrated to the United States from sub-Saharan Africa and the Caribbean (Welch, 2003). For the purpose of distinction and inclusiveness, this research study will use the term AA to refer to both the people of African descent who trace their ancestry to the people who came to the US through slavery and the slave trade as well as to those who immigrated to the United States from sub-Saharan Africa and the Caribbean regions. Given their low numerical numbers compared to NHW individuals, AA individuals are considered a minority group in the United States.

Historically, AA individuals have experienced severe disparate socio-economic opportunities especially related to income and occupation (Collins, 2006). Minority groups in the US have experienced higher rates of poverty compared to NHW individuals (Shi & Stevens 2010). As a minority group of 13.6 % of the US population, AA individuals have a poverty rate of 28% that is higher than any other group (CDC, 2012; CDC 2013). Disparities also exist for health and health care services available to them (Collins, 2006). AA women aged 45 to 64 are 10 and 5 times (respectively) more likely to die of heart diseases and diabetes than other ethnic groups in the US (Collins, 2006).

This literature review focused on the issues AA women with T2DM experience as a vulnerable population. This review focuses on the issues and indicators of vulnerability that is

prevalent among AA women in general, and among AA women with type T2DM in particular (Shi & Stevens, 2010). The issues examined in this literature review affecting this population include socio-economic conditions, educational level, demographic factors, historical experiences, and most importantly, health and health care issues. The primary focus of this literature review was on the risk perception of developing diabetes complications among AA women with T2DM and the sociocultural and economic context in which T2DM self-management occurs. Discussions in the literature review include factors of vulnerability and the socio-cultural and economic factors related to the disproportionately high prevalence of diabetes among AA women. Finally, the review discusses the gap in the available literature regarding the perception of risk for developing diabetes complications among AA women with T2DM. In addition, suggestions for further research on this issue are also discussed.

Theoretical Perspective

This study used critical social theory (CST) perspectives that helped explain how the sociocultural and economic context of AA women diagnosed with T2DM influences their diabetes self-management behaviors. Therefore, CST was used in this study as an umbrella-guiding perspective that heightened awareness of the racism, and sociopolitical factors, including discrimination in the society that may play a role in AA women's diabetes self-management.

CST posits that people comprehend reality and the social, political, cultural, ethical, as well as gender-based forces operating in society that creates that reality. Therefore, what people know as reality is what society has refined and crystallized overtime into the social structure (Cohen & Crabtree, 2006).

CST is not a theory; rather it is a perspective that challenges and undermines traditional knowledge regarding the quality of health care people receive in our society. CST stresses that all experience is historical and subjective, and that ‘objective’ understanding can be misleading (Chinn & Kramer, 2008). CST focuses on revealing how sociopolitical practices may enable unfair treatment of vulnerable populations to benefit the mainstream (McEwen, 2005). CST strives to explain and understand people’s feelings and meaning of experiences beyond their narratives (McEwen, 2005). CST seeks to make a difference by critiquing the existing knowledge and understanding and illuminate social injustice based on gender, class, race, economic status, and age among other things (Chinn & Kramer, 2008).

CST assumes that cultural and societal factors influence decisions and choices related to healthcare and may explain the healthcare disparities the vulnerable population under study experience (Crist & Speaks, 2011). Within this sociocultural and economic context, the study will examine and describe AA women’s perception of risk for developing diabetes complications, and how their perception influences their diabetes self-management behaviors.

CST uses a societal perspective to uncover social differences in status that would keep people from achieving their goals in health care (McEwen & Wills, 2015). CST challenges all forms of power differentials and mistreatments and assumes that the truth is determined by society. Also, CST draws attention to dominations and limitations of human behavior. All aspects of human behavior, including: cultural beliefs, socioeconomic, sociopolitical, as well as personal values should be considered in order to successfully deal with illness and health of a population (McEwen & Wills, 2015). Using CST, the social perspective and personal values of

AA women with T2DM must be made explicit in order to understand their health behavior and the reason for disease prevalence despite the said availability of resources.

Using CST, the researcher moved away from the notion that the AA women with T2DM were non-compliant or non-adherent to treatment and, rather, explored sociocultural and economic influences on diabetes self-management among this population. CST posits that issues of health and well-being in communities need to be considered from an individual as well as a community point of view, and critically assessed to identify other social factors that influence a people's health behaviors (Crist & Escandón-Dominguez, 2003). CST enabled the researcher to critically look at how sociocultural and economic factors affect risk perception of AA women with T2DM, and how their risk perception of developing diabetes complications influences their DM self-management.

Conceptual Framework: The Health Belief Model

Health Belief Model (HBM) is a conceptual framework that was used in this study to better understand and describe how AA women with T2DM perceive their risk for developing diabetes complications. The HBM was first developed to predict preventative health behaviors (Hochbaum, Kegels, & Rosenstock, 1952). HBM has since been revised to include general health motivation to distinguish sick-role behavior from health behaviors (Noar & Zimmeman, 2005). Central to the HBM is the concept that health behavior is influenced by an individual's perception of disease and the approaches available to minimize its incidence (Rawlett, 2011; Zhang, Dalal, & Wang-mail, 2013; Hochbaum, Kegels, & Rosenstock, 1952). The HBM posits that health behavioral changes occur when an individual (patient) recognizes or perceives susceptibility, severity and threat of a disease, as well as barriers and benefits of behavioral

changes (Rawlett, 2011; Zhang, Dalal, & Wang-mail, 2013; Hochbaum, Kegels, & Rosenstock, 1952). For the purpose of this study, two of these concepts relate to this study: perceived severity and perceived benefit, as discussed further below.

Perceived Severity

This is the extent to which an individual perceives the seriousness of a disease and its complications (i.e., a person's judgment of how severe a disease condition and disease complications can be) (Rawlett, 2011; Hochbaum, Kegels, & Rosenstock, 1952). This concept allowed the researcher to describe the AA women's risk perception of developing diabetes complications. For example, a study by Adejoh (2014) revealed that individuals with high perception of severity of diabetes engaged in better DM self-management, and those with low perception of severity had poor DM self-management. In a study conducted to examine the association and influence of knowledge of diabetes and health belief on diabetes management among the Igala people in Nigeria, Adejoh used a 16-item questionnaire to measure perceived susceptibility, perceived severity, perceived benefit and perceived barriers. The items were measure on a five-point scale, ranging from strongly disagree to strongly agree (Adejoh, 2014). The items were then scored from the lowest to highest, depending on the respondent agreement, and then summed up to get the measure of the perception (Adejoh, 2014).

Perceived Benefit

Judgment of the usefulness or importance of a new health behavior intended to minimize the risk of a disease (Rawlett, 2011; Hochbaum, Kegels, & Rosenstock, 1952). Perceived benefit therefore contributes to how an individual takes action to prevent the severity of a disease. If an individual perceives that change in a behavior or taking a certain action is beneficial then he/she

is likely to engage in the behavior based on what the individual considers to be the benefits the behavior or taking action. People with DM who consider change in lifestyle/behavior to be beneficial in preventing DM complications engage in DM self-management behaviors such as blood glucose monitoring, taking medications as prescribed, monitor their diet, and follow up with their providers regularly as recommended by ADA.

Conducting Research among Vulnerable Populations

Vulnerable population (VP) refers to a group of people who are at a greater risk for poor health outcomes and poor access to healthcare. They are susceptible to and experience health disparities, unable to utilize healthcare services, and have a high mortality rate compared to other populations (Shi & Stevens, 2010). A vulnerable population may therefore be seen as a people who are at risk for poor physical, emotional, psychological, and social health (Baumhover & May, 2013). Vulnerability refers to being in a position in which an individual or a group of people is at risk of poor physical, psychological or social health (Aday, 2003). A population may therefore be referred to as vulnerable if it is susceptible to socio-economic injustices or needs help to meet basic needs. The end product of these factors with respect to any given population is limited access to health care and poor health outcomes (Shi & Stevens, 2010).

The vulnerable population of interest in this study is AA women with type T2DM living in rural Pinal County, Arizona. AAs represent 13.6% of the population of the United States (CDC 2013). In rural Pinal County, Arizona, AAs are 4.3% of the total population of 387,365 people (US Population Census, 2012). AAs are a minority group not only in the United States but also in rural Arizona. As part of a minority population, AA women with T2DM living in rural Arizona meet the criteria for vulnerability in a number of ways as discussed below. The

criterion includes a relatively high morbidity and mortality rate, their gender as women, their race and ethnicity, low level of education, low level of income, unforeseen life changes, and limited access to health care.

Current Morbidity and Mortality Rates

Morbidity and mortality reports indicate that for every 100,000 deaths among women with different diseases, the rate in 2010 for AA women was 898.2 compared to 741.8 for NHW women and 558.6 for Hispanics women (CDC, 2012). At the same time, homicide rates were reported to be higher among AA women from 1999 to 2007 than Hispanic women and NHW women (Logan, Smith, & Steven, 2011). Considering cardiovascular diseases, AA women have a high obesity rate of 53% predisposing them to diabetes and hypertension (HTN). AA women are more than twice as likely to get diabetes (13.1%) compared to NHW women (6.1%) (Warren, Wilcox, Dowda, & Baruth, 2012). It is also estimated that approximately 2.7 million AA adults have diabetes and 25% of them are AA women (Murrock, Taylor, & Marino, 2013). AA women with T2DM tend to have comorbidities related to diabetes such as obesity and HTN, and are more likely to develop diabetes related complications such as stroke, and cardiovascular diseases than their male counterparts (Murrock et al., 2013).

Determinants of Vulnerability

AA women with T2DM, living in rural Arizona, share similar historical, social and economic characteristics with their counterparts living elsewhere in the United States. Using Shi and Stevens (2010) individual model of understanding vulnerability, the common determinants of vulnerability may include gender, ethnicity and race, education, income, and life changes as discussed in details below.

Gender

Generally, women are known to be more vulnerable due to life stressors associated with family responsibilities and, sometimes, gender roles and social-cultural setting (Samuel-Hodge et al., 2000). High levels of stress inherent in child bearing and rearing, care giving and a high risk of injury due to domestic violence all contribute to women's vulnerability (Shi & Stevens, 2010). Other than these common gender responsibilities in the family, most AA women are the sole caretakers in their families. The burden of caring for their families, combined with formal work schedules, make it even harder for AA women with diabetes to effectively manage their disease (Murrock, Taylor, & Marino, 2012). Due to AA women's role in their families, AA women with T2DM are reported to have feelings of tiredness and psychological stresses that make it hard for them to fully engage in their diabetes self-care (Huffman & Vaccaro, 2012). At the same time, AA women are vulnerable because they have a comparatively poor health status (Shi & Stevens, 2010). It is therefore safe to say that most AA women with T2DM have a poor health status because they are women. As an important element of vulnerability, AA women in the US suffer disproportionate risk of ill health due to their vulnerability (Collins, 2006). For example, AA in women Pinal County in 2013 had a breast cancer incidence rate of 93.6 per 100,000 female population compared Pinal County overall rate of 87.6 per 100,000 females. Age adjusted death rate due to diabetes in Pinal County females was 22.7 per 100,000 populations compared to men at 22.5 per 100,000 population (Healthy Communities Institute, 2015).

Ethnicity and Race

Race is a major determinant of vulnerability in the US. Racial minority groups in the US have comparatively higher levels of poverty compared to NHW individuals (Shi & Stevens,

2010). AAs have 28% higher level of poverty than any other ethnic groups in the US (CDC, 2012). Due to their high level of poverty, AA women with T2DM have limited access to health care and essential health care resources necessary for personal and family well-being (Sampsel, 2007). At the same time, many AA women with T2DM are not in a position to get preventive healthcare services because they cannot afford it. Consequently, AA individuals in general have higher rates of morbidity from preventable diseases such as diabetes and HTN and an equally higher mortality rate compared to other ethnic groups and races in the US (Shi & Stevens, 2010). This is because many AA women with T2DM cannot afford preventive and tertiary health services necessary to manage their diseases.

Past historical experiences of AA as a population in the US also play a role in their vulnerability to diseases and poor health outcomes. Perceived discrimination, racism, poor quality of health care and painful memories of scientific abuse such as the Tuskegee syphilis study of 1932 to 1972 discourage the AA population in general from seeking health care services (Bhattacharya, 2012). Many AAs in general still hold the belief that just as the Tuskegee participants were not told the truth or informed by health care providers, and then they too are not being given the right information regarding their health by health care providers today. “I know as Black Americans that we are not told all the time the correct truth” (Scharff, 2010, p. 888). This mistrust may lead many AA women with T2DM to not seek needed health care services or engage in daily diabetes self-management behaviors resulting in higher comorbidities and, even more dramatic higher mortality rates (Scharff, 2010; Bhattacharya, 2012).

Education and Income

The level of education attained by the members of any community is a major determinant of their vulnerability. Generally, vulnerability in a community is inversely proportionate to its level of education: those with higher education are favored to have better health resulting from easy access to medical care and a greater chance of preventive health services (Shi & Stevens, 2010). Low education attainment on the other hand has negative consequences such as difficulty attaining jobs and having a poor health status (Mechanic & Tanner, 2007). Due to a low educational status, it may be harder for some AA women with T2DM to read, understand, and follow instructions regarding diabetes self-management. Inadequate knowledge and awareness of T2DM is responsible for medication non-adherence among AA with T2DM (Bhattacharya, 2012).

Statistics indicate that AA women have comparatively lower levels of education than NHW women. Only about 21% of AA women have a college and higher levels of education compared to about 29% of NHW women (US Census Bureau, 2012). It is logical to predict that the consequence of this low level of education would include less knowledge about diabetes self-management. Low education attainment also predisposes people to limited cognitive resources to draw from when dealing with a disease process including medication adherence (Bhattacharya, 2012). At the same time, the job market becomes very competitive for AA women due to their lack of professional training or unique skills required for well-paying jobs, which leads to low incomes (Mechanic & Tanner, 2007). Approximately 26% of AA women work in clerical and retail jobs that do not provide benefits such as health insurance and paid vacations. Therefore, many AA women are frequently working just to survive as they get lower pay. Additionally,

employed AA women are paid much lower wages compared to NHW women holding similar positions (National Partnership for Women & Families, 2014; Weller & Fields, 2011). For example in 2013, per capita personal income in Pinal County was estimated at \$25,511 (Economic Research Federal Bank of St. Luis, 2013). US Census Bureau (2010) reported a household median income of \$51,310; per capita income, \$21,716; and poverty level was 13.5% in Pinal County.

Life Changes

Like other women in the United States, AA women with T2DM experience life changes that predispose them to vulnerability as a group. One of such changes is job loss, which leads to loss of income and inability to pay for healthcare needs. For example, in 2007, only 5570 AA women were in fulltime employment in Pinal County, compared to 50,454 NHW counterparts (US Equal Employment Opportunity Commission, 2007). At the same time, Pinal County rural communities registered higher unemployment rates than the average rate of Arizona State rate in the past few years. For example, from May 2007 to July 2009, the unemployment rate in Casa Grande, which until recently met the rurality criterion of population, has ranged from 3.3 - 12.6% (Arizona Unemployment Rate Report, 2015). Other significant life changes often experienced by this population include advanced age and suffering from diseases such as diabetes complications including diabetic retinopathy, amputations, and end-stage renal diseases (National Women's Law Center, 2013). The loss of independence that comes with these life changes increase AA women's vulnerability as they will need other people to provide care and assist them with their activities of daily living. In a study by Weaver and colleagues (2014), some participants reported inability to buy healthful foods from nearby stores because they were

very expensive but the supermarkets were far from their neighborhood. These participants reported having to depend on their children for transportation to take them to the supermarket to buy food (Weaver, Lemonde, Payman, & Goodman, 2014). The issue of vulnerability is discussed under access to health care and health disparities below.

Access to Care

Low income and poverty among AA women with T2DM may have a number of actual and potential negative consequences on their diabetes self-management. For example, low income and poverty may prevent AA women with T2DM from getting health services they need, resulting in poor self-management of their diabetes (Shi & Stevens, 2010). The negative socio-economic conditions AA women with T2DM experience lead to poor diabetes self-management practices that result in diabetes complications and poor health outcomes (Guerra, 2013).

In addition, geographical factors such as living in low-income rural areas with a poor infrastructure make it difficult for residents to access healthcare services when they need them (Braveman, 2011). Diabetes is more prevalent among poor rural communities than among rich urban neighborhoods (O'Connor & Wellenius, 2012; Vanasse, Courteau, Cohen, Orzanco, & Drouin, 2010). There is a disparity in the rate of new incidences of T2DM and other chronic diseases between people living in poor neighborhood as compared to rich neighborhoods (Larson, Story, & Nelson, 2009). Poor neighborhoods with an average annual income of about \$15,000 are reported to experience one and a quarter ($1\frac{1}{4}$) times higher rates of new diabetes cases than neighborhoods with an average income of \$100,000 (Seligsoshare, 2010). The phenomenon may be explained by the fact that poor neighborhoods are characterized by inadequate recreational opportunities for exercise, unavailability of fresh food produce,

encroachment of fast-food restaurants, as well as poorly lit streets which discourage simple exercises needed for diabetes self-management (Seligsoshare, 2010; Larson, Story, & Nelson, 2009).

Even with a college degree, AA women still experience a comparatively higher rate of unemployment than NHW women. For example in 2011, the unemployment rate among AA women in general was 14.1% compared to 7.4% among NHW women. Among AA with a college degree the rate of unemployment was 6.9% compared to 3.9% among non-Hispanic white women (Weller & Fields, 2011). In general, studies show that 26% of AA women work in low paying clerical and temporary retail jobs that do not provide job related benefits such as health insurance (Mechanic & Tanner, 2007). It is estimated that one in every four AA women, including those in the workforce, are uninsured (Guerra, 2013). In general, only 13.2% of AAs have health insurance compared to 77.7% of NHW women (United States Census, 2013). In Pinal County, only 78.6% of all adult population had health insurance in 2013, which is still below the *Healthy People 2020* target of 100% (Healthy Communities Institute, 2014).

Health Disparities

A major goal of health interventions is to address the health problems among AA women with T2DM and reduce the existing health disparities in this population (Braveman et al., 2011). Health disparity refers to the differences in the health outcomes between groups or populations (Department of Human & Health Services, 2014). Health disparities refer to the gaps in the quality of health as determined by race, SES, poor health literacy, cultural beliefs and preferences, education levels and access to healthcare (Center for Prevention & Health Services, 2009). The root cause of these inequalities may be traced to differences in access to health care,

risk for diseases, genetics, culture, behavior, lack of research, and risk perception among other factors (National Institute of Allergy & Infectious Diseases, 2013; Siaki, 2009).

Of all the factors contributing to health disparities, behavior is the most important contributing factor (Siaki, 2009). Since risk perception is an important factor in health behavior changes, understanding the risk perception of AA women with T2DM is key to changing their health behavior and reducing their health risks. Understanding risk perception for developing diabetes complications of AA women with T2DM is important for practitioners to develop appropriate interventions to improve health outcomes and reduce T2DM health disparities in this population.

General Problem Overview

Diabetes has been and is still a major health problem in the United States (US). DM is particularly problematic for AA individuals. AA women have a disproportionately higher prevalence of T2DM than Hispanics and NHW women. In this general problem overview, the burden of T2DM and DM complications are discussed. Statistics on T2DM and its effects in US, Arizona, and Pinal County are included to provide insight and an overview on the prevalence of DM as disease.

A number of research studies have investigated a myriad of health problems facing AAs as a population in the United States. AAs experience a great burden of diseases and illnesses in the US (Sadler et al., 2005). Heart disease, cancer, cardiovascular diseases, and diabetes still pose the greatest health risks and mortality among AA women. For example, out of over six hundred thousand (600,000) people who died of heart disease in the United States in 2008, African Americans made up 24.5% of the cases (CDC, 2014).

Nonetheless, diabetes is still a major health problem not only in the US but also worldwide. Diabetes is the fourth leading cause of disease-related death throughout the world (Skelly et al., 2008). In 2006, the World Health Organization estimated that over 180 million people throughout the world had diabetes; by 2025, an estimated 380 million people will have it (Skelly et al., 2008). Statistics show that of 25.8 million Americans, 8.3% of the population has diabetes and approximately 18.7% of non-Hispanic blacks have it (American Diabetes Association, 2013).

Diabetes alone affects nearly 10% of the entire United States population including 25% of older adults: it is estimated that 1:3 people in the US will have diabetes by the year 2050 if the trend continues (American Diabetes Association, 2013). It is also estimated that between 2000 and 2050, the number of people with diabetes will increase by 165% (Omolafe, Moutapa, McMahan, & Tanjarsri, 2010). In terms of cost, it is reported that diabetes related care takes up about 11% of the total US healthcare expenditure (Skelly et al., 2009). This statistic underscores the magnitude of the economic burden of diabetes in the US.

Among the AA population, diabetes is ranked second among the four leading causes of death in women 45 years and older; it is twice that of NHW women (Sandler et al., 2005). AA women are disproportionately diagnosed with T2DM and its associated complications (Willig, Richardson, Agne, & Charrington, 2014). AA individuals in general are 50% more likely to develop T2DM than NHW individuals. They are 1.5 - 2.5 times more likely to lose their limbs to amputation due to diabetes complications than NHW individuals (Omolafe et al., 2010). This disproportionate prevalence of T2DM among AA women also comes with a disproportionate economic impact on the population due to hospitalization costs (Sumlin & Garcia, 2012).

