

EXPLORING PERCEPTIONS OF CORONARY HEART DISEASE RISK IN
AFRICAN AMERICAN WOMEN WITH TYPE 2 DIABETES

Carolyn McKenzie

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Approved by

Advisor: Anne H. Skelly

Reader: Noreen Esposito

Reader: John Carlson

Reader: Iris Carlton-LaNey

Reader: Shilda Rodgers

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ABSTRACT

CAROLYN MCKENZIE: Exploring Perceptions of Risk for Coronary Heart Disease
in African American Women with Type 2 Diabetes
(Under the direction of Anne H. Skelly)

African American (AA) women have disproportionately high rates of both coronary heart disease (CHD) and type 2 diabetes mellitus (T2DM). Many women with diabetes do not recognize their risk for CHD and, therefore, fail to engage in prevention behaviors. Leventhal's Theory of Illness Representation (IR) and the Common Sense Model were used in this study to explore the relationships between CHD risk perception and selected factors thought to influence perceptions of risk in AA women with T2DM.

An explanatory, mixed methods design was used to examine factors that may affect perceptions of risk for CHD in 48 AA women with T2DM in North Carolina. Initial data collection occurred during home visits using a survey of all participants. A second home visit for semi-structured interviews was conducted with six participants purposefully selected by levels of risk perception.

Perception of risk for CHD was not associated with participants' age, socioeconomic status, or duration of diabetes. African American women who knew their highest blood pressure (BP) or their last BP readings perceived their risk for CHD to be higher than those who did not know this information about their BP. A

faith-based concept called *claiming* emerged during the study and influenced beliefs about risk for CHD for many participants. *Relationships with their health care providers* (HCPs) emerged as an important issue. Based on data from the study, an initial explanatory model of the variables that contribute to CHD risk perception in AA women with T2DM was developed.

Perception of risk for CHD is not part of the IR of diabetes for most AA women with T2DM. Claiming or not claiming an illness, as part of participants' faith, may influence risk perception. The relationships between AA women with T2DM and their HCPs are important in the development of the risk perception for CHD and achievement of health outcomes. The results supported previous findings of studies using Illness representations of diabetes.

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LIST OF ABBREVIATIONS

AA	African American
ADA	American Diabetes Association
AHA	American Heart Association
BMI	body mass index
BP	blood pressure
CDC	Centers for Disease Control and Prevention
CHD	coronary heart disease
CSM	Common Sense Model
CVD	cardiovascular disease
DPP	Diabetes Prevention Program
HCP	health care provider
HDL	high-density lipoprotein
IPQ	Illness Perception Questionnaire
IPQ-R	Illness Perception Questionnaire-Revised
IR	illness representation
LDL	low-density lipoprotein
LOT	Life Orientation Test
LOT-R	Life Orientation Test-Revised
MI	myocardial infarction

NCHS	National Center for Health Statistics
NHANES	National Health and Nutrition Examination Survey
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
PI	principal investigator
PORQ	Perception of Risk Questionnaire
T1DM	type 1 diabetes mellitus
T2DM	type 2 diabetes mellitus

CHAPTER I

INTRODUCTION

Background and Statement of the Problem

Diabetes is a major cause of morbidity and mortality in the United States. The Centers for Disease Control and Prevention (CDC; 2007) estimates that 23.6 million Americans, 7.8 percent of the U.S. population, have diabetes, up from 20.8 million in 2005. The rate of type 2 diabetes mellitus (T2DM) in women has grown into epidemic proportions in the US (Wild, Roglic, Green, Sicree, & King, 2004). More than 11 million women in America have diabetes--90% of those have T2DM (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2007). The number of diagnosed cases of diabetes in women has risen by over 14% since 2003 (National Center for Health Statistics [NCHS], 2007).

Diabetes-related heart disease is the leading cause of mortality in persons with diabetes. Atherosclerosis is a known risk factor for coronary heart disease (CHD) and is enhanced by diabetes. In 2004, 68% of diabetes-related death certificates for persons 65 years or older had heart disease noted as the cause of death (NIDDK, 2007). Adults with diabetes have heart disease death rates about 2 to 4 times higher than adults without diabetes (NIDDK, 2007; Selvin et al., 2005). In the Atherosclerosis Risk in Communities (ARIC) study, the risk for CHD was 2.5 times

greater for atherosclerosis development among African American (AA) women than Caucasian women of the same age (Williams, Massing, Rosamond, Sorley, & Tyroler, 1999).

Cardiovascular disease (CVD), part of which is CHD, ranks independently as the major cause of mortality of women in the US (Selvin et al., 2005). Women with T2DM have a greater risk of developing heart disease than men with diabetes, and women or men without diabetes (American Heart Association [AHA], 2006; Lee, Paultre, & Mosca, 2005; Natajaran, Liao, Cao, Lipsitz, & McGee, 2003; Natajaran et al., 2005). Estrogen once was believed to protect women from the development of heart disease until the ages of 55-65 years. However, diabetes erases any protective advantage women may have in regard to CHD (Selvin et al., 2005). In fact, the risk of CHD to women with diabetes is as great as if they had experienced a cardiac event already (Hu et al., 2005, Natajaran et al., 2003, 2005). Women with T2DM are also more likely to die from an initial cardiac event than men with diabetes or women without diabetes (Crowley et al., 2003).

In diabetes, the *intima* of the blood vessels becomes inflamed due to the products of inflammation triggered by T2DM. Plaque deposits from increased cholesterol lodge in the intima as they flow through the blood stream. The risk for formation of atherosclerotic plaque in people with diabetes, especially women with T2DM, is so great that diabetes qualifies as a *heart disease equivalent* (Juutilainen, Lehto, Ronnemaa, Pyoraia, & Laakso, 2005). This term, heart disease

equivalent, means that women with T2DM should be treated as if they have already had a cardiac event of some type, such as myocardial infarction (MI) or angina, to prevent further damage.

Time since diagnosis of diabetes affects the development of CHD in all women. Because of the long-term effects of diabetes, women who have been diagnosed for 10 years with diabetes have a 14 times greater chance of developing CHD than men or women without diabetes (Hillier & Pedula, 2003).

In the National Health and Nutrition Examination Survey I (NHANES I), data showed that in women ages 45-74 years old, AA women had a three times greater rate of diabetes than Caucasian women (NCHS, 2005). Recent data from the 2007 National Health Survey shows that the diabetes diagnosis rate for AAs over age 20 years is 14.7% (NCHS, 2007).

African American women have equal or greater risk for developing both heart disease and diabetes among all ethnicities and both genders (CDC, 2006; Selvin et al., 2005). Statistics indicate a 2.5 to 3 times greater risk for diabetes in AA women when compared to Caucasian women (Robbins et al., 2000).

Risk Perceptions for Coronary Heart Disease

Risk perceptions are formed through the appraisal of experiences in a person's life. Learning how African American women with T2DM perceive their diabetes may give insight into their perceptions of CHD. Perceptions are important motivators to actions such as risk-reduction behaviors. Perceptions greatly

influence a person's self-management behaviors in diabetes and other chronic illnesses (Bradley et al., 1987; Hampson, 1997; Hampson, Glasgow, & Zeiss, 1994; Scharloo & Kaptein, 1997). Risk perception is influenced by multiple variables such as race, gender, life experiences, knowledge, or lack of knowledge (Weinstein & Nicolich, 1993). Individuals use labels to describe the illness and interpret their somatic experiences when constructing their view of an illness. This interpretation defines an illness representation (IR; Leventhal et al., 1997; Leventhal, Leventhal, & Contrada, 1998). Illness representation involves a woman's beliefs about the disease, including the risk of other illnesses that may come from a disease like diabetes. Examining her IR for diabetes provides important information about her perception of risk for CHD and underlying beliefs that may influence health promotion practices.

Rationale for This Study

Given the high risk of heart disease in women with T2DM, it is important to identify factors that affect women's perceptions of risk for CHD in order to determine the best course of action for intervening successfully with this group. Nurses who provide care to women with T2DM need precise knowledge of the most effective approaches to use when addressing women of various ethnicities. This knowledge of the patient is essential so that behavior changes can be successful and CVD prevented.

Women in general often have difficulty conceiving the risk of a potentially fatal disease such as CHD (Martin & Suls, 2003). A disease such as CHD increases a woman's fear when she considers CHD as an additional complication of diabetes, a disease that can cause amputation, blindness, and renal failure. Martin and Suls (2003) state that a woman's interpretation of symptoms of CHD may be attributed erroneously to aging and may not be linked in the woman's mind as a *female disease* because most lay people believe CHD is a *male disease*. African American women's beliefs require exploration because beliefs may vary between cultures and affect the way individuals view illness and attach meaning to it.

Organizing Framework for the Study

The organizing framework that guided this study is the Theory of Illness Representation, with the Common Sense Model (CSM) as described by Leventhal et al. (1997, 1998). The domains of the IR are identity, consequences, timeline, control, and cause. Illness representation of diabetes helps the individual form a perception of risk through appraisal of information and life experiences (Aalto, Heijmans, Weinman, & Aro, 2005; King, 2002; Leventhal et al., 1997; Leventhal, Kelly, & Leventhal, 1999; Leventhal et al., 1998; Petrie & Weinman, 1997; Scharloo et al., 1998; Schiaffino & Cea, 1995). In past studies, the interrelationships of the domains of IR and their influence on risk perceptions have not been examined. In this study, the domains of the framework (identity, time line, consequences, control, and cause) and their interrelationships were examined.

Also examined were the domains' relationships with participants' IR of T2DM, and the effect of those relationships on participants' level of risk perception for CHD.

The positive or negative outlook a woman has toward her illness may affect the outcome of that illness. Studies of heart disease demonstrate that the more optimistic a person is about life events, the better the outcomes may be (Kubzansky, Sparrow, Vokonas, & Kawachi, 2001; Scheier et al., 1999). This study examined the effects of optimism and pessimism on level of risk perception for heart disease. Also identified were factors in the health care environment and personal belief patterns that may assist health care providers (HCPs) to improve health outcomes for African American women with T2DM.

Personal characteristics, such as duration of diabetes, educational level, income, and familial experiences with diabetes or CHD, may play a significant role in the development of risk perceptions and may affect health outcomes. Some studies suggest that socioeconomic factors and educational level affect risk and risk perceptions due to the presence of barriers and misconceptions about health and disease. Validating these factors in African American women with diabetes is imperative to the design and implementation of successful interventions (Appel, Harrell, & Deng, 2002; Lee, Cheung, Cape, & Zinman, 2005; Robbins, Vaccarino, Zhang, & Kasl, 2000). For example, researchers report that African American women with diabetes, with less education and less income, have a greater risk for

CHD than Caucasian women with diabetes (Appel et al., 2002; Liburd, Jack, Williams, & Tucker, 2005; Williams et al., 1999).

Some researchers report that T2DM is more prevalent in AA women due to lower income and greater body mass index (BMI; Robbins et al., 2000). Other researchers state that educational level is a predictor of fatal disease outcome in women who already have CHD (Lee et al., 2005).

This study explored selected personal characteristics to determine if those characteristics correlated with levels of risk perception and health outcomes. Also examined were personal characteristics to determine if they predict levels of risk perception for CHD in AA women with T2DM.

There is little documentation about perceptions of risk for CHD in AA women with diabetes. The majority of studies examining perceptions of heart disease in women have been on sample populations of Caucasian men or women. When asked to prioritize their greatest risk, AA women rank cancer much higher as a serious health problem than heart disease compared to Caucasian women (81% compared to 31%; Sadler et al., 2005).

Therefore, studying how AA women with T2DM perceive their illness (diabetes) and how they perceive their risk for CHD gives insight into how HCPs, and especially nurses, can assist AA women with T2DM to improve their health outcomes. The following aims and research questions guided the research.

Research Aims

The research aims for this study were:

1. to determine if perceptions of diabetes in AA women with T2DM influence perceptions of risk for coronary heart disease (CHD).
2. to explore the relationships between the components of IR in AA women with T2DM.
3. to explore how age, personal characteristics such as education and income, and duration of diabetes relate to the level of risk perception for CHD in AA women with T2DM.
4. to determine if optimism or pessimism relate to the level of risk perception for CHD in this population.
5. to develop an initial model that can be used to predict the level of risk perception in AA women with T2DM.

Research Questions

The research questions were:

1. What is the relationship between perception of diabetes, as measured by IR, and the perception of risk for CHD in AA women with T2DM?
2. What are the relationships between the domains of illness representation, as described by Leventhal, in AA women with T2DM?
3. How do personal characteristics such as age, educational level, income, and duration of diabetes affect the perception of CHD risk in AA women with T2DM?

4. What is the role of optimism or pessimism in AA women's perception of risk for CHD?
5. How do AA women's perception of diabetes, level of optimism, and personal characteristics collectively predict the level of risk perception for CHD?

Summary

People experiencing diseases such as diabetes or coronary heart disease sometimes have very different perceptions of their illness from the perceptions of their HCPs. These perceptions affect self-management strategies and, thereby, health outcomes. In order to address those differences in perception, the HCP must know these perceptions exist. This study explored the perceptions of diabetes and CHD risk in AA women with T2DM in order to contribute to the body of knowledge currently available to nurses and to enhance their abilities to intervene effectively.

CHAPTER II

REVIEW OF THE LITERATURE

Type 2 Diabetes Mellitus and African American Women

Diabetes mellitus is a group of disease processes that are metabolically based and result in malfunctioning of the pancreas (American Diabetes Association [ADA], 2008). There are two types of diabetes. In type 1 diabetes mellitus (T1DM) the beta cells that produce insulin are damaged typically through what is thought to be an autoimmune response (Libman & LaPorte, 2005). This damage is believed to occur from either viral attack with a lack of appropriate immune response, or from environmental factors such as chemicals not specifically identified at the present time (Libman & LaPorte, 2005). T1DM tends to occur suddenly in younger adults and children when the beta cells fail to release insulin (ADA, 2008; De Blasio, Bak, Pociot, Karlsen, & Nerup, 1999). The term *diabetes* in the literature and this study, if not otherwise specified, refers to both T1DM and T2DM.

In T2DM the pancreas secretes excessive insulin over time and the person eventually does not produce enough insulin to manage glucose levels.

Researchers have identified a syndrome that is believed to be both a precursor to

T2DM and presents multiple risks for CVD, the *metabolic syndrome* (Kahn, Buse, Ferrannini, & Stern, 2005; Tonstad & Hjermann, 2003).

Metabolic syndrome exists when there are four conditions present upon examination or screening. According to Kahn et al. (2005), these conditions are obesity, insulin resistance (as manifested by hyperglycemia), elevated lipids, and elevated blood pressure (BP). Other researchers state 3 of 5 conditions must exist for the metabolic syndrome to be diagnosed (Wilson, D'Agostino, Parise, Sullivan, & Meigs, 2005). Wilson et al. list the 5 conditions as: increased waist circumference (>102cm for men, >88cm for women), BP elevation ($\geq 130/85$ mmHg), low high-density lipoprotein (HDL) cholesterol (<40mg/dl in men, <50mg/dl in women), high triglycerides (≥ 150 mg/dl), and hyperglycemia (≥ 100 mg/dl). Currently the metabolic syndrome or *insulin resistance syndrome* is thought to link diabetes and heart disease in T2DM, though researchers continue to define the syndrome variously (Kahn et al., 2005).

Type 2 diabetes mellitus develops from the metabolic syndrome over a period of time as the person gains weight, decreases physical activity, and increases abdominal adiposity, and as insulin resistance increases (Lorenzo, Okoloise, Williams, Stern, & Haffner, 2003). More than 90% of those with diabetes have T2DM (ADA, 2009).

Diabetes affects 23.5 million people age 20 years or over in the US, which is approximately 10.7% of this age group. Of those, 14.6 million are diagnosed and

6.2 million are undiagnosed (CDC, 2007). A concern for the US is the increasing prevalence of diabetes. In 2007, 1.6 million new cases of diabetes were diagnosed in people age 20 years or older (CDC, 2007). It is expected that by the year 2025 there will be 300 million people worldwide with diabetes (King, Aubert, & Herman, 1998). Type 1 diabetes mellitus affects about 1 in every 400-600 people under age 20 years--about 176,000 people--in the US. Type 2 diabetes is being diagnosed increasingly in younger children and adults because of obesity and inactivity in children and adolescents (Klein et al., 2004). National trend statistics show that in the younger age groups, 5-10% of all diagnosed cases are T2DM. Early-onset cases of T2DM are diagnosed most often in AAs, Hispanic or Latino Americans, and American Indians (Klein et al., 2004). Data on T1DM show an overall increase in prevalence, especially in AA males under age 4 years. The future impact of complications in this young age group could result in a greater burden on the healthcare system (Libman & LaPorte, 2005).

The diagnosis of diabetes increases with age. For adults over 65 years of age, the rate is 18.8%, with the lowest rate at 2.3% for those between 18-44 years of age (CDC, 2007). National trends show women are affected slightly more frequently than men are, with 8.0% of women nationally having diabetes compared to 7.4% of men (CDC, 2007). These rates continue to climb at an estimated 1/2 million women per year.

Persons with diabetes face challenges from the complications of the disease that can affect their lifespan and quality of life. Complications from diabetes are CVD, including CHD, peripheral vascular disease, and cerebrovascular disease/accidents; lower extremity amputation and foot ulcerations from peripheral vascular disease; peripheral neuropathy and retinopathy from microvascular problems; along with other concerns such as skin disorders and digestive problems. All of these complications create challenges for anyone with the diagnosis of diabetes.

Diabetes affects some ethnic groups more than others. In the US, 14.7% of all non-Hispanic AAs are affected. According to the 2004 CDC rates, non-Hispanic AAs were 1.8 times more likely to have diabetes than non-Hispanic Caucasians, and Mexican Americans were 1.7 times more likely to have diabetes than non-Hispanic Caucasians. American Indians and Alaska Natives are the most affected ethnic groups, both being 2.2 times more likely to have diabetes than non-Hispanic Caucasians (CDC, 2007).

There are 3.2 million non-Hispanic AAs with diabetes, and one of every four AA women over 55 years of age has diabetes. African American women have a greater risk for T2DM than AA men, although scientists cannot identify the exact cause of this difference (Robbins et al., 2000; Tilghman 2003; Tulloch-Reid et al., 2004).

Robbins et al. (2000) discussed potential causes of the higher rates of diabetes in AAs. They studied 961 AA women and 839 AA men, 1,641 non-Hispanic Caucasian women, and 1,537 non-Hispanic Caucasian men, ages 40-74 years, as a part of the Third NHANES (NHANES III; Robbins et al., 2000). Covariables examined in the study included BMI, waist-hip ratios, self-reported weight at age 25 years, physical activity, smoking status, and alcohol use (Robbins et al., 2000). Researchers found T2DM was prevalent in the AA participants regardless of socioeconomic status (SES) factors such as education and income (Robbins et al., 2000). The researchers explain that their study was focused on gender differences in SES and T2DM prevalence, versus differences in SES and T2DM prevalence based on ethnicity. Central obesity was a factor in the AA men's prevalence of diabetes, but the overall prevalence of diabetes in AA women was higher (Robbins et al., 2000).

The authors attributed economic disadvantage to the excess prevalence of T2DM in AA women, but did not attribute the same to men. Income based on family size seemed to be the defining factor between their results and previous results that did not find SES as a factor in increased T2DM prevalence in AAs. A limitation of this study was the use of secondary data for analysis. There was significant nonresponse in the initial data collection in NHANES III; therefore, the results may have been affected by the nature of the data.

Some of the major factors that contribute to T2DM may result from economic disadvantage and include high fat, high cholesterol, high sodium, high carbohydrate diets, abdominal obesity and high BMI, low physical activity levels, metabolic syndrome, and genetic predisposition (Tilghman, 2003; Tulloch-Reid et al., 2004).

Diet

Dietary recommendations from the ADA Clinical Practice Recommendations (2008) state that people with T2DM should all receive medical nutritional therapy by persons trained in teaching current diabetes dietary management guidelines. Those guidelines include either limiting carbohydrates past 130 g per day and choosing complex carbohydrates versus processed carbohydrates, or choosing a low-fat calorie-controlled diet. Emphasis is on choosing a diet that can maintain whatever weight loss the person is able to achieve on an ongoing basis. Limiting protein intake to the Recommended Daily Allowance of 0.8g/kg body weight also is recommended to preserve kidney function. Saturated fat is recommended to be less than 7% of the total daily intake. Weight loss is encouraged through the use of lifestyle changes such as increasing activity and limiting caloric intake for age and gender.

Diets that are culturally influenced, such as the traditionally Southern diet of AA women, the population in this study, may have high concentrations of processed foods, high fat, and high cholesterol (Anderson-Loftin et al., 2005; Samuel-Hodge

et al., 2006). Lower fat, low cholesterol, low sodium, moderate carbohydrate diets contribute to weight loss and better glucose, BP, and cholesterol levels for the person who can adhere to such a diet (ADA, 2008). Research also has shown that certain elements in the diet may help prevent the development of T2DM. For example, a recent study suggests that AA women who have adequate magnesium in their diets may have less risk for developing diabetes (van Dam, Hu, Rosenberg, Krishnan, & Palmer, 2006).

Abdominal Obesity and Body Mass Index

Research has shown that AA women have more abdominal obesity than other ethnicities on average, which contributes to the development of insulin resistance and progression to T2DM (Okosun, 2001; Tilghman, 2003; Tulloch-Reid et al., 2004). Along with abdominal obesity are the problems of increased BMI and heredity (Okosun, 2001; Tilghman, 2003). A body mass index above 30 is defined as obesity (ADA, 2008). Compared to their Caucasian counterparts, AA women have an average higher body weight, which has been linked to the development of T2DM.

Low Physical Activity Levels

Lack of adequate physical activity can contribute to the development of T2DM. Physical activity can decrease insulin resistance by assisting the body's cells and tissues to use insulin more efficiently. Physical activity is a means for preventing T2DM; however, some researchers propose that weight loss may be a more

efficient method of prevention of diabetes than physical activity (Weinstein et al., 2004). For example, researchers suggest that a moderate weight loss of 5-10% of the person's current body weight can significantly improve insulin sensitivity (Klein et al., 2004; Knowler et al., 2002). Increasing physical activity improves glucose control, but may not significantly impact weight loss (Klein et al., 2004). Therefore, a combination of potential causes must be addressed through multiple lifestyle changes such as diet and physical activity. The Diabetes Prevention Program (DPP; Knowler et al., 2002) study found that a combination of increased physical activity and a healthy diet significantly decreased the chances that a person with impaired glucose tolerance would develop diabetes.

Metabolic Syndrome

Of the five conditions that compose the metabolic syndrome (increased waist circumference, BP elevation, low HDL cholesterol, high triglycerides, and hyperglycemia), all increase risk for diabetes in AA women (Wilson et al., 2005). These risks are best addressed through lifestyle changes and medication (if necessary) to prevent progression of diabetes and its complications (ADA, 2008).

Genetic Predisposition

Genetic predisposition is an additional factor in the development of T2DM. African American women with first-degree relatives, such as parents or siblings, with diabetes have a greater chance of developing diabetes.

The DPP (Knowler et al., 2002) found that prevention is possible with lifestyle changes and medication. In the DPP study, approximately 20% of the participants in each arm of the study were AA. The DPP researchers found that diabetes could be prevented; however, the majority of participants (approximately 70%) in the landmark study did not have a family history of diabetes (Knowler et al., 2002).

Other researchers reported that even with a strong genetic predisposition to diabetes, changes in diet and increasing physical activity can decrease the chances of developing T2DM (Brekke, Jansson, & Lenner, 2005). In the pilot study, 77 Swedish participants, ages 25-55 years, with first degree relatives with T2DM were studied over 1 year. Three cohorts started at separate intervals, with family members kept together in the same cohort. One group (D; $n = 24$) made dietary changes for lower fat and lower glycemic, and increased vegetable intake. The next group (DE; $n = 25$) participated in the same dietary changes and added exercise for 30 minutes four to five times per week. The third group (C; $n = 19$), the control group, continued a normal lifestyle. Participants in intervention groups of diet or diet and exercise showed more positive lifestyle changes than those in the control group. The results show lifestyle changes can be maintained and were maintained for 2 years in the treatment groups. The researchers did not follow the control group for 2 years since the intervention was beneficial. They initiated the intervention with the control group after the first year. The intake of saturated fat, a high-risk substance linked to CHD, was decreased in all groups after the 2-year

timeframe. Participants in all groups were able to adhere to the dietary changes after the 2 years, with some decline noted after 1 year.

