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## A Qualitative Exploration Of Experiences And Motivations For Diabetes Self-Management In African American Men Between The Ages Of 40-85 With Type 2 Diabetes

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A QUALITATIVE EXPLORATION OF EXPERIENCES AND MOTIVATIONS FOR  
DIABETES SELF-MANAGEMENT IN AFRICAN AMERICAN MEN BETWEEN THE  
AGES OF 40-85 WITH TYPE 2 DIABETES

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## DEDICATION

This is dedicated to my grandfather, Charles Q. Rawlins. He could not read or write, but was yet, the smartest and greatest man I ever knew.

## ACKNOWLEDGEMENTS

Muhammad Ali once said: “You are not going to enjoy every minute of the journey, but the success you’ll find at the end will make it all worth it”. This indeed has been a very long journey, and I will forever be indebted to so many individuals. With the number of people who have contributed to this project and had an influence on my life, there is no way that I could possibly name and thank everyone. However, my first “thank you” goes to my Lord and Savior, Jesus the Christ. Next, my family, especially my mother (Jessie) and my sisters (Debra, Charlene, and Bernita), my brothers (Donnie and Darrell), and while they are no longer with me physically, my grandfather (Charles), Grandmother (Louise), father (Charles). They were the ones who instilled in me the drive, motivation, passion, and determination that helped fuel the fire when fuel was low.

A special thanks to my dissertation committee and hoping that they realize that words are too weak to define their importance to me and this project. Dr. Blake, thank you for your patience and willingness to mold the broken pieces into a final product that I hope will make all of us proud. Dr. Watkins (pause of gratitude), without you this would not have been possible. Thank you for not giving up on me during all of the bleak moments. Dr. Moore, thank you for having the fortitude to accept my train wreck and put it back on right track with your authentic advice and encouragement. Dr. Wilcox thanks for your meticulous and astute attention to detail, and your invaluable input. Thank you to my behind-the-scenes posse: Ten Lords of Discipline SPR83, Ruth B. Hummingbird,

Wilma Sims, Erica Searcy, Jan Lander, Vaidya Parekh, Kenita S.K. Chumas, J.J.M. Nguyen, and D. J. S. Hannon.

Always seek authentic friendship, because: “Friendship is Essential to the Soul” and uplift will always be my daily mission. Remembering in the words of Colin Powell: “There are no secrets to success. It is the result of preparation, hard work, and learning from failure.”

Anthony Q. Walker.

## ABSTRACT

Diabetes is a devastating disease that can affect an individual's health and quality of life, but if managed properly, individuals with diabetes can have a good quality of life. Diabetes strikes African American men at a high rate. This study used a qualitative design to explore African American men between the ages of 40-85 with type 2 diabetes (T2DM) and their definition of diabetes and motivation, their experience of living with diabetes, their self-management behaviors, their motivations for managing diabetes, and what they and healthcare providers believe motivates them to self-manage diabetes and to attend diabetes self-management education (DSME) programs. In-depth interviews were conducted with 22 African American men from the Piedmont area of South Carolina and 6 healthcare providers from various disciplines that treated African American men with T2DM.

The Self-Determination Theory was used as a framework to explore their motivations. Data were collected over a 6-month period and consisted of field notes, memos, reflections, and dually recorded, in-depth interviews. Data analysis consisted of using NVivo 10 to assist with data management and storage. Interviews were transcribed verbatim and analyzed using thematic analysis and an iterative process to develop the major themes. Results indicated that participants defined diabetes as “a mean nasty disease” and described initial reactions of being diagnosed with diabetes as disbelief, anger, scared, and denial. Participants described living with diabetes as challenging, but

“I got it under control” and had differing opinions on healthcare providers with some having great respect and others expressing distrust. Having family support, trying to practice good health and wellness behaviors, and dealing with the cost of diabetes medications were common concerns of most participants. Motivation was defined by participants as having “drive” or “attaining a goal”. For most participants, being there for family was their primary motivating factor for managing diabetes. No participants expressed pure intrinsic motivation for managing their diabetes as simply doing it for joy. Two participants were amotivated and did not have intentions of managing diabetes, but most had extrinsic motivation for managing diabetes such as wanting to see grandchildren grow-up or avoiding needles for insulin. Many participants believed that making diabetes classes more interesting and convenient could improve motivation to attend DSME classes. Healthcare providers viewed their roles as “cheerleaders”, “coaches”, and “lifestyle changers”. Most healthcare providers used fear tactics to motivate participants to manage diabetes such as emphasizing possible consequences of poorly managed diabetes as sexual dysfunctions and comorbidities. Additionally, healthcare providers believed that involving family, decreasing cost, empowering individuals, recognizing the importance of culture, and having more time with diabetic patients would improve participant’s motivations for managing diabetes.

In conclusion, diabetes has an enormous impact on the global, national, state, community, and individual levels. Individuals living with diabetes face many challenges such as emotional burdens, struggles to manage and cost of managing the disease. It is important to understand the lived experiences of African American men living with T2DM, their motivations to manage diabetes and to attend DSME programs, and the



mutual perceptions of motivation of African American men and health providers that treat African American men with T2DM to implement culturally sensitive DSME strategies and to help improve their diabetes self-management outcomes.

## PREFACE

Disparities in healthcare are well documented. As with many diseases, diabetes affects certain populations disproportionately. It is imperative that public health agendas continue to address the diabetes epidemic and close the gaps via addressing underserved populations in research, and by promoting health, healthy behaviors, and wellness. Learning more about how underserved and understudied populations live with certain conditions and what motivates them can improve strategies and aid in developing and implementing effective programs.

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## LIST OF DEFINITIONS

A1C- a test that measures a person's average blood glucose level over the previous 2-3 months. Hemoglobin is the part of a red blood cell that carries oxygen to the cells and sometimes joins with glucose in the bloodstream. Also, called hemoglobin A1C, the test shows the amount of glucose that sticks to the red blood cells, which is proportional to the amount of glucose in the blood (American Diabetes Association, 2016).

Amotivation- the state of lacking the intention to act. When amotivated, people either do not act at all or act without intent. (Ryan & Deci, 2000).

Diabetes Self-Management Education Programs - is the ongoing process of facilitating the knowledge, skill, and ability for diabetes self-care. This process incorporates the needs, goals, and life experiences of the person with diabetes and is guided by evidence-based standards. The overall objectives of DSME program are to support informed decision-making, improve self-care behaviors, problem-solving and to collaborate with the health care team to improve clinical outcomes, health status, and quality of life. (Funnell, et al., 2011).

Extrinsic Motivation - doing something because it leads to a separable outcome (Ryan and Deci 2000).

Intrinsic Motivation - doing of an activity for its inherent satisfactions rather than for some separable consequence. Doing something because it is inherently interesting or enjoyable (Ryan and Deci 2000).

Motivation - to be motivated means “to be moved” to do something.  
(Deci & Ryan, 2000).

