

BLOOD SUGAR AND BROTHERS' VOICES: AN EXPLORATORY STUDY OF  
THE SELF-CARE MANAGEMENT EXPERIENCES OF AFRICAN-AMERICAN  
MEN LIVING WITH TYPE 2 DIABETES

A Dissertation

by

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## ABSTRACT

Self-care is the key to living a long and healthy life for people with diabetes. Yet numerous studies show that self-care is far from optimal. This has resulted in attempts to understand the progress underlying self-care behavior in the efforts of mediating more effectively. While there are an abundance of studies focusing on African-American women and diabetes management, there is a considerable gap in health education literature regarding the self-care management experiences of African-American men living with type 2 diabetes. The management and impact of type 2 diabetes on the sense of self, lifestyle, and significant others of the African-American man are not clearly comprehended. Therefore, the purpose of the study was to explore the knowledge, beliefs, and self-care management practices of African American men living with type 2 diabetes.

This was an exploratory study utilizing qualitative methodology to understand the knowledge, beliefs, and existing self-care management practices of up to 50 African-American men, ages 18-70, living with type 2 diabetes. Participants had one-on-one semi structured interviews with the primary investigator. The instruments that were used consisted of two parts: one was a self-administered paper/pencil questionnaire to collect socio-demographic information. The second was a semi-structured interview. The study significance was to identify and understand the barriers to type 2 diabetes management and how they had an adverse influence on self-care. A combination of high barriers, poor daily self-care, management, and knowledge possibly put those with type 2 diabetes at an elevated risk for subordinate self-care management. Barriers had a role in

reality and diabetes researchers and educators are charged with recognizing the complications of what individuals with type 2 diabetes need to do improve and enhance their health.

The study findings revealed that the participants labored with managing their diabetes and some counted on their own potential or performance, as well as the encouragement of their family, extended family, neighbors, and friends. Also, many of the participants had a unified theme in that regarding self-care management, having type 2 diabetes affected those in their surrounding environment, not just the person living with the illness. In conclusion, the study findings suggest that future diabetes research and education among African-American men should give attention to male masculinity and the powerful influence it has on utilizing preventive health services. The limited amount of African-American men included in empirical type 2 diabetes research could help explain the under addressed barriers and complexities to positive self-care management.

## DEDICATION

I dedicate my dissertation work to my family and many friends. A special feeling of thankfulness to my loving, caring, and nurturing family, Joseph and Sandra Sherman whose words of encouragement, prayers, and love have always been my source of strength and direction. You all are my source of strength while on this journey because you have given up so much for Jerrell and myself to keep continue our education and this degree is for the both of you. My brother Jerrell, who I can always vent to and we both have been supportive and encouraging of each other. You are my best friend and I will always cherish our childhood and the memories that we share and the many more that are ahead of us. I would like to thank my grandparents, Eddie Pearl Allen & Leroy and Tommie Sherman who have always been there in so many ways.

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## NOMENCLATURE

African-American- Characterized by anyone who self-identifies as Black, Afro-Arab, Afro-Caribbean, Afro-Cuban, Afro-Haitian, Afro-Nigerian, & Afro-Trinidadian.

Culture- Airhihenbuwa defines culture “as a collective sense of consciousness that is vocal enough to reveal its sense of history and language but quiet enough to render its structures, values, and beliefs neutral and common” (C. O. Airhihenbuwa, 2004).

Facilitator- Defined by Wensing (1999) as “factors that enhance positive lifestyle changes that may lead to a more optimal level of health.

Fatalism- Powe and Weinrich (1999) define fatalism as a complex psychological cycle characterized by perceptions of powerlessness, hopelessness, and despair.

Health Literacy- Peek et al. (2009) define health literacy as access to health information and the ability to process such information in a meaningful way (p. 1136).

Health Promotion- Health promotion is the science and art of helping people change their lifestyle to move toward a state of optimal health. Optimal health is defined as a balance of physical, emotion, social, spiritual and intellectual health. Lifestyle change can be facilitated through a combination of efforts to: 1) enhance awareness, 2) change behavior, and 3) create environments that support good health practices. Of the three, supportive environments will probably have the greatest impact in producing lasting changes (O'Donnell, 1989, p. 5).

Masculinity- Reflects a shared understanding of what it means to be a man: what one looks like, how one should behave and so forth” (Edley & Wetherell, 1996).

Medical Mistrust- A lack of confidence in the treatment provided by medical systems as well as the information provided by these systems. (Thompson et al., 2004)

Phenomenology- To describe one of more individuals' experience of a phenomenon (Patton, 2002).

Perceived Barrier- In a summary conducted by Glasgow (2008), this is a person's estimation of the level of challenge of social, personal, environmental, and economic obstacles to a specified behavior of their desired goal status on that behavior.

Preventive Health- Routine doctor visits to a doctor or health professional; having blood pressure checked by a doctor or a health professional; having a blood cholesterol screening done by doctor or health professional; visiting diabetes doctor for advice and insight on proper management education (Hammond et al., 2010).

Self-Care Management- Defined as "the ability to manage the symptoms, treatment, physical and psychological consequences and life-style changes inherent in living with a chronic condition" (Barlow et al. 2002). Orem (1995, p. 95) defined self-care as the learned behavior that was purposeful, with patterned and sequenced actions, and suggested that individuals acquire the capacity for self-care during childhood, principally in the family, where cultural standards are learned and transmitted intergenerationally.

Social Support- Gottlieb (1981) suggests the following: "(a) social support defined in terms of people's level of social integration/participation; (b) social support defined as a by-product of people's interactions in a social network with particular structural properties; and (c) social support defined in terms of people's access to a set of resources typically present in their more intimate peer relationships" (1981, p. 32).

Theory- Provides insight into diverse psychosocial factors that contribute to and maintain health risk behaviors (Mc Leroy et al., 1993).

Type 2 Diabetes- Chronic illness in which the body either resists the effect of insulin or does not produce enough insulin to maintain a normal glucose level. According to the American Diabetes Association (ADA), type 2 diabetes, also known as noninsulin-dependent diabetes, is the most common form of diabetes (ADA, 2011).

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## CHAPTER I

### INTRODUCTION AND RATIONALE

There is a sizeable gap in health disparities and public health literature concerning the barriers and facilitators of the self-care management practices of African-American men living with type 2 diabetes. In an editorial written by Anderson et al, 1991, the specific barriers as described and identified by African-Americans were institutional racism, lack of knowledge, incorrect beliefs about diabetes (including fatalistic attitude and a belief that a “little sugar” is not a concern), lack of access due to inadequate health insurance, and cultural values and poverty that limits one’s ability to practice healthy behaviors. In order to better understand these practices, researchers must thoroughly explore the self-care management thoughts and experiences of African-American men living with type 2 diabetes.

Some researchers argue that since African-American men hold relatively lower social positions, they may delay healthcare utilization to symbolically exercise masculine dominion over their bodies (Courtney, 2000; Wallace, 1999; Staples, 2004). Other researchers posit that barriers to traditional male role fulfillment encourage African-American men to reject traditional masculinity, and adopt patterns of healthcare use that contradict dominant male behavioral norms, Abreu et al, 2000; Gordon, 1997; Aronson, Whitehead, & Baber, 2003; Wade & Brittan-Powell, 2001). My thoughts regarding this matter are that men among this group need to take control of their diabetes as opposed to their diabetes taking control of them.

Becoming educated about proper self-care management could help dismiss the misinformation that some men may have regarding type 2 diabetes management. Type 2 diabetes is a hidden but daunting illness. Historically, men regardless of ethnicity have not been instructed on how to combat something that is invisible or hidden, in this case type 2 diabetes. Therefore proper education and training about how to successfully manage the illness as well as how to discontinue harmful health habits (lack of exercise, no dietary changes, alcohol and tobacco, not monitoring blood glucose daily, etc.) that can negate positive self-management can assist with improving the overall health of men living with type 2 diabetes.

### Type 2 Diabetes in the United States

Diabetes is a serious chronic disease that has and will continue to exact a tremendous physical, psychological, social, and economic burden on African-Americans (Cowie, Rust, Byrd-Holt, & Eberhardt et al., 2006). Diabetes overall, is the seventh leading cause of death in the United States (CDC, 2010). There are two manifestations of diabetes: Type 1 and type 2. This study focuses on type 2 diabetes.

According to the American Diabetes Association (ADA), type 2 diabetes, also known as noninsulin-dependent diabetes, is the most common form of diabetes (ADA, 2004b). In type 2 diabetes, the body either resists the effect of insulin or doesn't produce enough insulin to maintain a normal glucose level. Some ethnicities have a higher risk for developing type 2 diabetes than others (Cowie, Rust, Byrd-Holt, & Eberhardt et.al., 2006). Type 2 diabetes is more common in African-Americans, Latinos, Native-

Americans, Asian-Americans, Native Hawaiians, and other Pacific Islanders (ADA, 2011).

### Epidemiology of Type 2 Diabetes

According to the 2010 Center for Disease Control and Prevention estimated figures, 25.8 million people in the United States aged 20 years and older are affected by diabetes (CDC, 2010). This represents about 8.3% of the total U.S. population. Of the 25.8 million people with diabetes in 2010, 18.8 million had diagnosed diabetes and 7.0 million had undiagnosed diabetes (CDC, 2010). The National Diabetes Information Clearinghouse (NDIC) has also reported that in the year 2010, 13.0 million men and 12.6 million women ages 20 years and older have diabetes (NDIC 2010). From these numbers, 4.9 million of diabetics are African-American. There are geographic patterns in the distribution of type 2 diabetes in the U.S. with the highest proportion found among populations in the southeastern U.S. (39.2%).

### Diabetes in African-Americans

The incidence of type 2 diabetes is 4 times higher for African-Americans than for non-Hispanic Whites (Onwudiwe et al. 2011). An estimated 4.9 million black adults in this age group have diabetes (CDC, 2010). Overall, the risk for death among people with diabetes is about twice that of people *of similar age* but without diabetes (CDC, 2010). Conventionally, type 2 diabetes has been characterized as onset after the age of 30. As noted in the goals of Healthy People 2010, diabetes inflicts an enormous burden of illness in minority communities (USDHHA, 2000). Type 2 diabetes is 1.2 to 2.3 times more prevalent in African-Americans than European-Americans and is associated with

higher rates of complications and greater levels of disability related to those complications (Chesla et.al., 2004).

African-Americans are disproportionately affected by diabetes. Overall, 14.7% of all African-Americans are living with diabetes, compared with 9.8% of their non-Hispanic white counterparts (NDIC, 2007). Among African-Americans 20 years and older, the prevalence of diabetes is 8.2% compared with 4.8% among non-Latino whites (CDC, 2010). Type 1 diabetes accounts for 5 to 10% of all cases among African-Americans, while type 2 diabetes accounts for 90 to 95% of all cases (CDC, 2010). Moreover, compared with other racial groups, African-Americans experience higher rates of 4 diabetes-related complications: blindness, kidney disease, amputations, and cardiovascular disease (ADA, 2009).

The problem of diabetes among African-Americans is an important example of a health disparity in the United States (Wenzel et. al., 2005). Both incidence and prevalence of diabetes are disproportionately higher in African-Americans, who are 1.7 times more likely to develop diabetes than Caucasians are (American Diabetes Association, 2009). Type 2 diabetes has been linked to both obesity and lack of physical inactivity, both of which can be modified for overall health improvement (CDC, 2010). In addition, among persons with type 2 diabetes, the highest proportions live in the southeastern United States (39.2%) and are black (60.15%) (Cowie & Eberhardt, 1995). Research indicates that depression is under diagnosed in African-American populations thus, it seems likely that the burden of managing diabetes merely compounds the preexisting problems of those with other economic, psychological, and social burdens.

The burdens of this complex chronic illness are particularly oppressive for members of the African- American community, who are less likely to have access to affordable, acceptable health care or to be covered by health insurance (AHRQ, 2000), (OMH, 1999).

### Diabetes Complications

Problems such as damage to the eyes, kidneys, nerves and skin have been found in many people who have not properly managed their diabetes. An acceleration of arteriosclerosis has been attributed to poor management which in turn can lead to heart attacks and strokes (Clement, 1995). Skin breakdown in the extremities can result in ulcerations, in which elevated blood glucose levels cause the ulcerations to heal slowly (Kishore, 2008). As these get worse over time, gangrene may develop and therefore amputation of a limb or digit would then be necessary. Typically, gangrene of the feet is more prevalent in most diabetics therefore resulting in patients having one or both feet amputated (ADA, 2004a).