A limitation of the study was the inclusion of the control study in the intervention after 1 year. Because of the inclusion, there was no control group for comparison at the end of the study. In addition, there were telephone assessments along the course of the intervention, which could have affected adherence to the program. The researchers did not discuss the effect of the assessment contacts on the participants. The ethnicities of participants, other than Swedish, are not indicated either. This omission leads to difficulty in applying the results to other ethnic groups.

In summary, the findings in the literature support that T2DM significantly affects AA women. The literature also supports that causes of T2DM relate to cultural, physiological, genetic, and socioeconomic factors.

Diabetes and Coronary Heart Disease

Diabetes creates an inflammatory response in the body that causes the release of C-reactive protein, a biomarker of inflammation that can be present with or without diabetes (Pai et al., 2004). C-reactive protein causes damage to the blood vessel walls, which promotes the formation of clots and plaque, increasing the risk of heart attack or stroke (Pai et al., 2004). Hyperglycemia from diabetes also causes direct damage to vessels, such as impaired vasodilation due to the release of nitrous oxide (Barrett-Conner et al., 2004). In diabetes, the clot-forming

properties of the blood also become overactive and lipid particles become adhesive, more easily forming thrombi on the vessel walls (Nicasio, El-Atat, McFarlane, & LaRosa, 2005). Atherosclerotic plaque formation is more prevalent in people with diabetes than in those without diabetes (Barrett-Conner et al., 2004).

African American women with diabetes have more hypertension and higher cholesterol levels (lipids) than women without diabetes (CDC, 2004). In fact, 73% of those with diabetes have a BP greater than or equal to 130/80 (ADA, 2009). Hyperlipidemia is the single most important risk factor for CVD in men and in women both with and without diabetes (Barrett-Conner et al., 2004). In 2005, total cholesterol levels were documented to be greater than 200 mg/dl in 48% of the population, which is equal to more than 106 million people (AHA, 2006). All of the aforementioned factors contribute to the development of CVD in people with diabetes.

Coronary heart disease is one of the major complications of diabetes that affects mortality. The ADA (2008) reports that CHD affects 65% of all adults with diabetes, who are two to four times more likely to have heart disease than adults without diabetes. Death from heart disease has not decreased in women. From the years of 1971-2000, men with diabetes saw a decrease in death from heart disease of 16.8 deaths per 1,000 to 8.1 deaths per 1,000. Among women with diabetes for the same years (1971-2000) the rates more than doubled from 8.3 per 1,000 to 18.2 per 1,000 (Gregg, Gu, Cheng, Narayan, & Cowie 2007).

The overall death rate from diabetes in the year 2000 was approximately 2.9 million, which is 5.2% of all deaths (Roglic et al., 2005). Since then, people with T2DM have seen very little change in death rates because the complications of diabetes, such as hypertension, dyslipidemia, and obesity, contribute to heart disease and mortality.

Cholesterol and lipid levels, both low-density lipoprotein (LDL) and HDL, are major factors in the development of CVD (Barrett-Conner et al., 2004; Lee et al., 2000). People with diabetes have lower treatment thresholds for LDL and triglycerides than any other disease group because of the multiple risk factors that contribute to the risk of CHD (Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults, 2001). High LDL is the primary factor in CVD development for people with T2DM. The increased adherence of the small LDL particles creates opportunity for red blood cell clumping and plaque formation (Barrett-Conner et al., 2004). Research also suggests that postprandial hyperlipidemia may contribute significantly to atherogenesis (Evans, Khan, & Rees, 1999). Antilipemics such as *statins* have been shown to aid in the prevention of CHD in people with diabetes, but are currently underprescribed to AAs (Jacobs et al., 2005).

Lloyd-Jones et al. (2009) reports that 75% of people with diabetes will die from either heart disease or a stroke. The burden of diabetes is evident in the economic

impact of the disease in the US. The total annual cost from diabetes in the US is \$174 billion (CDC, 2004). The total cost of CVD is estimated to be \$448.5 billion for 2008 (Lloyd-Jones et al., 2009). These amounts indicate a potential \$622.5 billion in 2009 will go toward fighting, treating, and surviving these two diseases.

Coronary heart disease is the leading cause of death for women in all racial and ethnic groups in the US. It has been estimated that 72% of all women with diabetes have a form of CHD which is in many cases fatal (Barrett-Conner et al., 2004; Huxley, Barzi, Woodward, 2006; Lee et al., 2000; Natajara et al., 2003, 2005; SoRelle, 2001).

In a meta-analysis of 37 cohort studies of women and CVD, which included a sample population of over 447,000 people with T2DM, the relative risk for fatal CHD in women with T2DM was found to be 3.50 (95% CI, 2.70-4.53) as compared to men with a risk of 2.06 (95% CI, 1.81-2.34; Huxley et al., 2006). This information translates to an almost 50% higher risk for fatal CHD in women than men (Huxley et al., 2006). In AA women, the risks of hyperlipidemia, hypertension, and higher BMI place them at greater risk than Caucasian women for fatal CHD (Freedman et al., 2005).

Because of T2DM, AA women's risk for CHD increases as their years since diagnosis of diabetes increases. For AA females, the death rate in 2004 from CHD was 148.7 for every 100,000 annually (Lloyd-Jones et al., 2009). The rate from

CHD in 2004 for Caucasian females was 114.7 per 100,000 (Lloyd-Jones et al., 2009).

A community-based study was completed by Natarajan et al. (2003) to examine mortality in diabetes and CHD. In this study, researchers examined 2,494 men and 2,749 women ages 35 to 74 years from the Framingham Heart Study and the Framingham Offspring Study for differences in mortality from CHD in the presence of diabetes or established CHD. The researchers used proportional hazards models to determine the independent effect of diabetes or established CHD on CHD mortality. Findings showed that the risk for CHD mortality was greater in women with diabetes than men with established CHD and men with diabetes. In men with diabetes, the hazards ratio was 2.1% for CHD death (95% CI, 1.3-3.3); in men with CHD only, the hazards ratio was 4.2 % (95% CI, 3.2 -5.6). In women, the corresponding hazards ratios were 3.8% (95% CI, 2.2-6.6) and 1.9 (95% CI, 1.1.- 3.4). Limitations of this study were that the majority of participants were White and information on multiple confounders of risk, such as inflammation and family history of CHD, was not available from the original data sets (Natarajan et al., 2003).

Obesity, another risk factor for CHD, presents a higher risk for fatal CHD events (Wilson et al., 2005). Obesity leads to insulin resistance and increased waist circumference, and has been linked to CVD risk as well as the development of T2DM (Li et al., 2006). The NHANES data shows 53% of AA women are obese by

current BMI calculations (BMI of 30 or higher) as compared to only 39% of Caucasian women.

Other factors that affect the risk of CHD include stress, lack of adherence to a diabetic regimen, hyperglycemia, genetic predisposition to CHD, lack of perception of risk for CHD, and barriers to self-care and healthcare. Some factors such as adherence to a diabetes regimen are alterable; others are not, such as genetics.

African American women identify stress as a factor in their everyday lives, which may interfere with improving health behaviors (Chang, Nitzke, Guilford, Adair, & Hazard, 2006). Stress in itself can be linked to CVD and the development of abdominal adiposity, a factor in the development of metabolic syndrome. Cortisol is released when a person experiences the stress response, which causes increases in abdominal adiposity over time as the stress continues to progress (Barrett-Conner et al., 2004). Thus, abdominal adiposity promotes insulin resistance and the evolution of diabetes and CVD.

Another risk factor in an AA woman's lifestyle is her ability to maintain her diabetes regimen and adhere to prescribed medications. Inability to maintain the necessary regimen can result from misunderstanding, economics, lack of education, or other factors yet to be determined. This lack of adherence to medications and treatments can result in a worsening of hyperglycemia, hypertension, and hyperlipidemia.

The next risk factor for CHD in AA women with T2DM is hyperglycemia during the course of their diabetes. This factor may present as a postprandial blood glucose of greater than 180, a fasting blood glucose greater than 126, or a hemoglobin A1C greater than 7. Prolonged elevated blood glucose damages the endothelium of vessels and elevates the levels of fibrinogen, increasing risk of clotting. Most risk factors such as hypertension and hyperlipidemia are enhanced because of hyperglycemia (Barrett-Conner et al., 2004).

Genetic predisposition (heredity) is a factor that puts a person with diabetes at further risk for CHD. If a person with diabetes has CHD in her family or has first-degree relatives with heart disease, the person is at greater risk for developing CHD. Having a parent younger than 50 years of age or siblings who have heart disease or who have suffered a MI also increases the person's risk for CHD.

Lack of perception of risk for heart disease is also a risk factor for development of CHD in AA women with T2DM. If individuals are unaware of their risk, they cannot take measures to prevent the disease.

Many AA women experience barriers to self-care and access to healthcare due to lower incomes and fewer educational opportunities than Caucasian women. The woman's financial ability to obtain the supplies she needs and the information she requires to understand her illness may impair her success in managing her diabetes and increase her risk for CHD. The ability to access care may be impaired further due to lack of insurance or transportation difficulty (Kamble & Boyd, 2008).

In Kamble and Boyd's comprehensive literature review, they found that in studies on percutaneous coronary interventions, the interventions were lacking in AA women participants. The researchers also found that living in a rural areas such as the Southern US resulted in worse post-MI outcomes because of the disparity in the provision of invasive services to persons having a cardiac event. These interventions are medical treatments to treat CHD and resulting MIs. The authors concluded that lower SES, lower education, higher stress, and higher depression resulted in poorer postcardiac event outcomes in AA women. It is evident from these studies that AA women with diabetes face multiple barriers that have the potential to affect their health and wellness.

Illness Representation Theory, Perceptions of Risk, and the Common Sense Model

Illness representation is the extension of a theory of explanatory models offered by medical anthropologist Arthur Kleinman (1980). Kleinman used illness stories to illicit how people interpret their experience of illness within their culture. Leventhal, Meyer, and Nerenz (1980) analyzed and altered explanatory models through the addition of crisis theory and stress-coping theory to the model. Leventhal then created the CSM to further explain the way behavior outcomes evolved from an IR (Leventhal et al., 1980).

Illness representation is a cognitive heuristic that is formed by the 5 domains of identity, consequences, timeline, control, and cause (Leventhal et al., 1997). An IR

is formed by an individual's beliefs. This representation influences how an individual creates a risk perception for the disease and, thus, engages in preventive health behaviors.

The five domains of IR in a condition such as diabetes are: (a) identity of the self and the disease; (b) time line of the illness; (c) consequences, including expected disability and experienced consequences; (d) cause, both stated and perceived; and (e) control, both stated and perceived.

The first component, identity, includes the multiple roles of the woman (e.g., mother, wife, daughter). It also includes her life's work or livelihood and the responsibilities this entails, as well as her role in the community as a church member, neighbor, and friend. The conflicting life roles and needs that a woman faces, especially if she is younger, may affect her ability to prioritize another disease process since she is already dealing with diabetes.

Leventhal, Brisette, and Leventhal (2003) believe that *identity* is the core domain and that the link of self to the disease comes through recognition and linking symptoms to the person. Any symptoms the woman has will affect her perceptions and her identity with diabetes and CHD (Scharloo & Kaptein, 1997). If a woman with T2DM does not have any signs of complications or symptoms she interprets as heart-related, she may not perceive a risk. A lack of symptoms is more dangerous for women with diabetes because they cannot attach a physical symptom to the disease to form an identity.

Women with diabetes may experience what is known as a *silent MI*, where the classic symptoms of chest pain, nausea, and vomiting are absent. The symptoms of heart disease can be equally as vague in women without diabetes (McSweeney et al., 2003). McSweeney et al. (2003) found symptoms of heart disease in women without diabetes included fatigue or difficulty sleeping. In women with diabetes, vague symptoms such as these may be misinterpreted as related to high blood glucose levels, exhaustion, or just getting older.

Another component of identity is family history. If a woman with T2DM has parents or siblings who have diabetes, the way those relatives manage their diabetes or heart disease affects her perceptions of the illnesses (Carroll, Naylor, Marsden, & Dornan, 2003).

The domain *timeline* includes the time since diagnosis and the expected time until the development of heart disease. A woman will weigh these factors and make a judgment about her risk. She may or may not be aware that the longer the time since her diagnosis of diabetes, the greater the risk of heart disease (Hillier & Pedula, 2003).

Hillier and Pedula (2003) studied 7,844 adults ages 18-44 years in a health maintenance organization with newly diagnosed T2DM between 1996 and 1998. In this longitudinal study, the researchers followed the participants for 3.9 years after their diagnosis. They examined patient data within 3 months of diagnosis for microvascular and macrovascular complications. They also examined the age of

the person at diagnosis and compared age and gender to the presence of complications and risk for CVD and MI. They found that with early onset of T2DM, women between the ages of 18-44 years had a 14-fold risk for having a MI as compared to men and women with T2DM who are diagnosed when older than 44 years of age. Results from this study directly impact the domain of *timeline* in that women diagnosed before age 44 years have a much greater risk for CHD and should be a target population for interventions.

In the third domain of the framework, *consequences*, the woman looks at consequences of the disease. Even though the chance of a fatal outcome from heart disease is greater than the chance of complications from diabetes itself in women with T2DM, women may not recognize the threat (Jones et al., 2002; Selvin et al., 2005). The woman may be unaware of the threat due to lack of accurate information so she may not have insight into consequences. Her processing of the risk information may cause her to fear the risk of the consequences of diabetes such as amputation and blindness more than the risk of heart disease (McDermott, 2008; Rothman, Kelly, Hertel, & Salovey, 2003).

The fourth domain is *stated and perceived causes of the disease*. Women may consider heredity as a primary cause of CHD and this may influence their perception of risk. They may feel there is nothing they can do about heredity, so they may not make any behavior changes related to reducing that risk. An example of a perceived cause is when women have certain beliefs about the disease that

may not be warranted, as in a patient who believes the pain in her feet is not due to high blood glucose but rather because she wore black shoes on a hot day. External causes may include lack of material resources to manage diabetes or lack of opportunity to learn more about diabetes. Motivation to perform self-care activities is an internal cause.

The fifth domain, *control*, encompasses *stated and perceived control* by the woman. *Stated control* is what the woman says she can control. *Perceived control* may be different, if she really believes there are only certain situations she can control. For example, a woman may ask questions such as: “Can I really do anything to change my diet?” or “Can I afford the medicines I need to prevent high blood sugar?” Control beliefs may change as people attempt strategies to control blood glucose and the strategy does or does not work for them.

Personal characteristics such as educational level affect perceptions through the person’s understanding of both diabetes and CHD. It is through knowledge, understanding or coherence that the ability to make changes occurs. Knowledge may be affected by selective screening of health information as it is presented to people and by biases of the HCP offering the information (Kamble & Boyd, 2008; Rothman et al., 2003).

Perception of risk involves the assessment and determination by the person of the threat posed by a situation (Weinstein & Nicholich, 1993). Personal risk is related to preventive behaviors; if a person’s personal risk is perceived as low, the

likelihood of the individual engaging in preventive behaviors for a certain illness or disease will be low (Weinstein & Nicholich, 1993). Factors that influence the adoption of preventive behaviors and practices include the influences of friends and family as well as new information about the risk. Barriers mentioned earlier such as education or income may affect the way a person is able to perceive a risk and, as a result, may influence behaviors (Weinstein & Nicholich, 1993). The person may compare her actual risk to her perceived personal risk and make a comparative risk judgment (Weinstein & Nicholich, 1993). Actual risk is the objective risk that a person possesses based on predetermined risk factors. A comparative risk judgment weighs the actual risk against the preventive behaviors and treatments the individual is performing to avoid risk (Weinstein & Nicholich, 1993).

Because perceptions of risk may have many influences, it is important to determine the underlying reasoning behind a person's perception of risk. Learning more about individuals' rationales may help determine why or how a person may respond to a perceived risk with behavior changes that can prevent illness and disability (Brewer, Weinstein, Cuite, & Herrington, 2004).

Leventhal et al. (2003) offer two propositions: that people act as "common sense scientists" when developing their IRs, and that IRs produce goals for self-management and shape how they will achieve those goals.

The CSM combines, through a parallel process model, the processing of stimuli, the representation of danger from the stimuli, the representation of fear of the stimuli, coping with the threat, and appraisal of the stimuli. Leventhal et al. (2003) state, “the critical source for the motivational effects of IRs and indeed the fear itself, was the individual’s concrete, perceptual experience and how that experience was interpreted” (p. 46).

Illness representation comes from the interpretation of symptoms and affects the health response behaviors of the person (Leventhal et al., 1997). A meta-analysis of studies on IR and the Common Sense Model reviewed a variety of disease processes such as irritable bowel syndrome, T1DM, T2DM, psoriasis, injuries, human immunodeficiency virus, asthma, epilepsy, surgical interventions, chronic fatigue syndrome, MI, breast cancer, chronic obstructive pulmonary disease, and hypertension (Hagger & Orbell, 2003). In 27 of the 45 studies (60%), each domain of IR was examined to varying degrees. These same studies were the only studies that used the Illness Perception Questionnaire (IPQ) or IPQ-Revised (IPQ-R) for evaluation exclusively.

Findings from several of the studies were related to beliefs about diabetes, self-care, or perception of CHD (Lawson, Bundy, Lyne, & Harvey, 2004; Petrie, Weinman, Sharpe, & Buckley, 1996). In a cross-sectional study on T1DM, researchers studied 84 participants (26.2% female), ages 26-48 years old, for diabetes care-seeking behaviors using the IPQ. Participants were found to hold

more negative views of the course, consequences, and control of the disease if they had less knowledge about diabetes (Lawson et al., 2004). Researchers discussed that more complete information about the behaviors would have been obtained if information about participants' beliefs had been measured in addition to illness representation (Lawson et al., 2004). Limitations of this study were that there were fewer women than men in the sample, so it is difficult to generalize the findings to women.

In a prospective study of 143 MI participants, primarily male ($n = 124$), ages 44-61 years old, researchers found that the stronger the patient's belief about control and potential for cure, the more likely the person was to participate in rehabilitation following MI. The results showed that the shorter the believed time of recovery, and the less the belief about the MI's severity, the more participants returned to work within a 6-week time frame post-MI (Petrie et al., 1996). This study exemplifies the need for individuals to have control over the severity of heart disease and diabetes. A limitation of these results is that there were few women in this study. Women's beliefs about rehabilitation following MI may be very different.

In a review of the literature, regarding women, the CSM, and cardiac rehabilitation, Shifren (2003) found that women are different from men in their beliefs about exercise following an MI. The author discusses how women do not participate in cardiac rehabilitation programs and presents reasons why the CSM and a modification of a personal narrative technique should be used to encourage

women to participate in cardiac rehabilitation programs. The author discusses that women must be allowed to express emotional connections and misrepresentations about their heart disease that may influence their behaviors (Shifren, 2003). Although it is not clear how many AA women were in the studies, the studies were focused on women, which is a strength.

Other studies on IR in CVD and diabetes show differing results. A qualitative study by Walter and Emery (2005) supports that the way a person experiences a disease in his or her family affects the perception of vulnerability to the disease. The researchers interviewed 30 persons with a family history of cancer, diabetes, or heart disease, using semistructured interviews, for their beliefs about how their family history affected their risk for the illness. There were 14 male and 16 female participants, with ages ranging from 22 to 60 years old. Their experiences with their families helped to form their perceptions and influenced whether they believed they had control over the outcomes of the illness (Walter & Emery, 2005). The researchers found that those participants with a family history of cancer felt most vulnerable, and those with heart disease felt less vulnerable than the cancer-linked participants. Those with diabetes in their family history felt the least vulnerable. A major limitation of these results is that AAs were not included in this study.

In another qualitative study with a sample of 221 older AA and Caucasian people with chronic illness conducted by Silverman, Musa, Kirsch, and Siminoff (1999), there was a difference between AA and Caucasian men and women and

their management of heart disease and arthritis. The mean age of the sample was 73.7 years old, with almost 64% of the participants being female. African Americans did not practice as strict self-management of their heart disease and diabetes as they did their arthritis (Silverman et al., 1999). The researchers suggested that the support for diabetes and heart disease might not be present for the AAs in the study. The pain from arthritis, a symptom of the disease, may have influenced their self-care practices. Heart disease and diabetes may be asymptomatic and, therefore, in those cases, self-management was not as strict. This assumption is based on theories of symptom recognition as an IR, by Baumann and Leventhal (1985).

This study's results are limited to self-care but offer information about beliefs related to self-care that influence older adults beliefs about their illness.

In a large cross-sectional study of 3,130 Finnish-speaking people, men and women, ages 45-74 years old, on illness perceptions for CHD in Finland, researchers found that once women were diagnosed with CHD there were changes in the typical belief that only men had heart disease. Diagnosis of CHD tended to make women more cognizant of the possible causes. Differences between the genders were that men thought CHD attributable to internal and behavioral factors, while more women attributed their disease to stress (Aalto et al., 2005). Women also reported more symptoms but less severity related to CHD.

The results support the belief that illness perception is more than just knowledge and is influenced by social and psychosocial factors (Aalto et al., 2005).

Culture is one of the social and familial factors that affects IR and may be reflected as beliefs regarding certain aspects of the illness. For example, an AA woman may believe heart disease risk in diabetes occurs only if she has hypertension and that only certain symptoms accompany hypertension. She may believe that she can have hypertension only if she feels tired or has a headache, and she may not realize that both symptoms may be linked to hypertension and hyperglycemia. If the woman has no symptoms, then she may not believe that she has hypertension or hyperglycemia.

Researchers have found a general lack of awareness of the risk of heart disease in women. In 1997, 30% of 1,000 women surveyed by telephone about the leading cause of death for women responded that it was heart disease (Legato, Padus, & Slaughter, 1998). In a 2000 study, Mosca et al. found in 1,004 women surveyed by telephone, only 8% felt heart disease was the greatest threat. In 2003, in a survey of 1,024 women, the increase in awareness of heart disease as the leading cause of death in women rose to 46%. Women younger than 45 years of age did not cite heart disease as a risk as frequently as older women (Mosca, Ferris, Fabunmi, & Robertson, 2004). All data was gathered from telephone surveys conducted randomly using general telephone directories. Of the 1,024 women in the 2003 study, only 11% had diabetes (Mosca et al., 2004). In 1997 and 2000, there was

no data gathered on the number of participants with diabetes. These results indicate that women are becoming more aware of CHD, but do not have the necessary degree of awareness for an adequate risk perception for CHD.

The AHA and the ADA in 2005 sought to increase knowledge of heart disease by launching initiatives to link heart disease in women and diabetes. The Make the Link campaign offered women information and guidance on protecting their heart when they were diagnosed with diabetes (ADA, 2006a). These programs started when researchers repeatedly found that women with diabetes were not aware of how much greater their risk was than women without diabetes (Carroll et al., 2003; Desalvo et al., 2005; Legato et al., 1998; Mosca et al., 2000, 2004).

In a qualitative study, Carroll et al. (2003) examined how people with T2DM perceive cardiovascular risk and how their perceptions may affect motivation to make lifestyle changes. The researchers studied 20 patients with T2DM, both men and women, ages 52-77 years, AA and Caucasian, using semi-structured interviews and template analysis of content.