Whereas there are a number of positive behavior changes that AA women with T2DM may adopt to reduce the high risk of developing diabetes and its complications, research indicates that AA women with T2DM are not taking the necessary initiatives to manage their diabetes and improve their conditions. For example, although AA women have comparatively higher levels of obesity than NHW women, AA women are less likely to engage in initiatives to lose weight as a healthy life style change (Willig et al., 2014). The irony is that AA women with T2DM are not ignorant of the risks of developing diabetes complications. However, there appears to be a major disconnect between knowledge, practice, risk perception and the actual risk of developing diabetes complications among AA women with T2DM. AA women with T2DM are likely to report their intention to observe recommended dietary practices when diagnosed with T2DM. However, research indicates that AA women are more likely to report their intended dietary compliance rather than their actual practice (Willig et al., 2014). Consequently, AA women with T2DM are likely to maintain higher body weights than recommended for diabetes self-care/management (Willig et al., 2014). A study involving AA women who had taken a diabetes education class revealed that their reported dietary practices were completely inconsistent with their actual eating habits. Surprisingly, the AA women participants reported eating for the sake of it even when they were not hungry. The participants reported eating “until they felt sick or physically uncomfortable” (Willig et al., 2014). This phenomenon has been validated by a research study that revealed that AA women’s awareness of their diseases was not translated into actions needed to reduce their disproportionate disease-related mortality rate even after diabetes education (Sadler et al., 2005). Simple awareness of a disease does not necessarily elicit appropriate health promotion behavior in AA women with diabetes (Sadler et al., 2005).

Problem Overview in Arizona

In the state of Arizona, African Americans make up approximately 4% of the total state population. Like in the rest of the United States, AAs living in the state of Arizona experience disproportionately higher prevalence of diabetes than their NHW individual counterparts. The prevalence of diabetes among AAs living in Arizona is approximately 16% (Arizona Department of Health Services, 2014). This is almost three times higher than that of NHW living in the state. Compared with other racial groups living in the state of Arizona, the risk for diagnosed diabetes is 77% higher among AA adults than NHW individuals, only lower than Central and South Americans and Puerto Ricans, with 87% and 94% (respectively) (Arizona Department of Health Services, 2014).

Problem Overview in Pinal County

Pinal County encompasses 5,374 square miles with a total population of 375,770 people. AAs form 4.6% of the total population in Pinal County (US Population Census Bureau, 2012). This implies that African Americans fall under the minority groups not only in the United States, but also in the rural County of Pinal, in Arizona. As part of the minority population, AA women with T2DM living in Pinal County meet the criteria for vulnerability in a number of ways including: gender, ethnicity and race, education and income, and access to healthcare services (Bhattacharya, 2012; CDC, 2012; Guerra, 2013; Shi & Stevens, 2010,) as discussed in detail below.

In 2010, there were 2258 deaths recorded in Pinal County. During the same period, cancer, heart disease, lung disease, substance abuse, and diabetes were reported as the leading causes of death. DM was listed as the fourth leading cause of disease-related deaths in Pinal

County (Pinal County Community Health Assessment, 2012). Diabetes affects approximately 10% of the total population of Pinal County, with adults accounting for 8.4% of the cases. (Centers for Disease Control and Prevention: National Diabetes Surveillance System, 2008).

Access to Health Care in Pinal County

There is a major disparity in access to health care in Pinal County among the different racial groups. This situation has contributed to increased vulnerability among the minority population, particularly the AA women living in Pinal County. Although only 10.8% of the Pinal County population does not have health care insurance, this statistic is not reflected among all racial groups. For example, 30% of AA population does not have health insurance (Arizona Adult Access to Health Care: Arizona Health Survey, 2010). Approximately 22% of AA reports difficulties in getting recommended diagnostic tests, and or treatment due to lack of health insurance, and 30% of the population rate their health as being fair or poor (Arizona Adult Access to Health Care: Arizona Health Survey, 2010).

Economically, 13.9% of the Pinal County population lives below poverty level (Arizona Adult Access to Health Care: Arizona Health Survey, 2010). However, there are no statistics specific to AA women living in Pinal County. Based on available statistics, AA women fall under the category of “other,” with 33% poverty rate (Kaiser Family Foundation, 2014).

Factors Explaining Prevalence of T2DM and its Complications among AA Women

There is no clear-cut explanation as to why AA women experience a disproportionately higher prevalence of T2DM and its related complications than Hispanics and NHW in the United States (Willig et al., 2014). However, many researchers have suggested a number of factors to explain this unfortunate phenomenon (Arthur & Hall-Clifford, 2009; Jones, Koegel, & Wells,

2008; Samuel-Hodge et al., 2000; Seligsoshare, 2010; Skelly, 2004; Welch, 2003). The factors are culture and beliefs, religion, geographical location and environment, stigma, knowledge of diabetes self-care/management, and distrust for establishment/providers as discussed below.

Culture and Beliefs

Many researchers attribute high T2DM incidences and complications among AA women to their cultural beliefs and practices (Samuel-Hodge et al., 2000). Culturally related issues not only increase the chances of developing T2DM among AA women, but they also increase their chances of developing diabetes related complications (Samuel-Hodge, 2000; Skelly, 2004). Cultural issues such as multi-caregiver roles and food preparation complicate and worsen diabetes self-care/management among AA women who already have T2DM (Skelly, 2004).

Culture not only defines the day-to-day living of a people, but also the type of food they eat, their individual responsibilities in the community, as well as their understanding and resolving role assignments and conflicts in society. Culturally AA women play a multi-caregiver role in their families by feeling responsible for providing emotional as well as tangible care and aid to family members and friends. Although this practice could ensure that AA women with T2DM are taken care of by their family members, the practice presents a complex socio-cultural situation that hampers diabetes self-management for AA women with T2DM (Samuel-Hodge et al., 2000).

The multi-caregiver role is therefore a major hindrance to appropriate diabetes self-care/management among AA women with T2DM. An example of a hindrance highlighted by Samuel-Hodge et al., (2000) is the issue of food preparation. Despite being aware of the need to practice responsible diabetes self-management, AA women feel responsible for taking care of

their family's interests first. For example, AA family members are used to a certain way of food preparation, such as fried food. Although many AA women with T2DM are aware that they need to bake their food rather than frying it, the rest of the family prefers fried food as a cultural practice. This practice forces AA women to fry food to avoid offending family members (Samuel-Hodge et al., 2000). Rather than practicing appropriate diabetes self-management as prescribed by their providers, AA women with T2DM practice their diabetes self-care/management based on their family's needs and demands, which always take priority over personal care. The belief that, "I will put my family first" as opposed to what providers prescribe, guides the construction of their reality of what constitutes diabetes self-care.

Religion

Religious beliefs also play a complex role in diabetes self-management among AA women with T2DM. Research shows that a number of AA women's reality is influenced to some extent by their religious beliefs. The popular belief that "my main doctor is Dr. Jesus" (Samuel-Hodge et al., 2000) hinders early diagnoses and individual compliance with a diabetes treatment regimen among AA women with T2DM.

AAs in general have a common practice of using religion as a coping and healing method as well as belief in the power of prayer in healing diseases. The role of religion in T2DM care/management among AA women cannot be dismissed, as religious beliefs are by no means futile or less important in health management practices. Religious beliefs play an important or positive role for life satisfaction, emotional coping and support for AA women with T2DM (Samuel-Hodge et al, 2000). The problem, however, is that while religion may provide the most needed emotional support in times of illness, it often leads to delays in seeking professional

health care services (Welch, 2003). Delays in seeking health care services are due to complacency, and belief in God's plan is a consolation for most AA women. This may lead not only to late a diagnosis of T2DM among AA women, but it also increases their risk of developing disease complications.

AAs also have other unique beliefs related to health and wellness in general. AAs across all social, economic and geographical strata have a common distrust of the established health care or medical system due to past historical experiences (Welch, 2003; Jones, Koegel, & Wells, 2008). For example, the Tuskegee syphilis experiment in which many AAs lost their lives in a public health research project has created skepticism and distrust of the established health care system among AA's in general (Jones, Koegel, & Wells, 2008). Many AA women with T2DM in general find it hard or are reluctant to discuss their health situation or follow a treatment regimen due to distrust in the health care system.

Geographical Location/Environment

The disproportionately high incidence of T2DM and its complications among AA women is also attributed to geographical factors. Studies have shown that there is a close association between onset incidence of T2DM and environment of residence. A study of AA women's health revealed that geographical environment contributes to AA women developing diseases (Seligsoshare, 2010). This is because poor neighborhoods are characterized by inadequate recreational opportunities for exercise, unavailable fresh food produce, encroachment of fast-food restaurants, and poorly lit streets, which discourages simple exercises, among other factors (Seligsoshare, 2010). All these dynamics increase the chances for AA women to develop T2DM complications. The study therefore concluded that no matter how much an AA woman may try to

maintain good health her environment poses a risk for developing T2DM and its related complications (Seligsoshare, 2010). It is therefore logical to state that environment plays a role; not only in increasing the chances of developing T2DM among AA women but also poses a challenge for T2DM self-management.

Stigma

The term stigma may be defined as the use of labels/stereotypes or categorizations to describe an individual or a group of people (Link & Phelan, 2001). The modern understanding of the term stigma is derived from the work of Erving Goffman in the 1960's who viewed stigma as a social construction of identity (Arthur & Hall-Clifford, 2009). Typically, stigma is associated with negative labeling or characteristics of an individual or group of people. When an individual or a group of people internalize stigma, it degenerates or reduces their ability to hold onto to what is important in their lives and social and environmental relationships, wealth and life chances (Arthur & Hall-Clifford, 2009).

Stigma has been identified as a problem facing AA women with T2DM. Stigma poses a great challenge for their diabetes self-management. Many AA women with T2DM have difficulty eating a healthy diet due to the stigma associated with diabetes (Willig et al., 2014; Browne, Ventura, Mosley, & Speight, 2013). Because of the community stigmatization of diabetes, AA women with T2DM have difficulty practicing healthy eating/dietary habits or even informing family members or friends of their diabetes diagnoses, which further complicates their adherence to a diabetes self-management regimen (Willig et al., 2014). In addition, AA women who self-blame and believe that they are responsible for their conditions are trapped in a helpless dietary situation that complicates their diabetes self-management and increases their chances of

developing diabetes complications (Willig et al., 2014; Browne, Ventura, Mosley, & Speight, 2013). The feeling of helplessness coupled with the frustrations caused by family and community members' change of attitude and interactions with them about their lifestyle choices do not help them manage their disease (Willig et al., 2014).

The fear of stigmatization also influences AA women with diabetes to act against important diabetes self-management behavior and practices. This is particularly true for adhering to diabetic dietary practices in social gatherings. AA women with T2DM find it difficult to refuse food or extra portions in the company of friends or family members who are unaware of their diabetes diagnoses (Willig et al., 2014). This deliberate choice of not practicing the recommended behavior due to fear of stigmatization may lead to poor health outcomes among AA women with T2DM. Poor psychosocial adjustment and denial have also been found to contribute to poor diabetes self-management among AAs with T2DM (Collins-McNeil, Edwards, Batch, Benbow, McDougald, & Sharpe, 2012).

Knowledge of Diabetes Self-Management

Diabetes self-management refers to an individual's ability to provide personal diabetes care following evidence-based practice (Funnell et al., 2011). Diabetes self-management includes monitoring blood glucose; foot examinations; self-administering medications; following up on appointments; screening for complications such as dental care, eye exams, and cardiovascular follow ups (Collins, Bradley, O'Sullivan, & Perry, 2009; Funnell et al., 2011). The American Association of Diabetes Educators (AADE) outlines seven essential self-management behaviors necessary to achieve desired diabetes management outcomes (AADE,

2010). The behaviors include healthy eating, being active, monitoring blood glucose level, taking medication, problem solving, reducing risks, and healthy coping (AADE, 2010).

Diabetes self-management is impeded among AAs due to poor knowledge of diabetes as a disease and denial of diabetes as a serious medical problem (T2DM) (Collins-McNeil, Edwards, Batch, Benbow, McDougald, & Sharpe, 2012). As health care systems increasingly empower patients, the concept of self-management has been drawing more attention in health care settings. The movement is necessitated by the fact that people are increasingly living much longer with health problems, making it ideal for patients and family members to get involved in-patient care particularly for cost reduction purposes (Orem, 2013).

Diabetes self-management may therefore be defined as the process whereby a person with diabetes takes initiative to promote and manage health and delay the onset of diabetes complications. Diabetes self-management may also be defined as the process of acquiring the necessary knowledge and awareness to manage the complexities of diabetes on day-to-day life (Shrivastava, Shrivastava, & Ramasamy, 2013). Generally, family members, friends and patient perform the daily care of people with diabetes who are unable to care for themselves. As such, it is imperative that the parties involved in DM self-management learn appropriate skills and behaviors to effectively manage the disease (Shrivasta et al., 2013).

The principal objective of any DM management is to improve glycemic control with the ultimate goal of deferring and or preventing the onset of diabetic complications. The key to achieving this goal lies in proper diabetes self-management (Skelly et al., 2009). Effective diabetes self-management not only requires knowledge of diabetes, but most importantly, knowledge of the basic but complex procedures (Skelly et al., 2009). Knowledge of the basic

self-management procedures is important to accurately perform diabetes care activities to achieve the desired goals and outcome. In addition, having knowledge of diabetes complications or symptoms is key to diabetes self-management. Symptoms are not just important as pointers to the underlying disease progression, but most importantly the guide to implementing appropriate diabetes self-management behavior (Skelly et al., 2008).

Healthful eating involves making healthful food choices, portion control as well as when to eat. Healthy eating is essential not only to delay and or prevent the onset of T2DM, but also to control and achieve an ideal blood glucose level for people with T2DM (AADE, 2010). Being active means participating in appropriate exercises on a regular basis with the ultimate goal of improving glycemic control, losing weight, and reducing stress as part of DM self-management strategy (AADE, 2010). ADA defines DM self-management as the ability to obtain education/skills to manage not only the glycemic control, but also to engage in behaviors that prevent acute complications and reduce the risk of long-term DM complications (ADA, 2014).

Monitoring blood glucose levels daily helps patients with diabetes to understand the effectiveness of their other self-care behaviors to appropriately adjust and or change their activities already in place (AADE, 2010). Taking medication as prescribed is essential for controlling progression of the disease, for lowering blood glucose and delaying or minimizing the onset of diabetes complications (AADE, 2010).

It is therefore essential that a person with DM have sharp problem solving skills at all times, since diabetes is a progressive disease and may present different symptoms that require an immediate decision and action for their safety. As patient ages, it is important for both patients

and their caregivers, if they do not manage their own care, to continuously keep pace with the knowledge of symptom changes for effective disease management (AADE, 2010).

Reducing risky behavior is an important part of diabetes self-management. Smoking cessation, regular medical and dental checkups help to reduce diabetes complications and improve the quality of life of diabetic patients (AADE, 2010). Healthy coping involves implementing behaviors that help to reduce psychological distress associated with T2DM. If left uncontrolled, psychological distress may affect a person's motivation to monitor or check his/her diabetes complications (AADE, 2010).

Unfortunately, AA women with T2DM demonstrate a high deficiency in many areas of diabetes self-management required to achieve the desired glycemic control. AA women with T2DM are also reported to misunderstand the concept of diabetes self-management (Lynch et al., 2012). One study revealed that the concepts of diabetes self-management understood by AA women with T2DM were limited to only medication, diet and exercise. Worse still, the AA women's definitions or concepts of these terms and the idea of how to manage their diabetes were shown to be inconsistent with evidence-based recommendations (Lynch et al., 2012). For example, AA women's understanding of exercise entailed mild physical activities such as walking up and down the stairs once a day (Lynch et al., 2012). In contrast, evidence indicated that the ideal exercise for people with diabetes should include moderate to vigorous physical activities of 150 minutes per week to achieve the desired glycemic control (Lynch et al., 2012).

Distrust for Establishment/Providers

AAs in general have a history of distrusting the establishment including the health care system. Many AAs find it difficult to speak to their healthcare providers in an open or honest

way (Grace, 2011). AA patients have a tendency to shut down when questioned by their health care providers. They feel that the provider is invading their privacy and seeking information that is not necessary for them to provide health care, which may lead to hostility and failure to adhere to treatment (Grace, 2011). This may result in reluctance to seek medical care. This may in turn result in a late diagnosis of diabetes and initiation of treatment that leads to a poor disease prognosis (Grace, 2011).

In addition, the historical abuse such as that of the syphilis study in Tuskegee adds to the already existing distrust of the healthcare system and makes it difficult for researchers to conduct experimental studies with this community (Jones, Koegel, & Wells, 2008). Inadequate knowledge of diabetes self-management, misconception of the recommended practices, distrust of the established health care system, and negative historical experiences may partly explain the high prevalence of T2DM among AA women and the related diabetes complications.

Summary

A number of factors come into play to complicate T2DM among AA women suffering from the disease. Strong cultural and religious beliefs and practices, distrust of the health care system influence AA women's diabetes self-management. In addition, vulnerability factors such as socio-economic status, demographics, geographical location, low level of education, as well as social ills such as racism have all created complications for AA women with T2DM to adhere to treatment and manage their diabetes. A number of studies relating to AA women with T2DM have focused on the high prevalence of the disease risk factors as well as the health perceptions of AA women with T2DM. AA women with T2DM are known to have a high risk of developing diabetes complications resulting in blindness, amputations, kidney failure, and cardiac problems,

among others. However, no research has investigated how this population perceives their risk for developing T2DM complications. Sociocultural and economic context approaches as the overarching framework will be used explore and describe the risks perceptions of developing diabetes complications among AA women with T2DM.

CHAPTER III: METHODOLOGY

Qualitative research is a term used in reference to a range of research techniques that describe, decode, and translate naturally occurring phenomena in the social world to get to the root of their meanings (Miles, Huberman, & Saldana, 2013). The design endeavors to inform the researcher's understanding of and explanation for why people act or how things happen the way they do in the social world/setting (Miles, Huberman, & Saldana, 2013; Munhall, 2012).

Qualitative data are potentially authentic, rich, and all-inclusive; can provide vibrant and reliable data that reveals the complexities of the phenomenon under study and is grounded in real life (Miles, Huberman, & Saldana, 2013). Qualitative data put emphasis on people's lived experiences, which provides the best means of understanding the meanings people place on their day-to-day actions and social structures as they go through daily life and connect them to the real world (Sandelowski, 2009).

Qualitative Descriptive Methodology

Qualitative descriptive (QD) methodology provides a flexible means to participants in answering questions of 'how,' 'what,' and 'why' with respect to their actions, which allows the researcher to collect adequate informant data needed to make verifiable and trustworthy findings (Sandelowski, 2009; Munhall, 2012). QD methodology uses plain language to describe the participants' perception of their risks. A qualitative descriptive methodology using interviews creates an informal environment for data collection that allows informants to provide more individualized, in-depth information and describe their risk perception from their point of view (Baker & Ponton, 2013; Polit & Beck, 2008; Sandelowski, 2009). QD methodology allows the researchers to stay close to events and data as described by participants (Sandelowski, 2009). It

allows informants to describe their actual experience and researchers to collect adequate data for analysis. QD methodology involves a unique kind of data interpretation that presents low-inferences that are likely to result in easier acceptance and consensus among researchers (Rovai et al., 2013; Sandelowski, 2009). Qualitative descriptive method helps the researcher to unravel the phenomenon under study in a way that allows for exploration, description, and interpretation of the collected data (Sandelowski, 2009).

The choice of QD methodology was based on its advantages and relevance to the research topic of interest. Well-collected qualitative data are known to focus on naturally occurring ordinary events in natural settings. QD methodology potentially gives a true picture of what life really is on the ground (Miles, Huberman, & Saldana, 2013). QD allows the researcher to collect data and stay close to a specific situation, and take into account the influence of the local context (Sandelowski, 2009; Weiler, 2007). The design also enables the researcher to learn and understand the concealed underlying issues that may not otherwise be obvious (Miles, Huberman, & Saldana, 2013, Sandelowski, 2009).

A QD methodology allows data to be collected over a sustained period of time. The data collected provide a powerful tool for an in-depth study of social phenomena including historical events. Therefore, the data are best suited to answer the “how” and “why” questions of social events as they take place in a specific situation. The flexibility of the QD methodology is that it allows the researcher to adjust the time and methods of data collection and can help the researcher manage on the progress of the study (Miles, Huberman, & Saldana, 2013; Sandelowski, 2009).

Sampling

To best answer to the research questions in this study, a purposive sampling technique was used. The goal of the sampling process was to recruit AA women with T2DM who volunteered and agreed to participate in this study and provide rich information to help answer the research questions. The study focus was to understand risk perception of developing diabetes complications, how the levels of perceived risk of developing diabetes complications influences diabetes self-management, and how the sociocultural and economic context in which diabetes management occurs influences DM self-management among AA women with T2DM.

In accordance with Patton (2000), the choice of participants was aligned with their ability to provide information for answering the research questions. The sample population was AA women with T2DM. After getting the IRB approval, the participants of the study were recruited from the AA women population living in rural Pinal County in Arizona.

The choices of research geographical locations were based on the ease of accessibility and proximity to the researcher's residence. The idea was to make data collection more convenient and less costly in terms of transportation and time. Because a widely varied population is desired in this study, the five rural communities in Pinal County provided suburban, urban, and rural experiences, which enhanced the diversity of the data collected. The data collected through these diverse criteria yielded results that enhance transferability, which increased the potential applicability, and transferability of the research findings to other similar situations or contexts (Munhall, 2012).