One of the problems for African-Americans and diabetes is that they are more likely to develop diabetes complications and experience greater disability from the complications than whites. In 2009, the frequency of diabetic retinopathy was 40 to 50% higher in African-Americans than in white Americans (NDIC, 2009). In 2009, African-Americans with diabetes experienced kidney failure about four times more often than white Americans, as well as endured lower extremity amputations than white Americans and Latinos with diabetes (NDIC, 2009).

## Diabetes Management

Diabetes self-management is the knowledge and skills needed to perform self-care, manage crisis, and make the lifestyle changes required to successfully manage the disease (Clement, 1995). Management of type 2 diabetes focuses on lifestyle interventions, lowering other cardiovascular risk factors, and maintaining blood glucose levels in the normal range (Ripsin, Kang, Urban, 2009). There are seven key areas of self-management for people with diabetes. These areas are: healthy eating, being physically active, monitoring blood sugar daily, taking medication, problem solving, reducing risks, and healthy coping (AADE, 2012).

Successful self-management can reduce the chance of developing complications including disease, eye disorders kidney disease, and nerve damage. Healthy eating, physical activity, and blood glucose control are the basics for managing type 2 diabetes. In addition, many people with type 2 diabetes require oral medication, insulin, or both to control their blood glucose levels (Ripsin, Kang, Urban, 2009). People with diabetes must take responsibility for their day-to-day care, and keep blood glucose levels from going too low or too high. If a person does not properly manage their diabetes they may develop serious health problems.

### Why Study Perspectives of African-American Men in Diabetes Research?

While anecdotal, my initial perusal of the literature yielded virtually no studies which consider the perspectives of the African-American men specific to diabetes self-management. There are data on incidence, prevalence, and complication rates.

However, the personal perspective of this group is non-existent. In other words, they do not have a voice. As a result of the exclusion of the African-American men perspective, the management and impact of type 2 diabetes on the sense of self, lifestyle, and significant others of African-American men is not well understood (Liburd, et al., 2004).

There are few published studies that have addressed the facilitators and barriers of type 2 diabetes self-management among African-Americans, more specifically African-American men. I consider this a profound gap in the body of knowledge about diabetes self-management given the disproportionate burden of the consequences of poor management that African-Americans face relative to other racial, ethnic and gender groups. An understanding of the facilitators and barriers will help in the design of tailored interventions to improve the lives of African-Americans living with type 2 diabetes (Chlebowy, Hood, LaJoie, 2010).

#### Statement of the Problem

In spite of the well-documented disproportional burden of diabetes prevalence and incidence among African-Americans in the research literature, there appears to be:

- 1) little known regarding the existence and quality of empirical studies specific to diabetes management specific to AA/B men, 2) little known regarding the utilization of appropriate (i.e., culturally relevant) theories utilized in diabetes self-management research with AA/B men, and 3) a lack of studies representing the perspectives of AA/B men as they cope with this disease. While these observations are anecdotal, it warrants a systematic investigation.

### Purpose

The purpose of the overall study is to expand on what is known about type 2 diabetes self-management among African-American men. Specifically, this study will address several sub-purposes which include: 1) clarifying what is known in the research literature about chronic disease self-management among African-American with type-2 diabetes, and 2) investigate the experiences of diabetes self-care management among African-American men living with type 2 diabetes and identify barriers and facilitators to positive diabetes self-care management among this group.

### Research Questions

The over-arching research question is: “What is known in the research literature about type 2 diabetes self-care management among African-American men?” The current study will address this via three sub-studies which will include two comprehensive reviews of the literature to examine specific aspects of the research literature in this area, and a qualitative study to gain experiential understanding of the phenomenon.

The over-arching research question will be addressed via three sub-studies, of which each will be presented as a stand-alone manuscript. This dissertation will be comprised of five chapters. Chapter I (current chapter) provides an overview of the entire study and a brief introduction and rationale. This also includes a definition of terms which will be found throughout the entire study.

Chapters II, III and IV will be in the form of independent manuscripts described below. Sub-study one’s research question is “How well are African-American men

included in empirical studies of diabetes self-care management?” and will comprise Chapter II of this dissertation. It is prepared to meet the requirements for submission to the *American Journal of Health Behavior*, including an abstract word count not to exceed 125 words and a manuscript word count not to exceed 5000 words (approximately 18 typed double-spaced pages), excluding the title page, abstract, references, tables, and figures. It is a comprehensive literature review designed to address how well African-American men are included in empirical studies of diabetes self-care management.

Sub-study two’s research question is: “To what extent have theories and/or constructs been utilized in diabetes self-care management research with African-American men?” It is formatted for submission to *Diabetes Spectrum* journal, in which abstracts are not to exceed 250 words and there is no set guideline regarding the word count limit of each manuscript. Sub study three’s is a qualitative study that is focused on understanding the essence and lived experiences of African-American men living with type 2 diabetes. It is prepared as a manuscript for submission to *American Journal of Men’s Health*, which has an abstract word count of 250 words or less and the length of the manuscript is not to exceed 30 pages. Chapter V will be comprised of the conclusion, limitations, discussion and future directions of the overarching study, and highlight to the reader how these independent studies relate to one another.

## CHAPTER II

### HOW WELL ARE AFRICAN-AMERICAN MEN INCLUDED IN EMPIRICAL STUDIES OF DIABETES SELF-CARE MANAGEMENT?

The National Institutes of Health requires the inclusion of underrepresented minorities in medical research (NIH, 1993). Despite this requirement, there continues to be a lack of African-American male representation in academic and medical research. Many reasons are cited in the literature for the low participation of ethnic minorities in research, including socioeconomic constraints (Areán & Gallagher-Thompson, 1996; Hodge, Weinmann, & Roubideaux, 2000; McCabe, Varricchio, & Padberg, 1994; Stark et al., 2002; Zambrana & Cart-Pokras, 2001), language and literacy barriers (Cook & de Mange, 1995; Kaluzny et al., 1993), lack of access to medical care (Dennis & Neese, 2000; Harris, Gorelick, Samuels, & Bempong, 1996; McCabe et al., 1994; Powell & Fleming, 2000), and an inability to recruit minorities into research studies (Moyé & Powell, 2001; Ness, Nelson, Kumanyika, & Grisso, 1997; Swanson & Ward, 1995).

Mistrust of the scientific community is also theorized to be a significant reason for the shortage of ethnic minorities in clinical studies (Baker, 1999; Blendon et al., 1995; Cook & De Mange, 1995; Corbie-Smith, Thomas, & St. George, 2002; Davis & Reid, 1999; Earl & Penney, 2001; Fouad et al., 2000; Gamble, 1997; LaVeist, Nickerson, & Bowie, 2000; McGary, 1999; Sambo, 2001; Thomas & Quinn, 1991). From a historical standpoint, the history of slavery of African-Americans sets a powerful precedent for mistrust of authority figures and government leaders (Earl & Penney,

2001; Shavers-Hornaday et al., 1997; Thomas & Quinn, 1991). In addition, the prominent Tuskegee syphilis experiment is a constant reminder and lasting image of African-American men's involvement in research, which has constructed an immensely negative view of research among African-Americans in general.

### Diabetes Self-Care Management and African-American Men

African-American men experience higher rates of at least 3 of the serious complications of diabetes: blindness, amputations, and end-stage renal disease (ESRD) compared to other groups (Hendricks and Hendricks, 2000). Despite the irregular burden of diabetes and its associated ramifications among African-American men, rarely has clinical or ethnographic research been devoted specifically to type 2 diabetes management in this population. Accordingly, a critical need exists to improve what is known about the self-care management (SCM) practices of African-American men with type 2 diabetes. Exploring the perceptions and practices of SCM in this population could possibly help explain poor health outcomes among African-American male diabetes patients. The purpose of this systematic review is to identify and synthesize the research literature centered on one major research question: How well African-American men are included in empirical studies of diabetes self-care management?

### Methodology

The review process involved rigorous methodological initiatives to generate a comprehensive analysis of the published research literature on type 2 diabetes self-care management (SCM). The methodology used for this systematic review is detailed below. Major steps include (1) database search to identify relevant articles, (2) development of

inclusionary/exclusionary criteria to select articles, (3) three-step screening process to identify SCM factors among published articles, (4) instrumentation to guide extraction process, and (5) data extraction to retrieve study characteristics among retrieved articles.

#### Database Search

A systematic search was performed to retrieve peer-reviewed articles addressing SCM among African-American men living with type 2 diabetes. Five major health literature databases- Academic Search Complete (EBSCO), ERIC (EBSCO), ScienceDirect (Elsevier), MEDLINE (Ovid), and PsycINFO- were searched using keywords such as type 2 diabetes management, self-care management, African-American men and type 2 diabetes, and men's health and type 2 diabetes. The date of the last search was August 2012.

#### Inclusionary/Exclusionary Criteria

Articles were selected if they (a) were empirical studies that included African-American men in their sample (b) the sample participants had a medical diagnosis of type 2 diabetes and (c) written and published in English between the years 1996 and 2011. The year 1996 was selected as the starting point because it marks when diabetes blood testing strips entered the English health education research literature. All study design types were included (cross-sectional, focus groups, case-control, qualitative, quantitative, longitudinal, group randomized, quasi-experimental). Exclusionary criteria included (a) theoretical studies and thought pieces that did not include African-American men living with type 2 diabetes and (b) studies that did not address male involvement and participant in type 2 diabetes research.

### Screening of Articles

Screening process involved three tiers. First, screening questions based on inclusion and exclusion criteria were generated to guide retrieval, yielding 122 abstracts. Second, full articles were evaluated for fit with other inclusionary criteria. Irrelevant titles, duplicates, and narrative/commentary pieces were automatically excluded. Studies that addressed type 2 diabetes SCM were kept in the pool. Third, additional articles were identified by purling, or the performance of a thorough review of the references/citations of retrieved articles for publications that might have been missed through the database search. Purling is often performed to ensure that all relevant articles are retrieved (Garrard, 2004).

### Instrumentation

A coding protocol spreadsheet (CPS) was used to standardize data extraction methods applied to reviewed studies. The CPS was designed to guide identification and assessment of methodological characteristics among reviewed articles (e.g., key factors associated with SCM, characteristics of the measures used to assess such factors). The CPS also details the data extraction process, the type of information extracted from reviewed studies, and the rationale used to determine key study and methodological characteristics.

### Data Extraction

Characteristics of articles (e.g., purpose of study, study design, theoretical framework) were entered into the CPS, and then categorized based on similarity of study aims, and of investigated factors (e.g., Health literacy and its association with diabetes knowledge, perceived self-efficacy & disease self-management).

### Results

Among 122 articles initially identified, 49 met the criteria. Out of the 49 articles, only 15 gave a clear indication pertaining to how many African-American men and women were in the study. Table 1 shows the rubric that was used to score each research article for the inclusion of African-America men. Table 2 details how many men were included in each research study.