The sample included 10 participants with CHD and 10 without CHD; all were unaware of the strong link between diabetes and heart disease. During the interviews, people described themselves as not being at risk for different reasons. Most used “personal and family narratives to conceptualize the disease and its outcomes” (Carroll et al., 2003). For example, one participant suggested that it is “just my body make-up” while another suggested, “it’s in your genes, I think,

personally.” Thus, their knowledge and beliefs were based on how they saw diabetes and heart disease not on evidence obtained from a HCP. An example of findings from this study is a statement by a female participant that she believed since she had a healthy lifestyle that she was less at risk for heart disease than others in her family. The researchers also found that the family milieu influenced the participants’ behavior. Their conclusion was that HCPs should not assume that patients have the same beliefs about risk as they do and should explore the patients’ individual health beliefs (Carroll et al., 2003).

A limitation of the study by Carroll et al. (2003) was that the principal investigator (PI) was a HCP. Having some preconceptions about illness may bias the findings to some degree, though the PI did have nonmedical researchers co-code the data to offset that limitation. The researchers concluded that, overall, the participants in the study were not aware of the link between diabetes and CVD. Their perceptions of diabetes and heart disease were very different from that of conventional medicine (Carroll et al., 2003).

In a cross-sectional study where 31% of the 128 female urban AA respondents ($n = 40$) in the sample had diabetes, participants underestimated their risk for CHD when compared to their actual number of risk factors (DeSalvo et al., 2005). This population was at very high risk, with 77% of the participants being obese, 72% with hypertension, 48% with elevated cholesterol, and 49% with a family history of heart disease. Sixty-three percent of those at high risk did not perceive their risk for

CHD. This means that regardless of whether they are rural- or urban-based, AA women may not have an accurate risk perception for CHD when they have T2DM. The researchers also found that stress played a role in the recognition of heart disease. Desalvo et al. (2005) propose that the stressors of inner city poverty might be too great for women to overcome and may contribute to the development of heart disease. Limitations of this study were that they studied Southern urban females who were seeking care versus a community cohort. The researchers also state that access to care related to insurance status was a potential confounder of the results. Use of stress-reduction interventions might serve to reduce cardiac risk to some degree in this population and should be studied in the future.

How people deal with stress and how they cope with illness and the risk of illness can depend upon their outlook on life. Factors that mediate risk perceptions for CHD are unclear. In one of Leventhal's studies (Kelly et al., 2004), the authors looked at optimism or pessimism as a possible influence in the way a person perceives risk. In this longitudinal study of 86 Jewish women with a family or personal history of breast cancer gene mutation that placed them at risk for breast cancer, the women did not evaluate their risk as high, even when it was. One explanation for the inaccurate risk perception, even after receiving genetic counseling, is that the women may not trust the results they received. In a related monograph Leventhal et al. (1999) suggest the possibility that unrealistic optimism

or pessimism may cause women to underestimate or overestimate the actual risk they have for an illness.

Optimism in an extreme form is called optimistic bias and is defined as the belief that a person will not develop a disease, for various reasons, when compared to others of the same age, race, and circumstances (Weinstein, 1989). Weinstein states that the effects of optimistic bias on risk perception are that the people cannot appraise their risk accurately.

Optimistic bias was suggested as well in a study of men and women with diabetes and their risk perceptions for CVD (Carroll et al., 2003). Carroll et al. (2003) suggest that optimism should be explored in relation to risk perception formation since it may influence the development of a sense of risk.

Dispositional optimism, which is the general expectation that positive events will occur in the future, is helpful when trying to determine a person's outlook and has been shown to affect outcomes for CHD positively. However, if there is an extreme sense of optimism, such that the person cannot appreciate the actual risk they possess for a disease, they may not change behaviors because of that optimism (Chang, 2001).

Assessing the levels of optimism and pessimism gives valuable information about the person and her approaches to health risk and behavioral change to prevent illness. The way a person addresses life, either with an optimistic or

pessimistic approach, affects choices, beliefs about control, and eventual health outcomes (Scheier, Carver, & Bridges, 1994; Scheier et al., 1999).

Conclusions

Review of the literature presents several important facts about AA women, diabetes, and the risk of CHD. The first is that AA women are at great risk for T2DM and the resulting complication of CHD. Second, AA women may be unaware of the severity of their risk for CHD when they have T2DM. Third, AA women have IRs that influence their lifestyle choices. Fourth, AA women with T2DM may have certain characteristics that influence their development of risk perception beyond knowledge. Some of those characteristics are lack of easy access to information, cultural beliefs about the disease, personal experiences that influence their beliefs, lack of resources to manage diabetes and poor experiences with the health care system. Finally, the literature indicates that AA women would benefit from further education about the risks of diabetes and CHD.

This research will contribute to the understanding of AA women's perceptions of risk for CHD when they have diabetes. It is through such research that HCPs can learn how to provide the most effective and culturally appropriate care to AA women with T2DM at risk for CHD.

CHAPTER III

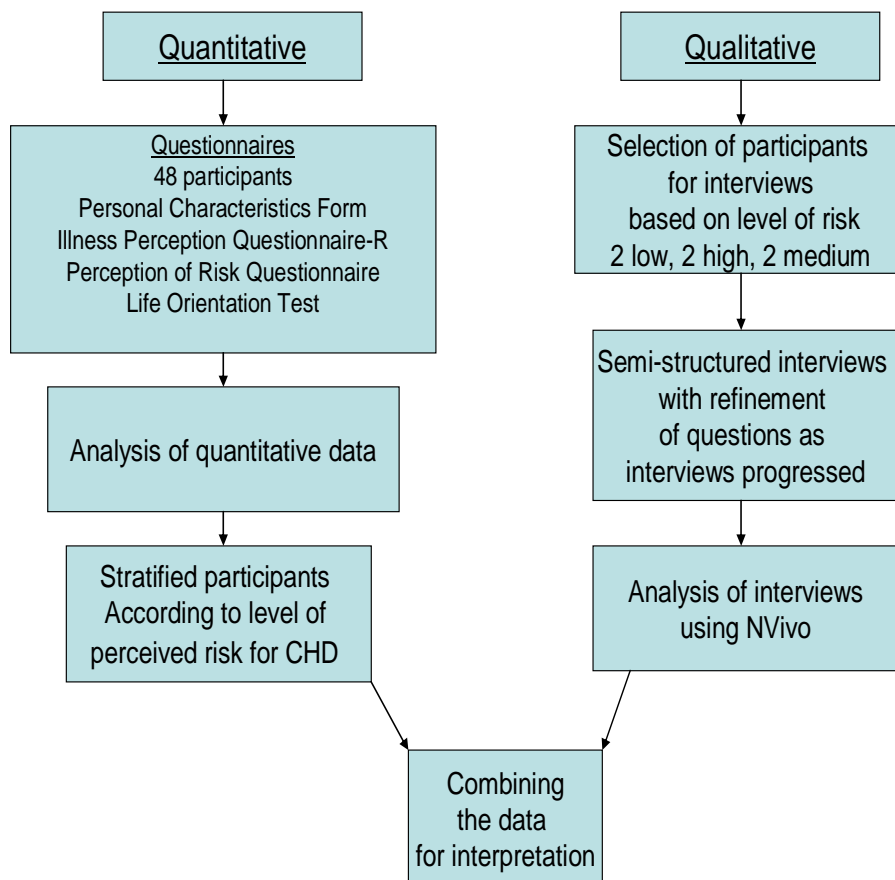
RESEARCH DESIGN AND METHODS

Study Design

In the *Exploring Perceptions of Risk for CHD in AA Women with T2DM* study, a sequential, explanatory, mixed methods design was used to examine perceptions of cardiac risk in a group of 48 AA women with T2DM. The level of perception of risk for CHD was measured and then the underlying beliefs affecting those perceptions were explored with follow-up, semistructured interviews in a subset of the sample. The cases were categorized based on the level of risk perception for CHD (none, low, medium, high, or very high). Mixed methods was the preferred design because the data was not extensive or rich enough using simply the quantitative tools. Semistructured, in-depth interviews allow the researcher to explore the foundation of a person's belief pattern in more detail, and thus were employed in the second phase of the study (Tashakkori & Teddlie, 2003). The quantitative and qualitative methods were separate until the analysis phase, where the data was integrated. Initial quantitative data analysis helped assure variations of perceptions of CHD and diabetes in participants were being addressed (Figure 1).

Figure 1

Sequential, explanatory study design, and analysis approach



Setting

The initial settings for the study were general practice physician's offices and churches, with follow-up with participants in their homes in the counties of Alamance, Guilford, and Randolph in North Carolina (both Alamance and Randolph Counties have less than 50,000 population in the largest city; U.S. Census Bureau, 2006). Guilford County is an urban county due to a higher population in its largest city. Participants from either metropolitan or rural environments in any of the three counties were asked to participate, regardless of their residential situation. There are 83,630 AA females documented in the counties of Alamance, Guilford, and Randolph in North Carolina who comprised the potential participants for the study (U.S. Census Bureau, 2006). In 2004, statewide statistics showed the leading cause of death for African American females was heart disease, with diabetes as the fourth leading cause of death, which means both disease processes are prevalent in both counties (NCHS, 2005). Demographic information for all the counties in the study is in Table 1.

Recruitment

The PI contacted general family practice offices for recruitment of participants because most women use these offices for their primary care. The PI used selected physician practices that have populations comparable to the county statistics for percentage of African Americans utilizing the practice. The PI chose physician offices that have well-established, well-known, and respected African

American physicians, or offices in largely African American-populated towns or cities. These practices typically will have more African American females who may be more willing to participate if their physician approves the study.

Recruitment for the study was initially through direct mailings and flyers in the physicians' offices. The physicians and nurse practitioners in the family practice offices assisted with recruitment into the study after instruction on the requirements for inclusion. When the number of participants slowed over time, personal referral was used by contacting current participants for names of friends and family who might be eligible for the study. The PI asked all participants for permission to contact them for a second interview and all participants agreed.

Recruitment letters were sent to potential participants with a description of the study and the eligibility requirements listed. A toll-free phone number was issued to potential participants for contacting the PI. The PI explained the study further by phone call and the PI enrolled participants at the scheduled visit at the participant's place of choice. This process allowed for more timely completion of the study.

During the recruitment phone call, the PI introduced herself and stated:

I am Carolyn McKenzie from the University of North Carolina at Chapel Hill School of Nursing. I am doing a study on African American women with type 2 diabetes. In order to be in the study you should be between 30 and 65 years old, have had diabetes for more than one year, and not have had a heart attack or have heart disease. I will come to your home or anywhere you want to meet. We will talk about what you believe about your diabetes and I will pay you \$10.00 for talking with me. I will also give you a gift bag with some items you can use to help manage your diabetes. Would you be interested in doing this?

The woman then decided to be in the study or asked further questions about the study. The participant and PI made an appointment and agreed on a location and time. The PI gave the participant the toll-free phone number in case she had to change the appointment for any reason.

There were seven initial phone calls made from the first physician's office. Five of those participants qualified and were enrolled into the study. Fourteen letters were sent from the second physician's office and five participants enrolled. Four additional participants responded to the flyers in the second physician's office.

As time progressed, the initial sources for recruitment were exhausted or slowing greatly. Recruitment for the study expanded to Chatham, Caswell, Wake, Orange, Durham, Vance, and Person Counties with IRB approval after approximately 6 months.

When the study expanded to more counties, the PI sent 33 recruitment letters to women who had requested participation in a diabetes research study through UNC. Eight participants came from that list. The PI recruited five participants at a housing unit in Guilford County through the nurse practitioner's clinic at the site. Several participants were recruited by person-to-person contact ($n = 15$). Many were family or friends of women contacted through one of the initial sources.

The PI also contacted African American churches in Randolph, Alamance, and Guilford counties ($n=4$) for recruitment presentations because many African American women seek out health information from their church family or rely on

religious beliefs to deal with their diagnoses (Abrums, 2004; Jones et al., 2002; Wenzel, Utz, Steeves, Hinton, & Jones, 2006). Six participants came from the churches.

Table 1

Demographic information on counties

County	% AAs	% Below Poverty Level	Diabetes Prevalence (BRFSS)	% Female	Total Population (Total AA Females)
Alamance	18.4%	11.8%	9.1%	52.2%	140,533 (13,266)
Guilford	29.9%	14.7%	8.8%	51.5%	443,519 (66,549)
Randolph	5%	11.5%	6.3%	49.3%	138,367 (3,815)
Person	28.2%	11.8%	10.2%	51.8%	35,623 (6,049)
Chatham	13.7%	11.3%	10.5%	50.8%	61,455

					(2,203)
Caswell	34%	15.8%	11.3%	49.7%	23,261 (4,141)
Wake	20.6%	8.5%	6.4%	50.4%	832,970 (61,912)
Orange	12.4%	7.7%	9.1%	50.8%	122,117 (8,426)
Durham	37.6%	15.9%	4.8%	51.2%	256,500 (45,233)
Vance	54.5%	22.4%	12.1%	52.9%	42,992 (1,789)

Notes. BRFSS = Behavioral Risk Factor Surveillance System

Sample

Participants were 48 women of self-reported AA ethnicity with a diagnosis of T2DM for more than 1 year, and without currently diagnosed heart disease. African American women were selected for the study because they are at higher risk for the development of CVD due to a higher prevalence of T2DM compared to women of other ethnicities (ADA, 2008).

Because AA women with T2DM are at such great risk for CHD, it was appropriate to use a convenience sample and enroll those participants who met the criteria and were willing to complete the study with the semistructured interviews. Participants in the semistructured interviews were selected using a stratified purposeful sampling technique that assured there were 1-2 cases in each of the levels of risk perception (none, low, medium, high, and very high) as determined by the quantitative data (Sandelowski, 2000).

Inclusion Criteria

Participants in the study were women with T2DM for more than 1 year since diagnosis and who were between 30-65 years of age. The study included 30-65 year old females to include women who will have ample time to make life changes once they perceive the risk facing them and will be able to prevent major problems from heart disease. Women with hypertension, peripheral vascular disease, and benign arrhythmias such as atrial fibrillation were included in the study because these conditions are not exclusive to CHD but are included in CVD.

Exclusion Criteria

Exclusions included women with a diagnosis of T2DM for less than 1 year or those diagnosed with MI, congestive heart failure, or angina if known prior to the interview. It takes approximately 1 year to adjust to a chronic diagnosis such as diabetes, and this exclusion avoided the confounder of a new diagnosis. Other exclusions included those who had diagnosed heart disease (such as MI, congestive heart failure, or angina) because people with these diagnoses should know their risk and the idea of risk changes when you have a positive diagnosis. The exclusions were not always successful because the women did not make the connection that heart failure was a form of heart disease.

Sample Size Calculations

The basis of the statistical power requirements for the study used results from a meta-analysis of studies using the CSM of IR to study various disease beliefs (Hagger & Orbell, 2003). The median effect size found in the meta-analysis was .20 ($R^2 = .20$) (Hagger & Orbell, 2003).

Power analysis was conducted using multiple regression with 1 set of predictors including 3 variables selected from the measures of IR, optimism, and personal characteristics. The power analysis estimated that the model would require a sample size of 48 participants to restrict the possibility of committing a Type 1 error to 5% ($\alpha = 0.05$; power = 0.80) if R^2 was set at .20 for the model (Borenstein et al., 2000).

Procedures

Procedures for Conducting the Study

The PI recruited participants from general practice physician offices and church groups in Alamance, Guilford, and Randolph Counties in North Carolina. The PI's experience includes nursing practice of diabetes and CVD management in both acute and home care settings, and teaching area health education centers classes on diabetes management for nurses. The PI did not have prior knowledge of any of the participants' health information before obtaining consent from participants.

Recruitment

The PI recruited physicians through individual meetings educating the doctors about the study and the potential benefits to participants. The PI presented the study to staff and identified key contact personnel in each office. The PI asked physicians who agreed to allow their practices to become study sites to give to patients, or mail out, an IRB-approved, preprinted, postage-paid letter. In this letter was a description of the study and requirements for participation to all female AA patients whom the physicians and nurse practitioners identified as potential participants for the study based on the inclusion criteria. Flyers were posted in each physician's office, in examining rooms, about the study. Contact information for the PI was provided in the letters and flyers so potential participants could contact the PI through a toll-free number to volunteer for the study or to obtain more information.

Initial Home Visit

Once the participant indicated a willingness to be in the study, through phone call or message to the PI, the PI returned the call to determine if the potential participant met the inclusion criteria. If the participant qualified for the study, the participant received an explanation of the study and an appointment for the PI to make a home visit to obtain written informed consent and administer the questionnaires. At this home visit, the PI explained the study to the woman again. The PI reviewed consent forms verbally, answered participants' questions, and discussed time requirements for study participation. After obtaining written consent, the PI asked the participant to complete the IPQ-R, the Perception of Risk Questionnaire (PORQ), the Life Orientation Test-Revised (LOT-R), and the personal characteristics form. The PI assisted the participants by reading the questions aloud for all but one participant who wished to read the questionnaires independently. This interaction took 30-45 minutes. Any additional questions from the woman were discussed after the questionnaires, being careful not to discuss heart disease risk in-depth at that point. The PI then gave the woman a \$10 cash incentive and gift bag with a journal, pen, lotion, and other small self-care items. Consent was obtained for follow-up interviews from all participants.

Data Collection

Predictor Variables

The predictor variables for the study were IR of diabetes, including measurement of the IR components of identity, timeline, consequences, control and cause; optimism-pessimism; and personal characteristics of age, educational level, income, and duration of diabetes. The definitions of the variables are as follows.

Illness Representation

The definition of IR, also known as illness perception, includes how a person views her diagnosed illness. For example, this study addresses AA women's perceptions of diabetes. Illness representation includes affective and cognitive representations of the illness and social influences, as well as personal background and experiences (Cameron & Leventhal, 2003). The components of IR include identity, timeline, consequences, control, and cause. Identity is defined as the disease symptoms and labels and how the person connects those elements to self. *Timeline* is the perception of the time it requires for a disease to develop and includes the duration of the illness. *Consequences* are what the person believes may occur because of the illness as well as what actually occurs in a *classic case* of the disease. Identified *causes* include what the person and science designate as elements that initiated the illness. The final component is *control*, which is the perception of the ability to change the course of the disease or its symptoms. In IR,

control is how the person believes she can affect the disease through her own actions or behaviors (Lau & Hartman, 1983).

Optimism and Pessimism

Optimism is a positive outlook that a person holds about an event or situation. Optimism is an expectation that good things will happen in one's life (Chang, 2001). Pessimism is a negative outlook that a person holds about an event or situation. Pessimism is an expectation that bad things will happen in one's life (Chang, 2001).

Optimism has been associated with better health outcomes in patients with heart disease in instances such as following coronary bypass surgery (Scheier et al., 1999). The way a person addresses her life, either with an optimistic or with a pessimistic approach, can affect her choices, beliefs about control, and eventual health outcomes (Chang, 2001; Kubzansky et al., 2001; Scheier et al., 1994; Scheier et al., 1999).

Personal Characteristics

Personal characteristics include age, the years of formal education the person has completed, and income, which is the total income for the household reported in the U.S. Census Bureau income levels. Duration of diabetes is the number of years since a HCP told the participant she had diabetes.

Outcome Variable

The outcome variable is perception of risk for CHD, which includes levels of none, low, medium, high, and very high. A risk perception involves how the person views the threat of an event (in this situation, CHD), and how it occurs and develops. The person at risk may minimize, through use of cognitive processes, the perception of risk of a disease in order to understand the risk (Cameron & Leventhal, 2003). Coping with the threat of the illness may cause an individual to minimize or lessen her perception of risk as she assesses her own vulnerability to the illness (Weinstein, 1989).

Instruments

The instruments used in the first phase of the study are the IPQ-R, the Life Orientation Test (LOT), the PORQ, and the Personal Characteristics Form. The instruments are presented separately as follows.

Illness Perception Questionnaire-Revised

The IPQ-R is an established tool used to measure IR of T2DM (Moss-Morris et al., 2002). The IPQ-R (Moss-Morris et al., 2002) is used to measure five components (also called *domains*): identity, timeline, consequences, control, and cause. The IPQ-R is a revised version of the original IPQ (Weinman et al., 1996) and was used in this study because it is shorter for the participants to complete, and includes items which measure emotion, an essential element of the CSM (Cameron & Leventhal, 2003).

The modified IPQ-R contains 67 items with 53 rated by five responses (0 = strongly disagree, 1 = disagree, 2 = neither agree nor disagree, 3 = agree, 4 = strongly agree). The final question of the questionnaire asks the participant to rank-order what she believes to be the three most important causes of her illness. The questionnaire generates summed scores for all subscales, except for the prioritized list of causes the participant writes in at the end. This written list of causes determines common causes and identifies participants who do and do not believe that specific causes exist for their diabetes.

The first 14 items on the IPQ-R are symptoms of the illness, used to measure *identity*. The items are scored as 1 = *yes* and 0 = *no*. Items not associated typically with diabetes include sore throat and stiff joints. All other listed symptoms may relate to either T2DM or CHD. The IPQ-R includes emotional representation, which the original IPQ did not. This change supports Leventhal's self-regulation model, which includes coping and parallel cognitive approaches such as problem solving, as part of IR, which leads to making a judgment of risk.

Specific groups of items measure the remaining components of the model. Scoring of items is on a 5-point scale (0 = strongly disagree, 1 = disagree, 2 = neither agree nor disagree, 3 = agree, 4 = strongly agree). Reverse items include items IP1, IP5, IP12, IP14, IP16, IP19, IP20, IP21, IP22, IP30, IP31, IP34, and IP35.

Items IP1-IP2 and item IP15 measure *timeline*. *Timeline* refers to how long the person believes their diabetes will last. An example of a *timeline* item is “I expect to have diabetes the rest of my life.” Items IP3-IP8 measure *consequences*. *Consequences* refers to the effect the person believes diabetes has on their life. An example of a *consequences* item is “My diabetes has serious financial consequences”. Items IP9-IP14 measure the area of *personal control*. *Personal control* refers to how much the person believes they can control diabetes. An example of a *personal control* item is “There is a lot I can do to control my symptoms.” *Treatment control* items are IP16-IP19. *Treatment control* refers to how well the woman feels treatment work to improve her diabetes. *Illness coherence* items are IP20-IP25. *Illness coherence* refers to what the woman feels about her understanding of diabetes. An example of an *illness coherence* item is “My diabetes is mystery to me.” Two other factors are measured. *Timeline cyclical* items are IP26-IP29 (summed). *Emotional representations* are summed items IP30-IP35 (e.g., coping). *Timeline cyclical* refers to the fluctuating nature of the illness, and *emotional representation* refers to the negative feelings a woman has regarding her diabetes. An example of a *timeline cyclical* item is “My symptoms come and go in cycles” and an example of an *emotional representation* item is “My diabetes does not worry me.”

Possible causes are items C1-C18 which are a list of identified causes. The participant identifies the final three causes in rank-order format to indicate her

personal causes. The final three causes were those of the participant's choosing. The participant did not have to choose from the preceding list of causes, but could put the cause into her own words. The IPQ-R is in Appendix B.

Summed subscales combine to predict a positive or negative IR. For example, high scores on identity and timeline indicate the woman believes the illness to be very severe and shows a negative IR. If combined subscale scores are high on personal control, treatment control, and coherence items, then the woman feels she can control her illness and understands the illness, and therefore she has a positive IR. In each subscale, the higher the score, the stronger the link with that component. The score of each subscale is independent. The psychometrics of the IPQ-R includes an alpha on all subscales, which ranged from 0.79 to 0.89 (Moss-Morris et al., 2002).

Perception of Risk Questionnaire

The PORQ is used to measure perception of CHD risk using a tool modeled after previously used tools measuring risk perception. The PORQ is adapted from studies on heart disease awareness and diabetes risk (ADA, 2006b; Broadbent et al., 2006; Mosca et al., 2004; Walker, Mertz, Kaltzen, & Flynn, 2003). An experienced researcher verified content validity of the questionnaire. This tool was pilot-tested with a sample of 10 women meeting the study criteria prior to use in this study to refine items and obtain feedback on clarity and issues with completing the questionnaire. The PI examined the PORQ and reviewed items for inclusion or

deletion. There are six items on the tool. Items one, three, and four specifically address the woman's perception of risk for heart disease, and the risk compared to others like her. Items two, five, and six, all measure comparative risk for another disease women see themselves at risk for, such as cancer, and a random event such as an automobile accident. Scores were on a 5-point scale (0 = none, 1 = low, 2 = medium, 3 = high, 4 = very high). Scores were grouped into three categories (low, medium, and high) for interpretation of the items. The *low* group included those responding *none* and *low* to risk questions. The *medium* group responded their risk was *medium* on the item, and the *high* group included the *high* and *very high*-risk responders. The PORQ is shown in Appendix C.