Self-Determination Theory – developed by Edward L. Deci and Richard M. Ryan, it represents a broad framework for the study of motivation and personality. It is a theory of motivation that is concerned with supporting our natural or intrinsic tendencies to behave in effective and healthy ways. The Self-Determination Theory postulates that extrinsic motivation can vary greatly in the degree to which it is autonomous (Deci & Ryan, 2011; Deci & Ryan, 2000).

Thematic Analysis – thematic analysis is a widely-used qualitative data analysis method that can be used to identify patterns of meaning across a dataset. It has been widely used across the social, behavioral and applied sciences. Patterns are identified through a rigorous process of data familiarization, data coding, and theme development and revision. It can be used within different frameworks to answer different typed or research questions (The University of Auckland, 2017)

Type 2 Diabetes (T2DM) - diabetes mellitus (DM) is a condition characterized by hyperglycemia resulting from the body’s inability to use blood glucose for energy. In



T2DM, either the pancreas does not make enough insulin or the body is unable to use insulin correctly. T2DM accounts for 90-95% of those with diabetes. It was previously referred to as non-insulin-dependent diabetes, type 2 diabetes, or adult-onset diabetes, and includes individuals who have insulin resistance and usually have relative insulin deficiency (American Diabetes Association, 2016).

## LIST OF ABBREVIATIONS

AA.....	African American
AMEZ.....	African Methodist Episcopal Zion
DSME.....	Diabetes Self-Management Education
IMI.....	Intrinsic Motivation Inventory
MNT.....	Medical Nutrition Therapy
SAED.....	South Atlantic Episcopal District
SDT.....	Self-Determination Theory
T2DM.....	Type 2 Diabetes Mellitus

# CHAPTER 1

## INTRODUCTION

Diabetes mellitus (DM) is a chronic debilitating disease that places an enormous burden on healthcare on global, national, and state levels (American Diabetes Association, 2015; South Carolina Department of Health and Environmental Control, 2015; WHO, 2016). In efforts to address the escalating crisis of diabetes, diabetes self-management education programs (DSME) continue to be improved and implemented (Centers for Disease Control and Prevention, 2011; Funnell, et al., National standards for diabetes self-management education, 2011; American Diabetes Association, 2017). Significant research suggests that participants benefit from Diabetes Self-Management Education programs by improving self-management strategies, improving diabetes knowledge, decreasing A1C, and improving nutritional strategies (Diabetes Educator Competencies Work Group , 2016; Funnell, et al., National standards for diabetes self-management education, 2011). However, there has been very little research regarding the motivations for self-managing diabetes in African American men. Understanding experiences living with diabetes and motivations to self-manage diabetes, may lead to improved diabetes self-management strategies and outcomes in this underserved population.

DM is the seventh leading cause of death in the U.S based on death certificate data, and in 2010, had an estimated total economic cost of 245 billion dollars with 176

billion dollars being in direct medical cost and 69 billion dollars in reduced productivity (American Diabetes Association, 2016). From 2007 to 2012, the associated cost of diabetes rose 41%, and the economic burden associated with diagnosed and undiagnosed diabetes of all ages, gestational diabetes, and pre-diabetes for adults was more than 322 billion dollars with that amount consisting of 244 billion dollars in excess medical cost and 78 billion in reduced productivity (Dall, et al., 2014). Every 21 seconds someone is diagnosed with diabetes (American Diabetes Association, 2017).

Nearly 30 million Americans have diabetes, and 84 million Americans have pre-diabetes and are at risk for developing diabetes. African Americans and Hispanics are over 50% more likely to have diabetes than non-Hispanic whites. Type 2 diabetes (T2DM) disproportionately affects African Americans and other ethnic minorities (American Diabetes Association, 2011; U.S. Department of Health and Human Services, 2016). When compared to non-Hispanic whites, the risk of diagnosed diabetes is 1.2 times higher among Asian Americans, 1.7 times higher among Hispanics, and 1.7 times higher among non-Hispanic blacks (American Diabetes Association, 2015). Furthermore, 12.8% of Hispanic/Latino adults in the United States have diagnosed diabetes and 13.2% of non-Hispanic black adults in the United States have diagnosed diabetes (American Diabetes Association, 2015).

Living with diabetes can be demanding and can affect an individual's life in various ways. Complications from diabetes include diabetic retinopathy, heart disease, stroke, diabetic neuropathy, foot ulcers, kidney failure, erectile dysfunction, depression, dental disease, and possible limb amputation (Centers for Disease Control and

Prevention, 2011; American Diabetes Association, 2016; American Diabetes Association, 2015).

There is a tremendous cost associated with diabetes. This is in part reflected in the average cost of insulin nearly tripling between 2002 and 2013 and a health care cost that is 2.3 times greater for individuals with diabetes than those without diabetes (American Diabetes Association, 2017). Additionally, 1 in 3 Medicare dollars is spent on care for people with diabetes, and 1 in 5 healthcare dollars is spent caring for people with diabetes (American Diabetes Association, 2017; American Diabetes Association, 2015). The International Federation of Diabetes (2012) reports that the expected cost of diabetes-related complications will reach 490 billion dollars by the year 2030.

Patient characterizations of diabetes have emerged from qualitative research that describes diabetes as: “Your body will let you know”; “I thought I was fine, but wasn’t”; “The only way out is to die”; and “You just go on” (George & Thomas, 2010). Sentiments such as these support the need for continued diabetes education and suggest that confusion remains regarding what diabetes is, how to cope with diabetes, and how to manage diabetes. Organized diabetes self-management education programs can address these issues (Funnell, et al., National standards for diabetes self-management education, 2011). Lifestyle changes and pharmacological interventions, along with incorporating physical activity and proper dieting can help reduce the rate of progression to T2DM in people with impaired glucose tolerance (Gillies, et al., 2007; Bassuk & Manson, 2005; Lindstrom, et al., 2003; Diabetes Prevention Program Research Group, 2002).

Millions of people have undiagnosed diabetes, and many additional individuals diagnosed with diabetes do not seek treatment or follow-up with recommended

physician's orders to seek DSME and training (American Diabetes Association, 2015; CDC, 2009). This research project focuses on exploring the definition of diabetes and motivation, the experience of living with diabetes, diabetes self-management behaviors, motivations for managing diabetes, what healthcare providers who treated African American men with T2DM felt about their motivations for managing diabetes, the role of the healthcare provider in assisting African American men with T2DM, and what would motivate African American men with diabetes to attend a diabetes self-management education program using a Self-Determination Theory as a framework.

**Specific Aim 1:** To explore the definitions of diabetes, experiences living with diabetes, and diabetes self-management behaviors of African American men between the ages of 40-85 with T2DM.

Research questions:

- 1) How do African American men between the ages 40-85 with T2DM define diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM describe their experiences living with diabetes?
- 3) How do African American men between the ages of 40-85 describe their diabetes self-management behaviors?