<b>Table 1: Scoring Rubric</b>	<b>Score</b>
AA Men not targeted, nor included	0
AA Men targeted, but some included	1
AA Men targeted, but none included	2
AA Men targeted and included	3

<b>Table 2: Breakdown of How Many Men Were in Each Study if Provided</b>				
<b>Study</b>	<b>African American Men Included?</b>	<b>Number of AAM</b>	<b>Proportion of AAM</b>	<b>Score</b>
1	No	0	0%	0
2	Yes	10	34%	3
3	Yes	591	39%	3
4	Yes	12	24%	3
5	Can Not Determine	Can Not Determine	Can Not Determine	0
6	Can Not Determine	Can Not Determine	Can Not Determine	0
7	Can Not Determine	Can Not Determine	Can Not Determine	0
8	Can Not Determine	Can Not Determine	Can Not Determine	0
9	Can Not Determine	Can Not Determine	Can Not Determine	0
10	Can Not Determine	Can Not Determine	Can Not Determine	0
11	Yes	34	52%	3
12	Can Not Determine	Can Not Determine	Can Not Determine	0
13	Can Not Determine	Can Not Determine	Can Not Determine	0
14	Can Not Determine	Can Not Determine	Can Not Determine	0
15	Can Not Determine	Can Not Determine	Can Not Determine	0
16	Yes	12	35%	3
17	Yes	16	100%	3
18	Can Not Determine	Can Not Determine	Can Not Determine	0
19	Yes	43	100%	3
20	Can Not Determine	Can Not Determine	Can Not Determine	0
21	Yes	10	34%	3
22	Can Not Determine	Can Not Determine	Can Not Determine	0
23	Yes	63	40%	3
24	Can Not Determine	Can Not Determine	Can Not Determine	0
25	Can Not Determine	Can Not Determine	Can Not Determine	0
26	No	0	0%	0
27	Can Not Determine	Can Not Determine	Can Not Determine	0
28	Can Not Determine	Can Not Determine	Can Not Determine	0
29	Yes	49	100%	3
30	Can Not Determine	Can Not Determine	Can Not Determine	0
31	Can Not Determine	Can Not Determine	Can Not Determine	0
32	Yes	22	56%	3
33	Yes	152	100%	3

<b>Table 2: Continued</b>				
34	Can Not Determine	Can Not Determine	Can Not Determine	0
35	Yes	187	61%	3
36	Yes	610	100%	3
37	Yes	216	100%	3
38	Yes	16	100%	3
39	Yes	386	100%	3
40	Yes	20	48%	3
41	Yes	31	42%	3
42	Yes	63	23%	1
43	Yes	44	24%	3
44	Can Not Determine	Can Not Determine	Can Not Determine	0
45	Yes	40	100%	1
46	Yes	15	48%	3
47	Yes	5	15%	3
48	Yes	63	23%	3
49	Yes	5	15%	3

A majority of the articles, the title consisted of “African-Americans”, in which the study participants included both females and males. Very few articles had the words “African-American Men” included in the title, where the study was intended solely for men. Most studies (47%) scored as 0, indicating that African-American men were not targeted and not included. Two studies (4%) scored a 1, indicating that African-American men were targeted and included some in the study. Twenty four articles (49%) scored a 3, which meant that African-American men were targeted and included in the study. Lastly, none of the studies received a score of 2, which would mean that African-American men were targeted, but not included in that study.

## Discussion

The current study utilizes a comprehensive systematic review of the body of literature on the inclusion of African-American men in research regarding diabetes self-care management during the period of 1996-2011. As previously stated, 1996 was selected as the initial date because that was the year diabetes blood test strips first entered the English-language based health education research literature. Findings of this review indicate that a number of issues regarding the inclusion of African-American men in diabetes self-care management research have been inspected, with a majority of the measure of the reviewed studies focusing on the barriers to inclusion and participation in research. In their research, Anderson et al., (2005) indicate that culturally competent approaches, caring, trusting relationships, follow-up, funding, and incentives made a difference in overcoming significant challenges in research with African-Americans with diabetes.

Masculinity, trust/mistrust, decision making, social support, symptom experience/management, and perceptions about barriers to self-care management are the main topics from the studies that were found in the search. Trust requires a reciprocal relationship, with a mutually beneficial exchange of expertise and resources, between researchers and adults and the organizations that serves them, Moreno-John et al., 2004). Little attention has been centered on the recruitment and retention of African-American men in research, as well as barriers to entry into studies. Research also indicates that there are other barriers such as historical mistrust of biomedical research, lack of cultural

relevancy and competency, and less access to care (Hueston & Hubbard, 2000; Larson, 1994; Murdaugh, 1990).

An important role of medicine, nursing, and public health is to help reduce and or eliminate health disparities among racial and ethnic populations (Blustein, 2008; Bostick, Morin, Benjamin, & Higginson, 2006; Gebbie, Rosenstock, & Hernandez, 2003; Smith, 2007; Voelker, 2008). An equally important role of these three disciplines would be to explore ways to conduct research that can examine the many root causes of health disparities, or in this case, African-American men, operating at the levels of the individual, family (and other social networks), community, and society. The epidemiological burden of diabetes in the United States, particularly the tremendous burden of diabetes among Black Americans, continues to be a national priority (Mukhtar, Jack, Martin, Murphy, & Rivera, 2005).

From the search that was conducted, there were no studies were detected that investigated examining perceptions of masculinity, such as self-identified gender contention conflict and how these perceptions are implicated among men diagnosed with diabetes, exclusively African-American men living with diabetes. Gender-tailored research targeting African-American men may lead to the identification of gender-based buffers and risk factors that shape family risk factors that can help reduce generational risk for diabetes. Examples of potential family risk factors include low marital satisfaction; high criticalness, hostility, and conflict, low closeness/ cohesion, and lack of congruence in diabetes beliefs and expectations (Fisher, 2006). How these potential family risk factors contribute not only to the poor self-management of diabetes but also

to the family's ability to manage diabetes, (e.g., family management) represents an exciting area of future research (Chesla et al., 2004).

A diagnosis of diabetes can have a profound effect on a man's self-image. The expression of manhood as autonomy and non-dependence is threatened by the potential loss of body parts, the ability to work and the ability to get around without assistance (Liburd, Namageyo, and Jack, 2007). The entire family system is affected because sex roles shift; income is often reduced; living standards are subject to change; and specialized care for the diabetic man places added demands on the emotional, physical and financial resources of family members. If family resources are already stretched to the limit, a lower-extremity amputation, kidney dialysis or blindness can be devastating for the household (Liburd, Namageyo, and Jack, 2007).

Diabetes is an intangible but imposing foe. Men are rarely taught how to fight an enemy that they cannot see or touch, and thus must engage in an imitation of masculinity that diabetes can erode. From a good portion of the articles found in this search, some the African-American male participants monitored the devastation of diabetes in the lives of family members, friends and in their social support networks, and feared like outcomes for themselves. With more representation and involvement of African-American men empirical research studies, researchers as well as physicians can replace these fears with power by equipping this particular group of men with the skills and knowledge needed to prevent these complications.

### Strengths and Limitations of the Study

The objective of this review was to synthesize the research literature on factors related to how well are African-American men included in empirical studies of diabetes self-care management, critically examine research literature on inclusion of African-American men in research, with emphases on identifying factors specific to inclusion and analysis of research approaches used (e.g., design). Implications of this study are that it offers a comprehensive analysis of various points of concentration for how often African-American men are included in research and identifies gaps in the knowledge base in this area. Despite its usefulness, the review has several constraints that should be considered.

First, it is possible articles were missed due to search strategies employed, or overlooked in the identification and screening process. Second, this review focused on published studies written in English. Third, this search was only centered on African-American men in the United States, who are living with type 2 diabetes. Forth, the initial year of the search began with 1996 and stopped with 2011. Despite potential limitations, the review provides insight on guidance and direction for future research, identification of the difficulty of recruiting and barriers to participation in empirical research, and the need for developing culturally appropriate, effective recruitment strategies. These strategies should firmly address factors such as lack of minority researchers, socioeconomic status, physician reassurance, factors being studied, mistrust, and data confidentiality.

### Implications for Practice

Increasing the number African-American male participants in empirical research requires an improved understanding of the factors affecting the decision to participate. Attention to sensitivity of information collected and collaboration with African-American investigators, colleges, universities, the medical sector, community members, and researchers may improve African-American male representation in empirical research studies. It is apparent from the research studies in this article that the key to successful diabetes management is heavily dependent upon the education, knowledge, and self-care management practices of each person, regardless of ethnicity. Future research efforts should address more efficient and distinct recruitment methods tailored to African-American men, should the research be focused on this particular population. Also, detailed consideration regarding worthy incentives for participants, as well as participant/researcher trustworthiness, and follow-up communication should be given so that researchers and educators can provide promote diabetes self-care management.

CHAPTER III  
TO WHAT EXTENT ARE THEORIES AND/OR CONSTRUCTS BEING UTILIZED  
IN DIABETES SELF-CARE MANAGEMENT RESEARCH WITH AFRICAN-  
AMERICAN MEN?

Diabetes mellitus is an extensive health complication that affects all racial and ethnic groups in the United States. Yet diabetes disproportionately affects African-American men and contributes to other leading causes of death such as heart diseases, cancer, unintentional injuries, strokes, and homicide, and was the sixth leading cause of death for African-American men in 2009. (CDC, 2009; Casares, Ro, Braithwaite, 2006). Type 2 diabetes accounts for 90-95% of all diabetes cases (CDC, 2011). Nationally, compared to non-Hispanic Whites, African-Americans have two to four times the rates of type 2 diabetes and associated kidney failure, blindness, lower limb amputations, and amputation related mortalities (CDC, 2011; Adler and Rehkopf, 2008; CDC, 2008).

It is estimated that up to 85% of lower extremity amputations can be prevented through programs for preventing and treating foot ulcers, preventing reoccurrence of ulcers, and educating patients about proper foot care (American Diabetes Association 2001). Physicians, diabetes researchers, and health educators argue that complications of type 2 diabetes can be prevented because while it is a chronic condition, it is also manageable. Other researchers argue that type 2 diabetes is a complex disease to manage, especially as most of the care involves self-management (Chelbowy, Hood, and LaJoie, 2010). Self-management is defined as the knowledge and skills needed to

perform self-care, manage crises, and make the lifestyle changes required to successfully manage a disease (Clement, 1995).

Regardless of severity or complexity, type 2 diabetes requires the patient to monitor and manage their own treatment. The current literature suggests that African-Americans are significantly less adherent to self-management recommendations than non-Hispanic Whites. This may account for the increased complications and mortality rates among this population (Shenolikar et al., 2006; Trinacty, Adams, and Soumerai, 2007). Yet there is little information available to clarify the reasons for the low rates of treatment adherence among African Americans. Given the disproportionate disease burden and complications among this group, it is important for stakeholders to understand factors which enhance or detract from successful self-management of this chronic condition.

#### The Role of Theory in Understanding Disease Management Behaviors

Theory provides insight into diverse psychosocial factors that contribute to and maintain health risk behaviors (McLeroy et al., 1993). Theories and their components (i.e., constructs) and processes (i.e., mechanisms or relationships among constructs) can provide insight into human behaviors as related to a variety of influential (or influenced) factors. Not only can we learn the “what”, but also the “why” which is guided by empirical work performed across various social and behavioral science disciplines. Women are more likely to engage in a broad range of preventive and health-promoting behaviors than men, while men are more likely to engage in over 30 behaviors that have been shown to increase the risk of morbidity, injury, and mortality (Courtenay, 2000).

Courtenay, 2000 stated that men are more likely to engaging in risky behavior, declining to take part in health-promoting activities, and claiming that high-risk behaviors (e.g., alcohol drinking) will not impair performance (e.g., driving) are often demonstrations of the norms of masculinity in the larger culture, and ways in which men construct and reinforce their masculinity.

Theories specific to gender may help us understand what contributes to these disparities, and theoretically-driven systematic inquiry should yield significantly to our understanding of chronic disease self-management. Presumptions about male masculinity and manhood may lead men to either take actions that do harm to them or to refrain from engaging in health-protecting behaviors. Efforts to redefine the cultural meaning of manhood in positive ways will require parallel changes in cultural institutions and social structures to reinforce positive health behaviors in men over the life course (Williams, 2003). Yet there is insufficient indication that concepts of masculinity or race (or its interactions) are included or accounted for in health behavior research.

Questions about theory often arise when researchers begin to identify research questions that require more complex analysis and need to investigate deeper into their data to explore how illness and health care are conceived and practiced (Kelly, 2010). In particular, what extent have theories and/or constructs specific to race and culture been utilized in diabetes self-care management research with African-American men? In order to address the question, it becomes necessary to examine and determine how well theory

and theoretical constructs, particularly those relevant to African-American men, have been applied and adopted in diabetes self-care management research.

The research question driving this study seeks to clarify to what extent have theories and/or constructs been utilized in diabetes self-care management research with African-American men? Thus the aim of this paper is to assess the utilization of appropriate (i.e., culturally relevant) theories and/or constructs in diabetes self-management research among African-American men. A secondary aim is to identify factors – specifically barriers - most utilized in research specific to this area. After reviewing type 2 diabetes research literature pertaining to African-American men, research studies with this group have not clearly demonstrated how and why the sustained dietary modifications, blood sugar maintenance and other self-management customs are not used as consistently as recommended. Therefore, there are not many studies that have analyzed the reasons or barriers for this deficit and or how those living with diabetes view the suggested lifestyle changes.

### Methodology

The current investigation was conducted by first, conducting a systematic exploration of the research literature. This was followed by evaluating each article that meets the inclusionary/exclusionary criteria based on the following parameters utilized by Delissaint and McKyer (2008) as shown in Table 3.