Life Orientation Test-Revised

The LOT-R (Scheier et al., 1994) is used to measure general life optimism or pessimism by measuring overall differences in positive versus negative outlooks on life. The tool consists of 10 items with five response options varying from *I agree a lot* to *I disagree a lot*. Three positive items are reverse-scored. There are four items filling in the tool that do not indicate positive or negative outlook. The analysis does not include these four items. A high overall score on the respective optimistic items indicates optimism and a high score on the pessimistic items indicates pessimism. Lack of distinction for optimism or pessimism will indicate ambivalence about life orientation. Scheier et al. (1994) compared the LOT-R items with the original LOT and other similar scales to establish convergent and

discriminant validity. Reliability was .78 for all six items on the test. Test-retest reliability over 4 months, 12 months, 24 months, and 28 months was .68, .60, .56, and .79, respectively.

In recent studies, the LOT was used with AA women in studies about breast cancer and psychosocial status (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Friedman et al., 2006). The study by Friedman et al. showed a Cronbach's alpha of .81 on a population of 45 AA women. Deimling et al. conducted a study with a population of 60% women and 38% AA, with an alpha of .78 reported. The PI did not locate any studies focused on optimism in AA women with T2DM. The LOT is found in Appendix D.

Personal Characteristics Questionnaire

The Personal Characteristics Questionnaire (Skelly, Carlson, Leeman, Holditch-Davis, & Soward, 2005) measures personal characteristics significant to the perception of risk. Personal characteristics include age, race, educational level, income, duration of diabetes, diabetes self-care (home glucose monitoring, medications, insulin use, diet, physical activity, and foot care), comorbidities, how participants learned about their diabetes (from a friend, physician, nurse, family member, or other), and how participants make decisions on care (by discussing with friend, family, physician, nurse or other; Appendix E).

Educational level was measured using last grade completed in school. Income measurements use the U.S. Census Bureau income brackets (U.S. Census

Bureau, 2006). The Personal Characteristics Questionnaire also questioned the woman about her past medical illnesses and family history.

Methods of Analysis

The PI collected all data and reviewed data collection instruments immediately after collection for completeness and accuracy of coding. The PI double-entered the data on a weekly basis into a data entry program and performed range checks to ensure timely completion, prevent data entry fatigue, and reduce errors.

Frequencies, means, standard deviations, and ranges described personal characteristics of age, educational level, income, and duration of diabetes in the sample. The alpha level will be .05 and the sample size will be 48.

Analysis of Question 1

In analysis of the first research question, the level of perception of absolute risk and comparative risk was examined as measured by the PORQ subscale scores. The PI correlated the levels of risk with the IPQ-R components using Pearson product-moment correlations. The absolute and comparative risks, as dependent variables, were then regressed on the IPQ-R components of identity, timeline, consequence, control, and cause as the independent variables, to determine the contribution of each component in forming the risk perception.

Analysis of Question 2

Analysis of research question 2 included plotting the domains of diabetes perception (identity, timeline, consequence, control, and cause) against each other and then correlating them using Pearson product-moment correlations .

The PI performed factor analysis on the five domains of IR to determine if they were distinct or if fewer domains adequately described the women's perception of diabetes. The first step involved screening the data using Kaiser's Measure of Sampling Adequacy. The PI examined eigenvalues for the number of significant components present, and a scree plot was used also to help determine the number of significant factors. The factor pattern was rotated using orthogonal (varimax), then oblique (oblimin) rotations.

Analysis of Question 3

Research question 3 was answered by plotting the levels of CHD risk perceptions against the variables of age, educational level, income, and duration of diabetes. The PI correlated perceived risks using Pearson product-moment correlations , with the personal characteristics of age, education, income, and duration of diabetes. The PI then used regression analysis with the perceived risks for CHD against the same variables of age, SES (income and education), and duration of diabetes to determine how these variables affect risk perception.

Pearson product-moment correlations were determined initially to explore the relationships between the personal characteristics and the IR components of identity, timeline, consequence, control, and cause; levels of optimism; and levels

of perception of risk for CHD (Moss-Morris et al., 2002; Tabachnick & Fidell, 2001).

The analysis used scatter plots to identify outliers and to visualize the shape of relationships (Tabachnick & Fidell, 2001).

Analysis of Question 4

To answer question 4, the perception scores were plotted against the LOT-R scores. The CHD risk perception scores were correlated using Pearson product-moment correlations with the LOT-R scores to determine the relationships between optimism and pessimism and the perception of risk for CHD.

Analysis of Question 5

Research question 5 was examined using multiple regression. Levels of risk scores were regressed against all predictor (independent) variables (perception of diabetes, level of optimism, age, educational level, income, and duration of diabetes). Then the PI used discriminant function analysis (SPSS version 12) to examine the level of risk for CHD as the dependent variable for prediction (Tabachnick & Fidell, 2001).

Qualitative Procedures

In-Depth, Semistructured Interview Questions

The PI administered the semistructured, in-depth interviews in a one-on-one interview setting in the participant's home or setting of choice. After the initial quantitative data was collected, interviews were scheduled to enrich an

understanding of participants' risk perceptions and beliefs. The semistructured interview guide is in Appendix F.

Selection. Participants were selected using stratified sampling of the levels of perception of risk (none, low, medium, high, or very high) and their perceived level of connection between diabetes and CHD.

The steps in this sequential explanatory study design are noted in Figure 1, p.43. and are: (a) quantitative tools administered to all participants, (b) results analyzed for all participants, (c) selection of stratified groups, (d) semistructured interviews administered, (e) results of interviews analyzed, and (f) findings from questionnaires and semistructured, in-depth interviews integrated and analyzed.

If a participant had not been able to complete the in-depth interview, the PI would have contacted another participant at the same level of perception of risk for CHD who agreed. If there were no other participants at the same level of perception of risk for CHD, the PI would have documented the situation and included that information in the findings of the study. All participants who were contacted for follow-up interviews were able to meet for the interview.

Procedures for conducting the interviews. As the quantitative data collection was ending, a stratified list of participants in each level of risk perception for CHD was developed. After 46 participants had completed the quantitative data collection phase, the first in-depth interview was conducted. The PI used purposeful sampling in order to interview participants at each level of risk perception for CHD.

Questions were also included based on the participants' responses to specific topics that emerged from the initial questionnaires (e.g., stress, claiming, faith in God). These topics evolved from *causes of diabetes* or emerged during the answering of questionnaires about perception of risk for CHD. For example, one participant may have had a low perception of risk for CHD and a low perception of risk for the connection of CHD and diabetes. Another may have had several comments about her faith and mentioned claiming or not claiming when answering the questionnaires. Claiming refers to whether or not the woman will accept a diagnosis such as heart disease as her own. The PI chose various participants because they had one of the characteristics that the study sought to explore.

The first in-depth interview participant was selected due to her low perception of risk for CHD and low connection of diabetes and CHD. After the interview with the first participant, the in-depth interview questions were revised.

The PI completed five more in-depth interviews in the participants' places of choice. Every participant in the study agreed to the follow-up interviews and were made aware that not everyone would be chosen for the follow-up interviews. Each participant was paid \$10.00 for the second interview and received a second gift bag with coupons for diabetic supplies and self-care materials. Each in-depth interviewee also received a gift bag with coupons and lotion along with a packet of information about diabetes and heart disease from the Cardiovascular Toolkit from the ADA (2008). After each interview, the PI reviewed the materials with the

participant and allowed her an opportunity to ask questions. The toll-free number, along with other contact information, was included in their gift bag for the participant to contact the PI if she had any further questions.

Data Management and Analysis

Each interview was transcribed using Sony digital recorder software. The verbatim transcript was entered into NVivo 8 software program for analysis. The PI transcribed each interview before progressing to the next interview. By personally transcribing each interview, the PI became closer to the data and grew in the experience of how to better field the questions to gain richer information (Bazeley, 2007). Field notes were kept before and after the interviews to enhance the audiotaped information.

Prior to the initiation of the follow-up, in-depth interviews, the PI developed a list of initial concepts (a priori) based on the supporting theory and conceptual framework of the study (Miles & Huberman, 1994). Initial concepts were the components of the IR of diabetes, perception of CHD risk, optimism/pessimism, and heart disease. These concepts supported the study's theoretical framework of IR and the CSM.

The follow-up interview questions were focused on determining, to a greater depth, what the individual's perceptions were regarding her diabetes and risk for CHD, along with positive and negative outlooks that may have affected those

perceptions (Appendix F). Interviews continued until the PI had interviewed participants at all levels of risk perception.

The PI entered transcripts into the NVivo 8 computer analysis program for qualitative data as interviews after being transcribed verbatim with the participant's dialect intact by the PI using Sony's software application to convert the recordings. All cases and written transcripts were numbered to assure the participants' confidentiality. The PI listened to the recordings multiple times for comprehension and emerging themes and patterns.

After the transcripts were entered, the concepts were entered as free nodes prior to analysis. As each case was coded, a comprehensive list of codes was developed. Information from the field notes generated additional codes and nodes that were not obvious prior to the quantitative phase of the study (Miles & Huberman, 1994). The additional nodes were entered in conjunction with the original concepts.

Codes were determined after reading and re-reading the transcripts. The codes were then moved to the tree nodes as a hierarchy developed and as connections were found (Bazeley, 2007). Codes were double-checked by the designated committee members and through use of coding stripes available in the computer program. The coding stripes helped identify connecting data. As the PI completed coding the data, queries were completed about the data (Bazeley, 2007).

All codes were defined operationally to assure consistency in labeling. Codes were determined both inductively (from the data) and deductively (from the theory; Miles & Huberman, 1994). The PI used triangulation of methods and theory and data interpretation to make determinations from the data (Flick, 2002).

The PI and two dissertation committee members discussed conclusions about the data, the transcripts, and their meanings. The PI made the final decisions about the interpretations based on the theoretical foundations of the study and support in the literature.

CHAPTER IV

RESULTS

In this chapter, results from the study are presented. First, the sample characteristics (demographics and health status) are presented, followed by an analysis of each research question. Next, the levels of perceived risk for CHD are explained, followed by a description of the process for sample selection for the follow-up, semistructured, in-depth interviews. Lastly, the qualitative analyses are presented.

Sample Characteristics

The PI interviewed 48 AA women between the ages of 34 and 65 years, using (a) a personal characteristics form, (b) the Perception of Risk for CHD tool, (c) the LOT, and (d) the IPQ-R. All had self-reported or physician-validated, T2DM and did not report having heart disease. All had been diagnosed with T2DM for more than 1 year. The number of years since diagnosis of diabetes ranged from 1 year to 41 years. The mean number of years since their diagnosis of diabetes was 9.9 years.

The women lived in nine central North Carolina counties of Alamance, Caswell, Chatham, Durham, Guilford, Orange, Person, Randolph, and Wake. Their incomes ranged from less than \$10,000 annually to more than \$30,000 annually,

with a mean income of \$10,000-\$15,000 annually (Table 2). Many participants (47.9%, $n = 23$) were disabled and 66.7% ($n = 32$) received Medicare or Medicaid. More than half (56.3%, $n = 27$) were on insulin and most (85.4%, $n = 41$) were on oral medications for their diabetes. Less than half of the women were using both oral medications and insulin (43.8%, $n = 21$); three used only diet and exercise (6.3%).

Table 2

Demographic information on participants ($n = 48$)

Personal Characteristics $N = 48$	Range	n	
Age (in years)	34-44	4	55.31 (<i>mean</i>)
	45-54	16	
	55-64	28	
Time since diagnosis (in years)	1-10	33	9.92 (<i>mean</i>)
	11-20	11	
	21-30	1	
	31-41	3	

Education	Middle school to some High school	14	High School Diploma <i>(mode)</i>
	Completed High school to some college	27	
	Graduated college to Masters Degree	7	
Income (annual)	< \$10,000	21	\$10,000 - \$15,000
	\$10,000-\$14,999	9	<i>(mode)</i>
	\$15,000-\$19,999	4	
	\$20,000-\$29,999	6	
	>\$30,000	8	

The typical study participant was a 55 year-old AA woman with T2DM for an average of 9.9 years. She was high school-educated, with an annual family income of \$10,000-\$15,000, and had five symptoms she related to her diabetes.

The sites of the data collection included patients' homes that ranged from single-family housing to apartments and mobile homes. Some patients preferred to meet in public places such as fast food restaurants, or their offices if they were working.

Approximately 42% of the participants ($n = 20$) lived in rural areas with the other 58% ($n = 28$) living inside larger city limits.

Research Questions

Research Question 1

Relationships among the subscales of identity, timeline (long-term), cyclical timeline (short-term), consequences, personal control, treatment control, illness coherence, and emotional representation were examined by calculating Pearson product-moment correlations between each pair of subscales. The findings are presented in Table 2.

Illness representation is a combination of factors identified as comprising a person's perception of an illness (Leventhal et al., 1997). The IPQ-R was used to gather this data. A positive IR refers to someone who has higher scores on the components of personal control, treatment control, and illness coherence. Those with a positive IR have positive beliefs about the controllability of their diabetes and a personal understanding of diabetes (Moss-Morris et al., 2002). Someone with a positive IR may be expected to manage her illness more effectively (Weinman, Petrie, Sharpe, & Walker, 2000). A negative IR refers to someone who has lower scores on the areas of identity, timeline, consequences, and emotional representation. They have fewer symptoms that they relate to their diabetes and do not believe that their diabetes is going to last a long time or the rest of their life.

Negative IR participants identify consequences as something they are concerned about, and identify emotional responses to their diabetes as worry and fear. Those with negative IR attribute a greater number of negative symptoms to diabetes. They also believe in the chronic nature of diabetes, the negative consequences of diabetes, and the cyclical nature of diabetes (Moss-Morris et al., 2002). Someone with a negative IR may not manage her illness effectively (Weinman et al., 2000).

The illness *identity* score is the number of symptoms the woman experiences and relates to her diabetes. The general symptoms most identified by the women, but not identified necessarily as related to their diabetes, were stiff joints (89.1%), pain (84.8%), fatigue (78.3%), sleep difficulties (73.9%), headaches (71.7%), breathlessness (65.2%), weight loss (63%), nausea (60.9%), dizziness (60.9%), and loss of strength (56.5%; Table 3). Participants related an average of 4.9 symptoms to their diabetes. The symptoms most related to their own diabetes were pain (52.1%), weight loss (52.1%), and fatigue (64.6%). For all other symptoms, less than half of the participants related the symptom to their diabetes.

Table 3

Symptoms reported and related to diabetes

General Symptoms	Percentage respondents	Percentage symptoms related to diabetes
Stiff Joints	89.1%	33.3%
Pain	84.8%	52.1%
Fatigue	78.3%	64.6%
Sleep Difficulties	73.9%	37.5%
Headaches	71.7%	31.3%
Breathlessness	65.2%	25.0%
Weight Loss	63.0%	52.1%
Nausea	60.9%	35.4%
Dizziness	60.9%	43.8%
Loss of Strength	56.5%	35.4%

Timeline is how long the woman believes her diabetes will last over the course of her life. Higher scores on *timeline* indicate the woman has beliefs that diabetes is a chronic illness. Three items on the IPQ-R were used to assess beliefs about whether the participant felt her diabetes was acute or chronic in nature (items 1, 2, and 15). All items were measured on a 5-point scale (1 = strongly disagree, 5 = strongly agree). The first item was “This diabetes will pass quickly.” The second item was “I expect to have diabetes the rest of my life.” The third item was “My diabetes will improve in time.” Possible scores were from 3-15, with actual scores ranging from 3-13. The actual *timeline* scores had a *mean* of 9.42 and a *SD* = 2.36. All scores were determined per IPQ-R instructions using the midpoint of the score range as the medium response score. Medium responses were grouped with the *disagree* responses because those participants were indifferent in their belief about the item. Forty-two percent of the participants ($n = 20$) disagreed or were indifferent about the chronic nature of their diabetes (i.e., they felt it would get better). Fifty-eight percent ($n = 28$) of the participants believed their diabetes is chronic.

Timeline cyclical is how much the participant feels her blood sugar and any associated symptoms fluctuate on an ongoing basis in her daily life. Higher scores on *timeline cyclical* indicate the woman has more symptoms that change over a period of time. The items ranged from “The symptoms of my diabetes change a great deal from day to day,” and “My symptoms come and go in cycles,” to “My

diabetes is very unpredictable,” and “I go through cycles where my diabetes gets better and worse.” Possible scores were 4-20 on four items (26, 27, 28, 29), with actual scores ranging from 4-17. Actual scores had a mean of 13.19 with a $SD = 4.25$. Participants with scores of 14 or more indicate they believe in the cyclical nature of their diabetes, whereas those with scores of less than 14 do not believe their diabetes is cyclical. Fifty-two percent ($n = 25$) of the participants reported their symptoms change in a cyclical manner. The remaining 48% ($n = 23$) did not feel their diabetes is as unpredictable.

Consequences reflect the participant’s beliefs about the severity and the chronic state of her diabetes. Items 3, 4, 5, 6, 7, and 8 on the IPQ-R measured consequences. The stronger perceived consequence items were “My diabetes is a serious condition,” “My diabetes has major consequences on my life,” “My diabetes strongly affects the way others see me,” “My diabetes has serious financial consequences,” and “My diabetes causes difficulties to those close to me.” The lesser perceived consequence item was “My diabetes does not have much effect on my life,” Possible scores were from 6-30, with the observed scores ranging from 12-30. The observed scores had a mean of 19.75 with a $SD = 4.03$. Higher scores of 18 or over on *consequences* indicate the woman believed that the consequences of diabetes are severe. A score under 18 indicates she believed there is less severity and fewer consequences from her diabetes. Seventy-nine percent ($n = 38$) of the participants believed diabetes has a major impact on their

life. The remaining 10 participants believed diabetes does not have much effect on their life.

The IPQ-R items 9, 10, 11, 12, and 13 measured *personal control*. Possible scores ranged from 6-30, with observed scores ranging from 12-30. The observed scores had a mean of 23.4 with a $SD = 3.01$. Higher scores of 18 or over on *personal control* correspond to a greater feeling that the woman can control her diabetes. Scores of less than 18 indicate feelings of less personal control over diabetes. Most of the participants (95.8%, $n = 46$) believed that they have control over their diabetes.

Higher *treatment control* scores of 15 or over correspond to a greater feeling that treatments or medicines can control diabetes. The IPQ-R items used to measure treatment control were items 16, 17, 18, 19, and 21. Possible scores were 5-25, with actual scores ranging from 12-21. The observed scores had a mean of 15.94 and a $SD = 1.66$. These items were "There is very little that can be done to improve my diabetes," "The negative effects of my diabetes can be prevented (avoided) by my treatment," "My treatment can control my diabetes," "There is nothing that can help my condition," and "My treatment will be effective in curing my diabetes." Results show that 77.1% ($n = 37$) of the participants believed their treatments are effective and that 22.9% felt their treatments were not effective in controlling their diabetes.

Illness coherence measures the understanding a woman feels she has about diabetes. The IPQ-R items 20, 22, 23, 24, and 25 measure *Illness coherence*. The items indicating less knowledge were “The symptoms of my condition are puzzling to me,” “My diabetes is a mystery to me,” “I don’t understand my diabetes,” and “My diabetes doesn’t make sense to me.” The item that indicated knowledge was “I have a clear picture or understanding of my diabetes.” Possible scores are from 5-25, with observed scores ranging from 8-25. The observed scores had a mean of 15.69 and a $SD = 4.22$. Higher scores on *illness coherence* (15 or over) demonstrate a better understanding of diabetes. Eighteen (37.5%) of the participants felt they had a good understanding of their diabetes. Thirty participants (62.5%) felt they had a poor understanding of their diabetes.

Emotional representation is the amount of negative feeling the woman attaches to her diabetes (e.g., anger, depression, worry, upset). The IPQ-R items 30, 31, 32, 33, 34, and 35 measure *emotional representation*. The items that indicated strong feelings were “I get depressed when I think about my diabetes,” “When I think about my diabetes I get upset,” “My diabetes makes me feel angry,” “Having diabetes makes me feel anxious,” and “My diabetes makes me feel afraid.” The item that indicated lesser feelings was “My diabetes does not worry me,” The higher the summed score of *emotional representation*, the more negative feelings the woman is experiencing. Possible scores for *emotional representation* ranged from 6-30, with observed scores ranging from 8-26. The observed scores had a

mean of 16.83 and a $SD = 4.89$. Per IPQ-R instructions, scores of 18 or more indicate a high emotional representation. A score of less than 18 would be a low emotional representation. Fifty percent ($n = 24$) of the participants stated they did not worry about their diabetes; half do worry about their diabetes.

The correlations between the components of IR are shown in Table 4. The strongest correlation is between *identity* and *emotional representation* (.507), which indicates a moderate association. This association means the greater number of symptoms the woman identifies as related to her diabetes, the greater the number of negative feelings she has about her diabetes. Another moderate correlation (.503) exists between *illness coherence*, the understanding of diabetes, and *treatment control*, which is how effective the participant believes her treatment for diabetes to be. Women who understand more about their diabetes also believe the treatments they are given will work for them. *Emotional representation* correlates positively with *consequences* (.473). This correlation indicates that participants with more negative feelings about their diabetes perceive that a higher level of severity accompanies the consequences of their diabetes.

Consequences were correlated moderately positively with *identity* in this population (.354), indicating that women who perceive more severe consequences from their diabetes report a greater number of symptoms. *Personal control* and *treatment control* also were correlated moderately at .488, indicating women who believe they have greater personal control also believe that the treatments issued

by their HCPs will be effective. *Identity* was associated with a greater belief that diabetes fluctuates over time (.322; timeline cyclical). The participants with higher scores on identity (number of symptoms related to diabetes) also had more negative feelings related to their diabetes (.507; emotional representation).

Inverse correlations include *illness coherence* (understanding of diabetes) and *identity* (number of related symptoms; -.464), indicating that as the women increase their knowledge they report fewer symptoms related to their diabetes. *Treatment control* and *emotional representation* also were correlated inversely (-.454), indicating that women who have greater beliefs that treatment can control their disease also have less emotional responses to their diabetes.

Emotional representation (feelings attached to diabetes) and understanding of diabetes were correlated inversely (-.416), indicating that as understanding of diabetes increased, feelings of fear and worry decreased for most participants. These findings indicate that understanding diabetes may be a key component that influences an individual's reactions and connections to diabetes.