The study also used homogeneous purposive sampling to select AA women with T2DM. Homogeneous sampling technique is used where the participants share common characteristics

such as gender, social background and the phenomena under study, among other characteristics. In selecting the research sample, geographical as well as social factors were considered or used as criteria for selecting the sample. In addition, a maximum variation sampling technique was used to select participants based on levels of education, age, income, occupation, and location of residency. Although each and every individual AA woman may have had her unique experiences and struggles with coping and managing diabetes, maximizing variation helped in facilitating and capturing of common themes and experiences shared among AA women with T2DM (Creswell, 2013; Horne et al., 2014; Patton, 2000).

Sample Size

Typically, qualitative study samples are smaller in size compared to quantitative study samples, because the researcher focuses on an in-depth understanding of the phenomena under study, as opposed to making generalizations (Patton, 2000). Qualitative methods often employ purposive sampling methods with relatively smaller sample sizes (Miles et al., 2014). The purpose of this study was to describe the risk perception of developing DM complications among AA women with T2DM. The researcher carefully selected a sample of AA women with T2DM for an in-depth study of their risk perception of developing diabetes complications. The ultimate goal in this study was to select a sample of AA women with T2DM who are willing to provide the researcher with rich information pertinent to the purpose of the study, and help the researcher gain insights and in-depth understanding of the phenomenon under study (Sandelowski, 2009). AA women with T2DM who participated in this study were selected due to their first-hand personal experiences with diabetes. Equally important, sample size in this study was also determined by what could feasibly be done and completed within a limited time frame and the

resources available (Patton, 2000, Sandelowski, 2009). In this study a small sample was important to allow the researcher to collect, analyze, and present the data in a scientific manner within the available time frame.

An ideal sample size was realized when data saturation was attained. Data saturation was met at the point in data collection when no new or relevant information emerged and data collected was sufficient enough to explain the phenomena of interest. The researcher determined at that point that no more data needed to be collected (Munhall, 2012). Attaining saturation therefor indicated that the data collected was consistent with the research questions, and therefore no new information was needed for the study (Munhall, 2012).

The purposive sampling method was therefore used in selecting the participants (Thorne, 2008) since the target audience was a specific and predefined population. The researcher planned to recruit 10-14 participants. This sample range was expected to take care of attrition and other factors including participants who did not provide relevant information to answer the research questions. A total of 10 participants were recruited and interviewed in this study. Of the 10 participants, five of them work in healthcare either directly or indirectly with patients.

Inclusion/Exclusion Criteria

In this study, the participants were AA women with T2DM between 30 and 70 years old because, typically, T2DM is diagnosed among people in this age range, and it is in this age range that most people have experiences that they can share. This age range allowed the researcher to interview AA women who were working, raising families, taking care of their aged parents and retired and have long experience living with T2DM in a socio-cultural context. Participants were residents of the rural Pinal County. Participants were AA women with T2DM and had been

diagnosed and lived with T2DM for at least one year. One year of DM diagnosis was considered long enough to enable the participant to accept the reality of DM diagnosis and be able to share their diabetes self-management practice and their risk perception of developing DM complications. Participants were also able to speak, read, and understand English. Finally, participants were those who were willing to voluntarily participate in the study.

Recruitment Process

The researcher gained entrance into the research sites through the local community organization leaders such as church pastors, and women group leaders. Initially, the researcher had planned to identify potential participants through community activities such as church functions, and community health fairs. Community leaders and church pastors were given recruitment fliers (Appendix D) containing the researcher's phone number for the potential participants to call her. The community leaders were also given permission to call forms (Appendix E) to have potential participants complete. This form was a consent allowing the community leaders to give the researcher the potential participants' phone numbers to call them and schedule interview dates. Community leaders, friends, and family members were used to identify potential participants through referrals. However, snow balling and referral proved more successful in recruitment process.

Individual participants expressed interest in participating by calling the researcher or by allowing the community leaders or family members to give the researcher their contact information. The researcher then called and scheduled an interview date and discusses a meeting place, which was either the participant's own home, or one of the designated churches. The researcher also provided the potential participant with a consent form detailing the purpose of the

study, the study procedures, the rights of the participants to voluntarily withdraw from the study at any time, the known risks of the study, and the expected benefits of participating in the study (Creswell, 2013). Participants were invited to ask any questions and to confirm their consent to participate by signing the consent forms, which were also signed by the researcher. Most participants were interviewed on the same day the consent forms were signed.

Recruitment flyers were given to women leaders, community leader, and church leaders who posted the flyers in their churches on their notice boards, and distributed to their church members and community members during church gathering and other community gathering. Some of the flyers were also distributed in the community by the researcher during events such as health fairs and community gathering. However, most of the recruitment was successful through snowballing where some of the participants referred their friends and relatives with diabetes to the researcher.

Data Collection Methods

Data collection is a complex chain of interconnected activities that a researcher engages in to answer a research question (Creswell, 2013). Data collection focused on obtaining information related to the three research questions in this study. Different techniques of data collection were used including demographic questionnaire, observation, individual interviews, field notes, and audiotape recording. Audiotape recording was only used to record data obtained through interviews.

The researcher started by introducing herself as a graduate nursing student. The researcher began by asking potential participants to review the consent form. The researcher asked the potential participants questions to ensure that the potential participants were informed

of the study. Some of the questions asked included: 1) what the study is about; 2) who is conducting the study; and 3) what is being asked of them (if they participate in the study). The potential participants were then asked to sign the consent form. The researcher wrote the consent form in English language and simple terminology to address potentially low literacy levels and for better understanding by the potential participants.

A demographic questionnaire (Appendix C) was also used to collect additional information related to participants' demographic characteristics. Participants were asked to complete the demographic questionnaire at the beginning of the visit after signing the consent and before the interview. To establish rapport or a working relationship with the participants, the researcher talked to participants at the beginning of meeting using conversational tone and identified the commonalities between researcher and the participants. For example, the researcher asked questions like, "where are you from?" Then the participant would talk about how they moved to Arizona from another place. The researcher would also share her story how she moved to Arizona from Kenya. The researcher then explained to the participants the process of data collection such as the researcher's writing of field notes to help remember the key information discussed during the interview, and audiotape recording.

Data Collection Process

Data collection is a lengthy process that involves elaborate preparation beginning with getting IRB approval, seeking permission to access the study site, and finally obtaining the consents of potential participants before the actual process of obtaining data from participants begins. The data collection in this study focused on discovering risk perception of developing diabetes complications in AA women with T2DM. How their perceived risk of diabetes

complications influences their diabetes self-management. How the sociocultural and economic context in which diabetes management occurs influences their self-management behaviors.

Observation and Field Notes

The researcher scheduled meetings with individual participants in their homes or at a local church. During this initial meeting, the researcher observed the participants' environment, general behavior, reactions, attitudes, and interactions in their social environment including participants' homes and social gathering and work place. Observation was used to gain contextual understanding of the environment in which the participants' diabetes self-management behaviors take place (Thorne, 2008). How people interact in their environment provides insight of how their sociocultural and economic factors influence their perception and their health behaviors. The researcher recorded the observation in the field notes as part of the data that was analyzed. This observation informed the researcher of participants' social environment, social interactions with their significant others and family members, and how this interaction influenced AA women with T2DM's risk perception and how their risk perception influence their diabetes self-management behaviors. Observation also provided the researcher with data to answer Research Question #3 (How do sociocultural and economic factors influence DM self-management among AA women with T2DM?) in addition to themes about sociocultural, and economic contexts derived from the narratives and from the literature. The choice of sites for interviews and individual participants was based on four major factors: accessibility; participants' comfort, willingness to participate in the study, and ability to provide information pertinent to answering the research questions as determined by their risk perception and health behavior (Croswell, 2013).

Interviews and Audiotape Recordings

Individual interviews were used to gain understanding of individual's personal experiences with the phenomenon under study (T2DM). A semi-structured interview was conducted lasting from 60-90 minutes. The interview guide (Appendix F) was used to direct the interview process and help the investigation focus on the phenomenon of interest. Using open-ended questions, participants were interviewed, and subsequent probing questions were determined by participants' responses to the initial questions. The oral interviews were audiotaped to preserve participants' information in their own words/language for transcription. Open-ended questions were also used to provide participants with flexibility to share individual perceptions of their risk for developing diabetes complications and how the participants' risk perception of diabetes complications affect their diabetes self-management behaviors. During the interview, the researcher used probing questions to explore, clarify, or seek explanations to gain more information and insight on the topic being described (Appendix B). Memos were written during and after interviews to remind the researcher of important issues described during the interview and to help during data analysis.

Rigor to Ensure Trustworthiness

To ensure trustworthiness of the findings, the researcher used Lincoln and Guba's (1985) trustworthiness criteria. In this set of criteria, the term trustworthiness is used to refer to the quality of a research report (Munhall, 2012). The criteria for ensuring trustworthiness used by the researcher include credibility, transferability, dependability, conformability, and reflexivity.

Credibility

The criterion of credibility refers to the ‘truth-value’ of the research finding. Credibility is to qualitative research what internal validity is to quantitative research. Credibility is achieved through “prolonged engagement, persistent observation, triangulation, peer debriefing, referral adequacy, member checks and negative case analysis” (Munhall, 2012). Member checks were used (Lincoln & Guba, 1985) to establish the trustworthiness of the data. Some participants received interpretations/descriptions of the data to verify that it reflects what they meant when they were interviewed. The researcher also conducts peer debriefing to establish credibility (Lincoln & Guba, 1985). In this study, the dissertation chair and researcher met weekly to discuss and debrief after conducting an interview.

Transferability

Transferability is the applicability of the research findings to another population with similar characteristics. Transferability in a qualitative study is similar to external validity in quantitative research methodology (Munhall, 2012). External validity ensures the generalizability of findings to similar situations. Therefore, the study could be replicated in a similar context. Study findings that are transferable means that the findings have applicability in other similar contexts.

The researcher ensured transferability by using the purposive sampling technique. The researcher used maximum variation in education, geographical locality and age parameters to capture a wide range of population characteristics (Horne, McCracken, Walls, Tyrrell, & Smith, 2014). This ensured transferability because the findings were inclusive of other factors.

Dependability

Dependability is the consistency of research findings, showing that the findings could be repeated in similar circumstances. In qualitative methodology, dependability is what reliability is in quantitative research methodology (Munhall, 2012). In this study design, the researcher will achieve dependability through data saturation. Data saturation is achieved when no new information can be obtained from the respondents (Horne et al., 2014). Data saturation shows that the research findings are consistent and could be repeated in a similar context.

Confirmability

Confirmability is the criteria for honesty in the research. Confirmability is the extent to which two different researchers may arrive at similar and non-biased research conclusions (Polit & Beck, 2008, p. 750). Confirmability in qualitative research design is therefore similar to objectivity in quantitative research methodology (Munhall, 2012). In this study, the researcher ensured confirmability by staying close to the data and using the participant's own statements during the data analysis.

Reflexivity

Reflexivity refers to the researcher's awareness of her/his personal influence on the outcome/result of a study. When conducting qualitative studies it is difficult to separate a researcher from the study. The researcher plays a major role in data collection, analysis and interpretation (McDermid, Peters, Jackson, & Daly, 2014). As the saying goes, "knowledge cannot be separated from the knower" (Clarke, 2006). In social science, the quality of data analysis and interpretation depends on the researcher's awareness of his or her values and assumptions that could influence the outcome of their study (Clarke, 2006). In this study, the

researcher reflected on her biases after each interview. The researcher was aware of her potential influence on the data analysis therefore she wrote notes to remind her of important information discussed during the interviews. The researcher wrote notes in form of memos to refer back to during data analysis. When conducting the interviews the researcher realized that her role as health provider was influential in how she conducted the interview. The ‘question/answer’ strategy used in clinical practice greatly affected the first three interviews. The researcher was thinking of the next question that she was going to ask the participants rather than pay attention to the details of what the participant was describing. The researcher had to constantly remind herself that she was doing research and that her role as a provider was not needed at the time. Constant reminder and note taking and active listening changed and improved the researcher’s interviewing skills and the way the rest of the interviews were conducted.

Human Subjects Protection

Institutional Review Board (IRB) approval was obtained from The University of Arizona Human Subjects Protection Program before conducting the study (Appendix A). Informed consents were explained to and signed by the participants before beginning the interviews. Participants were informed of their rights to not respond to a question if they did not want to and that they may discontinue or withdraw from the study at any time without any repercussions. Participants were also informed of what to expect, the potential risks and benefits of participating in the study, and what was expected of them as volunteers in the study. Consent forms (Appendix B) were written in simple English language to ensure that all participants understood the document irrespective of their literacy level.

Data Management

Data collection was completed via a short demographic questionnaire, interview, observation, and field notes were transcribed and recorded into electronic Microsoft Word documents and saved into password-protected files. These qualitative password protected files were then imported into Atlas.ti version 7.1.8 for data management and further data processing. All information was kept confidential and numbers/symbols were used to identify participants. The data were transcribed and saved in a word document, in a password-protected computer.

Data Analysis

Data analysis is the process of methodically employing numerical and/or sensible approaches to describe and exemplify, summarize and outline, and appraise data (Lacey & Luff, 2009). Data analysis is the process of turning data collected through interviews, observation, and field notes into meaningful research findings (Lacey & Luff, 2009). Data analysis in qualitative research begins in the field at the time of observation and interview as the researcher identifies and collects information that will answer the research question(s). Qualitative data analysis therefore evolves throughout the research process, beginning from observation or interview, to drawing conclusion (Miles, Huberman, & Saldana, 2014; Lacey & Luff, 2009). The primary analysis design for this study is qualitative. The quantitative analysis is minimal, to describe the sample.

Qualitative Analysis

In the process of qualitative data analysis, the researcher seeks to stay close to the data in its naturalistic form (Sandelowski, 2009); therefore qualitative content analysis was used to enable the researcher to focus on the naturally occurring events and meanings attached to the

events by participants (Miles, Huberman, & Saldana, 2014; Sandelowski, 2009). Coding occurred in three steps: (1) open coding, (2) theoretical coding, and (3) thematic coding.

(1) Open Coding

Open coding involved reading through the data several times and identifying words, phrases, or sentences that summarized what was seen happening (not based on existing theory. just based on the meaning that emerges from the data) (Miles, Huberman, & Saldana, 2014). Words or phrases that appear repeatedly in the participants' responses may show patterns in a social setting.

Included in open coding, the researcher used in vivo coding to prioritize or honor participants' voices. This involved using participants' own words or short phrases from the participants' own language in the recorded data (Miles, Huberman, & Saldana, 2014). The words or phrases, which may have been culture specific or indigenous to the group (participants), were placed in quotation marks to distinguish them from the codes generated by the researcher (Miles, Huberman, & Saldana, 2014).

Participants were considered to have higher knowledge of T2DM if they described diabetes, related complications, symptoms of hypoglycemia and hyperglycemia, and the consequences of not following the recommended lifestyle modification of DM self-management.

(2) Theoretical Coding

Theoretical coding is a process in which a researcher has an existing theory or conceptualization based on clinical evidence, and then applies a theoretical model to the data or to the research questions (Miles, Huberman, & Saldana, 2014). The open codes were put into categories, which consisted of the three *a priori* research questions that were developed based on

the specific research aims. If open codes did not fit into the *a priori* categories, additional tentative categories were created.

The researcher, in consultation with the dissertation chair, developed a codebook based on the three main categories: (1) risk perception of developing DM complications; (2) impact of levels of risk perception on diabetes self-management; and (3) the context of sociocultural and economic factors on diabetes self-management. These theoretical codes were named based on the three research questions: (1) What is the perceived risk among AA women with T2DM of developing diabetes-related complications?; (2) How does the level of perceived risk of developing diabetes-related complications influence DM self-management among AA women with T2DM?; and (3) How do sociocultural and economic factors influence DM self-management among AA women with T2DM? The researcher and dissertation chair first open coded the first three interview transcripts independently, and both the researcher and the dissertation chair compared and reviewed the codes together to ensure the consistency and appropriateness of the coding. As coding proceeded into theoretical coding, the researcher and the dissertation chair continued to collaborate in the same way while placing open codes within the theoretical coding categories, and identifying overall thematic conclusions.

(3) Identifying Overall Thematic Conclusions

In the next step, the researcher then grouped the codes into categories themes that were used to draw final conclusions. The codes relevant to each theme were gathered and put together systematically according to their meaning. After putting together the first 5-10 pages of codes into themes, the researcher consulted with the dissertation chair to discuss the progress. Together with the dissertation chair, the researcher continued to review with the chair the evolving themes

to ensure they work according to the coded extracts and the entire research data before proceeding with the final analysis process and final thematic conclusions. When all analyses were completed, reports were generated based on the findings.

Software for Data Management

Qualitative data analysis software Atlas.ti version 7.1.8 was used to assist with data analysis and organization. Once the codebook was developed, the codes and their definition were inserted into the software and the transcripts were exported into Atlas.ti to complete the coding process.

Data Display

Data display using tables is helpful in drawing conclusions and representing the findings in a clearer ways (Miles, Huberman, & Saldana, 2014). In this study, tables were used to display data to assist the researcher to clearly visualize the data and get the sense of every participant's line of story, and draw overall thematic conclusions about the themes that emerged from the categories.

Data Dissemination

The research findings of this study will be archived in the University of Arizona School library for other students and scholars/researchers to read and use for references. The research findings will also be disseminated through publication in journals.

CHAPTER IV: FINDINGS

The findings in this study revealed numerous factors that were associated with development of diabetes complications among AA with T2DM. However, risk perception stood out to be associated with all the factors.

The central focus of the data analysis in this study was to answer three research questions. The research questions are considered the categories under which themes are reported. Research Question/Category 1: What is the perceived risk among AA women with T2DM of developing diabetes-related complications? Research Question/Category 2: How does perceived severity of risk for developing diabetes-related complications influence DM self-management among AA women with T2DM? Research Question/Category 3: How do sociocultural and economic factors influence DM self-management among AA women with T2DM? Tables containing themes and sub-themes are used to help summarize the research findings as they emerged from the data analysis. Also included in the table are excerpts of participants' own words that were extracted from the raw data to validate the reported findings.

Sample Description

Descriptive statistics were used to analyze the demographic data that describes the sample. Demographic data were presented to provide specific background information of the participants who were interviewed in the study. The demographic data include age, marital status, level of education, employment, status, insurance status, primary care providers, and use of screening.

The sample population in this study consisted of ten AA women with T2DM, of ages between 26 and 69 years. Of the 10 participants, five (50%) reported being married, two (20%)

reported being single, while three (30%) reported being divorced or separated. Eight (80%) of the participants reported that they live with family members consisting of either their children or spouses, while two (20%) reported living alone in their homes. A total of eight (80%) of the participants reported being homeowners, while two (20%) reported being renters. In terms of education attainment, three (30%) of the participants reported completing bachelor degrees, two (20%) had associates degree, four (40%) had high school, and one (10%) had eighth grade level. In terms of employment, six (60%) reported being in full-time positions, two (20%) were part-time, while other two (20%), were either retired or disabled. Out of the eight participants who were in active employments, five (about 63%) were healthcare professionals, while the other three or (approximately 37%) were employed in different professions. On annual income, two participants (20%) reported annual income of \$16,000 to \$30,000, three (30%) reported income of \$ 31,000 to \$45,000, three (30%) reported income of \$ 61,000 and above, while two (20%) declined to give a report on their income. All participants (100%) reported they have some type of health insurance. Nine out of ten (90%) of the participants had primary health care providers and reported receiving annual health screening, while one (10%) reported she neither had primary provider, nor did annual screening. Demographic data is presented in Table 1 that provides an overview of the population sample from which the study findings emerged as illustrated below.

TABLE 1. *Demographic Profile of the Sample.*

Characteristic	Total N=10
Age	
Mean	51.2
Range	26-69
Marital Status, No, (%)	
Single	2 (20%)
Married	5 (50%)
Separated/divorced	3 (30%)
Living Status, No, (%)	
Lives alone	2 (20%)
Lives with family/spouse	8 (80%)
Employment status No, %	
Full time	6 (60%)
Part time	2 (20%)
Other (Retired/disabled)	2 (20%)
Annual Income	
\$0 - \$15,000	
\$16,000 - \$30,000	2
\$31,000 - \$45,000	3
\$46,000 - \$60,000	
\$61,000 and above	3
Other	
Insured No, (%)	
Yes	10 (100%)
No	
Primary Care Provider	
Yes	9 (90%)
No	1 (10%)
Health Screening	
Yes	9 (90%)
No	1 (10%)

(Note: 10 participants were recruited for this study.)