<b>Table 3: Theory Utilization Scoring Scheme</b>	
<b>Score</b>	<b>Criteria</b>
3	Clear identification/operationalization of theory/constructs used.
2	Use of theory, but inferred (not clearly identified).
1	Some evidence of use of theory/constructs.
0	No evidence of theoretical basis driving the research.

### Database Search

The analysis for this study adapted the Garrard’s matrix method (Garrard, 2004) to perform a comprehensive literature review. Therefore, the literature review and analysis helped to frame the methodology that is being used. A systematic search was performed to retrieve peer-reviewed articles addressing SCM among African-American men living with type 2 diabetes. Eight literature databases- Academic Search Complete (EBSCO), ERIC (EBSCO), ScienceDirect (Elsevier), MEDLINE (Ovid), Cambridge Scientific Abstracts Databases (CSA), CINAHL, TOPICsearch, and PsycINFO- were searched using keywords such as type 2 diabetes management, self-care theory, African-American men and type 2 diabetes, and men’s health and type 2 diabetes. In addition, all reference sections were purled to ensure the inclusion of any articles omitted during the initial database search for relevant articles. In addition, all reference sections were purled to ensure the inclusion of any articles omitted during the initial database search for relevant articles.

### Inclusionary and Exclusionary Criteria

Research publications meeting these criteria were included only if the article: (1) was peer reviewed and published in English between 1996 and 2011, (2) presented

empirical studies (cross-sectional, focus groups, case-control, qualitative, quantitative, longitudinal, group randomized, quasi-experimental, and mixed methods) conducted in the United States, and(3) investigated type 2 diabetes self-care management (SCM) among African-American men.

#### Theoretically Driven Empirical Articles

Fifty articles were retrieved and screened for inclusion. Of this number, forty-nine of these studies were conducted in the United States. An extensive search of the literature databases revealed thirty-one empirical papers that met the inclusionary and exclusionary criteria. The one research study conducted outside of the United States was automatically excluded. The remainder of the eighteen studies conducted in the United States did not address type 2 diabetes self-care management (SCM) among African-American men.

These research articles address other issues pertaining to African-American men such as male masculinity, medical mistrust, perceived body image, health decision-making, discrimination, health information seeking, knowledge of average blood glucose level, depression, fatalism, and fear of having diabetes and its related consequences. In summary, thirty-one published articles based on research conducted in the United States assessed type 2 diabetes self-care management (SCM) among African-American men.

#### Results: Scores of the Studies and Theoretical Framework

Among the research articles, approximately twelve out of the fifty disclosed a theory and or constructs and how they were utilized. Table 4 details specifically each

scoring category and how many articles coincide with each category. Thirty four of the fifty articles received a score of “0” (i.e., there was no evidence of theoretical basis driving the research). Two out of the fifty articles received a score of “1”, which indicates that the article provided some evidence of theory and use of constructs. Two of the articles received a score of “2”, which would have meant that there was use of theory, but that it inferred or not clearly identified.

<b>Table 4: Article Scores and Usage of Theoretical Framework or Constructs</b>	<b>N</b>	<b>Score</b>
Clear identification/operationalization of theory/constructs used.	12	3
Use of theory, but inferred (not clearly identified).	2	2
Some evidence of use of theory/constructs.	2	1
No evidence of theoretical basis driving the research.	34	0

Lastly, the remaining twelve articles all received a score of “3”, which meant that in that article, there was clear identification and operationalization of theory and/or construct use. The constructs used within the reviewed articles were operationalized through a one on one interview, focus group, questionnaire, survey, or predetermined time period format. Table 4 shows the breakdown of whether or not a theory or constructs was found in each study. Table 5 below shows the theories, constructs and models that were found in 12 of the research articles, in which some articles used more than one theory or construct. Table 6 below shows the fifteen studies that clearly indicated with theory the researchers used in their study.

<b>Table 5: Scores of the Studies</b>		
<b>Study #</b>	<b>Score</b>	<b>Theoretical Framework</b>
1	0	Symptom focused conceptual model
2	3	Grounded Theory
3	0	Not reported
4	3	Health literacy framework; self-efficacy component of Bandura's Social Cognitive Theory
5	0	Not reported
6	1	Interview guides created based on Theory of Planned Behavior, Ecological Model, & Shared Decision Making Model
7	0	Nursing Care Management Model (major concepts: Sick Care, Health-making, Nurse-client relationship)
8	0	Not reported
9	0	Not reported
10	0	Not reported
11	0	Not reported
12	0	Not reported
13	0	Symbolic interaction theory
14	3	Self-efficacy theory
15	2	Not reported
16	0	Not reported
17	0	Not reported
18	3	Health Belief Model
19	0	Not reported
20	2	Not reported
21	3	Grounded Theory
22	0	Not reported
23	0	Not reported
24	0	Not reported
25	0	Not reported
26	0	Not reported
27	0	Not reported
28	0	Not reported
29	0	Not reported
30	0	Not reported
31	0	Not reported
32	3	ISAS Theory
33	0	Not reported
34	3	Health Belief Model; Self-Efficacy concept
35	0	Not reported
36	1	Not reported
37	3	Not reported
38	3	Andersen Behavioral Model; Theory of Reasoned Action
39	3	Kleinman's exploratory model of illness
40	0	Not reported
41	0	Not reported
42	2	Not reported

<b>Table 5: Continued</b>		
43	0	Not reported
44	0	Not reported
45	0	Not reported
46	3	Self-Determination Theory; Grounded Theory
47	0	Not reported
48	0	Health Promotion Model; Transtheoretical Model
49	0	Not reported
50	0	Not reported

<b>Table 6: Theoretical Frameworks and Constructs Identified</b>
Anderson Behavioral Model
Grounded Theory
Health Belief Model
Health Literacy Framework
Health Promotion Model
Kleinman's Exploratory Model of Illness
Nursing Care Management Model
Self-Determination Theory
Self-Efficacy Theory
Social Cognitive Theory
Symbolic Interaction Theory
Symptom Focused Conceptual Model
Theory of Planned Behavior
Theory of Reasoned Action
Transtheoretical Model

### Discussion

After a review of literature, approximately twelve out of fifty articles were found to have clearly stated one or more particular theories within the methodologies section of the research article. Analysis of these publications revealed that most (n=34) were not grounded in a theoretical framework of any kind. The authors of these research articles

may have failed to clarify how a theory or theories were applied. While the average score for theory utilization was low (24%), the result may be due to several reasons such as a limited sample size of African-American men in the research study as compared to African-American women, a lack of trust in research or the researcher, confidentiality, lack of prior participation in research studies, or not being to utilize any particular theory that the researcher(s) felt comfortable in using to address self-care management of type 2 diabetes.

Furthermore, the instruments used for analyzing these studies were not piloted or validated. As a result, measurement error is a possibility. Given the scarcity of theory utilization shown from table 2 clearly translates that there is abundant breach of the “quality” of qualitative research as well as quantitative research. The quality of a research study will be influenced by how the researcher attends to theoretical concerns at different stages of the research. Theory can inform qualitative research design and analysis and theory can also be developed from qualitative analysis (DiClemente, Crosby, & Kegler, 2002). Theoretical considerations play a part at all stages of the research process, though this often not made explicit (Kelly, 2010).

The findings from this investigation indicate that some diabetes researchers are (1) failing to use theory and constructs in directing research; (2) using theory superficially; or (3) using theory fully, but failing to be specific and clear about the distribution of the findings. For these reasons, one could argue that the progress towards improving application and utilization of theory into type 2 diabetes self-care

management research involving African-American men is still delayed, but is obtaining support in the research literature.

As previously stated earlier in this manuscript, the role that the theoretical framework has in research of any kind is to assist the reader in making logical sense of the relationships of the variables and factors that have been deemed relevant and substantial to the problem at hand. In a sense, theory provides definitions of the relationships between the variables so that the reader can understand the theorized relationships between them. The use of theory makes it possible for researchers to understand, and to translate for policy makers and health care providers, the processes that occur beneath the visible surface and so to develop knowledge of underlying principles (Reeves, et al., 2008). Above all, theory can help people move beyond individual insights gained from their professional lives to a situation where they can understand the wider significance and applicability of the phenomena (Reeves, et al., 2008).

Being explicit about the role of theory is part of being transparent to others regarding research design and the analytic process and it is also an important consideration in producing good quality research (Kelly, 2009). The depth and detail of analysis depends upon the focus of the research and available resources, such as time, level of experience and training of the analyst and access to expert advice. The benefit of greater attention to theory in qualitative research is that it enables a more sophisticated approach to the data so that a range of different questions can be asked of the data set (Kelly 2009).

Lastly, the application of theoretical frameworks in future research studies would lead researchers to identify the underlying issues associated with how African-American men positively or negatively self-manage type 2 diabetes. While reading and review each article, several major categories of barriers SCM were identified: shared decision making among African-Americans with diabetes, social support from family and friends, the role of spirituality in SCM, trust and distrust in physicians, masculine role identity factors, and patient perceptions about barriers to SCM. Further research should focus on most common barriers that identified by African-American men living with type 2 diabetes and how those barriers may have a negative impact on self-care management. Some barriers, if addressed, may be pliable to interventions that could advance health outcomes.

## CHAPTER IV

### WHAT IS THE ESSENCE AND LIVED EXPERIENCE OF SELF-CARE MANAGEMENT AMONG AFRICAN-AMERICAN MEN LIVING WITH TYPE 2 DIABETES?

#### Scope of the Problem

There is a sizable gap in health disparities and public health literature addressing the self-care management experiences of African-American men living with type 2 diabetes. Management of type 2 diabetes focuses on lifestyle interventions, lowering other cardiovascular risk factors, and maintaining blood glucose levels in the normal range. Type 2 diabetes is a problematic disease to manage, with most of the care incorporating self-management. The current literature conveys that African-American men are significantly less compliant to self-care management instruction than non-Hispanic white men, which could conceivably account for the elevated diabetes related complications and mortality ratios among this particular community of men.

The purpose of this study is to gain an understanding of the essence and lived experience of African-American men living with type 2 diabetes. What are the barriers or challenges that African-American men face regarding positive self-care management? What daily self-care practices do these men routinely incorporate in their lives? Self-management regimens typically include: engaging in daily physical activity; following a prescribed diet; administering oral medications and/or insulin; performing blood glucose monitoring; and managing daily stressors and life events.

Self-care management of type 2 diabetes can be a very complex matter for African-American men. This challenge can be due to lack of social support, low self-confidence, feelings of hopelessness, low health literacy, or lack of knowledge regarding positive self-care management skills. African-American men have 30% higher rates of diabetes related blindness and undergo twice as many amputations compared with non-Hispanic white men (Hendricks & Hendricks, 2000). Type 2 diabetes can become a staggering ailment if African-American men if their center of attention is not focused on treatment and maintenance. Diabetes self-management is defined as the knowledge, and skills needed to perform the self-care, manage crises, and make the lifestyle changes required to successfully manage the disease (Clement, 1995).

The successful management of type 2 diabetes requires daily attention to a complex adaptation of behaviors such as healthy eating, medication adherence, stress management, blood glucose monitoring and testing, management of hypoglycemia (low blood sugar levels), physical activity, and foot care (American Diabetes Association, 2004). While both genders and all ethnicities are confronted by the continual necessity of type 2 diabetes management, there is an insufficient amount of research literature centered on the African-American male and contexts in which these men go about living and managing the disease.

Published literature is beginning to expand in examining preventive health service delays, masculinity, mistrust, diabetes knowledge, fatalism, medical decision making, and the psychosocial impacts of self-management among African-Americans men (Hammond et al., 2010; Liburd, Namagego-Funa, & Jack Jr., 2007; Hart Jr. et al.,

2009; Chesla et al., 2004; Peek et al., 2008; Peek et al., 2009; Baptiste-Roberts et al., 2006; Sanders-Thompson et al., 2009; Jack Jr. et al., 2010; DeWalt, Boone, & Pignone, 2007; McCleary-Jones, 2011; Bhattacharya, 2012; & Walker, Stevens, & Persaud, 2010).

The significance of understanding the lived experiences of African-American men with type 2 diabetes and the struggles encountered in daily self-care management will help close the gap in published research literature, which has caused a low-level of research-derived information that can be used to improve health outcomes for this group. Diabetes is an example of a health issue in which little empirical information is available regarding research with African-Americans, especially African-American men. A greater understanding of the essence and lived experience of African-American men is needed to enhance self-management in this group.