Table 4

Correlations of illness representation components (N=48)

Subscale	ID	Time	PC	TC	IC	Cons	TimeCyc	ER
ID	1	-.044	-.259	-.396*	-.464*	.354*	.323*	.507*
Time	-.044	1	-.178	-.135	.043	.029	.196	.058
PC	-.259	-.178	1	.488*	0.12	0.18	-.148	-.217
TC	-.396*	-.135	.488*	1	.503*	-.098	-.301*	-.454*
IC	-.464*	.043	.124	.503*	1	-.353*	-.441*	-.416*
Cons	.354*	.029	.175	-.098	-.353*	1	.376*	.473*
TimeCyc	.323*	.196	-.148	-.301*	-.441*	.376*	1	.242
ER	.507*	.058	-.217	-.454*	-.416*	.473*	.242	1

Notes. * Indicates significant finding ($p \leq .05$ where $|r| \geq .285$ when $n = 48$)

ID = identity, Time = timeline, PC = personal control, TC = treatment control, IC = illness coherence, Cons = consequences, TimeCyc = timeline cyclical, ER = emotional representation

Associations

Next, the PI used factor analysis to analyze the components of IR in order to understand more clearly the relationships between the components. The set of items was identified as appropriate for factoring using Kaiser-Meyer-Olkin measure of sampling adequacy with a result of .71 (Ware, 2003), which is below the value commonly accepted as good (.80), but well above .50, which is a commonly accepted cut-off for factorability. The variables of *identity*, *timeline*, *timeline*

cyclical, *emotional representation*, *illness coherence*, *consequences*, *personal control*, and *treatment control* were analyzed by principal axis factoring. Three factors with eigenvalues greater than 1 were extracted. Given its low correlations with the other items seen in Table 5, one variable--*timeline*--had a very low communality. Likewise, in the rotated factor matrix (varimax), *timeline* stood alone as a third factor. All other variables had substantial correlations with one of the first two factors. Therefore, the analysis was rerun with timeline excluded in order to describe common factors among the remaining variables more accurately. In the reanalysis, the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.72, which suggests that the factorability may have improved slightly from the initial solution. The two factors with eigenvalues greater than 1 were rotated according to the varimax criteria, in which the factors remained uncorrelated and then by the oblimin method with Kaiser Normalization, which allowed the factors to become correlated. The oblimin rotation was preferred for interpretation because the rotation allowed the factors to be distinguished more clearly (Ware, 2003). Those results are presented in Table 5. Factor one, which explains 43.2% of the variance, includes the woman's beliefs about the chronic condition of her diabetes, her negative feelings about diabetes, her understanding, the number of symptoms she relates to her diabetes, and the fluctuating nature of diabetes. Factor two, which accounts for another 19.4% of the variance, consists of *personal* and *treatment control*. *Consequences* had a significant loading on factor two of .540. This means

that *personal* and *treatment control* are associated with the woman's beliefs about the severity of her diabetes. The more she understands about the severity of her diabetes, the more positive she is about her personal control and treatments she receives.

The correlation between the two factors was $-.208$. This means that two different aspects of illness were represented in this population and the two factors were not correlated. Symptoms and severity are linked because the presence or absence of symptoms is how the women measure the severity of their diabetes. *Personal control* and *treatment control* are linked because the women have strong beliefs about their ability to manage their diabetes if they are on effective treatments.

In this sample, the items related to diabetes perception can be described by three themes. The first theme (Factor I) includes *symptoms and the severity of diabetes*. The second theme (Factor II) is that of *control with treatments* and beliefs about personal ability to control diabetes. The third theme is *timeline*, the long- or short-term nature of diabetes. The components in Factors one and two are areas HCPs should address primarily since they make up the largest portion of the women's perception of diabetes. The third theme, *timeline*, may be one that is affected by deeper beliefs or misunderstanding of diabetes and could be clarified also by teaching from HCPs.

Table 5

Factor loadings for symptoms/severity (Factor I) and personal/treatment control (Factor II)

Component of Illness Representation	Symptoms/Severity Factor I	Personal/Treatment Control Factor II
Consequences	.809	.540
Emotional representation	.656	-.085
Illness coherence	-.644	.121
Timeline cyclical	.513	-.018
Personal control	-.079	0.63
Treatment control	-.454	0.6

Notes. Extraction method: Principal axis factoring. rotation method: Oblimin with Kaiser Normalization.

The next component of the IPQ-R includes the participants' beliefs about the causes of their diabetes. Participants indicate from a list of 18 established causes on the questionnaire the ones that they agree are a cause of their diabetes. From this list on the IPQ-R, the most frequent causes the women attributed to the development of diabetes include "diet or eating habits" (72.9%) "my own behavior"

(54.2%), “family problems or worry” (both 54.2%), “stress or worry” (52.1%), and “heredity” (47.9%).

The final section of the IPQ-R asked participants to develop and prioritize a list of the three top causes of their diabetes from that list or in their own words. This list is important for developing prioritized causes that the participants may perceive as areas they either can or cannot change. The list also helps gain information on potential perceived causes not listed in the original 18. The most highly prioritized causes the women identified (Table 6), when asked to name the top three causes for their diabetes, were *eating habits/wrong foods/poor diet* (31.3%), *heredity* (27.1%), and *stress/worry* (18.8%). *Eating habits and stress* were ranked second or third under each level of priority. These results demonstrate that the participants have knowledge of the possible causes of their diabetes, although some participants could not identify a third cause when asked (14.6%).

Table 6

Prioritized causes of diabetes as identified by participants (N = 48)

Causes	Priority #1 (# rated)	Priority #2 (# rated)	Priority #3 (# rated)
Eating habits/Wrong foods/Poor diet	15	17	8

Heredity	13	6	6
Stress/worry	9	9	11
Medical reasons (surgery, infection, blood sugar)	5	3	2
Overweight	3	4	1
No exercise	1	3	7
Not taking care of self	1	2	2
Pregnancy	1	2	0
Aging	0	1	1
Smoking	0	1	0
Race	0	0	1
Not drinking enough water	0	0	1
Poor health care	0	0	1
No cause given for this priority	0	0	7

The domains of the IPQ-R were then correlated with the levels of perception of risk for CHD (Table 7). *Timeline* was the only domain that was correlated significantly with the components of the PORQ. *Timeline* had a .297 correlation with *the chance of CHD*, a .356 correlation with *the connection between diabetes and CHD*, and a .412 correlation between *the chance of CHD as compared to others*. For the *chances of cancer* items, there were correlations of .343 for *the chance of cancer*, and a .261 for the chance of cancer compared to others. *The chance of an auto accident* was correlated at .389 with *timeline*. No other items of the IPQ-R were correlated inversely or positively with the PORQ items. These results showed that the more chronic the woman perceived her diabetes to be and the longer she had diabetes, the greater she felt her chances for CHD were.

Table 7

Correlation of timeline with the Perception of Risk Questionnaire (N=48)

	Timeline
Chance of CHD	0.297
Diabetes and CHD connection	0.356
Chance of CHD compared to others	0.412
Chance of cancer	0.343
Chance of cancer compared to others	0.261
Chance of auto accident	0.389

Notes. CHD = coronary heart disease

Research Question 2

In order to answer research question 2, personal characteristics and responses from the PORQ were examined. Personal characteristics were obtained from the Personal Characteristics Form (AHA, 2006; Skelly, 2006). The PORQ (Rosamond et al., 2007; Walker et al., 2003) provided data about Perception of Risk for CHD. Risk scores were determined by the responses on the scale from 0-4 (0 = none, 1 = low, 2 = medium, 3 = high, 4 = very high). The PORQ asked five questions. The first question was "What do you think your chances are of developing heart disease?" The second question was "What do you think are your chances of developing cancer?" The third question was "How much do you think diabetes affects whether or not someone gets heart disease?" The fourth question was "What do you think are your chances of developing heart disease compared to someone else of your same age and race?" The final question was "What do you think are your chances of having an automobile accident compared to someone else of your same age and race?"

Levels of risk perception were grouped together for presentation because medical personnel tend to separate information into low, medium, and high rankings. Groups were *high* (scores 3 and 4 on the scale), *medium* (score of 2 on the scale), and *low* (scores of 0 or 1 on the scale). An analysis of the frequencies of the perception of CHD risk data demonstrated that 43.8% ($n = 21$) of the

participants felt they had *none to low risk* for CHD. There were 35.4% ($n = 17$) who felt they had a medium risk for heart disease, and 20.8% ($n = 10$) of the women reported they felt they were at *high to very high risk* for CHD (Figure 1). These findings are supportive of the findings from surveys by Mosca et al. (2000, 2004) and Legato et al. (1998), though neither specifically studied AA women with diabetes.

In the next item, the women were asked how much they felt diabetes affected whether or not someone developed heart disease. ("How much do you think diabetes affects whether or not someone gets heart disease?") In contrast to the participants' responses above concerning personal risk, 56.3% ($n = 27$) of the women believed there was a *high to very high* chance that diabetes affected whether or not someone developed heart disease.

The next item asked participants how they compared their risk for CHD to others of their same age and race. When compared to others of their same age and race with or without diabetes, the participants were split relatively evenly in their beliefs. Results showed that 33.3% of the women felt there was *none to low chance as compared to others* for developing heart disease, 37.5% felt there was a *similar chance*, and 29.2% felt there was a *high to very high chance as compared to others* for developing heart disease (Figure 2).

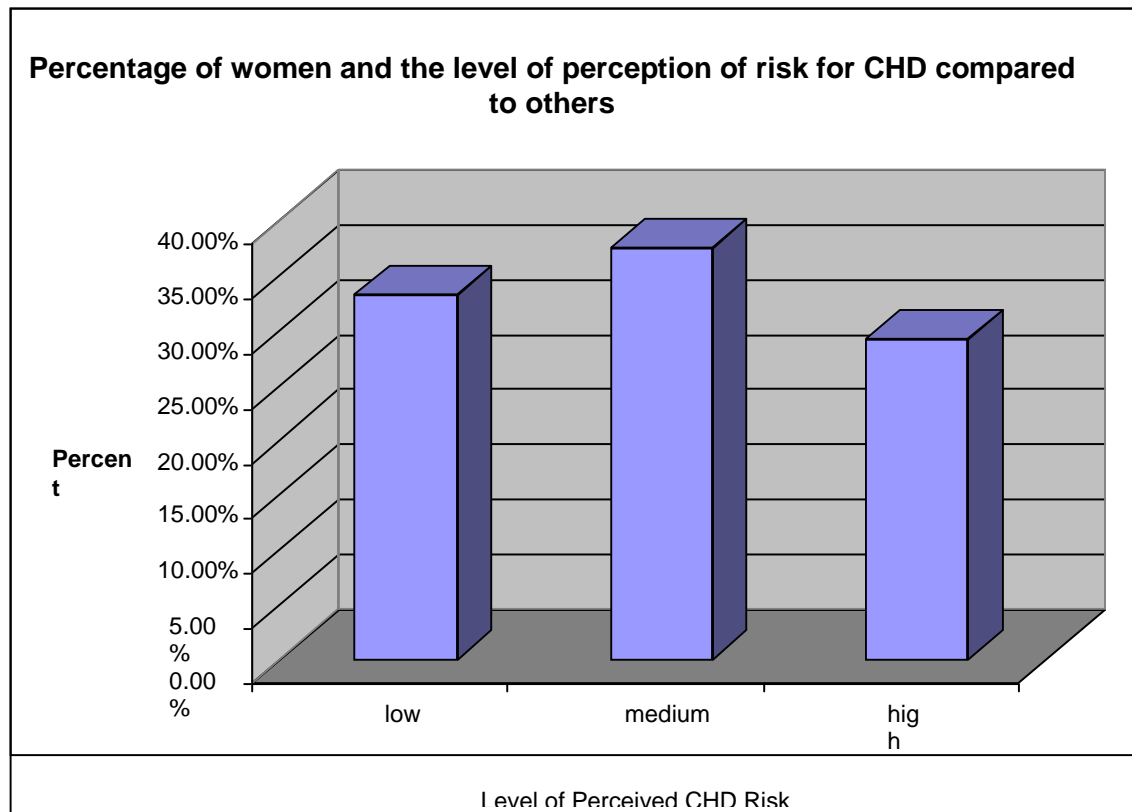
Another item asked participants about their beliefs about their chances of developing cancer. Thirty-one (61.4%) participants responded that they had a *low*

to no chance of developing cancer. When asked about their chances for developing cancer compared to others of their same age and race, 42 participants (87.5%) felt they had *medium to no* chance of developing cancer compared to others. Of those 42 responses, 21 were *medium* and 21 were *low to none*.

The last item asked women what they thought their chances were of having an automobile accident compared to others of their same age and race. The majority of the respondents 87.5% ($n = 42$) felt their chances were *medium to none*.

Figure 2

Perceived chance of developing coronary heart disease compared to others



Personal characteristics that required recoding for analysis were age, knowledge of last BP, knowledge of lowest BP, and knowledge of highest BP. The PI originally entered ages numerically. Recoded ages were in age ranges with ages placed into 5-year increments, for a score of 1-7 from ages 30-65 years. Original BPs were recorded with the actual reported BP reading. Blood pressure data was recoded into *1 = yes they knew their last BP, lowest BP, or their highest BP*, and *0 = no they did not know their BP reading*. Pearson product-moment correlations were used for analysis.

There were no significant correlations ($p \leq .05$) found between perceived level of risk for CHD and the personal characteristics of age, educational level, income, duration of diabetes, knowledge of last BP, knowledge of lowest BP, and knowledge of highest BP.

Regression was performed with perceived risk for CHD as the dependent variable, and age, educational level, income, and duration of diabetes as grouped independent variables. The relationship between personal characteristics and perceived risk of CHD was not significant ($F [4, 43] = .935$; $p = .453$). The variables of age, income, education, and years of duration of diabetes do not determine perceived risk level for CHD.

A distribution of the women's ages and their perception of risk for CHD is shown in Figure 3. The high-perceived risk of CHD group had the greatest number of

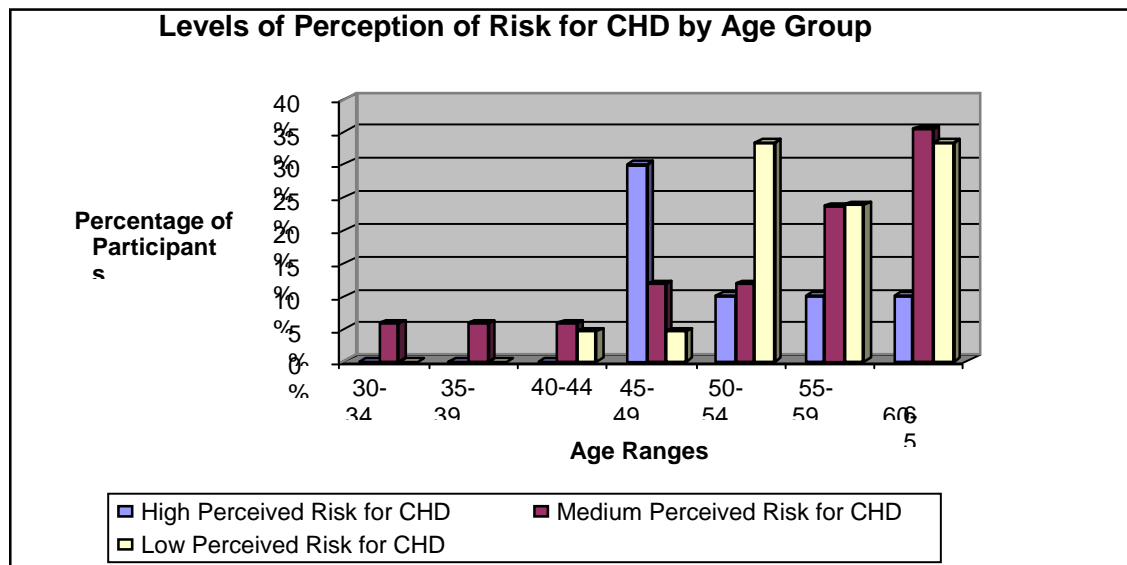
participants in the 45-49 year old group. The largest number of participants in the medium risk group was in the 60-65 year old group. The participants in the low perceived risk group were divided equally between the 50-54 year old and the 60-65 year old groups (Figure 2).

The PI then evaluated other personal characteristics that could affect CHD risk perception. After the cases were divided into low, medium, and high levels of perceived risk, it was noted that there is a higher percentage of those in the high perceived CHD risk group that knew their last BP ($n = 7$, 70%) and knew their highest BP ($n = 7$, 70%). Higher scores of perceived CHD risk correlated with the knowledge of last BP and highest BP with a .429 correlation for both variables ($p \leq .05$). This may mean that these women were more engaged in managing their health or that they simply understood more about the connection between BP and diabetes. *Knowing BP readings* also may result from the primary HCP telling the woman her BP, and what the numbers mean.

Further inquiry into the data demonstrated significant differences between the groups in perceived level of risk for CHD. These findings are discussed under research question three.

Figure 3

Perception of risk for coronary heart disease and age



Research Question 3

In order to answer research question 3, the symptoms identified by participants as related to diabetes were summed, per instructions from the IPQ-R directions for scoring. Then the correlations between summed identity scores, the number of symptoms identified with their diabetes, and the perception of risk for CHD scores were calculated.

Correlation of the ungrouped perceived risk for CHD scores and identity scores resulted in a correlation of .271 ($p = .062$). This result approaches significance and

indicated that a trend toward a moderate association was found in this sample between increased number of symptoms of diabetes and the perceived risk for CHD. Grouped perception of risk for CHD scores were not significantly correlated with identity (.180).

The levels of perceived CHD risk were examined for differences and similarities. There was not a significant relationship between age and perceived CHD risk ($p = .51$, with a correlation of $-.096$).

The perceived risk for CHD groups (high, medium, low) were compared with the respondent's beliefs about the association between diabetes and heart disease. The high and medium perceived CHD risk groups had a majority of participants ($n = 23$, 85.2%), who felt there was a strong (*high* or *very high*) connection between diabetes and heart disease. The alarming finding is that so few women in the low perceived risk group (19%, $n = 4$) believed there was a high connection between diabetes and heart disease. Only 14.6% ($n = 7$) of the total sample of women with T2DM believed there was a strong (*very high*) connection between diabetes and CHD. Chi square results were ($[4, n = 48] = 19.917, p = .001$). The number of participants and their responses to the connection between T2DM and CHD are presented in Table 8.

Table 8

Perception of risk for coronary heart disease and beliefs about the connection between diabetes and coronary heart disease (N=48)

Diabetes and CHD Connection	Low Perception of Risk for CHD	Medium Perception of Risk for CHD	High Perception of Risk for CHD	Total
Strongly disagree	4	0	1	5
Disagree	3	0	0	3
Neither agree nor disagree	10	2	1	13
Agree	4	12	4	20
Strongly agree	0	3	4	7

Descriptive statistics for the domains of illness representation and responses to items on the PORQ are presented in Table 9. The mean values as well as the minimum and maximum values show the variation in responses.

Table 9

Descriptive statistics for illness representation domains and coronary heart disease risk items (N = 48)

Item (sums)	Mean	SD	Minimum	Maximum
Timeline	9.42	2.36	3	13
Personal control	23.42	3.01	12	30
Treatment control	15.94	1.66	12	21
Illness coherence	15.69	4.22	8	25
Emotional representation	16.83	4.89	8	26
Timeline cyclical	13.19	4.25	4	32
Identity	4.94	3.84	0	13
Consequences	19.75	4.03	12	30
Diabetes and CHD	2.44	1.15	0	4
Chance of CHD compared	1.9	1.1	0	4
Chance of cancer	1.17	1.17	0	4

Chance of cancer compared	1.52	0.98	0	4
Chance of auto accident	1.25	1.02	0	4
Chance of CHD	1.6	1.18	0	4

Notes. CHD = coronary heart disease

One factor that emerged in the analysis was the connection between knowing your last BP and your highest BP reading and perceptions of risk for CHD (Table 10). More women in the high perception of risk for CHD group had knowledge about their highest and last BP readings than the participants in the medium and low groups. Chi square results for knowing highest BP were (2) = .570, $p = 0.06$.

Table 10

Perception of risk compared to knowledge of highest blood pressure (N=48)

Knowledge of Highest BP	Low Perception of Risk for CHD	Medium Perception of Risk for CHD	High Perception of Risk for CHD	Total
Did not know reading	15	12	3	30
Knew reading	6	5	7	18

Regression was used to examine the knowledge of highest BP scores (independent variable) to perception of risk for CHD scores (dependent variable). Correlation of the two variables resulted in a .299 correlation. Participants reported high BP values ranging as high as 240 systolic to over 110 diastolic. This result demonstrates the value of knowing your highest personal BP reading and the relationship to perception of risk for CHD in this sample of AA women with T2DM.

Pearson product-moment correlations were used to examine *knowledge of your last BP* to the perception of risk for CHD scores. These findings were not significant, with a correlation of .154. Most of the participants reported last BPs within a normal range.

Table 11

Comparison of knowledge of last blood pressure with perception of risk for coronary heart disease

Knowledge of Last BP	Low	Medium	High	Total
	Perception of Risk for CHD	Perception of Risk for CHD	Perception of Risk for CHD	
Did not know reading	11	8	3	22
Knew reading	10	9	7	26

Total	21	17	10	48
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The personal characteristics and the level of perceived risk for CHD are shown in Table 12. Shown are the number of women who report healthy behaviors and how they view their risk for CHD.

Table 12

Personal characteristics and level of perceived risk for coronary heart disease

Characteristic	High	Medium	Low	Total
	Perceived	Perceived	Perceived	<i>N</i> = 48
	CHK Risk	CHD Risk	CDH Risk	
	<i>n</i> = 10	<i>n</i> = 17	<i>n</i> = 21	
	(20.8%)	(35.4%)	(43.8%)	
Personal Characteristics				
	Age (in years)			
30-34	0.0%	5.8%	0.0%	2.1%
35-39	0.0%	5.8%	0.0%	2.1%
40-44	0.0%	5.8%	4.7%	4.2%
45-49	30.0%	11.8%	4.7%	12.5%
50-54	10.0%	11.8%	33.3%	20.8%

55-59	40.0%	23.6%	23.8%	27.1%
60-65	20.0%	35.4%	33.3%	31.3%

Time since diagnosis (in years)

1-9	57.2%	64.7%	60.0%	60.4%
10-19	33.3%	17.7%	30.0%	27.1%
20-29	9.5%	5.8%	10.0%	6.3%
30-39		11.8%		4.2%
40-49				2.0%

Education

Middle school, some high school	30.0%	35.3%	23.8%	29.1%
High school	20.0%	29.4%	47.6%	35.4%
Some college	30.0%	11.8%	23.8%	20.8%
College graduate	10.0%	17.7%	4.8%	10.4%
Masters degree and beyond	10.0%	5.8%	0.0%	4.2%
Income (less than \$10,000)	50.0%	41.2%	50.0%	45.8%

BMI (mean for group)	41.5	34.7	35.01	38.1
Diabetes self-care				
On insulin (% group)	70.0%	53.0%	52.4%	56.3%
Insulin compliance (% compliant)	85.7%	66.7%	100.0%	85.2%
Oral medication	70.0%	94.1%	85.7%	85.4%
Oral medication compliance (% always compliant)	85.7%	100.0%	88.9%	79.2%
Diet compliance (Most of the time or always compliant)	47.6%	53.0%	47.6%	43.8%
Health knowledge/behaviors				
Knows blood pressure (% with knowledge)	70.0%	52.9%	47.6%	54.2%

Watches sodium in diet (% yes)	90.0%	94.2%	90.5%	91.7%
Watches cholesterol in diet (% yes)	80.0%	94.2%	85.7%	87.5%
Knows highest blood pressure	70.0%	29.4%	28.6%	37.5%
Knows cholesterol level	30.0%	17.7%	14.3%	18.8%

Family history

Father had MI before age 55 years	30.0%	17.7%	14.3%	18.8%
Mother had MI before age 65 years	30.0%	17.7%	19.1%	20.8%

Metabolic control

FBS greater than 120	70.0%	59.0%	62.0%	62.5%
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Results show that there is an association between those who know their highest BP reading and the perception of risk for CHD. This finding means that the elevated BP readings played a role in helping form a perception of risk for CHD. Leventhal's Theory of IR also supports this finding in that it states that individuals place certain attributes onto the illness. A number indicating a high BP connects physical symptoms with an attribute for hypertension, which may make the appraisal for CHD risk perception more accurate and meaningful.

Research Question 4

First, the scores from the LOT, which measures a general outlook on life, were summed, per author directions, after extraneous filler questions were removed (items 2, 5, 6, & 8) and reverse coding completed for items that were negatively stated (items 3, 7, & 9). The summed scores were sorted into tertiles in order to aid understanding, which indicated the low, medium, and high scores for the questionnaire.

The overall percentage of women with high LOT-R scores was 39.5% (scores of 24-30; $n = 19$). This means over one third of the women had optimistic outlooks. The middle tertile consisted of 48% ($n = 23$) of the participants with moderate levels of optimism (scores of 18-23). A smaller percentage of the participants, 12.5% ($n = 6$), had pessimistic outlooks on life (scores 11-17). Therefore, the majority of the women in the study ranged from a general optimistic outlook to an ambivalent outlook on life.