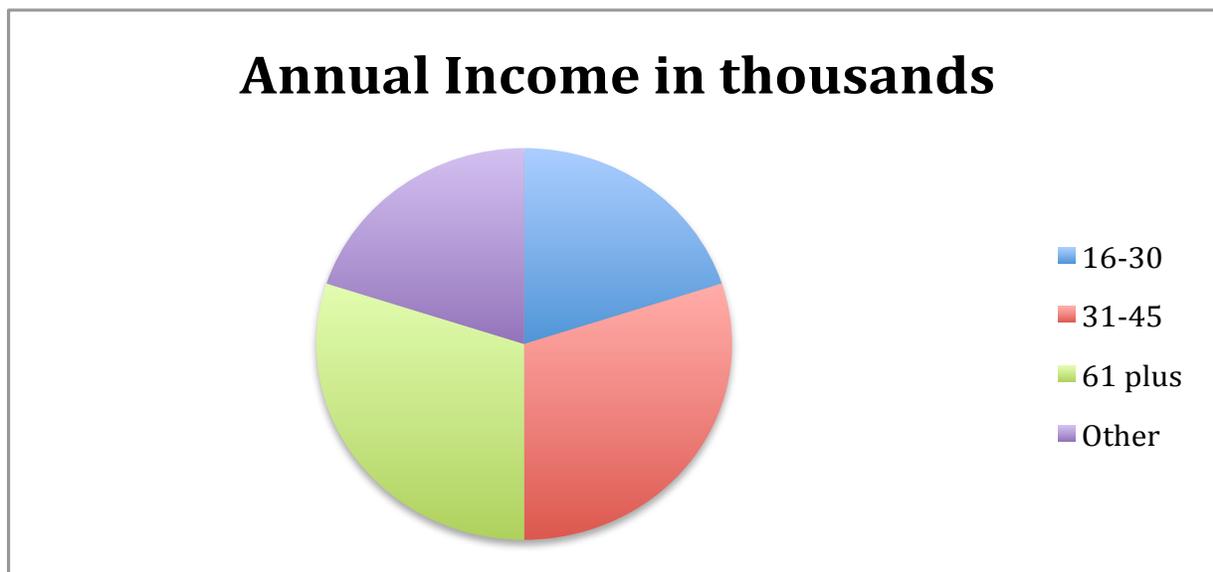


FIGURE 1. Participants Annual Income.

Findings from Narratives

Research Question/Category 1: What is the Perceived Risk among AA Women with T2DM of Developing DM Related Complications?

There was one theme and five sub-themes that were identified in this category. The theme identified was: reported knowledge of T2DM influences risk perception. Details of this theme are discussed below. The sub-themes were: a) gaining knowledge about diabetes; b) advocating for self; c) reported knowledge of diabetes; and d) misleading perceptions of diabetes.

Theme: Reported knowledge of T2DM influences risk perception for developing DM complications. The theme that emerged in this category was that reported knowledge of T2DM influences risk perception for developing DM complications. T2DM is a disease that requires self-management including behavior modification and lifestyle changes. Therefore, the

knowledge of T2DM was very important for effective disease control and self-management. For an individual to properly manage diabetes it was imperative to have knowledge of diabetes symptoms and complications to determine the health behaviors required to self-manage T2DM. Understanding the disease process of diabetes, how it affects the body and the complications that come as a result of having diabetes were shown to affect the participants' risk perceptions of developing diabetes complications. From the qualitative data, it was evident that participants with better knowledge of diabetes had an increased risk perception of developing diabetes complications, while those with reported little/limited knowledge of T2DM had decreased risk perception of developing DM complications. In addition, misleading perceptions of diabetes and its complications was also identified as influential in T2DM self-management in this population.

For example, in discussing her risk perception, one participant demonstrated how her knowledge of diabetes affected her understanding and risk perception for developing diabetes complications. "... *Because, I guess when I think of diabetes and I know that it's real, you know. I think of amputations and people not healing well from cuts and sores and stuff like that ...*" (CLG1). Participants who had a good understanding of what diabetes does to their bodies and the consequences of not taking care of themselves considered themselves to be at increased risk for developing DM complications. Under this theme emerged five sub-themes including: 1) ways to gain knowledge about diabetes; 2) advocating for self; 3) reported knowledge of T2DM influences risk perception; and 4) misleading information of DM affects risk perception. These themes are discussed in detail below.

Sub-theme 1: Ways to gain knowledge about diabetes. *Ways to gain knowledge about diabetes* also emerged as a sub-theme. Gaining knowledge about diabetes was categorized as a

sub-theme because participants reported different ways in which they obtained more information about diabetes. Discussing how they gained knowledge about T2DM, some participants reported doing research online, attending conferences, or attending classes on diabetes. For example, one participant reported attending a class for diabetes, completed the course, and earned a certificate. *“They have like a class where you go. Umm, I went in the evening and I got a certificate for going to this class to learn about diabetes. ... So I just, went and got the education.”* (CLG1). Two participants reported that their providers gave them information on the classes to attend. Other participants did not know that there were any classes for diabetes where they could learn more about diabetes and how to self-manage the disease.

Sub-theme 2: Advocating for self. *Advocating for self* was categorized as a sub-theme because most participants reported advocating for self in order to learn how to take medication or gain more knowledge on diabetes. Some participants reported that they had to search for the information about diabetes and diabetes care online or request that the providers give them more information on how to take their medications and take care of their diabetes. For example, one participant reported that she had side effects from one of the medication she was given. She reported that she was told by the provider to take the medication once a day, but the time of the day was not specified. When she went for a follow up appointment, she had to ask her provider about the time to take the medication after experiencing hypoglycemia every night. She said, *“I told him, wouldn’t be better if maybe I took the medication in the morning?”* (ELY1). Another participant stated that her provider discontinued one of her medications but she felt that the medication was helpful in controlling her blood glucose, so she requested the provider to prescribe it for her. She stated; *“I am still on metformin because I requested it back”* (CG6).

Some participants also reported that they had to make extra effort to obtain the necessary information through attending seminars on diabetes. For example, one participant reported that when she goes to her work related seminars she attends diabetes sessions because she wants to know the latest information on diabetes treatment. In her statement, she said; *“Like when I go to med-surg. Seminars I always make sure that I go to see what is new in the treatment of diabetes”* (CG6). Other participants reported using the internet to find more information and read on diabetes or ask friends who were also struggling with DM self-management.

Sub-theme 3: Reported knowledge of T2DM influenced risk perception. The third sub-theme in this category was that participants with reported knowledge of T2DM increased risk perception of developing diabetes complications. This was categorized as a sub-theme because it is directly related to the major theme of reported knowledge of T2DM influencing risk perception. However, the sub-theme focuses on the reported knowledge of T2DM and how it influences risk perception. Participants were considered to be knowledgeable about T2DM if they described diabetes, related complications, symptoms of hypoglycemia and hyperglycemia, and the consequences of not following the recommended lifestyle modification of DM self-management.

Participants who were knowledgeable of T2DM reported that learning about T2DM improved their knowledge of T2DM and the related complications. Other participants reported that through researching and learning about T2DM, they realized that they were at increased perceived severity of developing all the complications related to T2DM. One participant reported that based on her acquired knowledge of T2DM and its related complications, she had changed her DM self-management behaviors to prevent her from developing any of these complications.

This participant reported that she understood that having diabetes, she was at increased perceived severity of developing complications from a simple cut as compared to someone without diabetes. In her statement the participant stated, *“I know that if I have a wound and it doesn’t heal, I know I need to get it checked, it is not something that I play around with, because I know that I still have been diagnosed even though I will feel like I really don’t have everyday symptoms per se but I’m still very conscious of it. I know it’s been diagnosed and so I just watch it. I’m just very conscious of it. I’m very careful”* (CLG1). Reported knowledge of T2DM also increased the perceived severity of risk for developing diabetes complications, which improved DM self-management and health seeking behaviors. Participants who considered themselves knowledgeable of risk of developing T2DM complications also reported being cautious and seeking health care services whenever they had any symptoms of infection or complications. These were the participants who were able to assess, and so reported that an infection or complication was occurring and reported engaging in health seeking behavior to minimize the infection or complications. Having knowledge of T2DM was also found to be a motivation for searching more or newer information on T2DM treatment. Some participants reported that they checked online or asked their providers if there were new findings/things they could include in their daily DM self-management.

It was also reported that little knowledge of diabetes decreases perceived severity of developing diabetes complications. It was evident that little or limited knowledge of diabetes was a hindrance to participants’ perception of their risks of developing diabetes complications, as assessed by their description of diabetes, related complications, symptoms of hypoglycemia and

hyperglycemia, and the consequences of not following the recommended lifestyle modification of DM self-management.

The participants, who reported having little knowledge of T2DM, also reported decreased perceived severity of risk for developing diabetes complications. As a result, they made very little effort to make lifestyle changes to manage their diabetes. Some of the participants acknowledged lack of or little knowledge of diabetes, especially during the initial stages of diagnosis with diabetes. A number of participants described what they thought diabetes treatment consisted of, and their expectations of prognosis after taking their prescriptions. A participant describing her knowledge of diabetes, diabetes treatment, and perceived risk said, “... *take this much at this time and I remember thinking oh here is the pill. I will take it and it will fix the problem. So over the next few years when it didn't fix the problem, that is when my frustration set in*” (MCP1). Reported little knowledge of T2DM influenced participants' expectation of T2DM medication as indicated by participants (see Table 1 for more excerpts). Basically some participants thought that taking medication as prescribed was enough to treat T2DM. Participants reported not knowing that it was a chronic disease that required life-long self-management, as it later turned out to be. Some participants also reported that after being diagnosed with T2DM they did not take it seriously. After taking the medication they were given, the participants just ignored the prescribed treatment and continued with their normal life because they did not have any symptoms. These participants were not aware that with or without symptoms they still needed to manage their condition to prevent or delay the onset of DM related complications.

Sub-theme 4: Misleading information of DM affects risk perception. Another sub-theme that surfaced in this category is *misleading information of DM affects risk perception*.

This was categorized as a sub-theme in this category because people who reported little knowledge of T2DM were likely to be misled by hearsay from other people who reported little knowledge about DM and its related complications. Misleading information about diabetes as a disease played a fundamental role in how this population perceived DM self-management and their risk of developing DM complications. For example, information passed from one person to the other regarding diabetes and related complications influenced individual participant's DM self-management behaviors. Family members and friends formed an important social and emotional support among AA women with T2DM. In the process of providing social and emotional support, family members and friends gave their opinions about diabetes and shared what they knew about T2DM. Information shared by the family member and friends is not necessarily correct; however, it had a great impact on how some participants perceive their risk and self-manage their diabetes.

Some participants believed that nothing could be done to control the disease and related complications. Expressing her perception of diabetes, one participant stated, "... *diabetes is going to win anyway*" (ELY1). In her description of her experience, she reported that no matter how much you try to control diabetes it is not possible, because you still end up with complications. This participant reported that people thought of diabetes as a disease that cannot be controlled, which leads to perceived sense of powerlessness and lack of control among those with diabetes. She said, "*Yeah because they say it's going to kill us anyway...I don't know, I guess you can prolong it, but in the end...this is why a lot of people look at diabetes the way they do because, like me, they told me, that's what they said, it's going to get me anyway*" (ELY1).

Another participant reported that she received mixed information from different people, including her friends. She said, “...I know I read that if you don’t control it you’ll get cataracts, you know, I don’t know. Someone told me, you eventually are going to get cataracts anyhow” (CG2). Misperception of T2DM complications and management was a major factor in risk perception and DM self-management behavior among this population. Misperception led to poor management of DM because people with diabetes felt powerless, due to the notion that there is nothing that can be done to stop DM. The following is a table of themes within the category presented above.

TABLE 2. Themes within Research Question/Category 1: Risk Perception for Developing DM Complications.

Category	Theme	Sub-Themes	Excerpts
Perceived risk of developing diabetes –related complications among AA women with T2DM	Knowledge of T2DM influences risk perception	Ways to gain knowledge about diabetes	“They have like a class where you go. Umm, I went in the evening and I got a certificate for going to this class to learn about diabetes. ... So I just, went and got the education” (CLG1).
		Advocating for self	“I told him, wouldn’t be better if may be I took the medication in the morning” (ELY1). “I am still on metformin because I requested it back” (CG6).
		Reported knowledge of diabetes increases the risk perception	“Like when I go to med-surg. Seminars I always make sure that I go to see what is new in the treatment of diabetes” (CG6). “I know that if I have a wound and it doesn't heal, I know I need to get it checked, it is not something that I play around with, because I know that I still have been diagnosed even though I will feel like I really don't have everyday symptoms per se but I'm still very conscious of it. I know it's been diagnosed and so I just watch it. I'm just very conscious of it. I'm very careful” (CLG1).
		Reported little knowledge of diabetes decreases risk perception.	“...take this much at this time and I remember thinking oh here is the pill. I will take it and it will fix the problem. So over the next few years when it didn't fix the problem, that is when my frustration set in” (MCP1). “...diabetes is going to win anyway” (ELY1).
		Misleading information of diabetes affects risk perception	“Yeah because they say it's going to kill us anyway ... I don't know, I guess you can prolong it, but in the end ... this is why a lot of people look at diabetes the way they do because, like me, they told me, that's what they said it's going to get me anyway” (ELY1). “... I know I read that if you don't control it you'll get cataracts, you know, I don't know. Someone told me, you eventually are going to get cataracts anyhow”

Research Question/Category 2: How does Perceived Severity of Risk for Developing DM Related Complications Influence DM Self-Management among AA Women with T2DM?

Under this category emerged three themes: (1) decreased perceived severity of risk perception and DM self-management; (2) decreased perceived severity of risk perception and DM self-management; and (3) reported knowledge of diabetes complications influences the perceived severity of risk of developing DM complications. The themes showed that the increased perceived severity of risk of developing T2DM complications, the better the T2DM self-management behaviors; and the lower the perceived severity of risk of developing T2DM complications, the poorer the DM self-management behaviors.

Theme 1: Increased perceived severity of risk for developing DM complications and T2DM self-management. *Perceived severity of risk of developing DM complications and T2DM self-management* was categorized as a theme in this category because of its influence on DM self-management among AA women with T2DM. It was evident that participants who perceived themselves to have increased perceived severity of risk for developing diabetes complications (as measured by their description of diabetes, related complications, symptoms of hypoglycemia and hyperglycemia); and the consequences of not following the recommended lifestyle modification of DM self-management, also reported taking appropriate actions to prevent or delay the onset of developing T2DM complications. Some participants reported that once they were diagnosed, they had to modify their lifestyles in order to maintain normal blood glucose levels and take care of their disease process. Participants who perceived themselves to be at increased perceived severity of risk for developing T2DM complications were also more proactive in searching for information on how to take care of their diabetes. Life style modifications, driven by their past

experiences of T2DM among family members and friends who were suffering or had suffered from diabetes, were reported by a number of participants who considered themselves to be at increased perceived severity of risk of developing T2DM complications.

Participants who reported knowing the complications that are related to T2DM also reported themselves to be at increased perceived severity of risk for developing DM complications. These participants also reported consistency with follow up appointments with their healthcare providers and annual health screening. One of the participants reported, *“I had my cardiologist and I see him once a year, he did the stress tests in January everything is negative”* (CG6). Participants who considered themselves to be at increased perceived severity of risk of DM complications reported that knowledge of DM complications helped them become proactive and changed their lifestyle. Some participants reported that they were scared of developing DM complications; therefore, they tried as much as possible to follow the recommended lifestyle changes and diet to prevent DM complications. One participant said, *“Well I am very specific about what I eat and when I eat ... I don’t take sweet drinks, I eat a very small amount of carbohydrates during the day because the spikes are hard to deal with. It’s just part of who I am, I don’t do sugar at all. I don’t do white sugar, maybe in the rare occasion like dessert and I don’t do carbohydrates, I don’t eat bread or pasta because it’s just hard to stay on top of it. I have found for me, cause I am lazy, that not eating it is the solution”* (MCP1).

Due to increased perceived severity of risk for developing DM complications, some participants reported adherence to recommended screenings, keeping up with their medical appointments, and their daily care to ensure that their diabetes and their general health were in good condition. One of the participants said, *“I’m working on ensuring that my glucose is under*

control. Umm ... I do my yearly checkups to make sure that everything goes ... I check my feet when I take my shoes off; I make sure I wear socks when I have tennis shoes on. Umm ... if I'm going outside I make sure I have something on my feet so that I don't step on something" (CG6).

Some of the participants also reported that after gaining knowledge about diabetes and related complications, they were able to recognize the complications that they already had and were trying to make sure their complications did not get worse. One participant stated, *"I had my annuals, my eyes are the ones I keep up with because I have terrible vision and I was concerned that my prescription had changed ... So, I have an appointment with an endocrinologist to see if they can offer more insight, cause I want to know. I am concerned that it is related to the diabetes ... I am on the brink of going to bifocals which is a big change from 4 or 5 years ago"* (MCP1). As reported by some of the participants, knowledge of diabetes was very important in recognizing the symptoms of related complications. Participants who had decreased perceived severity of risk perception at the time they were diagnosed, and later learned more about T2DM and its complications, reported that their perceived severity of risk perception changed after gaining more knowledge of T2DM. Participants who reported to have had little or no changes in knowledge of T2DM from the time of initial diagnosis, also reported to have decreased perceived severity of risk perception of developing T2DM, which in turn influenced their DM self-management behavior, as discussed below.

Theme 2: Decreased perceived severity of risk of developing DM complications and DM self-management. Decreased perceived severity of risk for developing DM complications and DM self-management also emerged as a theme under this category. Decreased perceived severity of risk of developing DM complications was also identified as a factor that influences

DM self-management. Participants who demonstrated decreased perceived severity of risk of developing DM complications also reported poor DM self-management and having experienced at least one major DM complication. Most of these participants reported having had either a stroke or myocardial infarction between the ages of 46 and 50 years. These participants reported not knowing the complications from diabetes at the time of diagnosis and thereafter, until it happened to them. Some of the participants reported that little knowledge of diabetes complication was a major hindrance in the way they perceived their risk and even the way they took care of their disease process. These participants attributed their T2DM complications to little or limited knowledge of T2DM as a disease.

The participants reported that little knowledge or lack of knowledge of T2DM was the leading cause of poor DM self-management and severe DM complications. One participant reported that she had a stroke because her blood glucose was out of control; she believes it was a lack of knowledge of T2DM and related complications that led to her stroke. She said, “... *the lady at the reception, told my daughter, ‘I want you to know something, I am not trying to scare you, but your mom is having a stroke’ ... my blood sugar was so bad that it made sludge and he said, nothing can get through sludge*” (ELY1).

Decreased perceived severity of risk of developing DM complications was consistent with multiple DM complications experienced by some participants. Participants who demonstrated decreased level of perceived severity of risk of developing DM complications also reported experiencing multiple DM complications including kidney failure, peripheral neuropathy, and visual problems, among others. One participant stated, “*I have a lot of issues ... I have kidney problems, high blood pressure ... yeah, it’s probably easy to name what I don’t*

have ...” (GC3). Some participants, who reported decreased perceived severity of risk of developing T2DM, had other severe complications such as myocardial infarctions. One of these participants reported that she had open-heart surgery; she said, “... *I had to have a quadruple bypass*” (CG3). Another participant also reported that she had a heart attack. She said, “... *after my heart attack, my doctor told me to sleep nine hours a night ... one of my arteries was more than 90% closed*” (CG4). Participants who reported decreased perceived severity of risk for developing DM complications also demonstrated little knowledge of DM and related complications. Interestingly, some of the participants did not relate some of their health problems to T2DM. In describing her health problems and experiences, one participant stated, “... *I was already having problems ... I don't think it is related to diabetes. Heart, you know*” (CG3). This statement was typical of participants who believed they had decreased risk of developing T2DM complications, even though they were at increased actual risks.

Reported limited knowledge of T2DM was also shown to influence healthcare seeking behavior. Participants who reported more DM complications also reported that they had poor healthcare seeking behavior, including fewer follow up appointments with their primary care providers, dental care, eye specialists, and general annual health screening. Participants who exhibited little knowledge of T2DM and decreased perceived severity of risk for developing DM complications reported little knowledge of the symptoms of DM complications. These participants could not associate some of their health problems with T2DM. Some participants refused to acknowledge that the health problems they had were symptoms of diabetes complications. Other participants who demonstrated a decreased level perceived severity of risk for developing DM complications reported inconsistency in their DM self-management. One

participant reported, *“I put diabetes on the shelf ... And so then I came here and I really didn't have any symptoms so I just thought you know what, maybe it's gone again. So I chose not to look into it not go to the doctor again. I thought it was gone again”* (ELY1).

Participants who reported not having a clear understanding of diabetes as a chronic disease also reported little knowledge of DM related complications, and consequences. Some of these participants reported not being proactive in their DM self-management and health seeking behaviors. As reported by some participants, an individual can only ask questions or go back to see a provider if she understood the symptoms of T2DM and its complications. Since individuals with T2DM may be asymptomatic, some participant misinterpreted that being asymptomatic meant they were cured and did not require more treatment.

Theme 3: Reported knowledge of diabetes complications influences perceived severity of risk for developing DM complications. Under this category also emerged the theme, *“reported knowledge of diabetes complications influences perceived severity of risk for developing DM complications.”* This was categorized as a theme because it was related to the first theme *“increased perceived severity of risk for developing DM complications and T2DM self-management.”* Participants who reported increased perceived severity of risk for developing DM complications also reported increased knowledge of diabetes complications. The participants reported past experiences with DM complications among relatives or friends who died or were struggling with diabetes complications. Poor quality of life in the participants' loved ones and friends who have or had diabetes were described by participants as one of the major concerns of developing DM complications. Some participants described the fear of developing DM complications as the motivating factor for better DM self-management

behaviors. As described by one participant, *“I mostly see the feet and leg stuff and they just don’t function anymore, they are on disability and their families are taking care of them and they still don’t take care of it. I am very scared of that, of not taking care of myself”* (MCP1). Another participant also said, *“My parents, especially my dad, the end wasn’t too good. He ended up being blind ... I know there is so many complications if I don’t take care of it, myself”* (CG1).