Although DSME programs are available to individuals with diabetes, programs often fail to benefit older African Americans because of barriers such as limited financial resources, limited access to healthcare, inadequate physician-patient communication, lack of family support, and decreased knowledge of diabetes (Eakin, Bull, Glasgow, & Mason, 2002; Graham, 2006; Mann, Ponieman, Leventhal, & Halm, 2009; Piette,

Heisler, Harand, & Juip, 2010). Since there is limited data on African American men' experience and motivations for self-managing diabetes and attending DSME programs with regard to Self-Determination Theory and motivation (Deci E. L., 2012), this study sought to explore and further understand the underlying themes of their experiences living with diabetes and their diabetes self-management behaviors. Additionally, this research project will explore the feelings and attitudes of African American between the ages of 40-85 with T2DM on their definition of motivation, their motivations for managing diabetes, the types of motivation they exhibit in managing their diabetes, what healthcare providers think motivates them to manage their diabetes, and what would motivate them to attend diabetes self-management education classes.

Motivational theories have been evolving since the 1930's. White (1959) conducted early studies in motivation and identified competence motivation and biological motivation. White proposed that biological motivation regulates biological processes while competence motivation enhances the abilities of the individual. Harter (1978) developed the Competence Motivation Theory and proposed competence motivation as a basic construct that was related to the amount of approval or disapproval corresponding to a child's mastery of an activity. Edward Deci and Richard Ryan added to the field of motivational theories in the 1980's by developing the Self-Determination Theory. This study used concepts of the Self-Determination Theory (SDT) as a theoretical framework.

**Specific Aim 2:** To explore motivations of African American men between the ages of 40-85 with T2DM to engage in diabetes self-management behaviors, using a Self-Determination Theory as a framework.

Research Questions:

- 1) How do African American men between the ages of 40-85 with T2DM describe self-management of their diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM define motivation?
- 3) What type of motivation do African American men between the ages of 40-85 with T2DM exhibit in managing their diabetes as related to the Self-Determination Theory?
- 4) What do African American men think about the healthcare providers involved in managing their diabetes?
- 5) What do healthcare providers think influences motivations to manage diabetes in African American men between the ages of 40-85 with T2DM?
- 6) What motivates African American men between the ages of 40-85 with T2DM to attend diabetes self-management classes?

As with other health care areas that exhibit disparities, it is important that the disparities in diabetes in African Americans be addressed. Furthermore, ensuring that there is easy access to diabetes self-management education programs is equally as important in eliminating disparities in this area.



## CHAPTER 2

### LITERATURE REVIEW

The American Diabetes Association states that “Diabetes is a group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both” (American Diabetes Association, 2011, p. S62). Diabetes influences the way that the body uses digested food for growth and energy. The body breaks down all sugars and starches into glucose (American Diabetes Association, 2018), and insulin is necessary for the body to be able to use glucose for energy (American Diabetes Association, 2018).

There are three main types of diabetes: Type 1 diabetes (T1DM), T2DM, and gestational diabetes. T1DM is an autoimmune disease in which the immune system attacks and destroys the insulin-producing beta cells in the pancreas (American Diabetes Association, 2018). Consequently, the pancreas produces little or no insulin to be used by the body. T2DM is the most common form of diabetes, accounting for approximately 90-95% of all cases of diabetes, and is more common in African Americans, Latinos, Native Americans, and Asian Americans (American Diabetes Association, 2018), but the specific causes of T2DM are unknown. T2DM includes individuals who have insulin resistance and usually have relative insulin deficiency (American Diabetes Association, 2018). Over 85% of people diagnosed with T2DM are overweight (Centers for Disease Control and Prevention, 2017). Gestational diabetes occurs late in pregnancy and typically resolves after the birth of the baby, but if acceptable body weight and activity

levels are not maintained, women with gestational diabetes have a greater chance of developing T2DM within five to ten years (U.S. Department of Health and Human Services, 2012; U.S. Department of Health and Human Services, 2016).

It is important to understand diabetes self-management from the individual's perspective in order to implement programs that appropriately address their needs. Over a decade ago, Jack (2004) postulated that diabetes-related health issues from a male perspective have been inadequately investigated, and there is a need for more epidemiological, anthropological, behavioral, and clinical studies. Sherman and McKyer (2015) reported that, while there is an increasing amount of literature on managing T2DM, there is still a lack of information on high-risk groups such as African American men. In addition to suffering disproportionately from chronic diseases, racial and ethnic minorities in the United States do not receive the same standard of healthcare service delivery or routine medical services as other groups (Pleis, Lucas, & Ward, 2009; American Diabetes Association, 2007; American Heart Association, 2004; Agency for Healthcare and Research Quality, 2016). African Americans have higher rates of mortality than any other racial or ethnic group for 8 of the top 10 causes of death (Agency for Healthcare and Research Quality, 2016).

In a study to assess the receptiveness of African American men's receptiveness and awareness of diabetes Balls-Berry, et al (2015), used a barbershop-based program that focused on diabetes prevention and awareness in a church affiliated barbershop. The authors used focus groups, emailed flyers, audio recordings, transcripts and field notes to study African American men's perception of diabetes. Themes and subthemes were categorized by using content analysis. Themes that emerged from their work were: 1)

African American men had a general awareness of diabetes, 2) the barbershop was a good non-traditional research setting to reach the African American population in their environment, 3) a family history of diabetes increased the risk of acquiring diabetes, 4) unhealthy diet and lack of exercise contribute to the higher incidence of diabetes, and 5) there was confusion from inconsistent or frequently changing messages from family members and healthcare providers.

McAndrew, Horowitz, Lancaster, and Lenventhal (2010), noted that many minority individuals with diabetes rely on subjective cues such as depression, perceived impact of diabetes, and perceived adherence to diet when assessing their control of diabetes. This reliance can be detrimental to the management of diabetes because actual glucose control is related to objective factors, such as insulin use, BMI, and age. However, DSME programs can educate individuals with diabetes about these issues, and DSME programs should be a primary component for all individuals with diabetes attempting to achieve positive health-related outcomes (Mensing, et al., 2002; International Diabetes Federation, 2011).

In a qualitative study to explore self-management experiences among men and women with T2DM, Mathew, Gucciardi, De Melo, & Paula (2012) recruited participants from a diabetes education center in Canada and used focus groups and individual interviews to explore the experiences of women and men with T2DM. The authors concluded that women and men presented with different needs and challenges with self-managing their diabetes. For example, they found that men focused more on practical strategies to reduce their dependence on medication and manage diabetes via interest in technical aspects such as knowledge of glucose monitors, and women relied more on

affective strategies that are more related to fears and anxieties such as modifying their diets and misconceptions about nutrition as related to diabetes. The study noted that both men and women reported wanting physician support to assist in diabetes self-management. Additionally, men tended to be more private in their disclosure of their diabetic condition and less observant of maintaining nutritional recommendations in a social setting where their dietary habits could reveal that they have diabetes, but conversely, women tend to disclose their diabetic condition more openly and are seem to practice appropriate nutrition and self-care behaviors regardless of social settings.

Literature acknowledges the benefits of DSME programs, and although advances have been made, it is difficult to determine what factors actually contribute to improved outcomes in DSME programs. In a review of diabetes self-management education research, Jack, Liburd, Spencer, and Airhihenbuwa (2004), re-examined eight studies to assess theoretical frameworks, cultural appropriateness of interventions, instrument quality, and results. The authors suggested that future research should incorporate theoretical frameworks to more efficiently correlate the success of interventions to principles of the underlying theoretical framework. They also suggested that future studies should emphasize a multi-level approach of interventions focused not only on an individual level, but on a community and organizational level as well.