In order to improve a self-management and support will require revealing knowledge of the individuals' self-management practices, resources, awareness, priorities, and possibilities. Knowing the population in regard to self-management practices is likely important to improved self-management support and ultimately chronic illness care (Clark et al., 2008). Despite the extensive agreement that self-care practices have a substantial responsibility in the management of type 2 diabetes, there is still a gap in research regarding knowledge about daily self-care management practices of African-American men.

The primary purpose of this study is to gain an understanding of the essence and lived experience of African-American men living with type 2 diabetes. The two sub-

questions of this study are: *(a) What are the barriers or challenges that African-American men face regarding positive self-care management? (b) What are management methods do these men routinely incorporate in their lives?* This article extends the literature by providing information on African-American men's individual experience of how type 2 diabetes has impacted their lives, experience in managing type 2 diabetes, and the challenges that they confront in self-care management. This can further give clarity about which diabetes care measures and outcomes are relevant for African-American men.

#### Methods: Phenomenological Methodology

The researcher completed a thematic analysis of 19 transcripts using what is known as phenomenological methodology (Creswell, 2007). The focus of a phenomenological study according to Patton (1990) lies in the "descriptions of what people experience and how it is that they experience." The goal is to identify essence of the shared experience that underlies all the variations in this particular learning experience. Essence is viewed as commonalties in the human experiences (Creswell, 2007). This type of research methodology is used to study areas in which there is little knowledge (Donalek, 2004).

Describing is the key part of the phenomenology methodology. The fidelity to the phenomenon as it is lived means apprehending and understanding it in the lived context of the person living through the situation (Moustakas, 1990). The participants in this study in question, tell their own story and in their own terms, so therefore, excerpts

from their transcripts are not edited or corrected and are presented in their unique voice as it was recorded.

The phenomenological approach was used to ask questions and capture the lived experiences of the participants, who are all living with the same phenomenon of type 2 diabetes. Even though they all have the illness, their experiences with self-management practices, social support, and feelings about medical diagnoses will be quite different. Phenomenological research methods are consistent from other methods used in quantitative research. Mariano (1990) asserted that phenomenological could be difficult to understand, particularly if a person has had a limited background in philosophy. Although phenomenological research has sometimes been called a soft science, Streubert and Carpenter (2002) contend that this research method is rigorous, critical, and systematic.

#### Researcher Positionality

The author, an African-American male, has a background with diabetes education from years of teaching experience at the university level, as well as knowing people in the surrounding community and several family members who live with type 2 diabetes. As an African-American researcher, I understand the importance of race and cultural differences in medical adherence and carrying out diabetes management. I also understand how chronic illnesses are perceived in the African-American community is culturally formulated and has essence, and this essence has implications for successful diabetes management. My view as an African-American male with regard to type 2

diabetes within this group of men is that in doing this research I'm staying aware of the ongoing research and continuing to read published work that is relevant.

The work that has already published as well as those who also conduct research in this area with this population of men is important because it gradually begins to shed light on how diabetes researchers and educators can untangle the web of diabetes causality and maintenance in African-American men. Due to the paucity of research in this area as well as small amounts of African-American participating in research studies, the voices of these men need to be heard so that we as researchers can gain an understanding of the management and impact of type 2 diabetes on the lifestyle, sense of self, and family members of African-American men.

This research is important to the author because the ailment experience of type 2 diabetes among African-American men appears very complex and is not well-suited into an advisable health plan of care. Moreover, changing one's lifestyle in the interest of managing the disease and the impact that of diabetes complications on one's ability to meet routine obligations can affect spouses, siblings, coworkers, and others, as well as the person with diabetes (Liburd, Namaegeyo-Funa, Jack Jr., Gregg, 2004). The individual and non-individual ramifications of having type 2 diabetes combined with poor self-care management can be obscure. The study is important to include in this research journal because although few studies have examined the impact and influential relationships of family and friends on the management of diabetes, even fewer studies have examined the lived experiences and daily self-care management behaviors of African-American men living with type 2 diabetes.

### Sampling of Participants

The study consisted of a sample of 19 African-American men, ages 35-69, who are living with type 2 diabetes in southeast Texas. The age specification intended to include men who had been medically diagnosed with type 2 diabetes and possibly were not living with and/or managing any other major chronic illness, which might confound the aims of the study. The researcher created and passed out flyers and postcards to recruit men from Houston area barbershops that were located in predominately African-American communities. The researcher also passed out study information postcards with contact information at African-American churches, as well as to participants at the conclusion of their interview session. The participants for this study were recruited using snowball sampling due to issues of access and sensitivity of the topic. This technique is one in which the researcher collects data on a few participants of the target population and then asks those participants to provide any information needed to locate other men whom they know that are also living with type 2 diabetes.

Participants were asked to distribute the postcards to any other African-American men that they know who live with type 2 diabetes. Interested participants either spoke to the researcher the same day or contacted the researcher upon receiving the study information to ask questions before agreeing to participate in the study. Once a participant verbally committed, they were asked to provide the best day, time, and location of their choice for their interview session. Once the date and time were arranged, the researcher collected the address and telephone number of the participant. The inclusion criteria was: 1) participant was self-identified as African-American; 2) had

to be in the age range of 18 to 70; 3) were medically diagnosed with type 2 diabetes by their medical doctor. Each participant individually selected their interview location. Most of the participants chose to conduct their interview at their place of residence. Two of the 19 participants chose to conduct their interview at that place of employment because it was more convenient for them than at their residence. At each interview location, the interviewer and participant sat face to face in a private location.

#### Protection of Human Subjects

This study obtained Institutional Review Board (IRB) approval from Texas A&M University (TAMU). Once study was approved by the IRB office and given an IRB protocol number and authorization, the researcher and his advisor concluded final drafts of recruitment fliers and postcards and had them printed with the IRB authorization number to disseminate potential participants. The researcher obtained participant consent on the same day of the scheduled interview as well as consent to have his interview audio recorded. To insure confidentiality and anonymity, each participant was assigned a participant number between 1 and 19.

#### Data Collection

The researcher, who is also the author, conducted all 19 interviews. The researcher has a background in conducting qualitative interviews; therefore no interview training was needed. Each interview session used the following protocol: The interviewer (a) read and discussed the consent form with each participant, (b) had the participant sign the consent form that provided permission to tape record the session, (c) requested the participant to complete the demographic profile, and (d) performed the

face-to-face interview. Interviews lasted approximately 35 to 90 minutes. Each participant was given the option to end the session at any time without penalty.

Upon completion of the interview session, participants were provided with a \$25 gift card and offered a copy of the study findings, which would become available upon completion of the study and its write-up. The researcher recorded and saved each interview session using a hand-held digital recording device. These files were transferred and uploaded to a password protected hard drive located in the researcher's office. As requested by the TAMU IRB office requirements, all of the study data will be maintained and stored by the PI under locked file cabinets for a minimum of 7 years after completion of the study. Once the study is complete, data containing assigned numbers and key linking the subjects will be destroyed.

#### Interview Guide

The interview instrument was developed by the faculty advisor and researcher and was composed of two parts. Part I is the demographic profile in which is shown in table 7. The researcher and his faculty advisor developed 16 questions pertaining to age, marital status, education level, household income, insurance state, members of the household, and how long they have been living with type 2 diabetes. Accompanying questions pertained to diabetes doctor visit, attending educational sessions regarding diabetes management, and comfort level telling people about their diabetes. Part II is the semi-structured interview guide which is shown in table 8.

<b>Table 7: Demographic Profile Questionnaire</b>
1) What is your age range?
2) What is your marital status?
3) What is the highest degree or level of education you have completed?
4) What was your total household income during the last 12 months?
5) To the best of your knowledge, how long have you been living with type 2 diabetes?
6) How often do you visit your doctor about your diabetes?
7) Have you ever attended any diabetes educational classes or sessions since you developed type 2 diabetes?

The researcher and his faculty advisor designed this guide as the primary data collection instrument. The interview guide was developed according to the most recent type 2 diabetes research relating to minority populations, specifically, African-Americans. For content validity, further revisions were made by the researcher's qualitative research committee member, who primarily focuses on issues specific to African-American men and has an established record of qualitative research in the field. These revisions were made to address clarity, wording, and accuracy in response to formative research participant recommendations.

The semi-structured interview guide was used to collect data concentrating on six areas: diabetes management practices, knowledge and beliefs about diabetes, perceived barriers to diabetes management, social support, symptoms, and personal vs. interpersonal feelings regarding diabetes management. The end result is to show that beliefs about barriers to type 2 diabetes treatment can have an adverse influence on self-care. A combination of high barriers, poor daily self-care management, and knowledge could possibly put those with type 2 diabetes at an elevated risk for subordinate self-care

management. Barriers have a role in reality and diabetes researchers and educators are charged with recognizing the complications of what individuals with type 2 diabetes need to do improve and enhance their health (Chlebowy, Hood, LaJoie, 2010).

<b>Table 8: Interview Guide</b>
1) When your doctor first told you that you had developed type 2 diabetes, how did it make you feel?
2) What do you think caused you to have developed diabetes?
3) Do you have any fears about having type 2 diabetes?
4) What changes did you notice about your body that may have led to your diabetes diagnosis?
5) Have you experienced any other problems because of your diabetes?
6) What kind of treatment(s) do you prefer to help you manage your diabetes?
7) Describe how you control your diabetes.
8) Is there someone in your life who helps you control your diabetes?
9) What do you feel are the most difficult diabetes management behaviors for you to do on consistent basis?
10) Do you feel that you have more stress in your life since you found out you have type 2 diabetes?

### Data Analysis

From the initial start of each interview, the data analysis began. Parse, Coyne, and Smith (1985) wrote that the analysis of data from these types of studies requires that the researcher “dwell with the subjects descriptions in quiet contemplation” (p.5). The researcher then tries to uncover the meaning of the lived experience for each subject. Themes and patterns are sought in the data and therefore, data collection and data analysis occur simultaneously. First, the researcher typed the interview transcript at the conclusion of each interview for a total of 19 recorded interviews. This transcription process reinforced “active” listening and note taking, enabling the researcher to become

familiar with the data set. Second, the researcher wrote personal and theoretical memos (notes labeled either PN or TN). The personal memos (PN) kept a record of personal ideas or reflections, which emerged while listening to the data. The theoretical notes (TN) indicated points where transcript data reflected ideas or concepts from the research literature.

Third, the researcher listened to the interviews a third time and created codes or short labels to identify key words and structures in the transcripts. The codes or short labels, represented by words or phrases in the transcripts, emerged inductively from the transcripts themselves as patterns or themes. Braun and Clarke (2006, p. 82) describe a theme as “something important about the data in relation to the research question, and [something] that represents some level of patterned response” (p. 82). Fourth, the researcher organized the codes or short labels by theme into categories using memos and structures identified in the previous three steps.

The fifth and final step of the analysis process involved selecting essential statements from the participants’ interview transcripts that best answer the interview questions. Specifically, the narrative emerged from illustrative data extracts arranged according to the section headings of the semi-structured interview guide and organized according to the primary research question and two sub questions. Themes that emerged which did not fall under the three primary questions were considered new findings.

### Findings: Description of Interview Participants

Table 9 organizes significant variables from the demographic profile to identify useful characteristics of the study's sample population. The study's sample consisted of 19 African-American men, where two were in the age range of 35-44, four ranged from 45-54, six ranged from 55-64, and seven ranged from 65-70. Four participants had a reported household income that was over \$150,000, four participants ranged from \$100,000 to \$149,999, and four participants ranged from \$50,000 to \$74,999. Two of the participants were single, fourteen were married, one was widowed, and two were divorced. Seven of the participants had some college education, but did not have a college degree.

One participant had only a high school degree, seven participants attended college, but did not complete their degree, three had an associate's degree, five had bachelor's degrees, and three participants had a post graduate degree. Seven of the participants had been living with type 2 diabetes for 1-5 years, five for 6-10 years, two for 11-15 years, three for 16-20 years, one for over 20 years, and oddly one participant couldn't remember how long he had been living with his diabetes. When asked if the participants had ever attended any diabetes educational classes or seminars, nine said they had attended before and ten reported that they had not attended before. Finally, when asked how many times per year they see their diabetes doctor, eight reported they see their doctor 1-2 times per year and eleven reported seeing their doctor 3-4 times per year.