For some participants their increased perceived severity of risks of developing diabetes complications were attributed to their role as health care providers. Participants reported that working with people who suffered from DM had increased their understanding of the risks of developing diabetes complications. As described by one of the participants who was a registered nurse, her experience working in an emergency department and meeting people with diabetes complications had changed how she perceived her own risk of developing DM complications. In her report she stated; *“In the emergency room, it is a big reality check for me. I don’t think I took it seriously before that”* (MCP1). Another participant also stated, *“... I work in the hospital, which reminds me of my obligations to myself as a nurse, because as much as I see patients in hospital who are diabetic, I see myself in that position so it always reminds me of what the complications will be if I neglected myself”* (GC1). Experiences as healthcare providers had a great influence of perceived severity of risk of developing DM complications and DM self-management behaviors among the five participants who reported working in healthcare. Participants, who reported understanding of DM complication, also reported increased perceived severity of risk of developing DM complications and better DM self-management behavior. The themes discussed in the above category are presented in Table 3.

TABLE 3. Themes within Research Question/Category 2: How Perceived Severity of Risk for Developing DM Complications Influences DM Self-Management among AA Women with T2DM.

Category	Themes	Excerpts
How perceived severity of risk of developing diabetes-related complications influence DM self-management among AA women with T2DM.	Increase perceived severity of risk of developing DM complications and T2DM self-management	<p><i>"I had my cardiologist and I see him once a year, he did the stress tests in January everything is negative"</i> (CG6).</p> <p><i>"Well I am very specific about what I eat and when I eat...I don't take sweet drinks, I eat a very small amount of carbohydrates during the day because the spikes are hard to deal with. It's just part of who I am, I don't do sugar at all. I don't do white sugar, maybe in the rare occasion like dessert and I don't do carbohydrates, I don't eat bread or pasta because it's just hard to stay on top of it. I have found for me, cause I am lazy, that not eating it is the solution"</i> (MCP1).</p> <p><i>"I'm working on ensuring that my glucose is under control. Umm... I do my yearly checkups to make sure that everything goes...I check my feet when I take my shoes off; I make sure I wear socks when I have tennis shoes on. Umm...if I'm going outside I make sure I have something on my feet so that I don't step on something"</i> (CG6)</p>
	Decreased perceived Severity of risk for developing DM complications and DM self-management	<p><i>I have a lot of issues...I have kidney problems, high blood pressure...yeah, it's probably easy to name what I don't have..."</i> (GC3).</p> <p><i>"...after my heart attack, my doctor told me to sleep nine hours a night...one of my arteries was more than 90% closed"</i> (CG4)</p> <p><i>"...I was already having problems...I don't think it is related to diabetes. Heart, you know"</i> (CG3).</p> <p><i>"I put diabetes on the shelf...And so then I came here and I really didn't have any symptoms so I just thought you know what, maybe it's gone again. So I chose not to look into it not go to the doctor again. I thought it was gone again"</i> (ELY1).</p>
	Reported Knowledge of Diabetes Complications Influences Perceived Severity of Risk for Developing DM Complications	<p><i>"I mostly see the feet and leg stuff and they just don't function anymore, they are on disability and their families are taking care of them and they still don't take care of it. I am very scared of that, of not taking care of myself"</i> (MCP1).</p> <p><i>"My parents, especially my dad, the end wasn't too good. He ended up being blind...I know there is so many complications if I don't take care of it, myself"</i> (CG1).</p> <p><i>"In the emergency room, it is a big reality check for me. I don't think I took it seriously before that"</i> (MCP1). Another participant also stated, <i>"...I work in the hospital, which reminds me of my obligations to myself as a nurse, because as much as I see patients in hospital who are diabetic, I see myself in that position so it always reminds me of what the complications will be if I neglected myself"</i> (GC1).</p> <p><i>"...the lady at the reception, told my daughter, "'I want you to know something, I am not trying to scare you, but your mom is having a stroke'...my blood sugar was so bad that it made sludge and he said, nothing can get through sludge"</i> (ELY1).</p>

Research Question/Category 3: How do Sociocultural and Economic Factors Influence DM Self-Management among AA Women with T2DM?

Research Question/Category 3 encompassed a wide range of factors that help in defining the population in this study and the society in which they manage their diabetes. Due to the complexity of this category, the Research Question/Category 3 was divided into three sub-categories to allow for easier presentation of the findings. The three sub-categories are: (1) cultural factors and their influence on DM self-management; (2) social factors and their influence on DM self-management; and (3) economic factors and their influence on DM self-management. Under each sub-category emerged themes as discussed below.

Sub-category 1: Cultural influence on DM self-management. Cultural influence on DM self-management was categorized as a sub-category because participants reported their cultural background as having shaped their health behaviors and actions on their DM self-management. This sub-category is organized into two themes that were interrelated. A number of participants reported that their cultural background and upbringing did and still does have an impact on the way that they practice diabetes self-management. The themes identified in the cultural sub-category include: (1) food and DM self-management among AA women with T2DM and (2) family and DM self-management among AA women with T2DM. These themes are further categorized in sub-themes as discussed below.

Theme 1: Food and DM self-management among AA women with T2DM. *Food and DM self-management among AA women with T2DM* emerged as a theme. The discussion below includes the sub-themes that emerged under the food and DM self-management among AA

women with T2DM theme. The sub-themes included: (1) food preparation; (2) culturally dictated eating habits and (3). the value of food.

Sub-theme 1: Fried food preparation. *Fried food preparation*, as a characteristic of a family tradition, in African American culture was identified as a hindrance to diabetes self-management among most of the participants. Many participants reported that their traditional way of preparing food involved frying. One participant describing how she struggled to prepare healthful food, different from what she had grown up eating stated “*I didn’t know how to cook asparagus unless you fried it with oil...*” (MCP1). Another participant, describing her love for traditionally prepared food, stated, “*... you know I’m starving too and I might want fried fish because I don’t like baked ... or fried chicken, I love fried chicken, but I should be eating baked chicken ... I just like fried chicken*” (CG2). Participants reported that the traditional way of cooking is difficult to get away from. The types of food they were used to eating as they were growing up had a major influence on their present and current food choices and what appealed to the participants in terms of diet. This practice had a negative influence on the participants’ DM self-management. Some participants reported that they acquired a taste for and got used to the taste of foods they grew up eating. The types of seasoning that were used in their traditional cultural foods still appeals to them, and determine their food choices and preparation.

Sub-theme 2: Culturally dictated eating habits. Another sub-theme that emerged was *culturally dictated eating habits*. Participants reported that family eating habits, especially during gatherings or family visits, is one of the major challenges facing AA women in their struggle for DM self-management. Participants reported that their culturally prescribed etiquette prohibits turning down food offered from a family member or host. In describing her experience with this

etiquette and how it has continued to affect her eating habit she stated, “... *and I have to be a good guest so I am eating things I didn't like the taste of and didn't agree with my stomach. And it's just, try this baby ... and did you eat this ... and have a little more. And I still do that when I go to somebody's house and I never thought about it before*” (MCP1).

In addition, some of the participants reported that the cultural practice defined the portions of what to eat. Culturally, the AA diet consists of large amounts of food, with more starch than protein. Foods such as corn meals, bread, potatoes, cornbread, and pasta, among others, are served with all meals. Participants described how cultural background affects food choices and their eating habits, making it hard to follow the right DM diet regimen. As reported by one participant, “... *my background, we grew up eating a lot of starch at the main meal. So umm ... that affects me, that's what I have grown up eating and I miss that kind of food ... my mind is set I need to have this kind of portion, the starch portion more than the others.*” (CG1). A portion of participants reported that they do not feel like they have eaten unless they eat starch in their meals. Others stated that starch was always given in bigger portions because it was cheaper than protein. Some of the participants also reported that even though they are able to afford protein now, they still crave starch because they were used to eating more starch to fill their stomachs.

Sub-theme 3: The value of food. Participants reported that AA women are the ones, who prepare food for their families, and that they have to prepare many different types of food even when it is not all needed, or when there are not many people to feed at the moment. They reported that it is expected among AAs to prepare more food than is estimated to be needed. This cultural value attached to food was reported to be challenging to most AA women with T2DM,

because it affected the way they managed their diabetes. “*So food as a form of love and attention and gathering are huge in our family*” (MCP1). Also, when preparing food, the participants reported that they had to consider family first, which means that the food they prepared had to be food that the family loved to eat, even though it might not have been appropriate for someone with diabetes.

Theme 2: Family and DM self-management among AA women with T2DM. *Family and DM self-management among AA women with T2DM* was categorized as a theme in this sub-category because family tradition and practices was found to have a profound influence on DM self-management among AA women with T2DM. This theme is discussed in two sub-themes as follows: (1) the role of the family and (2) family loyalty.

Sub-theme 1: The role of the family. Among AA women with T2DM, family was reported to play a major role in individuals’ DM self-management. Many participants reported that family support provided hope and strength to individuals with T2DM. Some participants reported that their family members provided emotional support and the encouragement they needed for better DM self-management. One participant said, “*Yes my family supports me very much ... my husband always stresses, we want to have you longer. So he encourages me to take walks in the morning, encourages me to eat more fruits and vegetables ... reminds me to follow-up with the Dr. You know that is the support that I need*” (CG1). Another participant reported that her family kept reminding her to be careful with what she ate. “*... They are very supportive. When they ask me, you know, how my numbers are, how am I doing, my one sister, like if she sees me, If she thinks I’m getting ready to eat something bad, you don’t need that ...*” (CLG1). As reported by most participants, family members were instrumental in the participants’ lives,

and helped to determine the way they take care of their diabetes. Participants who reported strong social, family, and emotional support also reported better DM self-management. Some participants reported that their family members participate in the participant's care and remind them of what they should not eat.

Sub-theme 2: Family loyalty. Family loyalty, as a sub theme, emerged as social and family practices that are characteristic of family alignment in African American tradition. A number of participants reported that in African American tradition, the family comes first before an individual, and in the event of a conflict of interest, the family takes priority. Family loyalty was identified to have both negative as well as positive influences on diabetes self-management.

Negative influence: The negative influence of family loyalty was identified in cases where a mother, as caregiver, takes care of everyone else except herself. Family members look to a mother for help, emotional support, and daily meals. Therefore, a mother cannot be weak, sick or show signs of defeat or weakness. This practice robbed the AA women with T2DM of time and energy to self-manage their diabetes.

A participant describing how family loyalty is a hindrance to her diabetes self-care stated, “... *In a big family of strong southern black women, weakness is not something that is super acceptable. So, asking for help or not being well or not being able to take care of your children ... is not really acceptable culturally, in the whole arena. I get home at 7 pm, so I'll just cook something for them and I just don't really eat ... I'll make them something quick, and there will be nothing for me, or I won't be hungry, and by the time I am hungry it is 10:00 and I'm tired and I just go to bed So I bet that would make it harder to take care of your diabetes ... your kids comes first*” (MCP1).

Positive influence: The positive influence of family loyalty on DM self-management was also identified in this sub-theme. Strong family ties and support was found to be a motivating factor for better DM self-management. Some participants reported that their families are supportive and want to have them longer and therefore encourage them to take good care of themselves to prevent DM complications. One participant reported her family as her source of motivation for taking care of herself or managing her diabetes better. The participant stated that she does not want anything drastic to happen to her because she wants to be there for her family. The participant said, “... *I mean, I have children and grandchildren, husband, great-grandchildren, so I mean, I want to be around for them, you know. And I’m not ready for anything to happen to me*” (CLG 1). Participants reported that family come first, and when an individual takes care of herself, it is not just for her but also for the family. For the sake of family, AA women with T2DM reported a sense of owing their family their own self-care, so whatever they do is not just for themselves but also for the whole family.

TABLE 4: Themes under Sub-Category 1: Cultural Influence on DM Self-Management.

Category: Sociocultural and Economic Influence on Diabetes Self-Management			
<i>Sub-Category</i>	<i>Themes</i>	<i>Sub-Themes</i>	<i>Excerpts</i>
<i>Cultural influence on DM self-management.</i>	<i>Theme 1: Food and DM self-management among AA Women with T2DM</i>	Food preparation	<i>“I didn’t know how to cook asparagus unless you fried it with oil ...” (MCP1)</i>
		Culturally dictated eating habits	<i>“ ... you know I’m starving too and I might want fried fish because I don’t like baked ... or fried chicken, I love fried chicken, but I should be eating baked chicken ... I just like fried chicken.” (CG2)</i> <i>“ ... and I have to be a good guest so I am eating things I didn’t like the taste of and didn’t agree with my stomach. And it’s just, try this baby ... and did you eat this ... and have a little more. And I still do that when I go to somebody’s house and I never thought about it before.” (MCP1)</i>
		The value of food	<i>“ ... my background, we grew up eating a lot of starch at the main meal. So umm ... that affects me, that’s what I have grown up eating and I miss that kind of food ... my mind is set I need to have this kind of portion, the starch portion more than the others.” (CG1)</i>
		The role of the family	<i>“So food as a form of love and attention and gathering are huge in our family.” (MCP1)</i> <i>“Yes my family supports me very much ... my husband always stresses, we want to have you longer. So he encourages me to take walks in the morning, encourages me to eat more fruits and vegetables ... reminds me to follow-up with the doctor. You know that is the support that I need.” (CG1)</i> <i>“ ... they are very supportive. When they ask me, you know, how my numbers are, how am I doing, my one sister, like if she sees me, if she thinks I’m getting ready to eat something bad, you don’t need that ... ” (CLG1)</i>

TABLE 4 – *Continued*

Category: Sociocultural and Economic Influence on Diabetes Self-Management			
<i>Sub-Category</i>	<i>Themes</i>	<i>Sub-Themes</i>	<i>Excerpts</i>
	<i>Theme 2: Family and DM self-management among AA women with T2DM</i>	Family loyalty	<p>“ ... In a big family of strong southern black women, weakness is not something that is super acceptable. So, asking for help or not being well or not being able to take care of your children ... is not really acceptable culturally, in the whole arena. I get home at 7 pm, so I'll just cook something for them and I just don't really eat ... I'll make them something quick and there will be nothing for me, or I won't be hungry and by the time I am hungry it is 10:00 and I'm tired and I just go to bed ... So I bet that would make it harder to take care of your diabetes ... your kids comes first.” (MCP1)</p> <p>“ ... I mean, I have children and grandchildren, husband, great-grandchildren, so I mean, I want to be around for them, you know. And I'm not ready for anything to happen to me.” (CLG1)</p>

Sub-category 2: Social factors and their influence on DM self-management.

Participants in this study also reported social factors and their influence on DM self-management. Social factors were reported to have played a significant role in DM self-management among AA women with T2DM. Perceived challenges related to healthcare services emerged as social factors that influenced DM self-management among this population. Four themes emerged under this sub-category. The themes were: (1) perceived inadequate healthcare services by healthcare providers; (2) perceived provider assumptions of the patient's knowledge of diabetes; (3) perceived provider attitude toward patients; and (4) perceived stigma related to diabetes as a disease.

Theme 1: Perceived inadequate care services by healthcare providers. *Perceived inadequate care services by healthcare providers* was categorized as theme in this category because it was reported to not only influence the participants level of risk perception and DM self-management, but also the relationship between AA women with T2DM and their providers. Most participants reported that after being told they had diabetes, they were handed a prescription for medication, with no explanations or clarification on how to take the medication. Some of the participants also reported that they thought they would be cured once they completed the medication dose given to them. Other participants also stated they were not given even basic information about DM at the time of diagnosis that could help them answer any questions that arose in the process of learning to cope with the new diagnosis. Some participants reported that they were handed brochures on diabetes, and then told to go to diabetic classes, but were not provided with any information to help them understand why the DM education classes were important. In addition, some participants reported that they were given partial and incomplete information that was misleading to them given their limited knowledge or understanding of DM.

For example, some participants said, *“I was told to just watch what I eat. ... they told me not to eat like sweet stuff so I thought it was the sweet stuff that made it go up, then I found out I was eating the wrong stuff like potatoes and starchy stuff”* (ELY1). *“... they go, well are you checking you blood sugar, are you eating well here is the carb counting thing and they kind of throw the pamphlets at you that tell you how to eat and they don’t ask how it fits into your life. When you are at work, do you find it hard to sit and eat? What kinds of foods are available to you, what do you drink, do you drink enough water? They don’t ask you that they just say, here is*

the low carb diet for diabetics and you are just supposed to go and figure it out” (MCP 1).

Participants also reported that their providers did not take the time to provide them with the necessary information that was needed for better DM self-management. In addition, participants reported that due to lack of information on DM at the time of diagnosis, they could not perceive themselves to be at risk of developing the complications that they were not aware of. Participants reported that one could only perceive risk from a known disease process, related complications, and consequences.

Some participants reported difficulty accessing specialized health care services when they needed it due to rurality. For example, one participant stated; *“Yeah he doesn’t have time, and again let me be just honest with you. B is not a doctor and I don’t think he has the answers.”* Being a rural area, some participants were unable to access services such endocrinology, or podiatry. Describing her concerns a participant states, *“A place that specializes only in diabetes. That’s all they take care of is your diabetes. That’s where I would love to go to. That’s all they do, they don’t take care of uhh....hot flashes none of that stuff, the only thing they take care of is diabetes. To find a solution or cocktail that works for you. I would love that because the one place, all they do” (ELY 1).*

Theme 2: Perceived provider assumptions of the patient’s knowledge of diabetes.

Perceived provider assumptions of the patient’s knowledge of diabetes also emerged, as a sub-theme under this major theme of perceived inadequate care services by healthcare providers. Provider assumption of patients’ knowledge of diabetes was categorized as a subtheme because it was reported by the five participants who were healthcare providers, as one of the influences of risk perception and DM self-management. Interestingly, participants who work in healthcare

reported that providers made assumptions about patients' knowledge of diabetes, and that these assumptions may not be accurate. Participants who were health care workers (nurses) reported that they were not provided with adequate education upon their initial diagnosis with diabetes. As healthcare providers, the participants reported that inadequate education had a great impact on DM self-management and perceived risk. Some of the participants reported, *"They give your diagnosis and they give you some medicine ... I think they assume because I'm a nurse I don't need to be educated"* (CG6). *"I think sometimes when you are dealing with a healthcare provider they assume you know. I didn't receive so much information from my provider most of it is what I know about it, and I just hope this is not the way my provider deals with people who are not in the healthcare field because he didn't give me much information about it"* (CG1). Participants reported that they did not receive information or education during their initial diagnosis of diabetes, which led to poor low risk perception and poor DM self-management.

Theme 3: Perceived inadequate health care services and provider attitudes.

Perceived inadequate health care services related to discrimination were also categorized as a theme in this category because some participants reported that they perceived inadequate healthcare services related to discrimination. Participants reported that they felt like there were no good services for AAs with T2DM no matter how they tried to manage their diabetes.

Perceived inadequate healthcare services were attributed to provider unwillingness to give ample time to patients during visits and inability to answer a patient's questions. Some participants said, *"I can never get the full picture. Or you ask a question and they say no that's probably not it and they don't elaborate ... Or ask questions back, I am a patient, I just happen to be a nurse ... sometimes I am frightened, if somebody without medical knowledge went in there what*

impression they would leave with” (MCP1). “There is no good education or treatment around here, I am telling you that right now, for black people, I don’t know about other people either ... It is really bad on black people, because most people I see with amputated legs are black people. And feet yeah” (ELY1).

In addition, other participants reported that the provider’s attitude might lead to either poor DM self-management or better DM self-management depending on how the information is relayed to the patient. There were some participants who reported that their providers relayed the message of diagnosis in a way that was very demeaning and discouraging. They did not feel that they had enough support, compassion, and empathy from their providers. These participants stated that the providers’ attitude made them feel like it was their “fault”, and that is why they developed diabetes. In describing their experiences, the participants reported that the provider’s approach caused frustration and stress, which greatly affects their DM self-management. The participants reported, *“It was a bit shocking because of the way he related the issue to me ... he was telling me; you are overweight, you are a diabetic and very soon you will have all these problems. You will be blind if you don’t take care of yourself ...” (CG1). “I find it frustrating, I found myself avoiding going to the doctor ... I am always disappointed. My family always gets annoyed when I say if it gets worse then I will go to the doctor. I just don’t want to put myself through that ... Well I kind of felt like it was my fault. That I felt sick and if the pills didn’t work” (MCP1).* One participant in particular reported a better attitude from her provider, because they had a long-standing patient-provider relationship. She said, *“I didn’t receive it very well I can tell you that now. I didn’t want to hear that word. My doctor, I know her well enough to know that you know she treated it lightly when she said that because she knows how I feel about that word*

(diabetes)” (CLG1). From the participants’ reports, it was evident that the better the patient-provider relationship, the more increased the participant’s risk perception and better DM self-management. Participants also reported that providers’ positive attitude toward patients improves patients DM self-management behaviors. Patient who reported a positive attitude from their providers had a better DM self-management and more follow up appointments. The themes discussed in category 4 are presented in Table 5.

Theme 4: Perception of stigma related to diabetes as a disease. Perception of stigma related to diabetes as a disease among AA women with T2DM also emerged as theme in this sub-category. Perception of stigma related to diabetes as a disease was categorized as a sub-theme in this category because participants reported that stigma influences how AA women in this study self-managed their diabetes. As reported by some participants, people with T2DM are stereotyped in the society. Individuals with T2DM are socially associated with poor personal health care behaviors, considered unhealthy and leading poor and unhealthy lifestyles. Some participants reported that due to societal perception of individuals with T2DM, they do not feel comfortable sharing or telling people that they have diabetes. This is primarily because they do not want to be considered different or treated differently. Describing her experience, one participant said; *“I am having a drink and one of my old friends comes and says you should not be having that you are a diabetic and the other person would be surprised like you are diabetic? ... It feels like diabetes is a flesh eating bacteria and it feels extreme ... so yes in that aspect it is not something that I announce when I meet someone”* (MCP2).