In a study that used the Self-Determination Theory to predict medication adherence, quality of life, and physiological outcomes among patients with diabetes (Williams, et al., 2009), 3063 patients with diabetes in a nonprofit, mixed-model health maintenance organization in southeastern Michigan were identified. Using a telephone and mail survey, autonomous self-regulation for medication was measured, and the

authors concluded that healthcare providers' support for patients' autonomy and competence around medication use and diabetes self-management related positively to medication adherence, quality of life, and physiological outcomes among patients with diabetes.

In a randomized trial to test an intervention based on the Self-Determination Theory and process the model of health behavior change for tobacco cessation, Williams et al., (2006), studied 1006 adult smokers. Participants were in either a community care program or an intensive intervention program. The community care program consisted of a Public Health Service booklet for smoking cessation and a visit with their physician. The intensive intervention program consisted of the Public Health services booklet and 4 meetings with counselors trained in autonomy support for smoking cessation in 6 months. According to the authors, this clinical trial was the first to demonstrate that an intervention based on Self-Determination Theory facilitated the internalization of autonomous motivation and perceived competence and that the internalization of these motivations, in turn, resulted in increased use of cessation medications and 6 months prolonged abstinence from tobacco.

### **Diabetes in South Carolina**

Diabetes is a major health problem among African Americans in South Carolina (South Carolina Department of Health and Environmental Control, 2016; South Carolina Department of Health and Environmental Control, 2015). In an extensive undertaking to address the issues of T2DM in South Carolina, the South Carolina Diabetes Initiative (Myers, et al., 2011) was established. Some initial goals and aims of the South Carolina Diabetes Initiative are specifically related to diabetes self-management for diabetes and

access of high-risk populations: Goal I- To improve knowledge of diabetes, quality of life, and access to prevention and intervention services for people at risk and those affected by diabetes, and Aim 1.7 - To improve quality of life for persons with diabetes through learning and self-management.

Diabetes places a tremendous burden on the South Carolina healthcare system as is evident by a 37 percent increase in hospital costs in South Carolina for diabetes-related complications from 2005 to 2010 (South Carolina Department of Health and Environmental Control, 2016). South Carolina ranks 7<sup>th</sup> highest in the nation with in the nation in the percent of adult population with diabetes, and diabetes is the seventh-leading cause of death in South Carolina. It is estimated that 300,000-350,000 people may be living with diabetes with many not aware that they have the disease (South Carolina Department of Health and Environmental Control, 2015; South Carolina Department of Health and Environmental Control, 2016). Additionally, from the 1990's through 2008, the rate of diabetes in adults aged 45-65 years increased (Centers of Disease Control and Prevention, 2010; South Carolina Department of Health and Environmental Control, 2016), which indicates a need to study older adults with T2DM. In 2012, the number of new diabetes cases was highest in the age range of 45-64 and 65 years or older with 892,000 and 400,000 respectively and with rate of new diabetes cases per 1,000 unadjusted at 12.0 % and 11.5% respectively (Center for Disease Control and Prevention, 2014)

There are several factors involved with self- management of diabetes. Because individuals with diabetes perform about 95% of their own care (Funnell, et al., 2011), it is important that they assume an active role in managing their condition effectively and

efficiently (American Diabetes Association, 2011). There is evidence that interventions that promote the incorporation of healthy behaviors have been shown to significantly prevent or delay the onset of T2DM (Diabetes Prevention Research Group, 2002).

### **African Americans and Healthcare Disparities**

For decades, eliminating healthcare disparities has been a central goal of all major public health initiatives (U.S. Department of Health and Human Services, 2006; U.S. Department of Health and Human Services, 1996; U.S. Department of Health and Human Services, 2010; U.S. Department of Health and Human Services, 2000). Eliminating ethnic and racial disparities in disease morbidity and mortality is a national public health goal outlined in Healthy People 2020 (U.S. Department of Health and Human Services, 2010; U.S. Department of Health and Human Services, 2000). According to the Office of Minority Health (2018), African Americans are twice as likely to be diagnosed with diabetes, more likely to suffer complications from diabetes such as end-stage renal disease and lower extremity amputation, more likely to be hospitalized, and more likely to die from diabetes than non-Hispanic whites. Thus, there continues to be a need to address these issues and complications caused by diabetes.

Despite these public health initiatives that aim to address healthcare disparities, African Americans and ethnic minorities continue to die disproportionately from chronic diseases such as diabetes, hypertension, and heart diseases (Lewis-Moss, Paschal, Redmond, Green, & Carmack, 2008; Centers for Disease Control and Prevention, 2011; American Diabetes Association, 2011). Literature suggests that racial and ethnic minorities are less likely than whites to receive needed services and clinically necessary procedures, and that disparities exist across several diseases such as diabetes, cancer,

cardiovascular disease, HIV/AIDS, and mental illness (Nelson, 2002; Williams & Jackson, 2005; CDC, 2009).

### **Lack of African American Men in Research**

There is a significant amount of evidence that indicates that African American men are not being adequately represented in research. Recruitment of African American men in diabetes research has been challenging (Loftin, Barnett, Bunn, & Sullivan, 2005; International Diabetes Federation, 2009; Ledric & McKyer, 2015). Nearly 2 decades ago, Corbie-Smith, Thomas, Williams, and Moody-Ayers (1999) reported that African American participants consistently indicated levels of mistrust in doctors, the medical community, scientists, and the government. Unfortunately, these same problems still exist today and the concepts of trust and distrust are critical factors in African Americans seeking care. According to Jacobs, Rolle, Ferrans and Whitaker (2006), trust tends to facilitate care-seeking behavior and fosters patient honesty and compliance, while on the other hand, distrust decreases care-seeking and may lead to nonadherence.

There are disproportionately high rates of diabetes in ethnic and racial minority communities, and there is a need to develop diabetes self-management programs to help curtail the effects of diabetes on the African American community (Osborn & Fisher, 2008). Much of the research about diabetes self-management programs has been largely based on patients who are widely accessible and in academic medical settings, but efforts are needed to improve the accessibility of diabetes education programs and to culturally tailor the content of these programs to appeal to their preferred target population (Osborn & Fisher, 2008). Although physicians may refer patients to diabetes self-management programs, patients will not experience the benefits of these programs if they do not



attend. Thus, the mere act of getting African American men to attend diabetes self-management classes is important.

### **Recruitment of African Americans Men**

There is substantial literature that report the difficulty in recruiting African American men for research (Sherman & J.McKyer, 2015; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). According to Woods, et al (2004) many black men prefer one-on-one settings versus community settings with strangers regarding healthcare sites. While current literature supports the benefits of DSME programs, there continues to be a lack of information on the high-risk group such as African American men (Sherman & J.McKyer, 2015). Sherman and McKyer (2015) state that African American men must be included in research to help understand the factors that affect research recruitment and elements that influence their self-management of diabetes. Heisler (Heisler, et al., 2009), found that individuals participating in diabetes self-management classes conducted by community health workers that provided sustained and nonjudgmental assistance increased their motivation and confidence.