<b>Table 9. Summary of Participant Demographics</b>	<b>N=19 and Percent</b>
<b>Age Range</b>	<b>N and %</b>
35-44	2 (11%)
45-54	4 (21%)
55-64	6 (32%)
65-70	7 (37%)
<b>Annual Income</b>	<b>N and %</b>
<25,000	2 (11%)
25,000-34,999	2 (11%)
35,000-49,999	1 (5%)
50,000-74,999	4 (21%)
75,000-99,999	2 (11%)
100,000-149,999	4 (21%)
>150,000	4 (21%)
<b>Marital status</b>	<b>N and %</b>
Single	2 (11%)
Married	14 (74%)
Divorced	2 (11%)
Widowed	1 (5%)
<b>Education Level</b>	<b>N and %</b>
< high school	1 (5%)
some college but no degree	7 (37%)
associate's degree	3 (16%)
bachelor's degree	5 (26%)
graduate or professional degree	3 (16%)
<b>Living with T2DM</b>	<b>N and %</b>
1-5 yrs	7 (37%)
6-10 yrs	5 (26%)
11-15 yrs	2 (11%)
16-20 yrs	3 (16%)
> 20 years	1 (5%)
Don't know	1 (5%)

**Table 9 Continued:**

<b>Attended educational classes</b>	<b>N and %</b>
Yes	9 (47%)
No	10 (53%)
<b>Doctor visits per year</b>	<b>N and %</b>
1-2 times per year	8 (42%)
3-4 times per year	11 (58%)

### Results

Due to the methodology and analysis used for this study, the participants had an array of responses that really shed light on how they are with and experiencing type 2 diabetes. They also opened up and shared what they are doing to manage their diabetes and the difficulties that they sometimes face in doing so. This section will focus on questions 2, 3 5,and 6-9 from table 2 because these questions address the purpose as well as the two sub-questions of this study.

***Cause of Development.*** Participants' statements indicated that their family and lifestyle choices had an effect on them developing type 2 diabetes. In particular, participants discussed issues about their family history (mother's side vs. father's side) contributing to the illness. One participant said:

Participant: *"It's hereditary in my family. I found out that my sister has it... and she was a type 1 diabetic. And then I found that... that another sister had it... I have two sisters that have it. Then I found out by talking to them that it's hereditary."*

Another participant stated:

Participant: *"Umm... like I said hereditary, it's something that you know, if it's on your mothers' side or fathers' side, it's not like something that you just go out and catch. It's just in your genes or whatever from your mother or father and for me, it just so happened to be from my fathers' side of the family. So that's why."*

Participants' also shared how some of the choice they made in terms of diet and exercise may have caused the onset of type 2 diabetes. Examples included lack of exercise, high blood pressure & cholesterol, being overweight, eating late at night, not consuming vegetables regularly, and alcohol& tobacco. For example, one participant said:

Participant: *"For me, it was diet and the fact I wasn't getting enough exercise. I think both of those for sure. My job kept me from being real active. I wasn't at a desk, but it kept me from being active."*

While a few participants added with:

Participant: *"It probably stems from a long history of improper feeding. You had to have what you had and a lot of sugar was involved at that time. So I think that was probably one of the major causes. We ate a lot of potatoes and starchy stuff... stuff like that because we didn't know any better."*

Participant: *"Bad habits...eating, consuming liquids (laughing), the wrong kind of liquids... can I say alcohol? (laughing) Yeah, alcohol. Well... it's a product of my environment because everyone that's in my family either has high blood pressure, diabetes, asthma, so... I guess it's just in my genes."*

Participant: *“Family possibly had a lot to do with it, but I did also. In my younger years, I worked for the U.S. Post Office as a mailman, and I didn’t drink a lot of water, I was drinking Cokes. And the reason, because everywhere you go... there was a Coke machine. It was hot outside; I would just buy a Coke and drink it. So, I didn’t drink a lot of water, I drank mostly Cokes. That I think was the contributing factor.”*

Lastly and one that really stood out was that one participant stated that his diabetes came from his military background. His response to the question was:

Participant: *“I’m told by the VA that it was my exposure to agent orange during my two tours of combat in Vietnam.”*

***Fears about Type 2 Diabetes.*** The presence of fear or alarm was also identified as a challenge to positive self-care management of type 2 diabetes. Fears were primarily described as permanent bodily changes in the body that would further complicate daily self-care management. Having a variety of fears appeared to have a linkage to not knowing 100% what would happen next for the participant that cause other changes in the body that were permanent, such as progressing to type 1 diabetes, sexual dysfunction, sticking their fingers, limb amputations, kidney failure, and loss of vision.

Participant: *“Well yeah... I fear... I keep worrying that as I age, I hope that I don’t have to end up taking insulin shots. My biggest fear is taking insulin shots. That’s the biggest one and don’t want to be an amputee or lose any limbs.”*

Participant: *I say fear of eyesight because I've always been near-sighted since a child so I've always had contacts, glasses, something like that. And then with diabetes, that can affect your eyesight as well. But I know what I need to do in order for it to not get to that point.*"

Participant: *"Watching other siblings in my family, yes I do have fears. Dialysis, kidney failure, which would require you to be on dialysis, loss of limbs, eyesight, and other serious causes of diabetes."*

Participant: *"Yes. Loss of vision, Loss of limbs, Inability to perform sexually."*

A few participants stated that they didn't have any fears once they become educated and aware of what needed to be done to manage their diabetes properly.

Participant: *"Not anymore. Now that I've studied it, done research on my own. I know the do's and don'ts and I know that it can be handled. I don't have any fear at all."*

Participant: *"Like I said before I was sad because of some things that I heard from others about it. But once I started reading about and talking to different people that have it, it's a better chance of living longer when you're eating right and maintaining the way you eat. I feel more energy and more happier just by knowing more about it."*

**Other Problems Experienced from Diabetes.** Several participants stated that they began to notice changes in their bodies that were not prevalent prior to being diagnosed with

type 2 diabetes. Participants emphasized that these changes were due to an imbalance in their bodies as well as unstable and elevated blood sugar levels. Most commonly mentioned were changes in vision as well frequent urination. A few participants said that these changes ceased after receiving medication from their doctor.

Participant: *“Having to get up and got the restroom more often, I’m attributing that to diabetes. However, since the doctor put me on this medication, that’s no longer an issue.”*

Participant: *“Yes. The tingling in the fingers and the tingling in the feet and things like that and I ended up having to take medication for that.”*

Participants: *I was developing some problems with my eyesight until I started going to the eye doctor regularly. So I go to my eye doctor every three or four months too. And they do these pressure tests and give me eye drops so I take eye medication now and that has helped me improve me tremendously.”*

Participant: *I’ve noticed is that I have these spots that come over my vision. When I’m looking I see little black spots that come over my vision. That and it seems that I have more little spots that come on chest, shoulders, and arms and when I asked my doctor about that, she said that was a result of diabetes.”*

**Treatment Preferences.** Participants’ statements indicated three main commonalities regarding treatment preferences which were medication, dietary changes, and increase in exercise. Some participants were not favor of taking pills while some didn’t mind using them at all. For some of the participants, it appears that it’s easier for them to manage

their diabetes by prescription medication than by lifestyle changes such as diet and exercise.

Participant: *“I can do it with medication as long as needles aren’t involved... I can’t stand needles.”*

Participant: *“After going through this for a long as I have, the pills would probably be the easiest because there’s no injections, no pain.”*

Participant: *“My doctor has put me on medicine... it’s a little bity pill, one pill a day and that’s all I take... that’s all I have to take for diabetes. And it seems to be doing pretty good.”*

Participant: *I try to minimize eating sweets and having as proper of a diet as possible. I need to incorporate so more exercises in my life which is something that I’ve been thinking about. The hardest about that is trying to be motivated.”*

Participant: *“Other than exercise, I have gone to one or two diabetic classes to learn more about a balanced diet for diabetics and I have lost weight in the past. My biggest change is cutting sweets out. I love sweets, but I have cut back... very seldom do I have them.”*

**Daily Control and Monitoring of Diabetes.** Many of the participants stated that they now drink more water, eat a more balanced and healthy breakfast, in which they include more fruit and cut back on fast food breakfast items. Taking medication and also checking blood sugar levels is the first priority for some of the men. The response

primarily spoke to, dietary changes, routine control and close attention and monitoring of their blood sugar levels.

Participant: *“I eat small amounts. I eat breakfast before going to work so I don’t get tired. I make sure I have lunch. I also take crackers with me to eat in between because you never know if your blood sugar will get to low or get to high... you want to know how to manage that. And every morning, I always check my glucose. Even if I don’t feel right, I check it.”*

Participant: *“First thing I do in the morning is I have to take my pill. Then for breakfast, it’s only two things that I eat, oatmeal or Cheerios, Honey Nut Cheerios. And then I have to eat fruit every day and a little salad. But my biggest adjustment was sweets.”*

**Assistance with Controlling Diabetes.** Participants’ stated that they strong support systems surrounding them to assist them in managing their diabetes. This supportive network primarily consisted of relatives and extended family that assisted with joint exercise, appointment reminders, monitoring sugar intake, purchasing educational materials, and encouragement. One participant stated that he places the responsibility of management on himself even though he has a very supportive family.

Participant: *“My mind is so made up and so determined on this here that it’s usually just me. It’s like once my mind is made on anything, it’s a wrap! My mind is made up. I refuse to go back to that hospital and I refuse to eat all of those bad foods I once did. But I had an entire lifestyle change and my whole perspective has changed.”*

Participant: *“My wife. She’s ordered a whole series of cookbooks and other books that talks about diabetes and she watches it on TV religiously because she’s trying to keep me around here longer. She watches the TV program, she’s ordered the books and she’s been encouraging me.”*

Participant: *“My wife goes with me to every visit. She’s gone with me to every visit. That is encouraging in itself. And I want her there and she listens to what the doctors say.”*

Participant: *“My brothers of course... although we live in different geographical locations, we talk a lot on the phone and we encourage each other and check with each other. And since I have one brother that is diabetic, we check and talk to each other a lot.*

Participant: *Yes, my wife definitely... she buys groceries. So she shops and like I said before, she has the patience to check for carbohydrates in the foods and different things like that.”*

***Inconsistent Management Behaviors.*** Although there were a variety of responses across all of the participants, there were three main behaviors that the participants shared having trouble doing on a consistent basis. These behaviors are exercise, dietary changes, and taking medication. Starting with exercise which was commonly shared by majority of the participants, it appears that making the time as well as an advanced age are the primary barriers towards exercising.

Participant: *“My biggest thing is the exercise part. When I got to the doctor, they say you know...you need to exercise more... lose weight. If I can start doing that more, I can probably reduce my medicine a lot. As you get older, your body is not like it was 20 years ago and so your body can't respond to stuff at times, so main thing I want to do is reduce the insulin or get off the insulin. And my doctor says the best way to do that is by exercising and changing your eating habits, and the losing of the weight. Taking the time and putting it in a routine is what makes it hard to do consistently.*”

Participant: *“Sticking to the diet... eating healthy all of the time. Eating healthy doesn't have any taste... it doesn't. And for so long I've eaten the way I've eaten so it's just curving that. And then I have spells where I'll go eat sweets... I'll eat a lot of sweets.”*

Participant: *“The drinking (alcohol). I'm not saying I'm alcoholic but I love to drink. Every now and then it's like I'll go on a binge and start drinking a beer or something... I can't just have one. Where as I know alcohol is not a good part of the diet, but I guess we all have some demons that we have to deal with (laughing). If I drink them margaritas, then I got a problem.”*

Participant: *“Me, I hate medications. I truly, truly hate medications. And that was one of things that my doctor told me was with this was that I'm going to have go on medication. I've never been the type of person to take medication unless I was ill, which I know that I am having diabetes. Such as aspirin or antibiotic for*

*a cold... I just hate taking medication. I've just never been a pill popping guy. I only take it if it's absolutely necessary."*

### Discussion

After conducting, reading, and listening to the interviews, one take-away message that came across the board from the participants is that managing type 2 diabetes is very tedious and demanding. Many participants commonly feared amputation and vision changes. This finding suggests that diabetes researchers and educators may need to address African-American men's fears of long-term complexity candidly and strongly with guidance and consultation. To dispel fears of long term complications, educators and researchers need to repeat and reinforce the message that maintaining stable blood sugar control and having frequent follow-up visits with their primary health care provider and certified diabetes educator will increase the probability for a long and health life (Anderson, 1996).