Another participant reported due to fear of stigmatization, she feels uncomfortable eating where people are. The participant reported that she feels stigmatized when people make

comments when she eats certain foods. She stated; *“I sometimes don’t like eating where people are ... when you have diabetes, people judge you when you eat certain foods they think should not be eaten by somebody who has diabetes ... that’s why she has diabetes, she eats too much”* (CG 1).

Most of the participants reported not discussing their DM with anybody else except their family members and close friends, only from fear of being treated differently. Two participants said, *“I told my brother but, you know, I told him to check himself, you know, but, you know, not everybody else except for me”* (CG5). *“I don’t tell people that don’t know me, because of the stigma associated with it. So I could be with new friends and I just don’t say anything”* (MCP2). The issue of stigma was mostly noted among people who were diagnosed with T2DM at younger age. The participants reported that the issue of stigma was noted when they were younger, especially in their young adult age. The youngest participant in this study reported that she experienced situations where she was looked at and treated differently because she has diabetes. She reported, *“... the preconceived notions that people have about diabetes especially type 2, that people with diabetes are large and they live to eat and you know they have the sugar disease”* (MCP2). Interestingly the term “sugar disease” was reported as a term used among some AA communities especially those who migrated to United States from Africa and it is interpreted as a derogatory term that stigmatizes people with T2DM.

Theme 5: Economic influence on DM self-management. Economic influence on DM self-management was also identified as a theme in this category because of its influence on diabetes self-management. Individuals’ level of income as measured by the participants’ reported annual income, was also identified to have influence on a number of behaviors and practices that

can either promote or hinder diabetes self-management. Part of DM self-management involves following a recommended diet. Lower level of income was reported by the participants to be a hindrance to practicing recommended diet. Despite having a good knowledge of T2DM and related complications, some participant reported that low income posed a great challenge, especially in following a DM diet regimen. One participant reported that she was forced by her financial circumstances to feed on junk food just because she could not afford good or recommended food due to her reduced income level. Describing her experience this participant stated, “... *I mean there was lots of times that I wasn't eating well because I couldn't afford to feed all of us without buying junky processed carby foods ... we ate fast food more than we should because it was cheap and you eat cheap food with not enough good protein and all that kind of stuff ... well this is what I can afford, I can't afford to do that, I can't afford to go to a nutritionist. I have a pretty decent knowledge of what the right things are to eat even when I couldn't do it right*” (MCP1). Participants with low level of income reported difficulty following a diabetic diet. Participants reported that it is expensive to eat healthfully, especially if they have a large family. Buying good recommended food to feed a large family was reported to be very expensive which resulted in buying food that is not appropriate for people with diabetes.

TABLE 5. Themes under Sub-Category 2: Social Factors and Their Influence on DM Self-Management.

Category: Sociocultural and economic influence on diabetes self-management		
Sub-category	Themes	Excerpts
Social factors and their influence on DM self-management	Perceived inadequate care services by healthcare providers and rurality	<p><i>"I was told to just watch what I eat. ... they told me not to eat like sweet stuff so I thought it was the sweet stuff that made it go up, then I found out I was eating the wrong stuff like potatoes and starchy stuff"</i> (ELY1).</p> <p><i>"There is no good education or treatment around here"</i> (ELY1).</p> <p><i>"Cause some days when I go there I am so sick and they say oh we can't see you over there, what's your alternative?"</i>(ELY1)</p> <p><i>"They give you diagnosis and they give you some medicine ... I think they assume because I'm a nurse I don't need to be educated"</i> (CG6).</p> <p><i>"There is no good education or treatment around here, I am telling you that right now, for black people, I don't know about other people either ... It is really bad on black people, Because most people I see with amputated legs are black people. And feet yeah"</i> (ELY1)</p>
	Perceived provider assumptions of the patient's knowledge of diabetes	<p><i>"I think sometimes when you are dealing with a healthcare provider they assume you know. I didn't receive so much information from my provider most of it is what I know about it, and I just hope this is not the way my provider deals with people who are not in the healthcare field because he didn't give me much information about it"</i> (CG1).</p> <p><i>"It was a bit shocking because of the way he related the issue to me ... he was telling me; You are overweight, you are a diabetic and very soon you will have all these problems. You will be blind if you don't take care of yourself ..."</i> (CG1).</p>
	Perceived inadequate health care services and provider attitude.	<p><i>"I can never get the full picture. Or you ask a question and they say no that's probably not it and they don't elaborate ... Or ask questions back, I am a patient, I just happen to be a nurse ... sometimes I am frightened, if somebody without medical knowledge went in there what impression they would leave with. I find it frustrating, I found myself avoiding going to the doctor ... I am always disappointed. My family always gets annoyed when I say if it gets worse then I will go to the doctor. I just don't want to put myself through that ... Well I kind of felt like it was my fault. That I felt sick and if the pills didn't work"</i> (MCP1).</p> <p><i>"I didn't receive it very well I can tell you that now. I didn't want to hear that word. My doctor, I know her well enough to know that you know she treated it lightly when she said that because she knows how I feel about that word (diabetes)"</i> (CLG1).</p>
	Perception of stigma related to diabetes as a disease	<p><i>"I am having a drink and one of my old friends comes and says you should not be having that you are a diabetic and the other person would be surprised like you are diabetic? ... It feels like diabetes is a flesh eating bacteria and it feels extreme ... so yes in that aspect it is not something that I announce when I meet someone"</i> (MCP2).</p> <p><i>"I told my brother, but you know, I told him to check himself, you know, but, you know, not everybody else except for me"</i> (CG5).</p> <p><i>"I don't tell people that don't know me, because of the stigma associated with it. So I could be with new friends and I just don't say anything"</i> (MCP2).</p> <p><i>"... the preconceived notions that people have about diabetes especially type 2, that people with diabetes are large and they live to eat and you know they have the sugar disease"</i> (MCP2).</p>
Economic influence on DM self-management	<p><i>"... I mean there was lots of times that I wasn't eating well because I couldn't afford to feed all of us without buying junky processed carby foods ... we ate fast food more than we should because it was cheap and you eat cheap food with not enough good protein and all that kind of stuff ... well this is what I can afford, I can't afford to do that, I can't afford to go to a nutritionist. I have a pretty decent knowledge of what the right things are to eat even when I couldn't do it right"</i> (MCP1).</p>	

TABLE 5 – *Continued*

Category: Sociocultural and economic influence on diabetes self-management		
<i>Sub-category</i>	<i>Themes</i>	<i>Excerpts</i>
		<p><i>“Well sometimes, like now, cause at first I was getting a, you know more money, but now I'm just on social security. So my last bill, you know I managed it but, sometimes it's ... you keep thinking oh, that's kind of expensive. ... but a lot of time to get the right food, diet sometimes ... it's expensive ” (CG2)</i></p> <p><i>“I also experienced periods of not having insurance ... I would not go to the doctor for a long time I would not take meds and they would want to put me on Metformin and they would want to put me on something and I knew I wasn't going to be able to stick with it because I could not afford it”.</i></p> <p><i>“... my first husband passed away and we were on food stamps right after that It still wasn't enough to keep the lights on and food in the fridge that wasn't garbage you know it was surprising that went through eating that way for so long I absolutely think that if you can't afford the food it's hard enough to adopt a completely different lifestyle and to do the right things and 90 percent of the time you eat the right thing but then to add to that trying to budget for it and trying to seek out education when you're worried about keeping your lights on I know it's not easy it's really hard to do that. It's a lot easier to ignore it”</i></p>

Summary

In summary, risk perception for developing DM related complications is determined by knowledge of diabetes and related complications and perceived severity of risk of developing diabetes complications. Risk perception also influenced DM self-management either positively or negatively depending of the perceived severity of developing DM complications. Increased risk perception results in better DM self-management; and decreased risk perception of developing DM complications, results in poor DM self-management. In addition, sociocultural and economic factor were found to be very influential in DM self-management behaviors. Cultural factors such as food and family, among others, were reported to play a great role in DM self-management behaviors. At the same time, perceived challenges related to society's healthcare services including: perceived inadequate care services by healthcare providers, perceived provider assumptions of the patient's knowledge of diabetes, perceived inadequate health care-related to provider attitude toward patients, and perception of stigma related to

diabetes as a disease. Lastly, economic factors were reported to play a significant role in in DM self-management, especially in buying medications and adhering to the recommended DM diet. These results call for practice and research implications, described in the next chapter.

CHAPTER V: CONCLUSION AND DISCUSSION

The purpose of this qualitative descriptive study was to explore and describe risk perception of developing diabetes complications among AA women with T2DM. In this chapter, the research findings are discussed as they relate to the three research questions/categories: (1) what is the perceived risk among AA women with T2DM of developing diabetes-related complications?; (2) how does the level of perceived risk of developing diabetes-related complications influence T2DM self-management among AA women with T2DM?; and (3) how do sociocultural and economic factors influence T2DM self-management among AA women with T2DM? The three research questions/categories are used to guide the discussion of the findings in this study. The research limitations and implications for practice as well as recommendations for further research are also discussed in this chapter.

Research Question/Category 1: What is the Perceived Risk of Developing DM Complications among AA Women with T2DM?

The findings of this research indicated that knowledge of T2DM has a profound effect on risk perception of developing diabetes complication among AA women with T2DM. The findings revealed that participants who had more knowledge of T2DM, either through diabetes care seminars or through professional education, tended to better understand their risks for developing complications related to T2DM. Individuals with better knowledge of T2DM were better placed to understand the notion of prospects and risks. These individuals were more aware of the symptoms of T2DM, the complications related to T2DM, the consequences of not taking care of diabetes, and the benefits of taking actions to manage their diabetes. This finding supports the concept of perceived benefit in the Health Belief Model, which explains an

individual's positive health behavior as being motivated or influenced by the perceived or expected benefits of the health behavior, and the desirability of practicing the directed behavior in order to diminish the risk of developing disease complications (Houchbaum, Kegels, & Rosenstock, 1952; Glanz, Rimer, & Lewis, 2002; Rovner, Haller, Murchison, Hark, & Casten, 2014). In most cases, the participants who had at least junior college or higher level of education, or those who were health care professionals ($n = 5$) reported increased risk perception than those with lower levels of education. This finding is consistent with a study finding by Kim et al., (2007) and others who reported that people with lower education are likely to reports lower severely of risk perception (Kim et al., 2007; Rovner, et al., 2014).

On the other hand, limited knowledge of diabetes in general, and of T2DM in particular, had a negative effect in risk perception among participants with T2DM. This was particularly observed when participants were describing their perceptions during the initial or early stages of T2DM diagnosis. Several participants reported a distorted understanding of T2DM, treatment and prognosis expectations after taking their medications. The idea of taking diabetes medication and getting the problem "fixed" was common among many participants during the initial stages of their diagnosis of T2DM. The notion that diabetes was an infection that could be treated with a single dose or a few doses of medication made many participants under-estimate their risks for developing diabetes complications. This finding is in contrast with the findings from Rovner and colleagues (2014), which associated lower level of education with greater perception of individuals' health risk based on Risk Perception Survey, (RPS-DM) a 26-item self-rated instrument that assessed personal control (Rovner et al., 2014). The women with fewer years of education scored significantly higher on risk perception ($t = -2.26, P \leq 0.025$) (Rovner et al.,

2014). However, the finding of the present study is similar to what was reported in a research conducted to investigate the risk perception of Nigerian commercial sex women in Barcelona. The study revealed that the Nigerian commercial sex women who had higher levels of education perceived themselves to be at increased risk for contracting sexually transmitted diseases (STI/STD) as opposed to those with lower education levels (Coma Auli, Mejía-Lancheros, Berenguera, & Pujol-Ribera, 2015).

In some cases, little knowledge of T2DM led to some individuals having an exaggerated perception of their risks for developing complications. The belief that nothing can be done to control T2DM or to avoid the impending complications was reported by a number of participants who also reported lower level of educational attainment. This created a sense of powerlessness and despair among these participants. A statement made by one of the study participants who stated that people say diabetes is going to kill her anyway, exemplifies this attitude. This statement typifies less knowledge of diabetes or lower level of education, which leads to an erroneous health assessment. Other studies also reported that limited knowledge or education might lead to both overestimation and underestimation of risks for disease due to mistaken assessment of health status (Kim et al., 2007; Rovner et al., 2014).

Eight participants put the blame on their health care providers for not giving them the basic knowledge of T2DM, self-care practices, treatment, and prognosis. Several participants reported being handed medication prescriptions by their providers with the simple instruction to take the medications. This practice was reported to have contributed to their not understanding how to manage T2DM. This finding reflects the state of health literacy, which was not measured in this study.

Health literacy as defined by National Network of Libraries of Medicine (NN/LM) as the competence to acquire, process and comprehend or communicate basic health information and services needed to make informed health care decision (NN/LM, 2014). Eichler, Wieser, and Brügger, (2009) reported that prevalence of health literacy limitation in the US population ranges between 34-59%. The findings from this study revealed that majority of the participants' demonstrated lower levels of health literacy irrespective of their levels of education. These findings are consistent with those of Sayah, Majumdar, Egede, and Johnson (2015), who reported that inadequate health literacy is more common among ethnic minorities and people with low levels of income and compromised health status. Health literacy is also reported to be generally lower among people with DM, and is estimated to be between 15-40% depending on the population (Cavanaugh, 2011). Since health literacy is independently associated with worse glycemic control and higher rate of retinopathy among patients with T2DM (NN/LM, 2014), providers have a major role to play in improving health literacy among their patients. U.S. Department Health and Human Services (US DHHS) identified major barriers to patient education by providers. Some of the major practices identified include the use of confusing forms and instructions given to patients by the providers, overuse of medical and technical terms when explaining or giving vital information to patients, and insufficient time and incentives for patient education that make providers to rush over important information and only give limited education to the patients (USDHHS, 2010).

Research Question/Category 2: How Does Perceived Severity of Risk of Developing Diabetes Complications Influence DM Self-Management among AA Women with T2DM?

Perceived severity of risk of developing DM complications as it emerged in the data analysis is central to T2DM self-management among individuals with T2DM. The way an individual or a group of people considers or perceives the possible dangers and the likelihood of developing complications from a disease, determines their need and motivation to take actions to prevent or avert the danger (Rovner, Haller, Murchison, Hark, & Casten, 2014; Kim & Zane, 2015). The study revealed that the way individuals' perceived severity of their risk of developing T2DM complications influenced their diabetes self-management behavior. Individuals who considered themselves to be at increased perceived severity of risk of developing diabetes complication reported consistent and better T2DM self-management behavior. This finding is consistent with study findings by Kim and colleagues (2007) who reported that people who perceived themselves to be at increased risk for developing DM are more likely to modify their lifestyle to prevent the disease (Kim et al, 2007). This finding is in line with the concept of *perceived severity* of the HBM which states that, when individuals perceive a given health problem as severe, they are more likely to engage in behaviors that will prevent the health problem from getting worse, or reduce its severity (Houchbaum, Kegels, & Rosenstock, 1952; Rovner et al., 2014; Tseng & Chen, 2015). Participants who considered themselves to be at higher risks of developing T2DM complications also reported modifying their activities of daily living as well as food types and preparation, to control their blood glucose levels and to take care of their disease process. This finding is also consistent with the concept of *perceived benefit*, which states that when individuals believe that a particular action is likely to reduce the severity

of a disease; they are likely to engage in the behavior, regardless of the objective facts concerning the effectiveness of that behavior in reducing the severity of the health problem (Houchbaum, Kegels, & Rosenstock, 1952; Dehghani-Tafti, 2015; Tseng & Chen, 2015). Participants who believed that they were at increased perceived severity of risk of developing DM complications, engaged in DM self-management behaviors to prevent DM complications. This finding is comparable to a study that reported that participants who considered themselves at risk for developing complications from recurrent urinary tract infection were willing to engage in preventative measures (Javaheri Tehrani, Nikpour, Haji Kazemi, Sanaie, & Shariat Panahi, 2014; Tseng & Chen, 2015).

On the other hand, individuals who perceived or considered themselves to be at decreased risks of developing T2DM complications reported poor and inconsistent DM self-management behavior. DM self-management behavior was particularly worse among individuals who were ignorant of their risks of potential complications. This is consistent with a study by Rovner et al., (2014) who reported that DM self-management was lower among individuals with lower level of diabetes control adherence, resulting from limiter control of whether they develop diabetes complications. A study conducted to investigate the relationship between risk perception and DM self-management reported that, improved risk perception increased DM self-management behavior in the areas of dietary, exercise and medication adherence (Shreck, Gonzales, Cohen, & Walker, 2014).

Studies that explored the influence of risk perception in healthcare-seeking behavior of individuals have revealed that people are more likely to be involved in and committed to disease management and behaviors that promote good health, if they recognize that their risk of

developing disease complications is high (Calvin et al., 2011; Kim et al, 2007; Kim & Zane, 2015; Shreck, Gonzalez, Cohen, & Walker, 2014). However, no study has been done to investigate how risk perception of developing T2DM complications among AA women with diabetes influences their diabetes self-management.

Six out of ten participants in this study who talked about having better knowledge of diabetes also discussed having increased perceived severity of risk of developing T2DM complications and better diabetes self-management behavior. These participants reported knowledge of diabetes based on their experience with family member(s), relatives or friends having died or struggling with diabetes complications. The experiences or knowledge of diabetes through loved ones or friends struggling with diabetes complication were reported by a number of participants as the basis of their risk perception of T2DM complications, and the motivating factors for taking actions to manage their diabetes. One participant reported that based on the experiences her father went through, especially becoming blind from diabetes complications, she decided to do everything possible to avoid reaching that stage of diabetes complications. This finding reflects a report by Scollan-Koliopoulos and colleagues (2010) who stated that risk perception is influenced an individual's experience with a family member's history of DM complications (Scollan-Koliopoulos, Walker, & Bleichsome, 2010). Kim and colleagues (2007) also reported that individuals who reported family history of diabetes also indicated in their narratives that they had increased severity of risk perception for developing diabetes (Kim et al., 2007).

Five of the ten participants, who were health care workers, attributed their high risk-perception to their professional experiences as health care workers. For the five participants,

working with patients with diabetes increased their knowledge and therefore understanding of their risks of developing diabetes complications. Nearly all participants who were health care professionals reported high-risk perception of developing diabetes complications as well as better and consistent diabetes self-management practice. This is consistent with the literature that reports personal health risk perception to be higher among health professionals and scientists than general populations' perception of the same disease risk (Walker, Mertz, Kalten, & Flynn, 2003). Cavanaugh (2011) reported that diabetes knowledge was higher by about 34% among people with higher diabetes proficiency than those with lower diabetes proficiency.

In this study, all participants who reported perceived severity of risk of developing DM complications also reported taking actions to control their diabetes and demonstrated better diabetes self-management practices. This is consistent with the basic tenets of the HBM, that health behavior is influenced by an individual's perception of disease and the approaches available to minimize the disease incidence (Rawlett, 2011; Zhang, Dalal, & Wang-mail, 2013). Specifically in this case, is the HBM concept of *perceived severity*, which states that when individuals perceive the seriousness of a health problem, they are more likely to engage in behaviors to reduce, minimize or prevent the perceived health risk (Rawlett, 2011). This relates to the current findings of current study, as participants who reported increased risk perception also reported understanding the seriousness of diabetes complications and engaged in health behaviors to prevent the complications.

Research Question/Category 3: How Do Sociocultural and Economic Factors Influence DM Self-Management among AA Women with T2DM?

Sociocultural and economic factors have a profound influence on diabetes self-management among AA women with T2DM. The majority of the participants reported that their diabetes self-management behavior has a lot to do with their social and cultural background, as well as their current economic status or income.

Sociocultural background and practices, notably the cultural aspects of food type and food preparation practices, were mentioned by many participants as having an impact on how much they follow through with some of the diabetes self-management behaviors. Most participants reported that food preparation and portion size, as a family tradition/cultural practice among African Americans, was a major impediment to following a diabetes food regimen. Participants reported that their tradition of food preparation involves frying and making large quantities. Many participants reported that they did not know how, or find it hard, to prepare food (including vegetables), in any other way than by frying it. Other participants reported that they just love fried food, even though they know it is against their recommended diabetes self-care practice. At the same time, food among African Americans is part of regular family functions and gathering. Participants reported that their cultural expectation of food emphasizes quantity, and that people are expected to eat a lot. Also the social values attached to food determine how people view food in a social context. In African American culture, food is viewed as a way of expressing love to family members and friends. Whenever there is any celebration or family visit, people gather around the dinner table. A family gathering without food is viewed as a sign of selfishness and lack of compassion and love for family members.

The finding is consistent with Bhattacharya (2012), who reported that in African culture, food is associated with nobility, and big meals are signs of blessings and good times in the family. Food preparation is considered an art, and African American women take pride in preparing food, which can be labor intensive (Liburd, 2003; Cooper, Brathwaite, & Lemonde, 2015).

Family loyalty, as an embodiment of family tradition among African Americans, also emerged as a factor influencing diabetes self-management practice among AA women with T2DM. As part of AA traditional practice, the family comes first. In the event of conflict of interest between the family and an individual, the family comes first. Family loyalty was reported to have both negative and positive effects on diabetes self-management among AAs with T2DM. Some participants reported that, as part of their family loyalty, they are expected to prepare food the way the family wants it prepared, and then prepare other food for herself. These participants reported that they would sometimes get too tired to make their own food, and then end up eating the unhealthy food, or going without some meals. In this case, family loyalty was therefore reported to be a major hindrance to diabetes self-management practice. For example, family loyalty is reported to make it difficult for AA women with DM to make own decisions regarding their DM self-management (Poretzky, 2010). In some cases, AA women with DM have reported having difficulty following the recommendations of DM self-management/regimens due to the programs' conflict with family life and family food preferences (Worester, 2015).