Connecting with the African American male community is critical in the recruitment process. According to Woods, Montgomery, and Herring (2004) a culturally sensitive approach to recruit African American men using positive materials that portray African American men in a positive manner plays a significant role in recruiting African American men. The authors further contend that conscious efforts must be made to attract the men, engage their interest, and sustain their attention to improve recruiting African American men (Woods, Montgomery, & Herring , 2004).

In earlier research, Hendricks (1999) suggested that patience is a critical factor for healthcare providers working with African American men because it allows time for them to work through defense mechanisms such as denial, anger, fear, and helplessness. Additionally, Hendricks noted that having decreased availability and accessibility to their healthcare providers were major concerns. Unfortunately, availability and accessibility continue to be a major problem in South Carolina as well (Myers, et al., 2011).

Recruiting older African American men for research can be difficult. Spence and Oltmanns (2011), reported that their team increased participation by African American men by tailoring and targeting recruitment letters and materials, meeting participants in the parking lot, walking them into the location in which the research was being conducted, encouraging participants to ask questions, providing refreshments, and referencing African American men by their last names. The authors noted that changes in recruitment strategies increased from 71 during the first two years of the study to 147 during the final year and a half.

In a pilot study to examine depression in African American men, the study had to be halted after 9 months because of no participants for the study (Bryant, Wicks, & Willis, 2014). While the authors noted that part of their difficulties may have been attributed to the stigma of depression, they also noted that culturally insensitive recruitment materials and a failure to develop trust in the community before the research project began could have curtailed recruitment and enrollment in the study.

### **Diabetes Self-Management Education**

Diabetes Self-Management Education (DSME) is a skill-based approach to managing diabetes that focuses on helping individuals with diabetes to make informed

self-management decisions (American Diabetes Association, 2011). The purpose of DSME is to promote self-care behaviors and active engagement with the healthcare team to improve quality of life, health status, and clinical outcomes (Funnell, et al., National standards for diabetes self-management education, 2011). Multiple studies have found that DSME is associated with improved diabetes knowledge and improved self-care behaviors (Norris, Engelgau, & Narayan, 2001; Centers of Disease Control and Prevention, 2010; Diabetes Prevention Research Group, 2002; Diabetes Educator Competencies Work Group , 2016) improved clinical outcomes such as lower A1C (Norris, Lau, Smith, Schmid, & Engelgau, 2002), weight loss (Norris, Engelgau, & Narayan, 2001), improved quality of life, and lower costs. Effective DSME programs have a significant impact on healthcare systems, and the data shows that diabetes education saves money and decreases healthcare utilization, with hospitalization rates 34% lower for those patients having at least one educational visit (Robbins, Thatcher, Webb, & Valdmanis, 2008).

Diabetes education is most often provided by certified diabetes educators, and licensed healthcare professionals that include registered nurses, registered dietitians, pharmacists, physicians, or others working in various specialty areas. Diabetes educators come from various backgrounds such as biological and social sciences, communication, counseling, and education (Diabetes Educator Competencies Work Group , 2016). DSME can be provided in a variety of community settings, including community gathering places, the home, recreational camps, worksites, and schools, but in-home and worksite outcomes have not been as successful as community settings (Centers for Disease Control and Prevention, 2011). Self-management of diabetes is recommended in community

gathering places for adults with T2DM (Centers for Disease Control and Prevention, 2011). The best DSME programs are culturally sensitive and incorporate behavioral and psychological components (Funnell, et al., National standards for diabetes self-management education, 2011; Loftin, Barnett, Bunn, & Sullivan, 2005).

DSME programs play a vital role in education and prevention of diabetes and should be readily available and accessible to everyone (International Diabetes Federation, 2011). While it is critical for DSME programs to be available and assessable, it is equally as important to understand the contributing reasons and factors of why African American men choose to enroll or not to enroll in in DSME programs. Low literacy, poverty, and cultural differences are some of the issues faced when implementing DSME programs with underserved populations and must be overcome to meet the needs of this population (Anderson & Christison-Lagay, 2008).

It is important for individuals with diabetes to understand the critical factors in managing their condition, and this definitely needs to be addressed in underserved and understudied populations (U.S. Department of Health and Human Services, 2018; Liburd, Namageyo-Funa, Jack, & Gregg, 2004; U.S. Department of Health and Human Services, 2010). Additional research is needed to determine effective recruitment strategies, ideal types of providers for community settings, most effective intensity and durations of interventions, reducing barriers, cost effectiveness, and long-term maintenance capabilities (Centers for Disease Control and Prevention, 2011; Funnell & Piatt, 2017).

## **Theoretical Framework: The Self-Determination Theory**

This study used the Self-Determination Theory (SDT) as a theoretical framework. Initial research on SDT began in the 1970's, comparing intrinsic and extrinsic motives and the role that motivation played in an individual's behavior, but SDT was not officially introduced and accepted as sound theory until the mid-1980's (Deci & Ryan, 1985). SDT has been tested across many domains such as tobacco cessation (Williams, et al., 2006), diabetes self-management (Williams, McGregor, Zeldman, Freedman, & Deci, 2004), medication adherence (Williams, et al., 2009), and physical activity (McAuley, Duncan, & Tammy, 1987; McAuley, Jerome, Elavsky, Marques, & Ramsey, 2003).

According to Deci and Ryan (2008), since the mid-80's there has been a significant amount of literature and research on SDT applied to a wide range of subjects, and SDT has continued to expand over the last decade with most of its growth being in areas such as physical activity, education, and healthcare. SDT is based on the concept that humans have innate psychological needs for autonomy, competence, and relatedness and contend that behavioral regulation towards an activity can be amotivated, extrinsically motivated, or intrinsically motivated SDT (Deci & Ryan, 1985).

In SDT (Deci & Ryan, 2000), the need for autonomy is fulfilled when people perceive that they are the origin of their choices and decisions and competence involves an individual's need to feel mastery through effective interaction within their environment; and relatedness involves feeling securely attached to and being respected by others. While SDT has covered many domains, it has not been applied to older African American men with diabetes (E.L. Deci, personal communication, February 24, 2012). The Self-Determination Theory as a framework (Deci & Ryan, 1985) was selected

for this research project because it specifically addresses distinct types of motivation such as intrinsic motivation versus extrinsic motivation, and underlying constructs that might influence each type of motivation.

The goal of this study is to gain an understanding of the experiences of African American men living with T2DM and the factors to influence motivation to self-manage T2DM. This goal will be achieved by addressing the following specific aims.

**Specific Aim 1:** To explore the definitions of diabetes, experiences living with diabetes, and diabetes self-management behaviors of African American men between the ages of 40-85 with T2DM.

Research questions:

- 1) How do African American men between the ages 40-85 with T2DM define diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM describe their experiences living with diabetes?
- 3) How do African American men between the ages of 40-85 describe their diabetes self-management behaviors?