Next, the full LOT-R scores were correlated with the Perception of Risk for CHD scores. No significant correlation was found ($r = .046$, $p = .75$). The LOT-R scores were examined by level of perceived CHD risk for significance (Table 13). In the *low* and *medium* perceived risk groups, most participants (52.4%, 52.9%) had medium levels of optimism. In the *high* perceived risk group, the majority had high optimism (50%), and only 30% of the *high* group had a medium level of optimism. Chi square results for LOT-R scores recoded into three groups (1 = *low*, 2 = *medium*, and 3 = *high*) were ($[8, n = 48] = 6.475$, $p = .564$). Participants in the *medium* group are seen as ambivalent about life in general, whereas participants in the *low* group are seen as pessimistic (Scheier et al., 1994).

Table 13

Level of optimism compared to level of perceived coronary heart disease risk

	High Perceived CHD Risk	Medium Perceived CHD Risk	Low Perceived CHD Risk
High level: optimism	50% ($n = 5$)	35.3% ($n = 6$)	38.1%% ($n = 8$)
Medium level: ambivalence	30% ($n = 3$)	52.9% ($n = 9$)	52.4% ($n = 11$)

Low level: pessimism	20% (<i>n</i> = 2)	11.8% (<i>n</i> = 2)	9.5% (<i>n</i> = 2)
Total	100% (<i>n</i> = 10)	100% (<i>n</i> = 17)	100% (<i>n</i> = 21)

Research Question 5

To answer research question 5, the data was examined using discriminant function analysis to identify sets of variables that discriminate between the groups. Perception of Risk groups were collapsed for use in the statistical program to *low* which included none and low risk responders, *medium* (midlevel responses), and *high*, which included the high and very high responders.

The variables of age, income, education, and years since diagnosis; and LOT scores, timeline scores, personal and treatment control scores, illness coherence scores, emotional representation scores, identity scores, and consequences scores were entered simultaneously.

Mean scores and standard deviations for all variables for each level of perceived risk are presented in Table 14. Two distinct functions were identified; however, there were no statistically significant findings using discriminant function analysis. Eigenvalues were .631 for function 1 and .366 for function 2.

Table 14

Group statistics and membership for levels of perceived coronary heart disease risk

	Mean	SD
Low perceived risk		
LOT	Medium	3.93
Education	High school	1.38
Income	\$10,000-\$14,999	1.43
Age	~ 53 years	1.13
Years since diagnosis	9.17	7.01
Medium perceived risk		
LOT	Medium	5.35
Education	High school plus training	1.90
Income	~ \$15,000	2.16
Age	~ 51 years	1.89
Years since diagnosis	10.48	10.69
High perceived risk		
LOT	Medium	4.90

Education	Completed community college	1.82
Income	~ \$17,000	2.22
Age	~ 52 y.o.	1.17
Years since diagnosis	10.52y	12.19
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Low perceived chance		
Personal control	23.47	1.80
Treatment control	16.00	1.37
Illness coherence	14.95	4.03
Timeline cyclical	13.14	3.00
Emotional representation	16.23	4.88
Identity	4.09	4.10
Timeline	8.52	2.63
Consequences	19.95	3.45
<hr/>		
Medium perceived chance		
Personal control	24.05	3.52

Treatment control	16.11	2.14
Illness coherence	16.41	4.96
Timeline cyclical	12.11	3.68
Emotional representation	17.00	4.89
Identity	5.52	4.04
Timeline	10.17	2.09
Consequences	19.11	3.95
<hr/>		
High perceived chance		
Personal control	22.20	3.93
Treatment control	15.50	1.26
Illness coherence	16.00	3.26
Timeline cyclical	15.10	6.60
Emotional representation	17.80	5.20
Identity	5.70	2.71

Timeline	10.00	1.56
Consequences	20.40	5.39
<hr/>		
Total		
Personal control	23.41	3.00
Treatment control	15.93	1.65
Illness coherence	15.68	4.21
Timeline cyclical	13.18	4.24
Emotional representation	16.83	4.88
Identity	4.93	3.83
Timeline	9.41	2.35
Consequences	19.12	2.24
<hr/>		

In summary, the majority of participants did not perceive themselves at risk for developing CHD, a major cause of mortality in women with T2DM. Factors influencing perception of risk included: knowledge of highest BP readings, knowledge of last BP readings, and a family history of MI. No effects were found for personal characteristics of age, SES, and duration of diabetes, nor for levels of

optimism or pessimism, as predictors of perceptions of risk for CHD in AA women with T2DM.

Findings from the Semistructured, In-Depth Interviews

Six participants were chosen purposefully for follow-up interviews to gain further insight into the beliefs about diabetes and the perception of risk for CHD. After the interviews were transcribed by the PI, they were entered into NVivo version 8 for analysis purposes. The initial concepts were entered and then each interview was coded paragraph by paragraph. After the codes were completed, the PI made decisions as to how codes were related and categories were developed from codes with related meanings. Other committee members using coding stripes generated by the NVivo program reviewed codes, and categories and differences in interpretations were discussed. Repeating patterns of similar participant responses in the transcripts guided the analysis and interpretation of the responses. Queries of all the interviews were then completed for the categories, using codes to help group responses related to the code or category. The analysis is divided into two sections. The first section analyzes major categories identified from the interviews. The second section examines interview information that specifically enhanced the data from the first phase of the study. The blending of the data from the two phases, quantitative and qualitative, will be presented further in the discussion.

Organizing Major Categories

Major categories developed from analysis of the interviews are presented in the following section. Semistructured questions, focused on determining in-depth information about the formation of the perception of risk for heart disease, helped identify categories from patterns in participant responses.

Perceiving diabetes and heart disease was the first major category that was explored in the study and included experiences with heart failure, hypertension, medications, and the participants' relationships with their HCPs. *The relationship with their HCP* emerged as a new issue from the discussions.

Four other categories were identified during analysis. They included *not claiming, the challenges of diabetes, support, and balance*.

Perceiving Diabetes and Heart Disease

The focus of the study was to explore what the participants felt about their risk for heart disease since they all had T2DM. The participants were asked upon screening if they had heart disease. The responses showed that even when they identified a known risk factor for developing heart disease such as hypertension, they did not always feel that they were personally at risk for a heart attack. Participants did not make the link between heart failure or past cardiac events and the risk for heart disease. An issue that emerged was that being told by their physician or nurse practitioner that they had heart disease was a big part of knowing the risk.

Several participants discussed how, if the physician or nurse practitioner did not tell them specifically they had heart disease, they did not have it. They were emphatic in their discussion of heart disease from this aspect. They discussed being diagnosed in the past with heart failure or hypertension, but because they did not take medication for the condition any more, they did not believe they had the condition when the interview was conducted. Some believed that when they took medication for hypertension it meant they did not have hypertension anymore because their BP "was fine" as reported to them by their physician.

Lack of connection. Participants with low to medium perception of risk levels did not identify the connection between their diabetes and heart disease. Even when they said they had "heart disease" or "heart failure" there was a lack of connection between the heart problem and their diabetes.

One participant described her experience after being coded (resuscitated) and making the connection between her self (identity) and the possibility of heart disease along with diabetes. She described the basic information about diet and managing diabetes and then stated "...so it really keeps me busy with diabetes and heart disease different things that 'I have' (she emphasizes this in her speech)..." As the interview progressed she was asked if she would say then that she had heart disease. Her reply was: "No! I don't have heart disease. I don't have it. My Doctor ain't told me that I had it."

Another participant could not identify any symptoms related to her reported heart failure from the past, even when her physician or nurse practitioner had told her she had heart failure. This participant reported taking medications for hypertension. but she believed that since she did not take medication for her heart failure she no longer had it.

Lastly, a participant confirms the potential impact of accepting that you are at risk for heart disease when you already have diabetes: “I am not going to claim heart failure. You can get overwhelmed with it. It can overwhelm you psychologically.”

Avoiding a heart attack. Another aspect of the diabetes-heart disease link that surfaced was that even those who believed they were at risk for heart disease wanted to avoid the possibility of worsening high BP or of having a heart attack. They discussed not wanting to acknowledge that if they have chest pain they could be having an MI. This aspect of heart disease care, delay in seeking treatment by women having an MI, is documented in the literature (Banks & Dracup, 2006; Dempsey, Dracup, & Moser, 1995; Dracup & Moser, 1997; Higginson, 2008). An example of a woman avoiding the possibility of an acute cardiac event is described below. (This participant had a high perception of risk for CHD.)

... There are days when because my father had a heart attack and my mom had two. My Dad had several strokes even before that. I have had times when I have had (pause) what I call anxiety attacks. My doctor has always said to me- you come when you have them, because there's no way for us to tell over the phone or anything else when it is truly a heart attack or anxiety. I was having one actually on Monday, no on Wednesday, I got up

and I was having chest pains when I got up and I was just having severe chest pains (pause) and I was feeling fluttering the day before and Monday I was feeling it (pause). It was just pains in the chest and back and neck and arm and I said “this is all the symptoms.” And before I went to bed I said to my older daughter, Baby you know if something is wrong with Mom to call 911 right? And she said “yea I do, what’s wrong?” I said, well I just don’t feel good and you know if you ever get up and something’s wrong you just know to call (pause). I didn’t tell my husband. I just didn’t tell him.

Lack of knowledge. Several participants did not know they were at risk for heart disease or that their diabetes put them at risk for heart disease. As mentioned before, they felt that if their HCP did not tell them explicitly that they had heart disease, they did not have it. Many times when asked about the risk of heart disease from diabetes they would say “I don’t know, I just don’t know.”

Overall, participants seemed to believe that if they had heart disease they would experience pain or that maybe they would not even know if they had heart disease. Repeatedly, participants expressed that the only way they would *know* they had heart disease was if their doctor told them. They also did not link disease processes such as heart failure with heart disease or recognize the important links between diabetes, hypertension, and heart disease.

Not Claiming Diabetes and Heart Disease

This category of *claiming* diabetes and heart disease, which seems to affect the way a woman addresses her illness, developed in the initial phase of the study. Many participants stated that they did not want to claim the risk of heart disease or cancer. Since this was an unknown phenomenon for the researcher, a literature

review was completed. No references to the issue of claiming were found in the literature. Claiming was explored specifically during the semistructured interviews. Claiming is linked to faith and may be a stronger influence in some people than others.

Not claiming versus denial. According to the participants in the semistructured interviews, if the woman has a strong faith, she may fluctuate between denial of the disease and *not claiming it*. Claiming may affect the identity the woman forms with the disease in that she may ignore her symptoms, or give them over to God, rather than see the symptoms as warning signals of other problems. Claiming does not seem to affect self-care, but may affect perception of risk for CHD. One participant explains, “there is a fine line between not claiming and denial.”

Through analysis of these interviews, it was found that the women may not claim diabetes or heart disease, but that did not mean they eliminated self-care that would treat or prevent problems from the illnesses. They wanted to prevent complications as they understood them, so they tried to adhere to their regimen as best they could, considering the barriers they were facing.

In one situation, the participant described denial by saying she only believed she had diabetes after checking her blood sugar many times. It was the “the machine and the needles (glucometer readings)” that proved to her she had diabetes.

Another participant relates her experience with denial:

But yes, I was like all the rest of them. I was denying that I had diabetes knowing that I did, but I denied it. And then, I just sat down one

day and I said Lord, let me help you, help me to accept the things I cannot change, and that's how I learned to start dealing with it.

Another participant described claiming as “looking at the negative versus the positive” and also related “healing and not claiming” in the following way:

The healing comes because I believe God will heal my body. But I also believe He doesn't heal me for me to go back and do the wrong things again. Because I defile my body when I do things that go against it. So I believe that if I try to continue to do the right things God will give me long life.”

Having beliefs such as these could affect the way a person views future *consequences*, the *timeline* of diabetes, and could affect interpretation of information like mortality statistics on diabetes and heart disease, as well as perception of risk for further illness.

Challenges of Diabetes

In the third major category, the participants offered several viewpoints about the challenges they face daily. A question related to their daily challenges was used to begin the interviews and help guide the discussion. As they talked, their challenges became evident and they focused on the challenges that were hardest for them personally. All six interview participants discussed the challenges of managing their daily regimen and staying safe, which included caring for self, using and buying medications, costs and finances, eating and dieting, exercising, stressing, feeling down or depressed, knowing about diabetes, and working with their HCP.

Managing the daily regimen and staying safe. The participants talked about trying to avoid low and high blood glucose levels and what that meant to their eating habits and work schedules. One participant worked early hours and was on insulin. Her challenge related to staying on a schedule and being safe on her medication. She believed that it was dangerous for her to not eat and be on insulin because her HCPs had instructed her about this issue. She felt conflicted because she knew she needed to lose weight but she also “loves to eat.”

Another participant, whose blood glucose levels were elevated above 500mg/dl, per her report, found physical symptoms a challenge. She attributed symptoms such as “my hands feel numb, it makes me not want to move. It makes me slowful. It makes me not active” to insulin.

Another aspect of this challenge that participants discussed is managing other illnesses and medication regimens along with managing diabetes. One participant described her diagnosis of diabetes as a terrifying experience that has caused her a lot of anguish because she now has to manage blood thinners and blood sugars. Even though it seemed she was focusing on strict management of both conditions, she stated could not believe that she had *sugar*.

Other participants had several conditions such as spinal injuries and blindness that affected their ability to engage in exercise to help keep their blood glucose levels down. They felt managing an exercise regimen was very challenging and was not something they did daily.

Another perspective of managing the daily regimen was trying to pay for food, doctor visits, and medication when experiencing job loss or even when working and having multiple obligations. Participants discussed the need for help with medications that were very expensive. They also discussed wanting more information on new treatments that might work better for them from their HCP.

Support

The fourth major category that participants identified was support from their faith, friends, and family. Some participants did not use their biological family support as much as they used their church family for support.

Support from the faith community. Friends and family are a support to those who have built a support system or used the support system that existed for them. Several women spoke of the faith community as a part of their support. They described how prayer helps them feel better and gain strength to accomplish self-care. They sometimes engage their family members in the regimen by having them eat healthier on a daily basis to make the challenges less daunting. They described a love of their church family and looked to them for support in daily life and medical matters. Even when the participants are on fasts for religious reasons, they look to their pastors or pastors' wives to help them decide about medications and being faithful while staying well (Abrums, 2004; Samuel-Hodge et al., 2000, 2006). Several participants acknowledged that many women do not want to talk

about their diabetes, but that since they have learned to talk with others about diabetes they find it helpful and supportive in meeting their everyday challenges.

Balance

The fifth major category that emerged was that of balance and staying positive. The women were able to describe how they coped and maintained their positive outlook on life through all the challenges of diabetes.

Staying upbeat and staying positive. Participants talked about losing weight and being able to reduce their medication, which in turn would help them to feel better physically. The description one woman used was that “you are damned if you do and damned if you don’t” referring to the situation of losing weight and then not being able to afford new clothes that would fit her better if she did lose weight.

Several participants used friends and church family to help cope with the depression and discouragement, and talked about how important it was to stay positive and stay upbeat in their daily challenges with diabetes. The literature identifies the important issue of depression in women with diabetes (Lustman, Penckofer, & Clouse, 2008; Penckofer, Ferrans, Velsor-Friedrich, & Savoy, 2007). Research has also found that depression may accelerate the development of CHD in women with diabetes (Clouse et al., 2003).

Managing stress. Participants discussed beliefs about stress and how stress had a major effect on their self-care of diabetes. Stress came from various sources. Some of the stressful situations and sources were being caregivers, living

situations, managing work and the need for self-care, and simply just doing everything you should do to stay healthy with diabetes. One participant stated:

It may be the effects of stress that keep you from looking after yourself like you are supposed to. I don't really know how it works, but I find that if I have too many things going on mine (blood sugar) really gets out of whack when I have too much going on.

Doing it all. As for the challenge of *just really trying to do it all*, participants described how difficult it is for people with diabetes to do all of the “things” they are supposed to do on a daily basis just to keep blood sugars down, stay healthy, and feel good. They described how difficult it is to *stay on track* or *keep at a level* when trying to manage their blood glucose levels.

Choices. The women discussed the struggle of giving up the things they see as images of heart disease. One woman described fast food as her image of heart disease because of the fat and cholesterol in fast food burgers. She talked about her choices of turkey instead and how it helped her to balance what she was trying to do to prevent further illness. She talked about exercise and having asthma along with her other diagnoses as other parts of the equation she had to balance.

Major Categories and their Relationship to the Common Sense Model

The second section of the analysis involved examining what the interviews added to the analysis of the research questions and their application to the CSM. The first research question was enhanced by information from the interviews that described how the women viewed symptoms. Identity involves the symptoms the

woman experiences. Consequences are somewhat related to identity in that the woman may see the consequences as worse if she has more symptoms.

When asked about the relationship between stress and heart disease, the participants voiced complaints of tiredness and not really knowing if that was from heart disease or other problems such as diabetes. They also related stress from situations like losing their jobs and not being able to afford medications and supplies.

Other symptoms participants identified were not having “sores” and not feeling “blurry headed or dizzy headed.” They did not connect dizziness to heart disease but did believe that being thirsty or hungry and having a dry mouth were symptoms related to diabetes.

The women talked about leg pains and fatigue as problems from their diabetes. One participant discussed how she would never want to be on dialysis because her mother had been on it and she did not want to have dialysis as a treatment. She was a 47-year-old woman with children and she was not sure if she could follow through with a treatment that would prolong her life because she perceived dialysis to be “the last straw.” She was particularly sensitive about having her finger pricked for her blood sugars. Perhaps her perception of the pain that could be involved in dialysis was too much for her to handle emotionally.

One participant linked God and common sense when asked about claiming and her religious beliefs. She did not want to claim diabetes, heart disease, or heart

failure. When she was asked about how she managed to adhere to religious customs such as fasting and keep her blood glucose under control, she stated, “God gives us common sense too.”

Struggles when diagnosed. The women discussed perceived causes of diabetes when they talked about how their diabetes started. Several of them pointed out how their HCPs did not diagnose them in a timely manner. One participant talked about how she had to ask her physician several times to check her for diabetes. She was encouraged to follow through with her family physician by her “eye doctor” to get the testing completed. Another participant described that when she was diagnosed, she had to remind her HCPs to let her know her results.

The relationship with HCPs proved to be important to how successful the woman felt about controlling her diabetes. The women’s responses defined *good* and *poor* relationships. A good relationship existed when the woman could ask questions and the HCP provided the answers. In the good relationship, the woman described her ability to control her diabetes. A poor relationship was one where the participant expressed feelings of stress and anxiety in handling her diabetes. A poor relationship was when there were never any new or different treatment approaches prescribed that could help the woman manage her health more effectively without costing her more money.

Consequences. Although consequences of diabetes only focused on heart disease in the semistructured interviews, some participants discussed the “what

if's" related to not having diabetes or hypertension, or not having to stay on their medications any longer. One woman said that losing the weight that she had carried for so many years would be as gratifying to her as not having diabetes any more. She knew, however, that both were very hard for her to accomplish. Most women felt there were some consequences that would be harder for them than others. One participant described that a frightening consequence for her was the possibility of dialysis. She had observed her mother on dialysis and did not want to be in that condition. She felt she could not tolerate dialysis, even if she needed the treatment at an early age (she was 42 years old).

Causes. One participant talked about worry from a job loss causing her diabetes to occur. Other participants talked about stress as a contributor to developing diabetes. Another connected her cause of diabetes to family members having it. She also felt she was more at risk because she was overweight.

One participant had an interesting account where she said she was thinking about someone else who had diabetes and then she was diagnosed with diabetes. She really could not explain much more about "the thinking" but she believed her thoughts had some effect on the cause of her diabetes diagnosis. This woman had several familial and physical links that could cause diabetes that she did not identify as priority causes for her diabetes. She also had a diagnosis of depression per her report.

Timeline. The interviews did not explore the timeline of diabetes and heart disease directly, but there were some responses as to how long the participants felt it took to develop heart disease and diabetes. One participant said her ophthalmologist told her she may have had diabetes for 10 years before she was diagnosed. Another participant, when talking about the timeline of heart disease said, "I think it comes pretty quick. I think maybe you don't know you have it and then something happens and BAM it is right there on you! And your diet...another big thing is not eating right that has a lot to do with it too."

Control. The issue of control prevailed in participants' responses. The women discussed the sometimes hour-by-hour work of keeping their blood sugar under control. The women talked about exercise again with reference to control and how, if they could make themselves exercise, they knew it helped them control their blood sugars. Those who did not worry as much about their diabetes seemed to have integrated the exercise piece successfully into their lives. Control seemed to be focused more on how they controlled their glucose levels than having control over their life, although several participants discussed control in their lives also.

One woman described diabetes and acceptance in this way:

Now it don't bother me. I have learnt to accept that I am diabetes type 2. I can't change it. I can't fix it. The only person that can fix that is God. All I can do is to walk, stay in shape and eat the foods that I am supposed to eat. That's how I look at diabetes now.

Another participant described her dilemma with maintaining control of her life and her diabetes in this way:

You have a lot of people telling you what not to do, but the support system that you need also needs to help you with things to do. I got enough of family saying don't eat this don't eat that. Everybody is ready to take away something.

The frustration of trying to keep control of her life was evident in the way this participant discussed control and support.

When talking about control, the participants directed their responses at specific aspects of control. Whether it is blood sugar control or controlling their urges to eat, they voiced concerns about both treatment and personal control. They also voiced concerns related to the consequences of their illness and the potential outcome of their health because of diabetes. It was difficult for them to make the links among the areas of timeline, identity, control, cause, and consequences, although they did seem to wonder about symptoms and how the symptoms related to their diabetes.

The second research question was addressed through the discussion of money and job loss, even with education.

Barriers to self-care. Several of the participants either had lost their job or had financial problems even though they worked. They talked about not having energy, which could be from depression or from worsening diabetes. They worried about affording the things they needed when their diabetes got worse and they lost their

jobs. Several participants discussed choosing between food and medication when their money was short. Several reported that they did not return to their HCPs because they could not afford the charge for a visit and medication too. One suggested using electronic communication instead of physically going to the physician so time would not be lost from their job. Another participant asked, "Why do health care providers not offer more samples for people who are struggling to pay for everything?" The woman felt she should not have to ask for samples every time she went. Her feelings were that HCPs should know more about patients' needs.

The third research question was addressed through the responses about heart disease, diabetes, and the IR domains. Knowledge of heart disease and diabetes was enhanced by their lack of connection. The IR domains were enhanced through discussion of how their illness began and the daily challenges they faced.

Lack of perception of risk. Multiple responses in the interviews related to heart disease, diabetes, and the HCP's role. The responses support the importance of the HCP's role and the participant's processing of information. The participants were genuinely unsure about the diabetes and heart disease connection. They had some information but did not express that they felt confident in what they knew about the risk of heart disease from diabetes. They wanted to talk about hypertension because they had more information about hypertension and knew it presented a risk to them as AA women with diabetes. They discussed the role of

stress and hypertension, and the possibility of stroke. They believed the things they were trying to do to enhance their health would help them be less at risk for other disease, including heart disease, in the future. Their responses depicted the connection between symptoms, medications, and the participants' views of heart disease. The participants were able to describe what they understood about heart disease; however, in many cases their understanding was more about hypertension than heart disease.

The fourth research question was enhanced by the participants' responses related to staying positive and staying "upbeat."

Optimism and faith. In several instances, the responses given during the discussion were about trying to avoid depression, negativity, or pessimism. The women discussed staying busy and "not getting down." One participant related optimism to faith by saying,

What people have to realize especially in the Faith community is it's ok to hurt and it's ok to be down. It's just not ok to stay there. It's a difference in not having hope and just staying in that place. And feeling down and depressed or discouraged about something. It's a big difference. You can get angry but don't stay that way.

Most of the interviewees related optimism to their faith. They looked to their faith to provide the optimism and strength they needed to continue their daily quest for balance in life and health.

Regarding research question 5, the interviews provided further information about perceptions of diabetes, staying optimistic, and personal stories in which women discussed their beliefs about diabetes and heart disease.