The findings also showed that family history, heredity, and lifestyle choices were stated by over half of the participants, to be the foundation or essence of their type 2 diabetes. There is uniformed definition of family history. Baptiste-Roberts and Gary-Webb (2012) stated that family history is crudely defined as the presence of disease in any family member irrespective of the degree or type of relatedness or number of affected relatives. Family histories reflect both inherited genetic responsibilities and shared environments, which include cultural factors such as preferences, values, and perceptions and behavioral factors such as diet and physical activity (Keku, Millican,

Martin, Rahkra-Burris, Sanders, 2003). It is the interaction of the genetic, environmental, and behavioral components that makes family history of type 2 diabetes such a useful risk factor (Baptiste-Roberts and Gary-Webb, 2012). Accordingly, diabetes family history may be an informative resource to recognize persons with a greater danger of diabetes and focus on lifestyle changes that may possibly defer the illness and improve the quality of life.

Friends and family can generate a positive environment for diabetics who may be in a “self-inflicted” negative environment, which can be created by the self-care management behaviors that they choose or chose not to implement in their lives. Future research could examine the specific role that family history of diabetes plays among African-Americans regarding awareness of diabetes risk factors and practicing helpful health behaviors.

Many of the participants noted the effects that their families and friends had on the management of their diabetes. Most participants labor with managing their diabetes and some counted on their own potential or performance, as well as the encouragement of their family and extended family. These findings are constant with the results of other studies (Miller & Davis, 2005; Cohen, 1988), in which family and friend support was eminent to assist in the management of diseases. Family and friend involvement with type 2 diabetes management was very notable for this group. A good number of participants had a thoroughly positive attitude regarding their own self-care management and the support received from family and friends. Self-determination as well as spouse /family responsibility were stated as the primary motivator of management. The premise

of “fear” is constant with type 2 diabetes as well (Johnson, 2000; Mainous, King, Garr, Pearson, 2004).

Finally, Type 2 diabetes management involves an inclusive lifestyle change that is not simple for most people, not just taking medications appropriately, increasing weekly exercise, and diet modifications. These lifestyle changes can be conceptualized in the context of the Health Belief Model, a psychological model that attempts to explain and predict behavior change by focusing on beliefs and attitudes (Becker, 1974). There is existing evidence indicating that mild lifestyle changes such as increasing physical activity and a healthier diet can considerably decrease the development of type 2 diabetes in high-risk populations (Chiasson, 2002; Knowler et al., 2002; Tuomilehto et al., 2001). Physical activity or lack thereof, is an important risk factor for the development of type 2 diabetes (Tuomilehto, et al., 2001). Generally, physical activity levels among African-Americans are lower than those observed among non-Hispanic Whites (Centers for Disease Control and Prevention, 2007).

Two studies explored the relationship between family history and diabetes and physical activity. Forsyth et al., in a predominately Caucasian population, found no difference in physical activity levels between individuals with and without a family history of diabetes (Forsyth et al, 2007). Among participants of Project DIRECT, there was no difference in physical activity levels between African-Americans with and without a family history of type 2 diabetes (Baptiste-Roberts et al., 2007). Supposing the study participants were knowledgeable that planned exercise and activity were a risk factor for the onset of type 2 diabetes, the results indicate they were not actively

involved in physical activity despite having some knowledge of being at a higher risk of developing type 2 diabetes.

### Implications for Future Research

One item to recognize is that diabetes in general is not one lone person's illness. It affects those around in the surrounding environment such as family and close friends, as well as the person living with type 2 diabetes. Including the diabetic's family and friends self-care management training and instruction could improve the understanding of people who surround those living with type 2 diabetes in their daily life and improve encouragement and support by family and friends in self-care management. The goal of diabetes education is to promote self-care (Aljeseem, Peyrot, Wissow, Rubin, 2001). However, information itself is not enough to enhance the capacity of a person living with type 2 diabetes to embrace contemporary self-care management into their daily lives.

An argument can be made that those in the persons' inner circle such as family and close friends can assist with helping and encouraging positive self-care management of type 2 diabetes. Additional studies are needed to center on interventions adapted to African-American men and more ways to engage friends and family in helping with type 2 diabetes management. The objective is to help those living with type 2 diabetes improve the self-care experience and to increase changes for a healthy lifestyle that will be sustained throughout their existence towards a more favorable level of health. As noted by one participant, *“Actually, it's (type 2 diabetes) been a Godsend because it's something that you need to do anyway...dieting and exercise. So it just makes you a little*

*bit more aware of some of things you need to do anyway in a given light so I don't look at it (Type 2 diabetes) as being that negative."*

## CHAPTER V

### SUMMARY: THE STATUS OF HEALTH RESEARCH ON AFRICAN-AMERICAN MEN

The overall purpose of the dissertation research is to expand on what is known about type 2 diabetes self-management among African-American men. The research was conducted and written into three manuscripts that addressed the inclusion of African-American men in empirical research, theory utilization in type 2 diabetes research with African-American men, and understanding the essence and lived experiences of African-American men living with type 2 diabetes. After investigating these three areas in the published literature, there is paucity of research targeting African-American men, explicitly with type 2 diabetes. The research did reveal that some theoretical frameworks are being used, however, after further investigating the lived experiences of a sample of African-American men living with type 2 diabetes, I question why theories of race and gender issues such as masculinity and manhood meaning are not incorporated in diabetes research involving this group of men.

The review and analysis of the literature adds to the notion that not only men, but African-Americans in general have been underrepresented in clinical and empirical research. Additionally, African-Americans have historically been underrepresented in health planning and overwhelmed with economic and social inequalities, which have contributed to a disproportionate burden of diabetes and other health conditions in this population (Ekundayo & Buckner-Brown, 2012). Thereupon relating to the African-American men, the imbalance of chronic health illnesses has only recently started to gain

recognition and presented. Jack Jr (2004) argues that due to the few studies exclusively targeting African-American men participants that more epidemiological, anthropological, behavioral, and clinical studies are needed (Jack Jr., 2004).

The deficient use of theory in self-care management studies involving African-American men is inconvenient because theories, social or behavioral, would assist in helping to understand why people do or do not practice health promoting or management behaviors. The application of theoretical frameworks in future research studies would lead researchers to identify the underlying issues associated with how African-American men positively or negatively self-manage type 2 diabetes. Theories can help identify what information is needed to design an effective intervention strategy and provide insight into how to design a program so it is successful (Clark & Becker, 1998).

### Discussion

The deficiency of diabetes management and education research among Black men living with diabetes is striking, given that Black men have two to four times the rate of renal disease, blindness, amputations, and amputation-related mortality than that experienced by non-Hispanic Whites (Lanting, Joung, Mackenbach, Lamberts, & Bootsma, 2005). The comprehensive findings regarding the manuscript one suggests that there is a substantial deficiency of African-American men in type 2 diabetes research literature; more specifically in self-care management of diabetes literature. Expanding the number of African-American men in research requires an enhanced understanding of the causes affecting the decision to participate. In their report, Casares et al. (2006) stated that diabetes disproportionately affects men of color and is the sixth leading cause

of death among men of color. In order for the number of men living with and managing this condition daily, the inclusion and participation of African-American men in type 2 diabetes research must increase.

The lack of African-American male participants in research is often attributed to investigators' differences in recruitment and retainment of minority participants (Moreno et al., 2004; Mason, 2005; Shavers-Hornaday et al., 1997). An argument could be made that African-American men living with type 2 diabetes are a "hidden" population living within the larger African-American male population. While searching the literature on this topic, very few articles were found that address and evaluate lack of inclusion factors. Those factors being culturally appropriate recruiting strategies, mistrust, lack of minority investigators, socioeconomic status, ease of participation, convenience, and physical encouragement are all elements of research participation (Diaz, Mainous, McCall, Geesey, 2008).

One subject area that brought about a wealth of knowledge to the search was the subject of African-American manhood and masculinity and how its attributes influence diabetes self-management behaviors. This subject area also focused on how medical mistrust has an effect on men's willingness to actually seek help for their medical health concerns. From the search, seven articles were found that concentrated on manhood and masculinity (Hooker, et al., 2012; Hammond, Matthews, & Corbie-Smith, 2010; Hammond, 2010; Hammond & Mattis, 2005; Hammond et al., 2010; Jack Jr, Totson, Jack, & Sims, 2010; & Liburd, Namageyo-Funa, & Jack Jr., 2007). An argument could be made that there is a shortage of African-American men in published research

pertaining to self-care management because these men may not feel comfortable sharing openly to others about their behaviors.

Manhood appears to have a tag of being responsible, and accountable for one's actions. Researchers, clinicians, and practitioners from across several diverse contributory disciplines (e.g., public health, nursing, medicine, sociology, anthropology, social epidemiology, social psychology, health systems, systems modeling) acknowledge that under the best scenarios, using the best available science, the identification of root causes and more importantly, what to do about them remains a challenging, but necessary task (Jack, 2005; Jack et al., 2004; Liburd, Jack, Williams, & Tucker, 2005). In their qualitative study, Hammond and Mattis found 15 categories of meaning that coded manhood (Hammond and Mattis, 2005).

For example, almost 50% of the respondents indicated that manhood means being responsible and accountable for one's actions, thoughts and behaviors, and this responsibility-accountability extends beyond the self to include one's family and community. In addition, manhood was associated with being independent; self-governing; and able to manage one's life, including having the power and freedom to execute decisions. Being able to provide for oneself and family in ways that extend beyond economic provisions was also an important category of manhood. Lastly, of particular note, achieving personal growth and maturity across the life span was important in African-American manhood as well as having focus and stability across the multiple domains of one's life (Hammond and Mattis, 2005).

According to Williams (2003),

Beliefs about masculinity and manhood that are deeply rooted in culture and supported by social institutions play a role in shaping the behavioral patterns of men in ways that have consequences for health. Men are socialized to project strength, individuality, autonomy, dominance, stoicism and physical aggression, and to avoid demonstrations of emotion or vulnerability that could be construed as weakness.

In the healthcare arena, this can mean infrequent encounters with the healthcare system, delayed attention to symptoms, poor medication compliance and an unwillingness to talk openly about health concerns (Williams, 2003). The issue of masculinity has both assenting and contradictory aspects that can be conveyed to either guide or weaken type 2 diabetes self-care management. Another way of looking at manhood and masculinity is through the social concept of gender. Moynihan (1998) states that gender is influenced by historical, social, and cultural factors, rather than anatomical factors, and is not part of a person's essential "natural", "true" self. Masculinity theory must be included in health and diabetes research targeting African-American men to provide a improved awareness of how masculinity impacts African-American men's capacity to self-manage type 2 diabetes.

In addition to masculinity, the mistrust of healthcare organizations among African-American men may also be associated with lack of men interested in participating in research studies, along with preventive health services such as routine health examination scheduling. Some researchers have found a relationship between mistrust and barriers to help-seeking among men (Mansfield et al. 2005). Mansfield et al. (2005) framed mistrust as a consequence of traditional masculinity ideology or the "endorsement and internalization of cultural belief systems about masculinity and the

male gender” (Pleck et al. 1993, p. 88). That is, these authors suggest that men’s mistrust of doctors and caregivers be observed as a help-seeking barrier shaped by traditional masculine beliefs about relational vulnerability. The finding that men report having less trust in medical organizations than women (Allice et al. 2001; Fiscella et al. 1998) supports this notion that mistrust may be gendered. It is important to note that constructions of masculinity vary with race, social location, and historical experiences (Connell 1995).

After a review of literature, approximately twelve out of fifty articles from manuscript two found to have clearly stated one or more particular theories within the methodologies section of the research article. Analysis of these publications revealed that most (n=34) were not profoundly grounded in a theoretical framework of any kind. The deficiency of reported theories in the development and descriptions of type 2 diabetes research studies should raise a concern among diabetes researchers and educators. After conducting a separate search for theories that can be used in type 2 diabetes research, four theories were found that appear to be an appropriate fit in type 2 diabetes self-care management research to help explain the learning and adaptation of patient education. These four theories are: Self-Regulation Theory, Dual Process Theory, Self-Determination Theory, and Social Learning Theory. Self-Regulation theory in type 2 diabetes management focuses on a persons’ illness representation or personal model of diabetes as a key determinant of their behavioral and emotional responses to illness (Skinner et al., 2003).