Specific aim 1 explores how older African American men define diabetes, their experiences living with diabetes, their general perception of living with diabetes, and their motivations for managing their diabetes.

**Specific Aim 2:** To explore motivations of African American men between the ages of 40-85 with T2DM to engage in diabetes self-management behaviors, using the Self-Determination Theory as a framework.

Research Questions:

- 1) How do African American men between the ages of 40-85 with T2DM self-management of their diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM define motivation?
- 3) What type of motivation do African American men between the ages of 40-85 with T2DM exhibit in managing their diabetes as related to the Self-Determination Theory?
- 4) What do African American men think about the healthcare providers involved in managing their diabetes?
- 5) What do healthcare providers think influences motivations to manage their diabetes in African American men between the ages of 40-85 with T2DM?
- 6) What motivates African American men between the ages of 40-85 with T2DM to attend diabetes management classes?

As with other health issues, it is important that the disparities in diabetes in African Americans be addressed. Furthermore, ensuring that there is easy access to diabetes self-management education programs is equally as important in eliminating disparities.

## CHAPTER 3

### METHODS

This chapter details how this study was developed, depicts the research process, how the data was collected and analyzed, and outlines the processes used to interpret the data. This study used an interdisciplinary approach gained from the primary investigator's interdisciplinary training in physical therapy and rehabilitation science and continuous work with different healthcare and public health professionals. In-depth interviews were used to explore the definition of diabetes and motivation, living with diabetes, the self-management behaviors of African American men between 40-85 years of age with T2DM, what they and healthcare providers that treat African American men with T2DM believed motivates them to manage their diabetes and to attend diabetes self-management programs, and also explores what African American men and healthcare providers that treat African American men with diabetes feel about their respective roles in managing diabetes. Two interview guides were developed, one for African American men with T2DM and one for the healthcare providers, to direct the in-depth interviews. In addition, a modified Intrinsic Motivation Inventory (IMI) (Appendix A) adapted from principles of the Self-Determination Theory was used to provide descriptive data on motivation. The research study addressed the following aims:



*Specific Aim 1:* To explore the definitions of diabetes, experiences living with diabetes, and diabetes self-management behaviors of African American men between the ages of 40 and 85 with T2DM.

Research questions:

- 1) How do African American men between the ages 40-85 with T2DM define diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM describe their experiences living with diabetes?
- 3) How do African American men between the ages of 40-85 describe their diabetes self-management behaviors?

**Specific Aim 2:** To explore motivations of African American men between the ages of 40-85 with T2DM to engage in diabetes self-management behaviors, using the Self-Determination Theory as a framework.

Research Questions:

- 1) How do African American men between the ages of 40-85 with T2DM self-management of their diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM define motivation?
- 3) What type of motivation do African American men between the ages of 40-85 with T2DM exhibit in managing their diabetes as related to the Self-Determination Theory?
- 4) What do African American men think about the healthcare providers involved in managing their diabetes?

- 5) What do healthcare providers think influences motivations to manage their diabetes in African American men between the ages of 40-85 with T2DM?
- 6) What motivates African American men between the ages of 40-85 with T2DM to attend diabetes management classes?

### **Study Setting**

For this study, a total of 28 participants were interviewed. Twenty-two African American men with T2DM between the ages of 40 and 85 were recruited to address research questions for specific aim 1, and the same twenty-two African American men along with six healthcare professionals were recruited to address the research questions for specific aim 2. Demographic information for this study was attained from a demographic questionnaire (Appendix B) filled out by the participants prior to the in-depth interviews at the interview location. African American men with T2DM were recruited from local churches in the Piedmont area of South Carolina and included participants from Spartanburg, York, Lancaster, and Chester counties in the South Carolina Conference of the South Atlantic Episcopal District (SAED) of the African Methodist Episcopal Zion (AMEZ) church. Figure 3.1 illustrates the research study's pathways.

### **Rationale for Qualitative Design**

This study is a qualitative study design using in-depth interviews, with open-ended questions, and the Self-Determination Theory as a framework. Qualitative studies have long been used and have a valuable role in healthcare fields, social sciences, and nursing to study behavior (Miller W. R., 2010). While qualitative studies may not be generalizable to all groups, they can provide information that can be used to improve care

and influence behavior change for specific populations (Sandelowski, 1997). Using open-ended questions and probing strategies allows participants to respond in their own words rather than choosing from fixed responses, and it provides the researcher an avenue to direct the interview in a manner that via how may create responses that are meaningful and culturally relevant to participants and unanticipated by the researcher (Stuckey H. L., 2013). In-depth interviews have been used to find out more in-depth feelings of individuals with diabetes (Stuckey H. L., 2013), and DSME programs often incorporate open ended and close-ended data gathering strategies such as interviews, focus groups, and surveys to attain behavior specific data on the factors that influence poor self-management from members of the target population (Sarkisian, Brown, Norris, & Mangione, 2003).

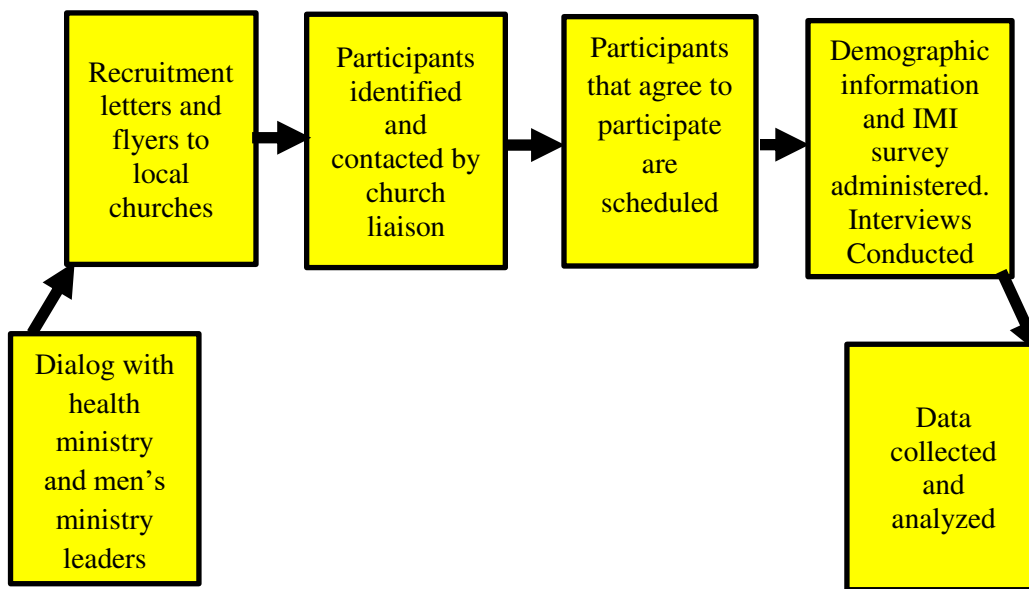


Figure 3.1 Research Study Pathways

Maxwell (2005) proposes an interactive model of a qualitative research design that is depicted below in Figure 3.2. Maxwell states that there are five interactive

components of a qualitative study: 1) Goals, 2) Conceptual Framework, 3) Research Questions, 4) Methods, and 5) Validity.