Predicting perception of risk for coronary heart disease. Participants who had more familial experience (i.e., a family history) seemed to have an adequate perception of risk for CHD; however, their preventive practices were similar to those who had no to low risk perception. All participants seemed unsure of the accuracy of their knowledge of diabetes, and how much “at risk” they were personally for another chronic illness such as heart disease.

In summary, the participants in the in-depth, semistructured interviews discussed different challenges and different experiences after being diagnosed with diabetes. They all felt unsure about their future and how to stop the cascade of problems, one of which is heart disease, which comes from having diabetes and being an AA woman. They expressed concern about what they knew and did not know about heart disease and diabetes in general. Overall, they knew they were doing the best they could do at that given time, though they expressed concern that staying positive and maintaining a balance was important to success. The results show how spiritual, situational, and health care difficulties influence how a person responds to diabetes and the perception of risk for CHD.

CHAPTER V

DISCUSSION

Survey of Major Findings

Diabetes and the Perception of Risk for Coronary Heart Disease

The majority of women in this study felt they were not at risk for heart disease because of their diabetes. Being AA females, they felt they were at risk for hypertension but not necessarily heart disease. Women who had positive family histories of heart disease or stroke indicated a higher perception of risk for CHD than those who had no positive family history. This finding is consistent with the findings from studies relating family influences upon the individual with diabetes (Scollan-Koliopoulos, O'Connell, & Walker, 2005, 2007). Researchers describe the *legacy of diabetes* that comes from an individual's family history. The influence of a person's legacy of diabetes may affect self-care positively and enhance self-care, or may affect self-care negatively and impair the ability to perform self-care. It is logical that the legacy could influence the perception of risk for heart disease also, if the affected family member recognized the connection between diabetes and heart disease.

Overall, the women did not make a connection between having diabetes and having an increased risk for CHD. In many cases, although they reported a history of heart failure, they did not connect heart failure and heart disease. Their basic understanding of heart disease and heart failure was not adequate for them to make the link between diabetes and CHD. Several participants said "I just don't know" when asked about the risk of heart disease. If their HCP did not tell them specifically they were at risk for heart disease, or that they have heart disease, they did not see themselves at risk.

These findings support studies of women and heart disease conducted by Legato et al. (1998) and Mosca et al. (2000, 2004). Women, in general, do not perceive themselves at risk for heart disease and will often delay seeking treatment for symptoms that are vague and different from classical heart attack symptoms. Persons with diabetes even may delay treatment if they have classic symptoms of MI or other cardiac events (Banks & Dracup, 2006).

These findings are supported by a study from Broadbent et al. (2006) who examined perception of risk for future MI in persons who had a recent MI. In this study of 96 men and women, researchers found very low risk perception for future MI in those who had an actual high risk for repeat MI. The actual risk was based on MI risk scores calculated from participants' physical data. This dissertation study is unique from the above studies in that perception of risk for CHD was studied

specifically in Southern AA females with T2DM--an understudied, but high-risk population.

Comparative Risk Perception

When asked how they felt their chances were of developing heart disease as compared to others of their same age and race, those with low risk perceptions for CHD also had low risk perceptions when comparing themselves to others.

Participants with higher risk perceptions for CHD did not appraise themselves to be at greater risk than others of their same age and race. These findings are similar to findings from Leventhal's work with women with cancer (Leventhal et al., 1999). In the work of Leventhal et al., it was found that when comparing actual risk to perceived risk, women tended to underestimate risk when treatments were deemed effective.

Although women with diabetes who are obese have a greater risk of cancer (Tilghman, 2003), the participants in this study had similar responses for the question comparing cancer risk as the question for the risk for heart disease. Participants generally felt their risk for cancer was as great as their risk for heart disease.

Personal Characteristics and Perception of Risk

One of the initial questions for the study related to how personal characteristics such as age, income, education, and duration of diabetes affected the woman's perception of risk for CHD. Although these personal characteristics did not

demonstrate statistical significance in their effect on perception of risk for CHD, there were some characteristics found that did influence perception of risk for CHD.

Women who knew their highest BP indicated a higher risk perception of risk for CHD. Those who did not know their highest BP or their last BP did not perceive themselves at risk for CHD. Those participants with a low perception of risk for CHD did discuss the problem of high BP in AAs. Hypertension in AAs has been in the mainstream media for years, and the message of the risk of high BP for stroke has been well-recognized in the AA community, as indicated by the responses of participants in this study. The finding of “identifying with a symptom or a number” is supported by Leventhal’s work on IR that showed the importance of a symptom or a label in connecting to an illness and forming the representation of that illness (Leventhal, Leventhal, & Cameron, 2001). .

Studies have shown also that when a person has more severe symptoms, such as with the onset of an MI or with the onset of diabetes, the stronger their appraisal of the need to seek treatment (Petrie & Weinman, 1997). In forming a perception of risk for CHD, the participant would have to experience symptoms that could be interpreted as an MI in order to make the connection. One participant in the qualitative phase discussed her symptoms of a possible MI that she did not act upon because she labeled the symptoms as anxiety, not cardiac-related, although she had a high perception of risk for CHD.

Support for the Common Sense Model

The CSM proposed by Leventhal et al. explains that individuals appraise their beliefs and knowledge about an illness to form their view of that illness. Many women did not have extensive information about heart disease risk and T2DM, so making an appraisal was more difficult for them.

Overall, use of the CSM to form IRs of diabetes by AA women was supported in this study. Stress was not measured in this study but was identified as a concern related to diabetes and BP in both phases of the study by the participants. Stress is associated with Leventhal's coping portion of the CSM. Coping is used in making an appraisal of the risk from an illness (Kelly et al., 2005). Participants connected stress to interactions with superiors in employment situations, money constraints, and causes of diabetes. Participants identified that managing stress and staying upbeat was important to their health.

The use of optimism seems to be relevant in that some participants used it to avoid depression, while others may have overused optimism to avoid or deny the issues they faced with their diabetes. This concept, known as optimism bias, is difficult to measure. It might have been beneficial to have measured optimistic bias as part of the study in order to determine how it influences health decisions in this population.

Linking the Common Sense Model to Perception of Risk for Coronary Heart Disease

The appraisal portion of the CSM becomes evident as the women related their health issues and the problem of high BP. Most women could explain the problem with hypertension and the connection between high BP and stroke. Women who had low perception of risk for CHD appraised their diabetes to be controllable, but did not have adequate knowledge of the complications of diabetes. Stress affects an individual's appraisal of their health or illness (Cameron & Leventhal, 2003). If the stress is perceived as severe, the symptoms a woman experiences can be attributed to the stressful event or situation rather than to the disease (Cameron & Leventhal, 2003). If the perception of risk for CHD is low, the appraisal may not include processing physical symptoms as potential cardiac-related symptoms because of this reasoning.

Findings Regarding Illness Representation

Control is a part of the perception of diabetes that was significant in this population. Regardless of their symptoms, the participants overall felt they had control of their diabetes and that the treatments were working. In the follow-up interviews it was found that the women had some concerns about how their diabetes was evolving, although they felt positive about their treatment and how they were managing their regimen.

The consequences of diabetes must be severe for the woman to experience negative feelings about her diabetes. Symptoms increase the severity of diabetes. Women in this study often did not know if the symptoms they were experiencing were or were not related to diabetes.

Symptoms are related directly to the identity the woman forms with her diabetes. If the symptoms are not associated clearly with her diabetes, she may not form an identity with the disease. Helping Southern AA women learn more about the symptoms related to diabetes will help them better identify with diabetes and increase their understanding of the risk for CHD.

Causes of diabetes were consistent with other studies. Heredity and dietary issues were high on the list of causes for this population. Education regarding methods of changing the typical Southern diet to a lower fat, lower carbohydrate, and lower sodium diet continue to be essential for this population.

Claiming and Not Claiming

Several of the participants who indicated a low to medium perception of risk for CHD, answered the question--“What do you think are the chances that you will develop heart disease?”--with the response: “I don’t want to *claim* the risk of heart disease.” “Not claiming” an illness is described by participants in this study as trusting God fully for the healing of an illness. Not claiming does not mean, however, that women do not follow through on their regimens of self-care.

Not claiming diabetes or heart disease may influence the perception of risk for CHD in that the woman may not accept her risk for another illness, even if she accepts her diabetes. Her faith may offer her healing and by “not claiming” she proclaims her faith in God. To HCPs who do not understand not claiming an illness, it might seem the woman is being noncompliant or that she is denying her illness. The key to not claiming is assessing whether or not the woman with diabetes follows her regimen and adheres to self-care needs in order to manage her diabetes.

Not claiming is a faith-based phenomenon. The impact of not claiming an illness is not understood fully from the brief explanations in this study, and should be explored further to determine how it influences decisions about health, preventive behaviors, and its cultural specificity.

Not claiming was not only significant to the findings of the study, but also to recruitment. Some women told the PI's colleagues who were recruiting for this study that they were afraid to talk about their diabetes. Perhaps this response was based on the assumption that “talking about an illness or disease may cause it to come to life.” This type of thinking was described by one participant in her description of how she was diagnosed as having diabetes. She said, “I was just thinking of someone having diabetes and then I had it.”

The qualitative findings showed that claiming or not claiming may be a powerful force in this population. Future studies should explore whether or not this

phenomenon extends beyond health issues, adversity and AA women to other groups.

The Revised Model of Perception of Risk for Coronary Heart Disease in African American Women with Type 2 Diabetes Mellitus

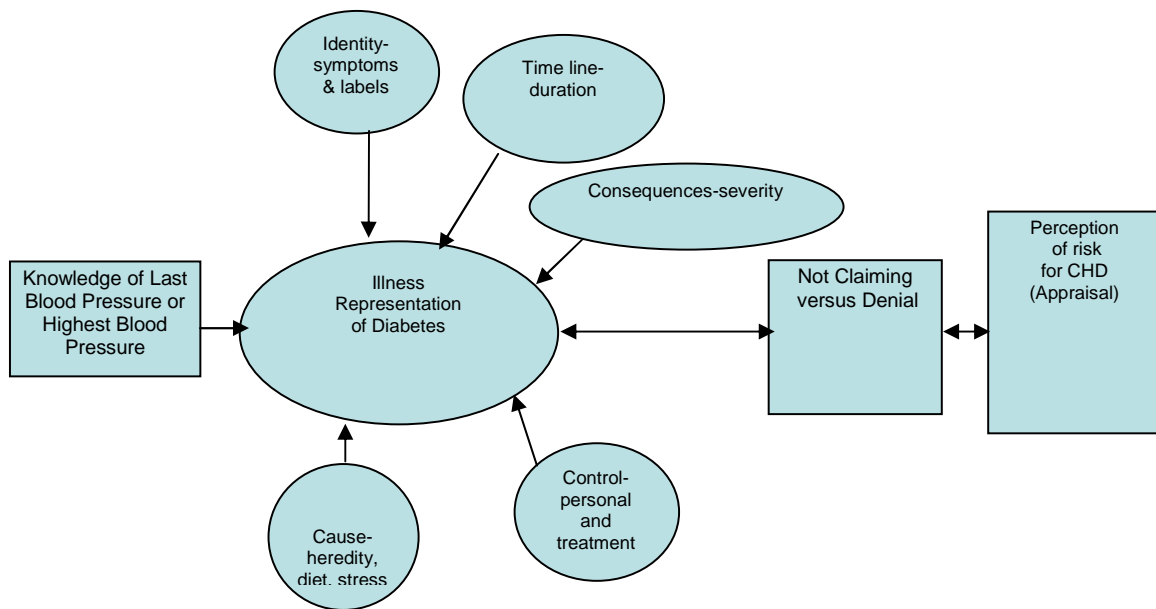
After analyzing the data from this study the following adaptations were made to the conceptual model depicting Perception of Risk for CHD in AA Women with T2DM. The revised model includes the concept of not claiming and specifies the components identified in the study that influence the perception of risk for CHD in AA women with T2DM (Figure 4).

Cost and Finances

Some issues may not be statistically significant, but may be clinically significant to participants. One of these issues is lack of financial resources for diabetes medications that may come with job loss or with progression of the illness. Three of the six interviewees discussed monetary issues. Two interview participants had lost their jobs, one due to a plant closing, and the other due to comorbidities resulting in her employer not holding her job position open for her. The third woman remained employed, but struggled to have enough to pay for her medications. This finding may have occurred because the women who receive disability or Medicaid are able to afford their medications and supplies, but perhaps not other life necessities. Women who are currently employed seem to be able to afford some life necessities, but not everything they need, including medications.

Figure 4

The Revised Model of Perception of Risk for coronary heart disease in African American Women with type 2 diabetes mellitus



Mixed Methods: Enhancing the Findings

Mixed methods analysis includes combining the information gained through quantitative inquiry with the results from qualitative inquiry to form an enhanced paradigm about the research topic. Data from the semistructured, in-depth

interviews enhanced the initial information. Semistructured interview data integrated further knowledge of risk perception and IR into the analysis of all the research questions. Further insight was necessary to understand the motivators and belief systems that influence the development of risk perception. Information about beliefs was valuable because underlying beliefs related to control, cause, and consequences of the diseases may influence behavior change (Cameron & Leventhal, 2003).

Both the quantitative and qualitative data yielded information about the importance of patients' beliefs, including claiming, and how their beliefs affect disease outcomes. Semistructured interviews provided data beyond that gleaned from the questionnaires and records of patients' reported information. According to Sandelowski (2000), combining data analysis at the *interpretative level* is an example of *expanding the scope* of the study.

Sandelowski (2000) also suggests that the varying paradigms from which a researcher approaches a study affect the way in which the researcher interprets the results. The question she poses is whether or not the researcher can hold two separate views that fully support both quantitative and qualitative paradigms (Sandelowski, 2000). She also proposes that paradigms remain separate in that scientific inquiry is a "framing of inquiry in two or more worldviews" (Sandelowski, 2000, p. 247).

In this study, the PI tried to separate her biases from the data when the two types of data merged at the conclusion of the study. Influences from the quantitative phase of the study included knowing the woman's perception of risk for CHD and her level of connection between CHD and diabetes. All other quantitative data was purposefully not reviewed prior to the follow-up interviews in order for the PI to remain as objective as possible.

Another strength of the use of multiple paradigms is that stronger, multiple inferences come from their use (Tashakkori & Teddlie, 2003). Multiple inferences complemented each other and thereby addressed multifaceted and complex social situations or interaction-based conditions (Tashakkori & Teddlie, 2003). Considering the potential future impact of this study's information on the care of AA women with T2DM, this method was imperative when exploring multiple inferences.

Without the use of mixed methods in this study, the findings would not have been as rich. The explanation of the quantitative findings would have been scarce and not as expansive. Because mixed methods were employed, the communication gap between HCP and patient was exposed and the lack of connection between the risk of CHD and diabetes was explained to a greater extent. The challenges of diabetes were depicted as one of the greatest problems AA women face. If perception of diabetes had been measured without the in-depth interviews, the data would have been incomplete.

Because of the follow-up interviews, it is known that religion and faith may play a role in the formation of risk perception and affect the way an AA woman perceives risk. Also known is that AA women use the CSM to make risk appraisals when they have sufficient information.

Acknowledgement of personal biases are always important when using qualitative research. In this study, personal experiences with the population through other studies gave the researcher insight into the problems they face. Use of genuineness and acceptance worked well, as no participants refused to participate in the follow-up interviews.

This study involved AA women between the ages of 30 and 65 years. Therefore, women of other ages may or may not have similar responses. The study examined beliefs of Southern AA women. Some of the cultural issues may be specific to Southern culture and may not be generalizable to AA women in other parts of the US.

Implications for Practice

Implications for HCPs are that women may not consider themselves at risk unless they are told directly they are at risk by their HCP. Direct discussion with patients and follow-up educational offerings after these direct discussions can help AA women better understand the connection between diabetes and CHD. The women in this study who had follow-up interviews had often talked to their HCPs after the initial interviews with the PI. The initial interviews had raised questions for

the women that they addressed with their HCPs. Raising the questions and giving people support to ask questions of their HCPs is important in empowering people with diabetes.

Assessment of the woman's faith and the influence of her faith upon her health practices is important in clinical practice. In addition, HCPs should understand the challenges women with T2DM are facing and advocate for them so they can be successful in self-care. Foremost, HCPs should instruct AA women with T2DM about their risk for CHD and its prevention.

Conclusion and Future Implications

This study demonstrates that the issues surrounding diabetes and CHD are complex. Analysis of the domains of IR gave information about the interrelationships that exist in this population between perceptions of diabetes and risk of CHD. Qualitative data further enhanced information about how the components interrelate.

The study also gives HCPs further insight into the strategies they may use to address the needs of their AA female patients with diabetes. Acknowledgement of the risk the women face for CHD as a result of their diabetes is imperative for HCPs. The findings of the study will give HCPs, especially diabetes educators, valuable insights into the way risk perceptions are formed in women at high risk for the development of heart disease. By increasing the knowledge of disease perception and risk information, HCPs can develop more appropriate interventions

and treatment plans and aid in the design of culturally appropriate and gender-specific action plans for AA women with T2DM. The message about elevated BP is reaching this population, but more needs to be done to communicate how AA women can best prevent the potentially fatal effects of CHD.

Future use of these findings may aid further development of the Theory of IR and the CSM. The application of cultural perspectives to the CSM may provide insight into portions of the model that need further expansion and explication.

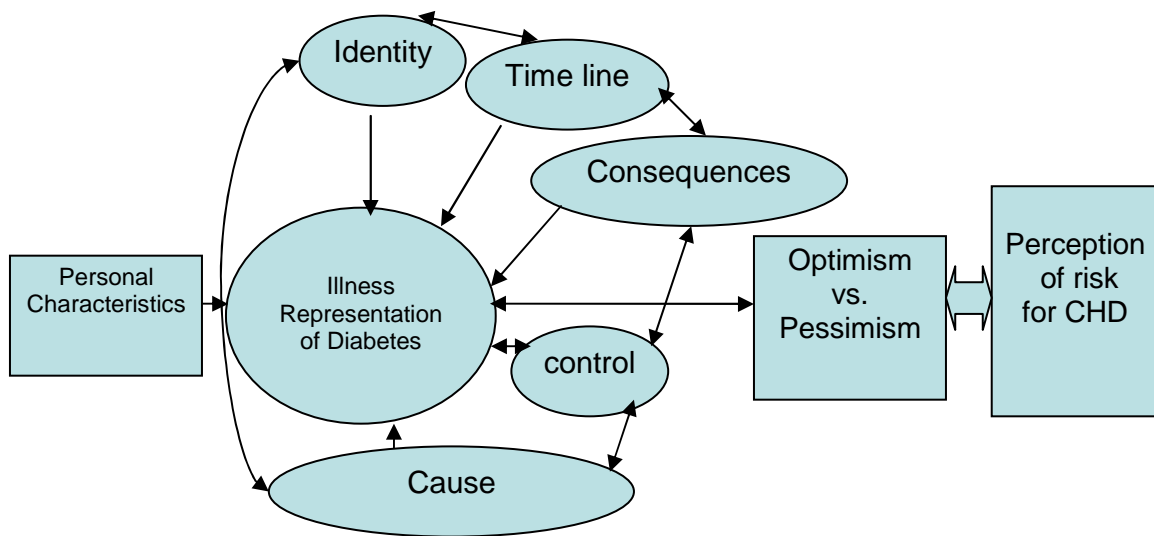
Future studies should address the issue of claiming and its influence on other populations, as well as interventions to help AA women understand the diabetes-heart disease connection and personalize it to their lives. Nurse-directed interventions that empower women with T2DM should be a focus of future studies.

Summary

In summary, HCPs need to be sensitive to cultural interpretations of health and illness. In particular, they need sensitivity in the way they communicate with patients around issues of risk for disease. Health care providers should explore issues related to health literacy and health numeracy in addition to communication style. Health care providers should be aware also of the important role of spiritual beliefs, as they may affect health care practices. Health care providers should explore innovative approaches to the delivery of care so that receiving care is not a burden in itself.

APPENDICES

APPENDIX A.



**Model for Perception of Risk for CHD in AA
Women with T2DM**

APPENDIX B.
Illness Perception Questionnaire-Revised
Your Views About Your Diabetes

Listed below are symptoms that you may or may not have experienced since your diabetes. Please indicate by circling Yes or No if you have experienced any of these symptoms since your diabetes, and whether you believe these symptoms are related to your diabetes. You may skip any question you feel uncomfortable answering.

	I have experienced this symptom since my diabetes		This symptom is related to my diabetes.	
	Yes	No _____	Yes	No
Pain	Yes	No _____	Yes	No
Sore throat	Yes	No _____	Yes	No
Nausea	Yes	No _____	Yes	No
Breathlessness	Yes	No _____	Yes	No
Weight loss	Yes	No _____	Yes	No
Fatigue	Yes	No _____	Yes	No
Stiff Joints	Yes	No _____	Yes	No
Sore eyes	Yes	No _____	Yes	No
Wheeziness	Yes	No _____	Yes	No
Headaches	Yes	No _____	Yes	No
Upset stomach	Yes	No _____	Yes	No
Sleep difficulties	Yes	No _____	Yes	No
Dizziness	Yes	No _____	Yes	No
Loss of Strength	Yes	No _____	Yes	No

We are interested in your own personal views of how you now see your current diabetes.

Please indicate how much you agree or disagree with the following statements by checking the appropriate box. You may skip any question you feel uncomfortable answering.

	VIEWS ABOUT YOUR DIABETES	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
IP1	This diabetes will pass quickly.					
IP2	I expect to have diabetes the rest of my life.					
IP3	My diabetes is a serious condition.					
IP4	My diabetes has major consequences on my life.					
IP5	My diabetes does not have much effect on my life.					
IP6	My diabetes strongly affects the way others see me.					
IP7	My diabetes has serious financial consequences.					
IP8	My diabetes causes difficulties for those who are close to me.					
IP9	There is a lot I can do to control my symptoms.					
IP10	What I do can determine whether my diabetes gets better or worse.					
IP11	The course of my diabetes depends on me.					
IP12	Nothing I do will affect my diabetes.					
IP13	I have the power to influence my diabetes.					
IP14	My actions will have no affect on the outcome of my diabetes.					
IP15	My diabetes will improve in time.					
IP16	There is very little that can be done to improve my diabetes.					
IP17	The negative effects of my diabetes can be prevented (avoided) by my treatment.					
IP18	My treatment can control my diabetes.					
IP19	There is nothing which can help my condition.					
IP20	The symptoms of my condition are puzzling to me.					

	VIEWS ABOUT YOUR DIABETES	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
IP21	My treatment will be effective in curing my diabetes					
IP22	My diabetes is mystery to me.					
IP23	I don't understand my diabetes.					
IP24	My diabetes doesn't make sense to me.					
IP25	I have a clear picture or understanding of my condition.					
IP26	The symptoms of my diabetes change a great deal from day to day.					
IP27	My symptoms come and go in cycles.					
IP28	My diabetes is very unpredictable.					
IP29	I go through cycles in which my diabetes gets better and worse.					
IP30	I get depressed when I think about my diabetes.					
IP31	When I think about my diabetes I get upset.					
IP32	My diabetes makes me feel angry.					
IP33	My diabetes does not worry me.					
IP34	Having diabetes makes me feel anxious.					
IP35	My diabetes makes me feel afraid.					

Reference: Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L.D., & Buick, D. (2002). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*. 17, 1-16.

CAUSES OF MY DIABETES

We are interested in what you consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by checking the appropriate box. You may skip any question you feel uncomfortable answering.

	Possible Causes	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
C1	Stress or worry					
C2	Heredity- it runs in my family					
C3	A Germ or Virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care In my past					
C7	Pollution in the environment					
C8	My own behavior					
C9	My mental attitude (i.e. thinking about life negatively)					
C10	Family problems or worry					
C11	Overwork					
C12	My emotional state (feeling down, lonely, anxious, empty)					
C13	Aging					
C14	Alcohol					
C15	Smoking					
C16	Accident or Injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you think caused YOUR diabetes. You may use items from the box above or you may use additional ideas of your own.