In some cases, family loyalty was reported in this study to be a major source of motivation and commitment to diabetes self-management practice among AA women with

T2DM. A participant reported that she has to observe good diabetes self-management practice because she does not want anything bad to happen to her, since she wants to be there for her family. At the same time, family units, both nuclear and extended, were reported to be great sources of the emotional support much needed for diabetes self-management. Other studies report that among AA community, family support is associated with better chronic disease management (Chesla et al., 2004; Jones et al., 2008). Literature further reports that members of the family may be beneficial in providing support to others with DM, and that the close family structures is positively related to quality of life and general satisfaction for people with DM (Poretsky, 2010). Family members provided encouragement and extended care for AA women with diabetes, making diabetes care to be a family rather than an individual process. In general, family loyalty was reported to be an integral part of diabetes self-management due to the emotional support, encouragement and surveillance it provided to AA women with T2DM in the process of their diabetes management.

Part of African American tradition prohibits turning down food offered by family members, friends or hosts, especially during gatherings (Willig, Richardson, Agne, & Cherrington, 2014). Some participants reported that as part of their prescribed AA culture they find it hard to observe their diabetes dietary requirements during family social functions or gatherings. This is consistent with literature that shows that changing diet is one the most challenging part of DM self-management among AA women with T2DM (Murrock, Taylor, & Marino, 2013).

Economic factors were also reported to play a major role in diabetes self-management. Some participants reported that their low economic status hindered their ability to effectively

practice some of the recommended diabetes self-management behaviors. Low economic status or level of income hindered the ability to afford healthful food or pay for the diabetes self-management supplies. Some participants reported that reduced/low income made it difficult for them to afford healthy diet and necessary health care services needed for DM self-management. This is consistent with the determinants of *vulnerability* and *characteristics of vulnerable populations* as described by Aday (2003). Aday's concept of vulnerability includes individuals with combinations of statuses such as being a minority elderly women, poor, having poor health and few material resources to manage their health care services and needs (Aday, 2003). The participants in this study meet Aday's description of vulnerable populations. The participants in this study have more than two combinations of the characteristic of vulnerable population as listed by Aday. The participants are women, poor, have poor health because they have diabetes, they have fewer resources, and they are minority. Like the participants in this study, vulnerable population is reported to have multiple risk factors, both at individual and community level, which negatively influence their health and healthcare experiences (Shi et al., 2008). Literature further reports that race (being ethnic minority), low family income or socioeconomic status, poor health, stigmatization, prejudice and discrimination as major contributors to vulnerability (Mechanic & Tanner, 2007; Shi et al., 2008).

Perceived Stigma Related to Diabetes as a Disease

One of the social issues that arose was the problem of perceived stigma (social unacceptability) related to diabetes as a disease among African American women with T2DM. Stigma is the discrimination, rejection or prejudice directed to an individual or individuals who have a disease, illness, or disorder which are considered undesirable (CDC, 2013; Goffman,

1963). The perceived stigma related to T2DM was particularly reported among participants who were diagnosed with diabetes at younger ages. Stigma presented a serious problem among the younger participants because it affected their diabetes self-management practice as well as their self-esteem and body image. Some participants reported a general societal feeling that people with T2DM are unhealthy, unable to take care of themselves, and therefore are treated differently in the society. The embarrassment and shame associated with social labeling resulted in some participants isolating themselves from social gatherings and friends. This feeling of social unacceptability associated with T2DM made many younger participants unwilling to share their problems with friends and some family members, for fear of being labeled unhealthy. This affected their diabetes self-management due to denial, lack of social and emotional support from friends and families. This finding is consistent with Browne, Ventura, Mosley and Speight (2013) who reported that younger people with T2DM are more likely to experience social stigma, resulting from the blame and shame attitude that the society has about people with T2DM. Similarly, Weiler and Crist (2009) reported that social stigma associated with diabetes among Latino Immigrants with T2DM resulted in shame embarrassment, and devastation leading to denial, withdrawal, and social isolation. Other studies show that people with T2DM in general perceive social stigma related to their disease, and that younger people with T2DM are more likely to experience the effects of social stigma and pressure due to feeling that the T2DM services available do not address their needs (Browne, Ventura, Mosely, & Speight, 2013). Browne and colleagues (2013) further report that negative stereotyping including labeling of being fat, lazy, over-eater, glutton, couch potato, and overweight are commonly experienced by people with T2DM (Browne, Ventura, Mosely, & Speight, 2013). Interestingly, Schabert and

colleagues (2013) report that there is general belief among people who do not have diabetes that diabetes is not stigmatized. On the contrast, stigma is reported as a significant concern among people with diabetes in different areas of their lives, including work place and relationships (Schabert, Browne, Mosely, & Speight, 2013).

Perceived Challenges Related to Health Care Services

Five participants interviewed expressed challenges related to the health care services they received, beginning from the early stages of their diagnosis with diabetes to the time of their interviews. These challenges related to health care services were of particular interest in this study because they had a significant impact on the perceived risks for developing T2DM complications, as well as diabetes self-management among AA women with T2DM.

Participants reported receiving no diabetes education from their providers at the time of their initial diagnosis. The participants stated they were simply handed prescriptions and told to take the medication and come back for a follow up appointment. This was a major problem because many participants, especially those who did not have a health care background, thought that they would be fine/cured after completing the medication doses prescribed. The lack of basic education/ knowledge about T2DM was reported as major factor in participants' risk perception of developing T2DM complications. The participants who reported not receiving diabetes education by the providers also reported a low risk perception as well as poor diabetes self-management. The participants reported low risk perception of developing DM complications because of inadequate knowledge about DM and DM complications. These findings are comparable to what Murrock, Taylor, and Marino (2013) reported; that AA women with T2DM were frustrated by the initial diabetes education they received. The AA women in the study

expressed frustration by the way DM education was delivered, and felt that it was not helpful in their DM self-management (Murrock, Taylor, & Marino, 2013). This poor communication is consistent with the findings of Peek and colleagues, who reported that AAs experience worse patient/provider communication, including less information sharing, respect, decision making, listening and supportiveness (Peek et al., 2013).

Another healthcare-related challenge reported by the participants included the provider's perceived negative attitude towards the patients (participants). Majority of participants reported a feeling that their providers addressed them in a demeaning and disrespectful manner and blamed them for their poor health when addressing their treatment options. The perceived negative attitude of the provider made a number of participants not want to go back to their providers for their follow up appointments. Participants reported that because they did not want to be embarrassed or blamed for their problems, they simply chose to avoid going back to their providers. Several participants also reported a feeling of discrimination by their providers. The perceived negative attitude of the provider and a feeling of being demeaned and discriminated led to poor diabetes self-management among the participants, due to the participants' distrust and unwillingness to share their problems with their providers, or adhere to follow up appointments. This is consistent with documented distrust by African Americans of the health care system in the United States, resulting from African Americans' perceived discrimination by the healthcare system (Armstrong et al., 2013). Street and colleagues report that AA and Hispanic patients are likely to report discontent with their rapport with providers and perceived poor quality of care resulting from distrust and providers' ways of communication with them (Street, O'Malley, Cooper, & Haidet, 2008). Literature also shows that there is persistent unintentional bias by

health care professionals in the treatment of AAs, resulting from long standing racial discrimination and segregation (Santry & Wren, 2011). Although only 20% of participants reported racial/ethnic discrimination or biases among their providers, literature reveals that there is a consistent implicit racial bias against AAs in general (Blair et al., 2013).

Significance and Implications of the Study for Clinical Practice

The central focus of this research study is on the perceived risk for developing DM complications among AA women with T2DM, and how AA women's perceived risk affects their DM self-management in the socio-cultural context within which their care takes place. The research findings from this study can be used in a number of ways that will be beneficial in clinical practice with this population. The findings will provide nurses and primary care providers with valuable knowledge of the right approach or questions to ask when caring for AA women with T2DM. Understanding how this population perceives their risks of developing diabetes complications is essential for providing quality care and quality patient education. Good patient-centered care recognizes that listening to patient's needs and concerns, values, and preferences is important for providing quality care (Epstein & Street, 2011). The findings of this study therefore emphasize the need for the providers to identify and refer their patients to: (1) community-based programs that address the social and economic factors that influence DM self-management among AA with T2DM; (2) population specific DM education programs that address the needs of AA women with T2DM; and (3) providers also need to implement the culture and gender tailored approaches that have been found to be effective for this population, which can help to address health disparities related to perceived discrimination among AA women with T2DM. Each of these recommendations are discussed in the following sections.

(1) Community-Based Programs that Address the Social and Economic Factors that Influence DM Self-Management among AA with T2DM

The study findings revealed a significant influence from social and economic factors in DM among AA women with T2DM. They identified perceived inadequate health care services, resulting from low socio-economic status, as posing serious challenges to DM self-management among this population. A number of participants reported an inability to effectively manage their DM due to inadequate economic resources, and reluctance to access health care services due to providers' perceived negative approaches and assumption of their diabetes knowledge. To address this problem, community-based program that take into account the needs and socio-economic challenges of this population will be vital. For example, health care providers need to identify and refer their patients to a community-based patient assistance program that provides inexpensive or discounted medications as well as healthful food items and diabetes care supplies. Referring patients to Wal-Mart for discounted medication and to local farmers' market for inexpensive fresh fruit and vegetable produce could be of help to AA women with T2DM. There are several organizations provide information regarding patient assistance programs that helps with low cost prescriptions for patients who are unable to afford their medications (ADA, 2014; Center for People in Need, 2010). Organizing and participating in free community-based medical outreach programs to provide free medication and health screening services would help supplement and prevent more costly tertiary treatments of treating DM complications, such as renal failure requiring dialysis and gangrene requiring amputations among AA women with T2DM. Although there is no documentation or available literature, this researcher has participated in a number of free community health screening programs organized by local

healthcare providers in Pinal County rural communities of Casa Grande, Arizona City and Coolidge. Also, encouraging and providing patients with information about the locally available diabetes education classes may also help improve patients' awareness of DM self-management practices for better health outcome. For example, Pinal County Department of Public Health provides free classes to people with diabetes and family members assisting loved ones with diabetes (Pinal County Government, 2015).

A study by Hooks and colleagues reported that AAs were more likely to be referred for diabetes education classes than their NHW counterparts were (Hooks-Anderson, Crannage, Salas, & Scherrer, 2015). However, out of the ten participants in this study, only three (30%) of the participants reported being referred to diabetes education classes, and out of the three, only one (10%) attended the classes. The participant who reported attending the diabetes education class also reported engaging in the recommended diabetes self-management practices. This is consistent with the research findings that participation in diabetes education classes leads to improvement in diabetes self-management skill (Naccashian, 2014).

(2) Population Specific DM Education Programs that Address the Needs of AA Women with T2DM

Literature reveals that the way people perceive themselves to be at risk of developing a disease or disease complications, determines the likelihood of behavior modification or changes in lifestyle to prevent the perceived risk (Kim et al., 2007). Understanding risk perception is therefore a crucial component of DM self-management practice among AA women with T2DM.

These research findings will inform the nursing profession and health care team in general of AA women's cultural preferences, values and the social-cultural context that may

influence their risk perception of developing diabetes complications. The findings of this research revealed the importance of tradition and culture among AA women in general. The research findings showed that culture permeates every aspect of AA women's lives, including activities of daily living, eating habits, and even DM self-management practices. Understanding of AA women's perceptions, cultural practices and values is critical in empowering AA women with T2DM to participate in their own self-care. For example, unlike the general practice of following the set guidelines in disease management, the providers should be able to incorporate the AA women's cultural values and beliefs into the DM management guidelines in order to maximize the patients' participation in DM self-management practices. This is consistent with the research finding, which shows that, culturally tailored community-based health interventions and education delivered by trained community members significantly reduced hemoglobin A1C among AAs and Latinos living in Detroit (Feathers et al., 2005). The same study indicated that the improved hemoglobin A1C was due to intervention material being adapted for AA and Latinos and were delivered by trained community members rather than professional healthcare providers (Feathers et al., 2005).

Cultural differences between providers and patients often pose a barrier between patient and provider that can lead to an inaccurate understanding of the patient's needs and a lack of useful advice (Epstein & Street, 2011). AAs in general experience inadequate communication and information sharing with their providers, leading to poor provider/patient relationship, dissatisfaction and compromised care (Peek et al., 2013; Street et al., 2008). The findings of this research will add to knowledge that will help identify AA women with T2DM's health needs, perceptions, and strategies for providers to approach their care in a way that may improve

their health outcomes. Understanding the AA woman's family roles, food preparation and the cultural meanings of food will help providers develop individualized plans of care that accommodates and integrates patients' cultural practices into their diabetes self-management plan of care.

The problem of perceived discrimination needs to be addressed by health care providers in order to improve AA women's patient care and to reduce health disparities among this vulnerable population. A number of AA women reported feelings of discrimination and negative attitudes towards them by their providers. To prevent AA women's perceived discrimination by the healthcare system, the providers should be trained to invite patients to participate in their care by explaining the disease process and making every visit interactive, to make the patients feel valued. The research findings in this study will therefore help providers understand the patients' background, preferences, and healthcare needs and appreciate the patients' contribution in their care (Epstein & Street, 2011). Literature suggests that the use of family-centered support system to help AAs with DM to participate in healthier life styles including visits to provider offices is effective in DM self-management among AAs (Treadwell et al., 2010).

The research findings of this study revealed general inadequacy in diabetes education and knowledge of diabetes among a number of AA women with T2DM. The study revealed a lack of knowledge on diabetes and its related complications, and recommended DM self-management practices, especially during the initial stages of diagnosis. As a result, a number of participants had low risk perception of developing diabetes complications, not because they were at lower risks, but because they downplayed their risks due to limited knowledge of potential DM complication risks. The inadequate knowledge of diabetes and diabetes complication among AA

women with T2DM calls for a population-specific education program to provide: (1) the education needed to understand the potential risks of developing diabetes complications; and (2) recommended T2DM self-management practices. The importance of this is to improve patient knowledge of T2DM and recommended self-management behavior. Dorresteijn, Kriegsman, Assendelft and Valk (2014) reported that patient-centered education improved knowledge and foot care behavior among patients with diabetes.

The findings of this study will also help to improve providers' understanding of the way AA women with T2DM perceive their risk of developing DM complications and why some of their perceptions are incongruent with their actual risks. Understanding risk perception of AA women with T2DM, and the factors that influence their risk perception, is a gateway to developing population centered approaches or strategies for educating AA women with T2DM on ways to improve their DM self-management. Providers therefore need to educate their AA women with T2DM patients on the basics of diabetes and its potential complications, including the potential future DM-related complications when not engaging in DM self-management behaviors. Institute of Medicine (IOM) reports that there is a strong evidence that when patients are fully informed of their situations, and are involved in decision making regarding their care, they are likely to be more satisfied with their care, hence reducing the cost of their care and improving health outcomes (IOM, 2013).

Research Implications

This qualitative descriptive research provides a foundation for further research to better understand the problems and challenges facing not only African Americans, but also other minority women with T2DM who share similar challenges. The findings of this qualitative

descriptive research, and the challenges and limitations of the study itself, call for further research to address the pertinent issues related to DM, its potential risks, best self-management practices, as well as risk perception of developing the DM complications among AA women with T2DM, in more detail. Based on these findings, the three questions of future research interest include: (1) what is the impact of primary care providers' approaches to increasing risk perception for developing diabetes complications, and better DM self-management among AA women with T2DM?; (2) what are the causes, experiences and consequences of perceived social stigma in diabetes self-management among AA women with T2DM?; and (3) how does culture influence risk perception for developing diabetes complications and DM self-management among AA women with T2DM? These questions are elucidated in the following sections.

(1) What is the Impact of Primary Care Providers' Approaches on Risk Perception of Developing Diabetes Complications and DM Self-Management among AA Women with T2DM?

Understanding of risk perception and sociocultural and economic dynamics and their implications in DM self-management among AA women with T2DM, calls for further research to better understand the needs and challenges facing this population. With the importance of risk perception on healthcare behavior having been discussed in these research findings, an intervention study focusing on improving risk perception among this population is important for improving their disease management skills in general. The findings of this study underscored the importance of risk perception in diabetes self-management among AA women with T2DM. The study findings revealed that the level of risk perception determines whether an individual takes action to manage their disease conditions, as well as their commitment to the self-management

practice and process. The study further emphasized the importance of diabetes education in shaping risk perception among AA women with T2DM. Since primary care providers play central role in diabetes education, care and self-management, understanding how primary care providers' approaches and involvement in DM management may shape DM risk perception among AA women with T2DM is key to improving DM management among this population. An investigation into how primary care providers' approaches influence the formation of risk perception of developing diabetes complications among AA women with T2DM is important in shaping risk perception and improving DM self-management among this population. An intervention study on how primary care providers can change their approaches to diabetes care to improve risk perception is necessary.

This study also generated or uncovered other major issues related to primary care providers that need to be investigated to help improve DM care and management among AA women with T2DM. Notably, the research findings revealed participants' general dissatisfaction with the primary care providers' approaches to diabetes education and management, and placing the blame for the initial poor management of T2DM on the primary care providers. AAs and Hispanics are reported to be more likely to report dissatisfaction with their providers, poor quality and more discontinuity of care and services (Street et al., 2008). For example, the general feeling by the participants that the primary care providers showed a negative attitude toward patients and did not provide appropriate diabetes education was reported by the findings of this study. It is therefore important to investigate how primary care providers' approaches to care may improve provider/patient relationship, improve care and influence risk perception for developing diabetes complications among AA women with T2DM. A qualitative study focused

on the appropriate primary care providers' approaches to DM education and management would help improve DM self-management among AA women with T2DM.

(2) What are the Causes, Experiences and Consequences of Perceived Social Stigma in Diabetes Self-Management among AA Women with T2DM?

The concepts of perceived social stigma related to DM as they arose from the research findings needs further exploration. While the issue of social stigma may not necessarily be exclusive to AA women with T2DM, an investigation of the origin of social stigma, its lived experiences and impacts or effects on diabetes self-management among AA women with T2DM needs to be studied further. The effect of perceived social stigma, in diabetes self-management as stated in the findings of this study cannot be minimized, for effective DM self-management. It is interesting that social stigma related to DM is rampant among community members who value family loyalty and social support in DM management. A general feeling of social isolation related to perceive social stigma was reported by one participant in the research findings. Although only one participant reported experiencing social stigma in this study, research shows that T2DM is a stigmatized disease, and other people with T2DM have reported evidences of stigmatization (Browne et al., 2013). Therefore, the impact of perceived social stigma on diabetes self-management calls for a logical study of the origin, experiences, and significances of social stigma in diabetes self-management, especially among younger AA woman with T2DM.

People with chronic diseases experience various forms of stigma and discrimination related to their chronic diseases. In a study investigating HIV associated stigma and social support among AAs, Galvan and colleagues, reported that HIV related stigma negatively affect AA with HIV (Galvan, Davis, Banks, & Bing, 2008).

Furthermore, T2DM is becoming a major concern among the AA population in general, and is shown to be increasing. T2DM is not just a problem of the stereotyped older generation who are unhealthy and unable to take care of themselves, but also among the younger generation and even educated and health care professional AA women. Since social stigma related to DM is a problem that was reported by only one of the participant in this study, it is not possible to draw conclusion that AA women with T2DM experience social stigma. However, given evidence in the current literature regarding social stigma among people with DM, there is a need to conduct further research focusing on social stigma in this populations. Browne and colleagues (2013) reported in their study that people with DM perceive and experience stigma, and that stigma have significant effects in different aspects of their lives (Browne et al., 2013). Browne and colleagues (2013) further report that stigma is mostly experienced among younger people with diabetes than older population (Browne et al., 2013). Other studies report that people with DM experience stigma from family and friends, healthcare professionals, and schoolteachers, particularly those diagnosed with DM at a younger age (Browne et al., 2014).

(3) How does Culture Influence Risk Perception for Developing Diabetes Complications and DM Self-Management among AA Women with T2DM?

The findings of this study also underlined the significance of culture in shaping risk perception and DM self-management among AA women with T2DM. The research findings revealed that cultural beliefs and practices had profound impacts on diabetes self-management, even among participants who reported higher risk perception of developing diabetes complications. Cultural practices related to food preparation and consumption were reported to have negative impacts on diabetes self-management behavior among a number of AA women

with T2DM, and sometimes overrode their knowledge of good DM management practices. This problem calls for an intervention study focused on how to incorporate cultural practices into diabetes education and self-management. Culture was also reported in the research findings to have influence on T2DM self-management. As part of cultural practice, diabetes management was reported to be more of a family, rather than an individual, process. For example, cohesive family structures among AAs are reported to provide emotional and social support for people with diabetes (Poretsky, 2010). Family support has also been linked with better outcomes in chronic disease management in general (Chesla et al., 2004). Jones and colleagues (2008) reported that when a person has DM it does not only affect that particular individual with diabetes, but also the family members (Jones et al., 2008). Based on these research findings, family structures may have positive impact on DM self-management among AA women with T2DM. Therefore, an intervention study on how to incorporate the family into the disease management process among this population would be vital in changing the course, prevalence and impact of T2DM among this population. Family and social support systems have been shown to have significant positive impact on diabetes management including adherence to diabetes treatment (Miller & Dimatteo, 2013). Family support and organized family environment or cohesion, have also been reported to have positive impact on adherence to diabetes management, metabolic control and quality of life among patients with diabetes (Pereira, Berg-Cross, Almeida, & Machado, 2008). Another study also showed that culturally tailored diabetes social support intervention improved T2DM knowledge and self-management behavior among Mexican American adults with T2DM (McEwen, Pasvogel, Gallegos, & Barrera, 2010). Since management of DM is considered to be a family, rather than individual affair, a culturally

tailored intervention involving family and close friends is likely to be embraced by individuals with DM for more effective management (Jones et al., 2008).