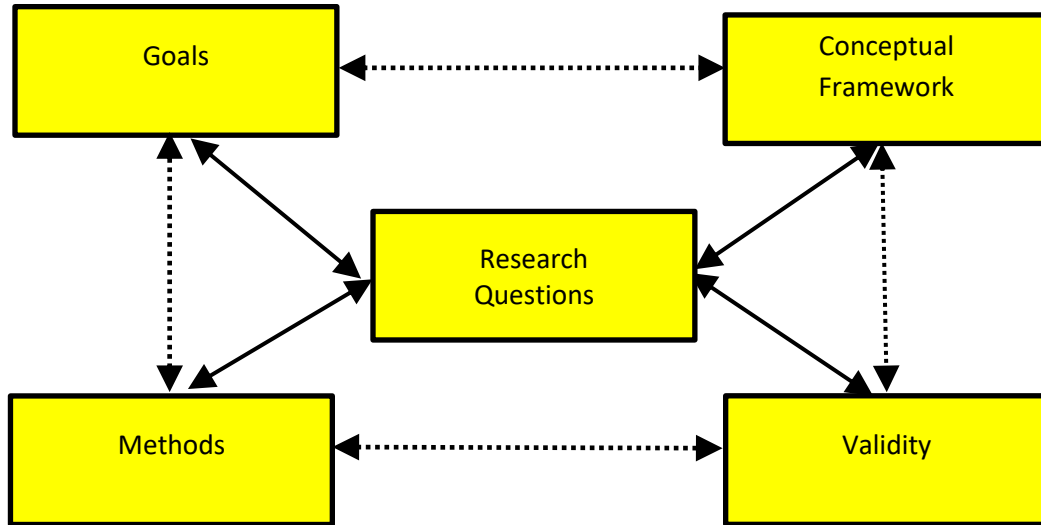


Figure 3.2 An Interactive Model of Research Design

In Maxwell’s model, the upper triangle of this model (Goals, Conceptual Framework, and Research Questions) should be closely integrated and related in that the research questions should be directly related to the goals of the research study, and the conceptual framework should be applicable to the phenomena being studied in the research study. The bottom triangle of this model (Methods, Validity, and Research Questions) should also be closely integrated, and the methods should allow the research questions to be answered, and the research questions are the center of the model and should be framed to allow the methods of the research study to address threats on validity.

**Theoretical Framework: Self-Determination Theory**

This study focused on motivation with a theoretical framework from the Self-Determination Theory (SDT). The constructs from the SDT are autonomy, related, and

competence. SDT posits that when three innate psychological needs (competence, autonomy, and relatedness) are satisfied, autonomous motivation will be increased (Ryan & Deci, 2000). The need for autonomy is fulfilled when individuals perceive that they are the source of their choices and decisions (Adie, Duda, & Ntoumanis, 2008). SDT (Deci & Ryan, 2008) is based on human motivation, development, and wellness, and postulates that motivation can be multifaceted and vary in amounts and types of motivation (Deci & Ryan, 2000). As defined by Deci and Ryan (2000), “Intrinsic motivation is doing something because it is inherently interesting or enjoyable, and conversely, extrinsic motivation that entails doing something because it leads to a separable outcome.” (p.56). According to Deci and Ryan (2008), autonomous motivation is achieved when an individual volitionally integrates an activity into their sense of self, and conversely, controlled motivation entails behavior that is predicated on external factors such as rewards and punishment.

Creating environments that provide an opportunity for individuals to make choices allows the individual to experience autonomy and can enhance the intrinsic motivation to engage in a particular behavior such as increased learning in a DSME program (Ryan, Williams, Patrick, & Deci, 2009; Deci & Ryan, 1985). Ryan and Deci (2000) contend that conditions supportive of autonomy and competence reliability facilitated intrinsic motivation. Thus, if autonomy and perceived competence increases intrinsic motivation to engage in a DSME program, individuals in a DSME program with a choice of options to learn or enhance their self-management skills may increase their willingness to participate in a DSME program or motivations to self-manage diabetes.

## **Participants**

This study was approved by the Institutional Review Board of the University of South Carolina. Permission to officially recruit members from the South Carolina Conference of the South Atlantic Episcopal District of the African Methodist Episcopal Zion (AMEZ) Church was granted by the presiding bishop during the 2008-2016 term. The selection of participants was purposeful, which is a form of nonprobability sampling that involves the deliberate selection of individuals by the research based on predefined criteria (DePoy & Gitlin, 1998; Creswell & Plano Clark, 2011; Patton, 2002). Participants fit the following inclusive criteria for aim 1: 1) African American men between 40 and 85 years of age, 2) a diagnosis of T2DM, and 3) or was affiliated with an African Methodist Episcopal Zion (AMEZ) church in the South Carolina Conference of the South Atlantic Episcopal District (SAED) in the Piedmont or Sandhill area of South Carolina.

For aim 1 there were (n=22) African American men with T2DM. For aim 2, there were a total of (n=28) participants consisting of African American men (n=22) between the ages of 40-85 years who were diagnosed with T2DM, and (n=6) healthcare providers who treated African American men with T2DM. The disciplines and ethnicities of the 6 healthcare providers were as follows: The disciplines and ethnicities of the 6 healthcare providers were: 2 African American male Family Practice Physicians, 2 European American male Family Practice Physicians, 1 European American female Nurse Practitioner, and 1 African American female Doctor of Pharmacy. Healthcare providers that practiced in or near the Piedmont area of South Carolina were selected via recommendation of healthcare providers practicing in the Piedmont area of South

Carolina. Table 3.1 illustrates the demographics data for the 22 African American men with T2DM who participated in this study.

### **Recruitment**

Over a 2-year period from 2014-2016, dialog was initiated in several settings to recruit African American male participants. Recruitment venues included diabetic self-management education programs in hospitals, community clinics, endocrinology offices, and primary care offices. Extensive efforts were made and hours of time invested consulting with diabetes educators, primary care physicians, and directors of diabetes self-management education programs. Initial recruitment of participants included contacting 11 primary care medical offices with 3 in Columbia, SC, 4 in Lancaster, SC, 2 in Rock Hill, SC, 1 in Orangeburg, SC, and 1 Heath Springs, SC. Five DSME programs were also contacted with 3 being in Columbia, SC, 1 in Rock Hill, SC, and 1 in Orangeburg, SC. Gaining access to the target population of African American men between 40-85 years of age was much more difficult than anticipated and expanding the target population to all ethnicities and genders was seriously considered to increase the participant pool, but the desire to have this study address African American men prevailed and other recruitment efforts were expanded to the SAED of the AMEZ church.

Although, the initial recruitment process with primary care medical facilities and diabetes self-management education programs did not yield any participants for the study, valuable experience was gained about the recruitment process and some of the recruitment barriers that exist. The majority of the primary care facilities and healthcare

clinics had front office staff, who were informative and cooperative on the initial conversation that introduced the study and the purpose of the study. However, the problem appeared to be that communication and importance of the study was not a priority as it moved up the administrative chain.