The most important causes for me:

1. _____

2. _____

3. _____

APPENDIX C.

Perception of Coronary Heart Disease Risk Questionnaire-PORQ

Please circle the answer that best fits what you believe. Skip any you do not feel comfortable answering.

1. What do you think your chances are of developing heart disease?	None	Low	Medium	High	Very High
2. What do you think your chances are of developing cancer?	None	Low	Medium	High	Very High
3. How much do you think diabetes affects whether or not someone gets heart disease?	None	Low	Medium	High	Very High
4. What do you think your chances are of developing heart disease as compared to other women of your same age and race?	None	Low	Medium	High	Very High
5. What are your chances of developing cancer compared to someone of your same age and race?	None	Low	Medium	High	Very High
6. What are your chances of having an automobile accident as compared to someone else of your same age and race?	None	Low	Medium	High	Very High

Scoring 0-4

References:

- Mosca, L., Ferris, A., Fabunmi, R. & Robertson, R. (2004). Tracking women's awareness of heart disease: an American Heart Association National Study. *Circulation*, 109, 573-579.
- Walker, E., Mertz, C., Kaltzen, M. & Flynn, J. (2003). Risk perception for developing diabetes: comparative risk judgments of physicians. *Diabetes Care*, 26 (9), 2543-2548.

APPENDIX D.

Life Orientation Test-Revised

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think

1. In uncertain times, I usually expect the best.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
2. It's easy for me to relax.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
3. If something can go wrong for me, it will.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
4. I'm always optimistic about my future.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
5. I enjoy my friends a lot.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
6. It's important for me to keep busy.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
7. I hardly ever expect things to go my way.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
8. I don't get upset too easily.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
9. I rarely count on good things happening to me.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot
10. Overall, I expect more good things to happen to me than bad.	I agree a lot	I agree a little	I neither agree nor disagree	I DISagree a little	I DISagree a lot

"most people" would answer. Circle your answer for each statement. Skip any you do not feel comfortable answering.

Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A re-evaluation of the Life Orientation Test. 67,1063-1078.

Patient ID# _____
Nurse Initials: _____

Date: _____ / _____ / _____
mm dd yyyy

APPENDIX E.
Exploring Perception of Risk for CVD in
AA Women with T2DM
Personal Characteristics Form

(You may skip any question you feel uncomfortable answering.)

A. Demographics

1. Name _____

2. Address _____

3. May we contact you by telephone? (1) Yes _____ (0) No _____

4. Contact telephone number _____

5. Age (in years) _____

6. Date of birth (mm/dd/yy) _____ / _____ / _____

7. What is your religious preference? (Check one):

- 1. _____ Protestant
- 2. _____ Catholic
- 3. _____ Jewish
- 4. _____ None
- 5. _____ Other (Specify: _____)

8. How much education have you had? (Check one)

RELIGION
(RECORD 1-5)

- 1. _____ Less than grade school
- 2. _____ Completed grade school (no high school)
- 3. _____ Completed middle (Jr. High) school (no high school)
- 4. _____ Completed some high school
- 5. _____ Graduated from high school (or have equivalency diploma)
- 6. _____ Completed a trade or technical program
- 7. _____ Completed some college
- 8. _____ Graduated from college
- 9. _____ Other (Specify: _____)
- 10. _____ Last grade completed: _____

EDUCATION
(RECORD 1-10)

Patient ID# _____
Nurse Initials: _____

Date: _____ / _____ / _____
mm dd yyyy

9. What is your marital status? (Check one)

- 1. _____ Single (never married)
- 2. _____ Divorced or separated
- 3. _____ Widowed
- 4. _____ Currently married

MAR_ST.
(RECORD 1-4)

10. How many children do you still have alive? _____

CHILD

11. What is your present living (residence) arrangement? (Who are you living with?)
(Check one)

- 1. _____ Live alone
- 2. _____ Live with children
- 3. _____ Live with spouse (or significant other)
- 4. _____ Live with children and spouse
- 5. _____ Children/ family live with me
- 6. _____ Other (Specify: _____)

LIVING
(RECORD 1-6)

12. What is your present place of residence? (Where are you living?) (Check one)

- 1. _____ My own home
- 2. _____ A rented home
- 3. _____ Apartment (rented)
- 4. _____ Senior citizen residence
- 5. _____ Other (Specify: _____)

PLACE
(RECORD 1-5)

13. Which of the following best describes your total yearly family income? (Check one)

- 1. _____ Less than \$10,000
- 2. _____ \$10,000 - \$14,999
- 3. _____ \$15,000 - \$19,999
- 4. _____ \$20,000 - \$24,999
- 5. _____ \$25,000 - \$29,999
- 6. _____ \$30,000 or more

INCOME
(RECORD 1-6)

Patient ID# _____
Nurse Initials: _____

Date: _____ / _____ / _____
mm dd yyyy

14. How do you presently pay for your health care? (Check all that apply)

1. _____ Medicare
2. _____ Medicaid
3. _____ Other insurance
4. _____ Co-payment (non-reimbursable)
5. _____ Co-payment (reimbursable)
6. _____ Uninsured
7. _____ Other (Specify: _____)

INSURANCE
(RECORD 1-7)

15. What is your present employment status? (Check one)

1. _____ Currently working (**continue with question 16 and 17**)
2. _____ Housewife (**omit question 16 and 17**)
3. _____ Disabled (**omit question 16 and 17**)
4. _____ Student; working part-time (1) Yes _____ (0) No _____ (**If yes, continue with question 16 and 17**)
5. _____ Retired (**omit question 16 and 17**)
6. _____ Currently unemployed (**omit question 16 and 17**)

16. Do you work full or part-time? (Check one)

1. _____ Full-time
2. _____ Part-time
9. _____ N/A

EMPLOYMENT
(RECORD 1-6)

FULL_PART
(RECORD 1,2,9)

17. How long have you been employed at your present job?

1. _____ Less than six months
2. _____ Six to twelve months
3. _____ One to four years
4. _____ Five years or longer
9. _____ N/A

B. Diabetes Care (Patient Self-Report)

TIME_JOB
(RECORD 1-4,9)

1. Do you take insulin injections?

1. _____ Yes
0. _____ No

INSULIN
(RECORD 0-1)

2. How many insulin injections are you supposed to take a day? (need times)

INS_RX

Patient ID# _____
Nurse Initials: _____

Date: _____/_____/_____
— mm dd yyyy

3. How many of your injections did you take in the last 7 days when you were supposed to?
(Check one)

1. _____ All of them (100%)
2. _____ Most of them (75%)
3. _____ Sometimes (50%)
4. _____ Occasionally (25%)
5. _____ None of them (0%)

INJ_COM
(RECORD 1-5)

4. Do you take pills to control your blood sugar?

1. _____ Yes
0. _____ No (**Skip to question 7**)

PILL_TX
(RECORD 0-1)

5. How often are you supposed to take your diabetes pills? (need times per day)

PILL_RX

6. How often in the last 7 days did you take your diabetes pills when you were supposed to?

1. _____ All of the time (100%)
2. _____ Most of the time (75%)
3. _____ Sometimes (50%)
4. _____ Occasionally (25%)
5. _____ None of the time (0%)

PILL_COMP
(RECORD 1-5)

7. What kind of diabetic diet has your doctor ordered for you? (Get ADA diet number;
any additional restrictions, e.g., sodium, cholesterol)

Total Calories: _____ (Fill in)

CALORIES

Sodium Restriction: _____ (1=YES, 0=NO)

SODIUM
(RECORD 0-1)

Cholesterol Restriction: _____ (1=YES, 0=NO)

CHOLESTEROL
(RECORD 0-1)

8. How often did you follow your recommended diet over the last seven days?

1. _____ All of the time (100%)
2. _____ Most of the time (75%)
3. _____ Sometimes (50%)
4. _____ Occasionally (25%)
5. _____ Never (0%)

DIET_COMP
(RECORD 1-5)

Patient ID# _____ Nurse Initials: _____
--

Date: _____ / _____ / _____ mm dd yyyy

9. How often in the last seven days would you say you ate something “off” your diet?

- | | |
|--------------------------------------|--------------|
| 1. _____ Never (100%) | |
| 2. _____ Hardly ever (75%) | |
| 3. _____ Less than once a week (50%) | _____ |
| 4. _____ At least once a week (25%) | DIET_OFF |
| 5. _____ Almost every day (0%) | (RECORD 1-5) |

10. Do you measure your blood sugar using a home glucose monitor? _____

- | | |
|--------------|--------------|
| 1. _____ Yes | B_TEST_TX |
| 0. _____ No | (RECORD 0-1) |

11. How often are you supposed to test your blood sugar? (need times per day)

_____	_____
	B_TEST_RX

12. How often in the last 7 days did you test your blood sugar at the times you were supposed to? (No more than 10 minutes early or late)

- | | |
|---------------------------------|--------------|
| 1. _____ All of the time (100%) | |
| 2. _____ Most of the time (75%) | |
| 3. _____ Some of the time (50%) | _____ |
| 4. _____ Occasionally (25%) | B_TEST_COMP |
| 5. _____ Never (0%) | (RECORD 1-5) |

13. Do you test for sugar in your urine? (Check one)

- | | |
|--------------|--------------|
| 1. _____ Yes | _____ |
| 0. _____ No | U_TEST_TX |
| | (RECORD 0-1) |

14. How often are you supposed to test your urine? (need times per day)

_____	_____
	U_TEST_RX

Patient ID# _____ Nurse Initials: _____
--

Date: _____ / _____ / _____ mm dd yyyy

15. How often in the last 7 days did you test your urine at the times you were supposed to?
(No more than 10minutes early or late)

1. _____ All of the time (100%)
2. _____ Most of the time (75%)
3. _____ Some of the time (50%)
4. _____ Occasionally (25%)
5. _____ Never (0%)

U_TEST_COMP
(RECORD 1-5)

16. Do you exercise on a regular planned basis?

1. _____ Yes
0. _____ No

EXER_TX
(RECORD 0-1)

17. What kind of exercise has your doctor (health care provider) recommended for you?

EXE_RX

18. How long do you exercise for? (need duration and strength, i.e., brisk, slow for each type of exercise)

Type of Activity: _____ (Walking, housework, gardening)

Duration: _____ (Time)

DURATION

Number of days per week: _____

DAYS

Pace: _____ (BRISK or SLOW)

PACE

19. How often in the last 7 days did you follow your exercise program? (Check one)

1. _____ Almost all the time
2. _____ Some of the time
3. _____ Not very often

EXER_COMP
(RECORD 1-3)

Patient ID# _____
Nurse Initials: _____

Date: _____ / _____ / _____
mm dd yyyy

20. How often in the last 7 days did you exercise when you planned to?

1. _____ All of the time (100%)
2. _____ Most of the time (75%)
3. _____ Some of the time (50%)
4. _____ Occasionally (25%)
5. _____ Never (0%)

EXER_PLAN
(RECORD 1-5)

21. Would you say you inspect your feet

1. _____ Almost all of the time
2. _____ Some of the time
3. _____ Not very often

FOOT_TX
(RECORD 1-3)

22. How often would you say you check your feet when you are supposed to?

1. _____ All of the time (100%)
2. _____ Most of the time (75%)
3. _____ Some of the time (50%)
4. _____ Occasionally (25%)
5. _____ Never (0%)

FOOT_COMP
(RECORD 1-5)

23. How did you learn to take care of your diabetes? (Check all that apply)

1. _____ Classes (individual)
2. _____ Classes (group instruction)
3. _____ Read printed materials
4. _____ From my physician (health care provider)
5. _____ From my family
6. _____ From my friend(s)

DM_TEACH
(RECORD 1-4)

24. Height: _____

Weight: _____

25. How long have you had diabetes? _____ years.

C. History related to CHD

1. Have you passed menopause or had your ovaries removed?

Yes _____ No _____

2. Did your father or brother have a heart attack before age 55?

Patient ID# _____

Nurse Initials: _____

Date: _____ / _____ / _____

mm

dd

yyyy

3. Did your mother or sister have a heart attack before age 65?
Yes _____ No _____
4. Did your mother, father, sister, brother or a grandparent have a stroke?
Yes _____ No _____
5. What was you last blood pressure reading?
____ / ____ Do not know _____
6. What has your highest blood pressure been?
____ / ____ Do not know _____
7. What has your lowest blood pressure been?
____ / ____ Do not know _____
8. Do you smoke cigarettes?
Yes _____ No _____
9. Do you live or work with someone who smokes cigarettes everyday?
Yes _____ No _____
10. Is your total cholesterol 240mg or higher?
Yes _____ No _____ Do not know _____
11. Is your HDL ("Good") cholesterol is less than 40 mg/dl?
Yes _____ No _____ Do not know _____
12. Do you get 30 minutes or more of physical activity on most days?
Yes _____ No _____
13. Are you at least 20 pounds overweight?
Yes _____ No _____ Do not know _____
14. Is your fasting blood sugar 120 mg/dl or higher?
Yes _____ No _____ Do not know _____
15. Have you ever been told you have heart disease?
Yes _____ No _____
16. Have you ever been told you have atrial fibrillation?
Yes _____ No _____
17. Have you ever been told you have had a TIA or stroke?
Yes _____ No _____
18. Have you ever been told you have disease of the blood vessels of your legs?
Yes _____ No _____

Patient ID# _____
Nurse Initials: _____

Date: _____ / _____ / _____
mm dd yyyy

19. Have you ever been told you have a high red blood cell count?

Yes _____ No _____

20. Have you ever been told you have sickle cell anemia?

Yes _____ No _____

21. What other illnesses have you been told you

have? _____

22. Do you currently have any of the following? (Check all that apply)

Leg pain or numbness _____

Chest pain _____

Tiredness _____

Kidney problems _____

Infection _____

Skin problems _____

Breathing Problems _____ Other _____

References: American Heart Association (2006)

Skelly et al., (2005)

APPENDIX F.

In-depth, Semi-Structured Interview Questions

PI- Thank you for meeting with me. Before we get started I want to go over the process for our conversation. I will tape our conversation with you so I do not have to take notes and we can talk without me having to write everything down. I am interested in what you think so there are no right or wrong answers to these questions.

(*the concepts addressed in the study are indicated beside the question)

Question 1: Tell me the story of your diabetes. (All concepts)

Probe 1: What do you think is the most important problem that you are dealing with from your diabetes? (priority)

Probe2: How could (*her identified problem*) affect your health in the future?
(control, beliefs)

Probe 3: How do you believe you could change your health in the future?
(control, beliefs, optimism, pessimism)

Probe 4: Is there anything that you are concerned about almost every day related to your diabetes? (priority, identity)

Question 2: Tell me... how would you know if you had heart disease?

(CHD, identity, cause)

Probe 1: What do you think of when someone says “heart disease”?

(CHD, beliefs, consequences)

Probe 2: What things happening to you now would cause you to develop heart disease in the future? (beliefs, cause)

Probe 3: Do you think AA women have more risk for heart disease? If so...tell me more about it...if not, tell ee why you think that....(cause, consequences, control)

Probe 4: Do you think it takes a long time to get heart disease, or is it something that comes upon you pretty fast? (timeline, cause)

Probe 5: When we talked earlier I asked about your beliefs about your chances of getting a disease like heart disease. Tell me- what have you thought about that since we first talked? (priority, beliefs, identity, cause)

Probe 6: Have you heard of the term “claiming an illness”? What does it mean to you?

PI: Ok- I am going to change the topic a little. I am interested in what you think about stress, diabetes and heart disease.

Question 3: What role do you think stress plays in developing diabetes, and heart disease? (cause)

(open follow up to her cues-want to be sure and see if she links diabetes and heart disease and stress through question 2 and 3)

Question 4: Are there any other things we have not talked about that you find especially hard about living with diabetes? (control, consequences)

Probe1: What is the easiest part of taking care of your diabetes? (identity, control)

Probe 2: How do you know you are taking good care of yourself? (control, cause, identity)

Question 5: What else do you want doctors and nurses to know about diabetes, and heart disease? (all concepts)

After participant finishes discussing last question, the PI will say the following:

Thank you so much for talking with me. I appreciate your willingness to be open and help others who may deal with diabetes in the future. I have \$10.00 for you for your help. I also have some materials I want to give you for your diabetes. I have included my contact information again on this folder. Please feel free to call me if you have any further questions.

APPENDIX G.

Telephone Recruitment Script

Script for return phone call: Hello Ms.-----. My name is Carolyn McKenzie. I am the nurse who is doing the research study on diabetes that your doctor mentioned (or that you called earlier about). Is it a good time to talk for you right now?

If *yes*... How are you today? (participant responds and social conversation occurs)

If *no*... I wanted to find out when I could come talk with you at your home. Could we set that meeting up now?

No. Ok, when is a good time to call you back?

Yes.. Great. When are you available?....

If *yes* ...I have few more questions to ask you about your diabetes. When would be a good time to come visit you? It will take about an hour.

APPENDIX H.

Exploring Perception of Risk for CHD in AA Women with T2DM

Checklist for contact of participants

1. Initial contact by phone from participant: date_____.
Phone number _____
Name_____
2. Physician_____Phone Number_____
3. Study explained_____
4. Met inclusion criteria Yes_____ No_____
- Comments_____
5. Consent reviewed and signed Yes_____ No_____ If NO
why?_____
6. Questionnaires completed _____
7. Incentive dispersed (\$10.00) _____Receipt_____
8. Follow up consent given_____
9. Date Data entered_____ Date Re-entered_____

APPENDIX I.

Exploring Perception of Risk for CHD in AA Women with T2DM

Site Information Form

Office Title:_____

Physician:_____

Contact information

Phone:_____

Office Nurse:_____ direct line:_____

Office Nurse:_____ direct line:_____

Initial materials left on:_____ person spoke to:_____
date_____

Mailings completed (date):_____ # mailed_____

NOTES:

APPENDIX J.

RECEIPT

Funds for participation in research study received: **\$10.00**

TO: _____

FROM: Carolyn McKenzie, RN, PhD-(c)

Date: _____

Account: _____



Carolina
School of Nursing

APPENDIX K.

March 31, 2009

Dear Ms. _____ :

I am writing to tell you about a research project you may be interested in. This is a program for African American women who are 30-65 years old with type 2 diabetes. You will get information on managing your diabetes through this program.

As part of the program, a nurse will visit you in your home 1-2 times, at a day and time that is good for you. She will not stay longer than an hour. She will talk with you about your diabetes, your diet, physical activity and home glucose monitoring and answering questions about your diabetes.

There is no cost to you or your insurance for this program and women who are able to participate will receive \$ 10.00 per visit. Participation in this program is voluntary. If you decide not to participate your health care will not be affected in any way.

If you would like more information about this project, please call the study at this toll free number: 1-866-000-0000. The principal investigator for this study is Carolyn McKenzie, PhD-(c), RN a doctoral student at UNC Chapel Hill in the School of Nursing. She is nurse who has worked with many patients with type 2 diabetes and teaches other nurses about diabetes.

Her faculty advisor is Dr. Anne H. Skelly, PhD, RN. She is a diabetes nurse practitioner and faculty member at The University of North Carolina School of Nursing.

This is a good opportunity for you to learn more about your diabetes and staying well.

Sincerely,

Dr. -----



Carolina
School of Nursing

African American women with Type 2 Diabetes read on...

If you are 30-65 years old and want to

learn more about diabetes

call Carolyn McKenzie at

1-800-961-6771 for more information

APPENDIX M.



June 4, 2008

Dear Ms. ,

Because you had expressed interest in participating in a study on diabetes in the recent past, I am offering you a chance to participate in a new study currently recruiting in your area. This study requires only that you agree to talk with the interviewer for 45-60 minutes in your home or a place of your choosing. There are no fingersticks or blood draws. You will be paid \$10.00 and will receive a gift bag for your participation. You will only have to discuss your beliefs about diabetes and other diseases. If you are between 30 and 65 years old, have had diabetes for over one year, and have not been diagnosed with heart disease, then you qualify for the study.

Please call the toll free number: **1-800-961-6771** and leave a message with your phone number if there is no answer. Carolyn McKenzie, RN, the Primary Investigator for the study will call you back. The study is part of a doctoral dissertation that is being mentored by Anne Skelly, PhD, RN, CS, ANP, Professor at the University of North Carolina at Chapel Hill School of Nursing. Dr. Skelly can be reached at 919-966-3612. Thank you for considering participation in this study.

Sincerely,

Carolyn McKenzie, PhD (c), RN

APPENDIX N.

University of North Carolina-Chapel Hill
Consent to Participate in a Research Study
Adult Participants *African American Women with T2DM Ages 30-65*
Social Behavioral Form

IRB Study # 07-0654

Consent Form Version Date: _4-9-07_

Title of Study: Exploring Perceptions of Risk for CHD in African American women with T2DM

Principal Investigator: Carolyn McKenzie, RN, PhD-(c)

UNC-Chapel Hill Department: School of Nursing

UNC-Chapel Hill Phone number: 336-625-7964

Email Address: mckenzie@email.unc.edu

Faculty Advisor: Anne Skelly, RN, PhD, CS, FAANP **Phone:** 919-966-3612

Study Contact telephone number: 1-800-961-6771

Study Contact email: mckenzie@email.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies. You do not have to be in the research study in order to receive treatment.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to learn about what you believe about diabetes and how those beliefs about diabetes affect your beliefs about other illnesses such as cancer and heart disease.

African American women have high rates of diabetes and are at greater risk for some illnesses than women of other races.

You are being asked to be in the study because you have been diagnosed with type 2 diabetes for more than one year.

Are there any reasons you should not be in this study?

You should not be in this study if you were diagnosed with either a heart attack, heart failure or angina in the past.

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 55 people in this research study.

How long will your part in this study last?

You will be asked to answer some questions that may take up to one hour to complete. The researcher will ask you these questions or you may read them and mark the answers yourself.

A certain number of participants will be selected for follow-up based on the answers to the questionnaires from those who agree to be interviewed. If you qualify for the follow up interview, the researcher will contact you at the numbers you provide in a few weeks. The follow up interview would take approximately one hour. The researcher will come to your home or designated meeting place. There may be several weeks between visits for the researcher to decide if you will be included in the follow up interviews.

What will happen if you take part in the study?

- The researcher will contact you by phone to set up the time to meet to answer the questions.
- The researcher will meet you at your home or another place that you choose.
- After answering the questions for the researcher, you will receive \$10.00 cash and diabetes information for your participation.
- Follow up interviews will take about one hour and will include recording the conversation.
- You will receive another \$10.00 after completing the follow up interview if you qualify for this part of the study.
- You may skip any question you choose during the study for any reason.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You may expect to benefit by learning new information about caring for your diabetes. You will have the opportunity to discuss your diabetes with a health care professional, and receive educational materials on self-management as well as diabetes and heart disease. Other African American women with T2DM will benefit from the knowledge this study will generate in that health care professionals will have a better understanding of African American women's beliefs and perceptions.

What are the possible risks or discomforts involved from being in this study?

There are minimal risks to participating in the study. Discussions may create questions about your diabetes that you may want to ask your physician. Although all confidential information will be protected at all times in a locked file, breach of confidentiality is a minimal risk.

How will your privacy be protected?

Participants *will not* be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety. In any published materials participants will not be identified. Only group data will be reported.

Only a master copy of identifying information will be kept for research purposes. The researcher will keep all information in a secure locked cabinet.

All digital audio tapes from follow up interviews will be changed into a verbatim written format and the audio tapes destroyed once the data is verified. If you qualify for the follow up interview you may request that the researcher not audiotape the conversation.

Will you receive anything for being in this study?

You will be receiving \$10.00 cash, free health products, and diabetes information for taking part in this study. If chosen for the follow up interviews you will receive another \$10.00, free health products, and more diabetes information.

Will it cost you anything to be in this study?

There will be no costs for being in the study

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Title of Study: Exploring Perceptions of Risk for CHD in African American women with T2DM

Principal Investigator: Carolyn McKenzie, RN, PhD-(c)

UNC-Chapel Hill Department: School of Nursing

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Date

Printed Name of Research Participant

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

* I agree to a second interview if needed: yes_____ no_____

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