People cannot influence their own motivation and actions very well if they do not pay adequate attention to their performances, the conditions under which they occur, and the immediate effects they produce. Therefore, success in self-regulation partly depends on the fidelity, consistency, and temporal proximity of self-monitoring (Bandura, 1991). Self-Regulation Theory looks at five key elements (Skinner et al., 2003): *Identity* (What is diabetes? What symptoms are experienced? What is actually wrong?) *Cause* (What caused my diabetes?) *Timeline* (How long will this last?) *Consequences* (How will diabetes affect me now and in the future?) *Treatment* effectiveness (How good is my treatment at controlling or curing my diabetes?)

Research in adults and adolescents with diabetes has consistently demonstrated that individuals hold a diverse set of illness beliefs that do not fit the medical view of diabetes and that these beliefs are robust and proximal determinants of patients' emotional well-being and self-care behavior (Hampton, 1997; Skinner, Channon, Howells, & Mcevilly, 2000). Often times, people have family members or know someone with type 2 diabetes and have heard about the related complications and begin to shape and form their own intuitions about the illness. Nonetheless, these intuitions are not thorough, precise, and modern.

#### Limitations

All research studies possess limitations. One limitation from manuscript one was that given the year range and number of the published studies targeting African-Americans living with type 2 diabetes, these studies include more female than male participants. This impacts the overall study limitations because the lack of participation

of these men in my opinion, further contributes to the existence of health inequalities among this group. Studies demonstrate African-Americans may be more difficult to recruit and have a variety of barriers to participation and retainment in research (Shavers-Hornaday et al., 1997; Loftin et al., 2005; Chandra & Paul, 2003). This underlines the need to create effective culturally appropriate recruitment approaches.

Future research should be directed about approaches to influence research participation. Another item to add from manuscript three is that 13 of the 19 participants were over the age of 55. The experiences and understandings of younger men with type 2 diabetes may be quite different than those disclosed in the manuscript. One limitation from manuscript two was that there was a considerable lack of theory and theory constructs used in type 2 diabetes literature targeting the African-American male. Incorporating social and behavioral theories in this subject area with any minority group is important because these theories that can help us understand the social elements of health and health behavior.

There could be some economic, social, and cultural factors that contribute to the advancement, continuation, and change of management behaviors. This impacts the overall study limitations because studies that lack any use of theory cannot help in developing culturally sensitive interventions that are not only centered on those living with type 2 diabetes, but also affecting the social, structural, and surrounding elements that most effect health behavior. Clinicians and diabetes educators can support African-American men with diabetes by acknowledging that they are aware of and sensitive to

the multiple complex psychosocial and cultural struggles these men must face and negotiate (Liburd, Namageyo-Funa, Jack Jr., Gregg, 2004).

One limitation from manuscript three was a qualitative study involving 19 participants from one geographic location and the findings are not representative of a national sample of African-American men. An appropriate sample size for phenomenological research can range from 6 to 12 persons (Morse, 1994, p.220). The aim is to advance the understanding of the phenomenon. This impacts the overall study limitations because type 2 diabetes literature has a shortage of African-American male participants in general and it is impossible to know and understand the essence of participants who are present in research literature than those who are not being included in the literature. The voices are not heard by those who are not in diabetes studies. The overall the findings from this study

#### Strengths

This study advances the field of health education and disparities by understanding the lived experiences of African-American men living with type 2 diabetes. Diabetes education has been a primary focus for a long time (Hurley & Shea, 1992). The objective of this education is to advance individual self-care. This study has shown that some African-American men take it on themselves to become more educated about what choices they should consider in order to manage their diabetes as best as possible. Some men rely on family and friends to help them manage their diabetes as accountability partners in physical activity, dietary changes, daily blood glucose monitoring, assistance with medication, and encouragement with implementing changes.

The study also showed that despite many of the stated fears about having type 2 diabetes, the participants still knew what needed to take place in order to manage their diabetes.

This study also adds to the field by this small sample of African-American men clearly indicating their treatment preferences for diabetes which were medication, dietary modifications, and an increase in exercise. Again, this is not a generalization of all men of this group nationwide. Some African-American men may not prefer any of the preferences that were stated by those of this study. Lastly, this study adds to the field by identifying which self-care management behaviors the men had a hard time doing on a consistent basis and why those were difficult for them. This again goes back to the notion that managing type 2 diabetes is very tedious and demanding.

#### Implications for Health Education Practice & Research

There are several messages to walk away with after completing this dissertation study, but I will only focus on four primary implications. One is that there needs to be a consistent effort on increasing the number of African-American male participants in empirical research studies. This is so we as researchers can have a heightened understanding regarding the parts that affect the decision of these men to participate in research. In order to improve the inclusion of these men in research, careful attention to the exposure of the collected information and cooperation with African-American researchers and physicians must be considered. Trust vs. mistrust in the health-care system, past research experiences if any, and the benefit to the participant should also be considered.

Second is that self-care management interventions should not only include the African-American male with type 2 diabetes, but also his self-identified social circle that serves as a source of encouragement and strength. This circle of family and or friends should receive more education about self-care management provided the necessary know-how to assist their person with managing his type 2 diabetes, which is a very complex, distressing, and lingering challenge. This education can include help adhering to the recommended exercise and dietary changes, assistance with stress management, and how to effectively monitor blood glucose levels consistently without any relapse.

Third, self-care management of type 2 diabetes is frequently linked to individual responsibility with adhering to recommendations for lifestyle changes. After conducting the study, lack of following these recommended changes was viewed as a personal downfall by some of the participants in this study. This study was done to gain clarity and understanding of the essence and lived experiences of African-American men living with type 2 diabetes and therefore provided some key insights into the inspiration, cultural, and support systems to positive self-manage type 2 diabetes. After conducting the interviews and reading and listening to the transcripts, I gained some meaningful information about the issues, whether positive or negative, that the participants experience daily in having type 2 diabetes. Future research would help benefit by investigating if men in other minority groups are faced with some of the same type 2 diabetes management barriers such as those that were identified by the African-American men in this study.

Fourth and to conclude, masculinity, a less explored root cause of health disparities is a socially constructed phenomenon operating at and across multiple levels: the individual, family, community, and society (Jack Jr, 2010). Researchers suggest that masculinity, although less applied to African-Americans, is an important construct to explore in diabetes management research (Jack, 2004; Liburd, Jack, Williams, and Tucker, 2005; Liburd, Namageyo-Funa, and Jack, 2007; Liburd, Namageyo-Funa, and Gregg, 2004). Considering that the facet of masculinity has not been well characterized in men's health research, I argue that we as researcher and educators need to provide a more comprehensive understanding of how masculinity intervenes the ailment experience of self managing type 2 diabetes so that we can assist in improving the healthcare of African-American men

Future diabetes research and education should give attention to how masculinity has a powerful influence on male behavior. This would add to health and diabetes literature in further understanding how and why men make decisions as negotiated within the order of masculinity. This would serve as a vital benefit of progressing men's health research studies and developing suitable self-care management programs targeting African-American men who live with type 2 diabetes. I feel that it will take a combined effort from entities such as national diabetes organizations, the African-American community, medical academies, national men's organizations, media, and healthcare providers to control and prevent diabetes, both type 1 and 2 among African-American men.

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## APPENDIX A

### DEMOGRAPHIC PROFILE (PART I)

Please provide the following information about yourself. All information will be reported as combined data. Any answers you provide will remain confidential and anonymous. Please mark your answers with a check mark.

- 1) What is your age range?
  - 18-24 years
  - 25-34 years
  - 35-44 years
  - 45-54 years
  - 55-64 years
  - 65 and older
  
- 2) What is your marital status?
  - Single (never married)
  - Married
  - Separated
  - Widowed
  - Divorced
  
- 3) What is the highest degree or level of education you have completed?
  - Less than high school
  - High school graduate
  - Some college, but no degree
  - Associate's degree
  - Bachelor's degree
  - Graduate or professional degree
  
- 4) Are you currently employed by Texas A&M University?
  - Yes
  - No
  
- 5) What was your total household income during the last 12 months?
  - Less than \$25,000
  - \$25,000 to \$34,999

- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 or more

6) What is your current employment status?

- Full-time
- Part-time
- Retired
- Not employed at this time
- Looking for employment

7) Do you have any form of health insurance?

- Yes
- No

8) Who else lives in your household? (You can check more than one.)

- I live alone
- Spouse/Partner
- Children
- Brothers/Sisters
- Other relatives
- Non-family members

9) To the best of your knowledge, how long have you been living with type 2 diabetes?

- 1-5 years
- 6-10 years
- 11-15 years
- 15-20 years
- 20 or more years
- Don't know

- 10) To the best of your knowledge, does anyone else in your family have diabetes?
- Yes
  - No
- 11) If you checked “yes” in the previous question, does this person have type 1 or type 2 diabetes? If you checked “no” skip ahead to question #12.
- Type 1
  - Type 2
  - Don’t know/Unsure
- 12) How often do you visit your doctor about your diabetes?
- 1 to 2 times per year
  - 3 to 4 times per year
  - I don’t visit my doctor about my diabetes
  - Don’t know
- 13) When you go in for a scheduled doctor’s appointment about your diabetes, who usually goes to this appointment with you?
- I go alone
  - My spouse/partner
  - My son/daughter
  - My son-in-law or daughter-in-law
  - Another family member
  - A friend
- 14) Have you ever attended any diabetes educational classes or sessions since you developed type 2 diabetes?
- Yes
  - No
- 15) Are you comfortable telling people that you have type 2 diabetes?
- Yes
  - No
  - Sometimes
  - It depends on who I’m telling

16) In the past, how do people around you respond to you when you tell them that you have type 2 diabetes? (Check all that apply)

- |                                      |                                      |  |
|--------------------------------------|--------------------------------------|--|
| <input type="checkbox"/> Surprised   | <input type="checkbox"/> Honest      | <input type="checkbox"/> Asked you questions |
| <input type="checkbox"/> Encouraging | <input type="checkbox"/> Rude        |  |
| <input type="checkbox"/> Supportive  | <input type="checkbox"/> Respectful  |  |
| <input type="checkbox"/> Sad         | <input type="checkbox"/> Considerate |  |
| <input type="checkbox"/> Depressed   | <input type="checkbox"/> Helpful     |  |
| <input type="checkbox"/> Quiet       | <input type="checkbox"/> Accepting   |  |
| <input type="checkbox"/> Angry       | <input type="checkbox"/> Sympathetic |  |

## APPENDIX B

### SEMI-STRUCTURED INTERVIEW GUIDE AND SCRIPT (PART II)

Hello, my name is \_\_\_\_\_ and today I will be asking you a series of questions related to your diabetes management, your health, support systems, your feelings about having type 2 diabetes, and any barriers that you face in managing your diabetes. The purpose of asking you these questions is to gain more insight about the experiences of diabetes self-care management among African-American men living with type 2 diabetes and identify barriers and facilitators to positive diabetes self-care management.

If you agree to participate, the interview will take relatively 45-60 minutes of your time. Your participation is completely voluntary and you may refuse to participate at any point during the interview. Your thoughts and opinions are very important for our research. The information you give me will be used to identify barriers and facilitators to positive diabetes self-care management and develop community as well as public health strategies for African American males living with type 2 diabetes.

We value your thoughts and opinions no matter the context or content. Please be open and honest. During the next 45-60 minutes, please share your personal experiences and views specific to the questions that we ask you. Do you have any questions for me before we get started? If not, let's begin!

1) When your doctor first told you that you had developed type 2 diabetes, how did it make

you feel?

2) What do you think caused you to have developed diabetes?

3) Do you have any fears about having type 2 diabetes? If so what do you fear most about

having diabetes?

4) How has your physical activity changed since you were diagnosed with type 2 diabetes?

5) How has your diet changed since you were diagnosed with type 2 diabetes?

6) Do you feel that your family provides help or support to you given that you have diabetes?

7) Do other people (outside of your family) help or support you with your diabetes?  
If so, how?

8) How important are the following in helping or supporting you given that you have diabetes:

Your community?

Church or faith in God?

Healthcare system?

- 9) What changes did you notice about your body that may have led to your diabetes diagnosis?
- 10) Have you experienced any other problems because of your diabetes?
- 11) What kind of treatment(s) do you prefer to help you manage your diabetes?
- 12) Describe how you control your diabetes.
- 13) Is there someone in your life who helps you control your diabetes? If yes, what are some things they do for you?
- 14) What do you feel are the most difficult diabetes management behaviors for you to do on consistent basis? What makes these behaviors difficult for you to do consistently?
- 15) Do you feel that you have more stress in your life since you found out you have type 2 diabetes?