The impact of culture on risk perceptions was also reported in the findings of this research. The research findings revealed that culture has a profound impact on risk perception of developing DM complications among AA women with T2DM. Since risk perception determines whether an individual takes action to manage and control his or her disease, it is important to investigate the impact of culture on risk perception for developing T2DM complications. A qualitative descriptive study focusing on the impact of culture on risk perception and whether cultural practices, beliefs and traditions create a sense of vulnerability or invincibility among AA women with T2DM needs to be done to answer these questions and help improve DM self-management among AA women with T2DM. A study investigating the influence of culture on risk perception among the Koreans revealed that culture has significant influence on risk perception (Yang, 2014). However, it is important to note here that the Korean risk factors investigated were social and environmental in nature, and believed to be created and managed by the society, as opposed to natural (health) risk factors. Among the Latinos, culture has significant impact on risk perception. Cultural or social expectations outline diabetes as a disease that makes the affected individuals sick and unable to perform activities of daily living. Based on this social definition, diabetes is perceived as a disabling disease with severe complications, including loss of limbs, heart disease and “purple legs,” among others (Weiler & Crist, 2009).

Limitations and Challenges

One of the limitations of this study was the recruitment challenge due to the potential participants’ (African Americans) distrust of the healthcare system, which made it difficult to

recruit the potential participants for the study. Research attributes the unwillingness of AAs, (particularly the males) participation in scientific study to lack of education and trust, and so recommends improving rapport (trust) and education among this population as the key to improving AA men's participation in research and clinical studies (Byrd et al., 2011). Exploring the challenges to recruiting hospitalized Mexican American elders and caregivers into research, Crist, Ruiz, Torres-Urquidy, Pasvogel and Hepworth (2013) reported that using community based participatory approach, accurately estimating the number of eligible participants and having adequate recruitment budget as essential to meeting recruitment goals (Crist et al., 2013). To overcome this challenge, the researcher had to involve close friends and relatives of participants in the recruitment process. Even so, there were difficulties in some cases, of obtaining more personal information, especially those related to income or family and sociocultural dynamics in T2DM self-management from some of the participants. Although the problem of distrust to research is not unique to AAs as a group, a study comparing the level of societal distrust revealed that AAs have higher level of distrust (21% vs. 7%) than NHWs (Durant et al., 2011). Although this problem could have led to inadequate exploration of the sociocultural contexts in risk perception and T2DM self-management, it was evident that the data collected was wide-ranging and exhibited saturation of the identified categories. The data saturation validated transferability of the research finding the applicability of the research findings to a different population with similar characteristics (Munhall, 2012).

Another major challenge faced in the recruitment process was the difficulty of getting the potential participants to actually participate in the study. A number of potential participants expressed initial willingness to participate in the study, but would not follow through and make

appointments to meet with the researcher. This led to a change or adjustment of the recruitment method through churches and community events, to snowballing or referrals by the participants who had already done the interview, or close friends and relatives of the potential participants. For some reason, my population of study (AA women) tended to be reserved and non-forthcoming to participation in scientific research. This is consistent with literature that reports that AAs are underrepresented in clinical research, which makes it difficult to recognize the effect of certain disease processes in this population (Leubbert & Perez, 2015). Studies further attributes underrepresentation of AAs in clinical studies to distrust, lack of communication about research by healthcare system and researchers (Brown et al., 2013; Leubbert & Perez, 2015; Scharff et al., 2010). Distrust for researchers and healthcare system among AAs traces back to unethical public health research of untreated syphilis in Tuskegee (Leubbert & Perez, 2015; Scharff et al., 2010). In this study, the researcher had to fully explain to the potential participants the whole course of the study, and assure them that no specimen will be taken, to gain their acceptance to participate in the study. To overcome this challenge, the researcher had to use close friends and or family members to help with recruitment and introduce the researcher to the potential participants. This resulted in recruiting participants who were more comfortable and willing to participate in the study. The researcher therefore resorted to the use of individual referral and snow-bowling techniques to recruit the participants. Because of this recruitment strategy, five of the participants in this study turned out to be healthcare providers, which may have affected the results of the study especially the socioeconomic factors. The fact that 50% of the participants were health care providers meant that the participants had better knowledge of DM, which in turn increased their perceived severity of risk for developing diabetes

complications. Since 80% of the participants were employed and reported regular income, the sample may have not been a fair representation of the socioeconomic status of AA women population in general. Ejiogu and colleagues (2011) noted the challenges of recruiting and retaining minority groups in research, and attributed it to mistrust of researchers, disease burden, transportation, economic and time constraints, and behavioral and social factors (Ejiogu et al., 2011).

It is therefore recommended that future researchers use community-based participatory approach that involves the potential participants and community leaders from the initial planning to the actual research data collection. This is consistent with Sankare and colleagues (2015) findings that community-based participatory study is more successful in AAs and Latino communities. In their study, Sankare and colleagues (2015) reported that use of close friends, word of mouth and use of trained community leaders recruiting from their own communities was very successful (Sankare et al., 2015). For any successful research to take place in the AA community, a researcher needs to be involved in the community ahead of the research study and develop rapport with potential participants before the actual study.

While a number of local churches were very welcoming and offered their facilities for recruitment and as a meeting point with participants, some of the public places, including local churches and community centers were not accommodating to outsiders (the researcher), and were unwilling to assist or allow recruitment process within their facilities. Some churches even asked for hourly charges to use their facilities to meet with potential participants. This made it difficult to recruit participants in areas where there were no referrals. The important lesson to learn from this experience is that the most effective method of recruiting research participants in

this community is through individual referrals. Despite the difficulties, the recruitment was widespread in geographical coverage and representative of the population of study.

Conclusions

Since risk perception is an important factor in a behavioral change model, understanding risk perception of AA women with T2DM is a key to changing their health behavior and reducing their health risks related to T2DM (Siaki, 2009). Understanding the attitudes and beliefs of AA women with T2DM regarding their risks for developing diabetes complications will be a powerful tool for the practitioner to use in increasing and improving health outcomes and reducing health disparities among this population. The results of this study emphasize the need to develop: (1) a population-specific DM education approach that addresses the needs of AA women with T2DM; (2) community-based programs that address the sociocultural and economic factors that influences DM self-management among AA with T2DM; and (3) culturally sensitive programs that helps to bridge the provider-patient relationship gap, and help reconcile and address health disparities related to perceived discrimination among AA women with T2DM.

APPENDIX A:
HUMAN SUBJECTS APPROVAL



Human Subjects Protection Program
 618 E. Helen St.
 P.O. Box 245137
 Tucson, AZ 85724-5137
 Tel: (520) 626-6721
<http://orcr.arizona.edu/hssp>

Date: February 13, 2015

Principal Investigator: Judith Muhonja Ochieng

Protocol Number: 1502678844

Protocol Title: Risk perception of developing diabetes complications among African American women with type 2 diabetes

Level of Review: Exempt

Determination: Approved

Documents Reviewed

Concurrently: **Data Collection Tools:** *Demographic Questionnaire (3).doc*

Data Collection Tools: *Interview Guide-Ochieng (2).docx*

HSPP Forms/Correspondence: *F107-Ochieng.doc*

HSPP Forms/Correspondence: *IRB Application form-Ochieng.doc*

HSPP Forms/Correspondence: *Signature page.pdf*

Informed Consent/PHI Forms: *Consent form 2-Ochieng v2015-02-11.pdf*

Other Approvals and Authorizations: *Permission Letter-Arizona City.pdf*

Other Approvals and Authorizations: *Permission to conduct study at the church.pdf*

Participant Material: *Community Resources.docx*

Recruitment Material: *Permission to contact- Ochieng.doc*

Recruitment Material: *Recruitment flyer-Ochieng.doc*

This submission meets the criteria for exemption under 45 CFR 46.101(b).

- . The University of Arizona maintains a Federal wide Assurance with the Office for Human Research Protections (FWA #00004218).
- . All research procedures should be conducted in full accordance with all applicable sections of the Investigator Manual.
- . Exempt projects do not have a continuing review requirement.

- . Amendments to exempt projects that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination. See the Investigator Manual, 'Appendix C Exemptions,' for more information on changes that affect the determination of exemption. Please contact the HSPP to consult on whether the proposed changes need further review.
- . All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented the approved consent(s) are attached to the approval notification from the HSPP Office.

Your proposal is in compliance with Federal wide Assurance 00004218. This project should be conducted in full accordance with all applicable sections of the IRB Investigators Manual and you should notify the IRB immediately of any proposed changes that affect the protocol. You should report any unanticipated problems involving risks to the participants or others to the IRB.

This project has been reviewed and approved by an IRB Chair or designee.

APPENDIX B:
CONSENT FORM

T502a – Consent Form

APPROVED BY UNIVERSITY OF AZ IRB.
THIS STAMP MUST APPEAR ON ALL
DOCUMENTS USED TO CONSENT SUBJECTS.
DATE: 02/12/15



The University of Arizona Consent to Participate in Research

Study Title: Risk perception of Developing Diabetes complications among African American women with diabetes type 2

Principal Investigator: Judith Ochieng MSN, RN, FNP

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to participate.

You may or may not benefit as a result of participating in this study. Also, as explained below, your participation may result in unintended or harmful effects for you that may be minor or may be serious, depending on the nature of the research.

1. Why is this study being done?

The purpose of this study is to describe the understanding of African American women with Type 2 diabetes mellitus regarding their risks of developing diabetes complications.

2. How many people will take part in this study?

8-14 women will participate in this study

3. What will happen if I take part in this study?

If you agree to participate in this study, I will make observation of your home environment, including your interactions with your family members and friends. I will then conduct an initial interview that will take 60-90 minutes. The study will involve volunteering your time, when I will come to your home for the first interview and ask you questions about your experience with diabetes type 2. The information provided will be written down, audio taped, and kept confidential. There will also be a follow up interview lasting 30-60 minutes. The follow up interview will be at a place of your choice, either in a private church office, community center, or

your own home, whichever you prefer. The follow up or second interview is not mandatory. However, the interview is important in clarifying and verifying information provided in the initial interview.

4. How long will I be in the study?

You will participate in the study twice within a 1-2 month period. The first interview will last 60-90 minutes, and the second visit/follow up interview will last 30-60 minutes. The time period between the first and the second interview will be approximately 30-45 days. The first interview will take place in your home, while the second interview will take place in a private place of your choice, either in your home, church office or community center.

5. Can I stop being in the study?

Your participation is voluntary. You may refuse to participate in this study. If you decide to take part in the study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your usual benefits. Your decision will not affect your future relationship with The University of Arizona. If you are a student or employee at the University of Arizona, your decision will not affect your grades or employment status.

6. What risks, side effects or discomforts can I expect from being in the study?

The potential risks for participation in this study are the possibility of your personal information being compromised/stolen, or being accessed by unauthorized individuals. There is also a possibility of you being upset when sharing your worries, concerns, or known risks about diabetes complications during the interview process. It is possible that talking about your personal experience in this way may cause some distress.

To safeguard against your personal information being compromised, I will keep the audiotapes and journals in a locked safe/cabinet in my home. The consent forms and information collected from you will be kept at the University of Arizona. The electronic data will be stored in a password-protected personal computer. Your personal information such as age and other demographic information will be encrypted to protect your identity. I will also ensure that no clues to your identity appear in the dissertation/report. Any extracts from what you say that are quoted in the study will be entirely anonymous. If your personal information is compromised or accessed by unauthorized person(s), I will discuss the issue with you and reassure you that the information is anonymous and contains no personal identification.

If you get upset or distressed during the interview, I will let you know that we (you and I) may discontinue or suspend the interview and resume when you feel ready to do so. Should you feel that you couldn't or do not want to proceed with the study, and want to terminate your participation, I will let you know that you are free to withdraw from the study at any time. If you experience distress during or after the interview, I will provide you with the contact information to the local community based resources for emotional support should there be need.

7. What benefits can I expect from being in the study?

There will be no direct benefits to participating in this study. However, the new knowledge gained from the study could be used to improve diabetes care among this population, by designing a culturally appropriate approach to individuals' diabetes care among African American women with type 2 diabetes. The new knowledge may in turn be used to help take care of diabetes and manage it well using the resources available in a way that is affordable to African American women with type 2 diabetes

8. What other choices do I have if I do not take part in the study?

You may choose not to participate without penalty or loss of benefits to which you are otherwise entitled.

9. Will my study-related information be kept confidential?

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law.

Also, your records may be reviewed by the following groups (as applicable to the research):
The University of Arizona Institutional Review Board or Office of Responsible Research Practices

10. What are the costs of taking part in this study?

There may be both monetary and non-monetary cost to you. Monetary cost may include expenses incurred for transportation from your home to the appointment places or interview sites. These may be in form of money spent on gas and or wear and tear on your vehicles. There is also cost in the form of time that you will spend participating in the study.

11. Will I be paid for taking part in this study?

There will be no direct compensation for the expenses incurred by you in the study. However, you will be given a \$20.00 gift card as a token of appreciation for volunteering your time and participation in the study.

12. What are my rights if I take part in this study?

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

You will be provided with any new information that develops during the course of the research that may affect your decision whether or not to continue participation in the study.

You may refuse to participate in this study without any penalty or loss of benefits to which you are otherwise entitled.

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

13. Who can answer my questions about the study?

For questions, concerns, or complaints about the study you may contact: ***Judith Ochieng at 520-450-7195.***

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at <http://ocr.arizona.edu/hssp>

Signing the consent form

I have read (or someone has read to me) this form, and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject

Signature of subject

Date and time **AM/PM**

Principal Investigator/Researcher

I have explained the research to the participant before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant.

Printed name of person obtaining consent

Signature of person obtaining consent

Date and time **AM/PM**

APPENDIX C:
DEMOGRAPHIC QUESTIONNAIRE



Demographic Questionnaire

Risk Perception of Developing Diabetes Complications Among African American Women with Type 2 Diabetes

1. Participant's Code ID
2. How old are you?
3. What is your marital status?
 - a) Married
 - b) Divorced
 - c) Widowed
 - d) Single
 - e) Partnered
4. Do you have children?
5. If yes, how many children do you have?
6. How many people live in your home?
7. Do you rent or own a home?
8. How many relatives, other than your own children and spouse, live in your home?
9. If you are comfortable, please tell me how many years you went to school?
10. Are you currently employed?
11. If yes, how would you classify your job?
 - a) Full time
 - b) Part time
 - c) Seasonal
 - d) Other _____

12. How do you classify your job category?
 - a) Professional
 - b) Non-professional
 13. How long have worked in this position?
 14. If you are comfortable, please tell me what your annual income category is?
 - a) \$0- \$15,000
 - b) \$16,000- \$30,000
 - c) \$31,000- \$45,000
 - d) \$46,000- \$60,000
 - e) \$61,000 and above
 15. Do you have any other source of income besides your job?
 16. Does your job provide health benefits (such as health insurance)?
 - a) Yes
 - b) NoIf no, do you have health insurance? If yes, what is it?
 17. If not currently employed, when was last time you were employed? Please tell me more.
 18. What is your current source of income?
 19. Do you have a primary care provider (physician, nurse practitioner, or physician assistant)?
 20. How often do you see your provider?
 21. How often do you see a dentist?
 22. How often do you go for eye checkup?
- Do you go for yearly checkup?

APPENDIX D:
RECRUITMENT FLYER



Research Study: Risk Perception of Developing Diabetes Complications Among African American Women with Type 2 Diabetes

Judith Ochieng DNP/PhD student from the College of Nursing, University of Arizona is conducting research in the area of Risk perception for developing diabetes complication among African American women with diabetes type 2. She is seeking volunteers for her study who are:

- **African American**
- **A woman**
- **Have type 2 diabetes**
- **Live in Eloy, Coolidge, Florence, Casa Grande, Maricopa, or Arizona City.**
- **Be between 30 and 70 years old**
- **Able to read and speak English**

Volunteers will participate in an oral interview with Judith Ochieng, which will last between 60-90 minutes. The volunteer will also participate in a second interview that will last 30-60 minutes to talk about information provided during the initial interview.

Volunteers will receive a small gift on the last visit by the principle investigator as a thank you for the time spent during the interview. If you would be interested in hearing more about the study, please contact: Judith Ochieng at 520-450-7195.

THANK YOU.



Judith Ochieng MSN RN, FNP-BC

DNP/PhD Student, The University of Arizona, College of Nursing

APPENDIX E:
PERMISSION TO CONTACT



Permission to Contact Regarding Research Participation
Research Study: Risk perception of Developing Diabetes Complications among
African American Women with type 2 Diabetes

A DNP/PhD student from the College of Nursing, University of Arizona, Mrs. Judith Ochieng is here conducting research in the area of Risk perception for developing diabetes complications among African American women with diabetes type 2. She would like to invite you to participate in her research study.

If you accept to volunteer, you will participate in two oral interviews with Mrs. Judith Ochieng. The first interview will last between 60 – 90 minutes and will take place in your home. The second interview lasting 30 – 60 minutes will take place in a place of your choice, either in church office, community center or your home. However, the second interview is optional, but it is important for verifying the information you provided during the first interview. At the end of the first interview, you will receive a gift card as a token of appreciation for your participation in the study. Would you agree to talk to her now?

I _____ do give permission to community member/Church leader Mr./Mrs. /Miss./Ms. _____ to give my contact information to Mrs. Judith Ochieng, to contact me regarding my participation in the above research study. My phone #: _____

Participant's Name: _____

Participant's signature: _____

Date: _____

A copy of this permission form should be given to you.

APPENDIX F:
INTERVIEW GUIDE



THE UNIVERSITY OF ARIZONA.

Interview Guide

For Risk Perception of Developing Diabetes Complications among African American Women with Type 2 Diabetes study.

- I. What is the perceived risk among AA women with T2DM of developing diabetes-related complications?
 1. What is your health like? Tell me a little bit about your health? Do you consider yourself healthy? (Do you think you have enough energy to go about your day?) Why or why not? (**Health perception**)
 2. What made you go to the provider (physician, nurse practitioner, physician assistant) at the time when you were diagnosed with diabetes? Was the primary problem addressed? Was the primary problem related to diabetes? And what type care did you receive? What were you told by the provider? (**Risk perception**)
 3. When were you diagnosed with diabetes? Was there anything going on in your life at the time. Can you talk about when you were diagnosed with diabetes? (**Risk perception**)
 4. How satisfied were you with the care you received when you were diagnosed with diabetes? How satisfied are you with the care you receive when you visit your health care provider's office now? (Please tell me more about it.) How do you feel that you are treated? Do you feel comfortable asking your provider questions regarding your care? (**Risk perception**)
 5. What are some of the possible diabetes complications that you know of that some people might get? Have you or your family members or friends suffered from these complications?
 6. Would you consider yourself at risk for developing diabetes complications? a) If you do tell me more? b) How much do you think you are at risk of developing these diabetes complications? (Low or High risk?) On a scale of 0-5, how would you rate your risk? What makes think so? (Tell me more.) Have you discussed your concerns with your Provider or family and friends? What steps are you taking to address these concerns? c) How does that affect how you take care of your diabetes?

- II. How does the level of perceived risk of developing diabetes-related complications influence DM self-management among AA women with T2DM? (**DM Self-Management**)
 1. Do you control your diabetes with food or medication or shots? (Tell me more.) Were you given any type of education on diabetes, please tell me more about it? Who did

- the teaching? How much did the teaching help you in understanding diabetes? Why or why not? (Please tell me more.)
2. How do you take care of yourself, what do you consider good way of taking care of yourself? Are you taking medication? What type of medication are you taking? Do you have insurance? Who pays for your medication and supplies? Are you able to afford your medication? (**Economic/poverty**)
 3. Other than medication, what other ways do you use to manage your diabetes? Do you feel like you have what you need to manage your diabetes? (**Economic/poverty**) How is the way you were brought up affect the way you take care of yourself? (**Cultural**)
- III. How do sociocultural and economic factors influence DM self-management among AA women with T2DM?
1. Do you have any major concerns about diabetes? If yes, what are they? Why are you concerned? (**Environment**) How far is it from your home to your provider's office (**Distance to clinic**) Who else lives in your house? (**People they live with**) Who do you call for help? How you get to the providers office? (**Transportation**)
 2. Do you make decision on the food you eat? Who does grocery shopping for you?
 3. Diabetes requires specific ways of food preparation, how does the way you were brought up affect the way you prepare food? How does your family structure affect the way you prepare food? (**Socio-cultural**)
 4. How does the way you were brought up affect your risk perception (the way you understand your risk) (**Socio-cultural**)
 5. How does your role in the family affect the way you manage your diabetes?
 6. What difficulties, if any, do you have in managing your diabetes? Have you discussed this with your provider or family and friends? (**Socio-cultural**)
 7. Are your family members and friends aware that you have diabetes? Why or why not? (**Socio-cultural**)
 8. If yes, do you get any support from family and friends in managing your diabetes? (Please explain). (**Socio-cultural**)
 9. What is your religion if you have one?

If you have one, do you think that your religion affects your diabetes management? If so, how? (**socio-cultural**)

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