Table 3.1 Research Study Demographics for African American Men

<b>Participant Characteristics (n=22)</b>	<b>Mean (range) or n (%)</b>
Age (years)	63.8 (47-81)
Education Level	
Grade 1-8	1 (4.5)
Grade 9-11	2 (9.1)
High School Graduate	5 (22.7)
1-3 Years College	5 (22.7)
College Graduate	9 (40.9)
Average Income	
<\$10K	3 (13.6)
\$10-15K	1 (4.5)
\$20-25K	4 (18.2)
\$25-35K	3 (13.6)
\$50-75K	3 (13.6)
>\$75K	7 (31.8)
Age diagnosed with diabetes (years)	51.4 (31-70)
Length of time diagnosed with diabetes (years)	12.6 (2-34)
Last doctor's appointment	
Within past 3 months	17 (77.3)
Between 3-6 months	5 (22.7)
Have health insurance	22 (100)
Self-description of health	
Poor	0 (0)
Fair	8 (36.4)
Good	11 (50.0)
Very Good	3 (13.6)
Excellent	0 (0)
BMI (kg/m <sup>2</sup> )	31.0 (21.0-44.0)
Height (inches)	69.7 (66-75)
Weight (pounds)	218.4 (148-330)
Marital Status	
Single	1 (4.5)
Married	14 (63.6)
Widower	1 (4.5)
Divorced	5 (22.7)



Additional barriers that prevented initiation of research at primary care medical facilities and diabetes education programs included: 1) some facilities were not accustomed to having research conducted at their facility and did not feel comfortable, 2) some facilities had concerns about their patients involved in research, 3) some facilities thought that it would be additional work for their staff, and 4) some facilities failed to continue communication with the primary investigator.

The recruitment team was comprised of the primary investigator, local health ministry coordinators and men's ministry leaders of local AMEZ churches in Rock Hill, SC. As recommended in previous studies dealing with African American men (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Woods, Montgomery, & Herring, 2004), a culturally sensitive and respectful recruitment letter and flyer was developed. A recruitment letter (Appendix C) and a recruitment flyer (Appendix D) was mailed to local AMEZ churches and their health ministry coordinators and men's ministry leaders in the Rock Hill, SC district of the SAED. The recruitment letter described the purpose of the study, inclusion criteria, and the role of the recruitment team. The recruitment flyer outlined the purpose of the study, the contact information for the principle investigator and research study coordinator. After the recruitment information was mailed to the health ministry coordinators of the local churches, periodic follow-up calls were made by the primary investigator to the health ministry coordinators to identify potential participants that may have given contact information. Recruitment information was also mailed and presented to men's ministries and at men's ministry workshops of the local churches.

Local health ministry coordinators identified potential participants from their congregation and community by making announcements pertaining to the study during church service and men's ministry programs at church services and church-related events. The primary investigator contacted the potential participants to schedule their time and location to participate in the study. An important recruitment strategy emerged as once the announcements about the study were made by the health ministry coordinators and the men's ministry at church and church-related events, church members and members of the men's ministry started to disseminate information about the research project via word of mouth. This led to more individuals being made aware of the study. Word of mouth and using to community-based organizations and community partnered participatory research has been proven to be effective with recruiting minorities for research (Sankare', et al., 2015; Mendez-Luck, et al., 2011).

### **Data Sources**

Data sources for this study included information gained from initial dialog with AMEZ clergy, health ministry and men's ministry leaders, DSME program administrators, and diabetes educators. Rich, detailed data came from the in-depth interviews, and demographic information came from a Demographic Information Sheet (Appendix B), and the Modified Intrinsic Motivation Inventory (IMI) in (Appendix A) was to gather descriptive data on intrinsic motivation. Memos, field notes, and reflections were also valuable sources of data that were critical in formulating the evolving themes of the participants.

## **Memos**

Memos were used to assist in deriving information from the data. Writing memos can occur during any phase of the research process to clarify, clarify research topic, and to facilitate the development of study design (Birks , Chapman, & Francis, 2008). Memos consisted of recordings of reflective notes, or summaries during data collection (Groenewalkd, 2008). For this study, memos were written after interviews, and during, during the transcription verification process. Writing memos does not have to be correlated to a rigid schedule or systematic implementation (Glaser, 1978), and it adds to the credibility and trustworthiness of qualitative research and allows meaning to be extracted from the data (Groenewalkd, 2008).

## **Field Notes**

Field notes are recordings of events, occurrences, observations that written by the investigator and can include the investigator's impression of the situation (DePoy & Gitlin, 1998). Field notes were handwritten on the interview guide of every participant before, during, and after the interview, and included information on various factors such as interesting revelations mentioned by participants or, body language, and statements that the participant mentioned after the recordings. Many times, after the interview was completed, participants wanted to add other information about diabetes or family members having diabetes.

## **Reflections**

Reflections were in the form of brief audio recordings made by the primary investigator that were made immediately after every interview. The purpose of the

reflections was to provide a brief and fresh summary of the in-depth interview. Each reflection was listened to immediately after it was recorded, and on several occasions afterwards with any new revelations incorporated in to memos. Reflections capture the highlights, interesting dialog, and points that may have been expressed after the interview was completed. Each reflection was no longer than 5 minutes.

### **In-depth Interviews**

The primary investigator conducted and dually recorded all 28 interviews using a smartphone recorder and a mini-digital recorder. For specific aim 1, and per each participant's preference, 5 interviews were conducted at the conference rooms of the participant's church and 16 were conducted in their homes, and one at a restaurant. Specific aim 2 used the same interviews from the 22 African American men used in specific aim 1 along with 6 in-depth interviews with healthcare providers. Five of the 6 interviews of the healthcare providers were conducted in the offices of the healthcare providers, and one held at a café.

The in-depth interviews were directed by the interview guide for the 22 African American men (Appendix E) and the interview guide for the 6 healthcare providers (Appendix F). The average time for the interviews for participants was 26 minutes for African American men and 24 for healthcare providers.

### **Interview guide**

The interview guides for specific aims 1 and 2 were developed with some questions adapted from Stuckey (2013) and organized in 3 topic areas with the first group of questions addressing personal topics, the second group of questions addressing practices of diabetes self-management, and the third group of questions addressing barriers and

factors for success in diabetes self-management. For specific aim 1, the interview guide for the 22 African American men with T2DM was comprised of 15, open ended-questions (Table 3.2 below and Appendix E).

For specific aim 2, the same interview guide for the 22 African American men used for specific aim 1 was used for the African American men, and a separate interview guide comprised of 14, open ended questions for healthcare providers (Table 3.3 below and Appendix F) was created. The interview guide used for the healthcare providers was similar to the interview guide used for the African American men participants and was also developed with some questions adapted from Stuckey (2013). The interview guide for the healthcare providers was organized in 3 topic areas with the first group of questions addressing personal topics, the second group of questions addressing practices of diabetes self-management and motivation, and their thoughts on diabetes self-education programs (see Table 3.3).

The same interview guide was used for the 22 African American men with T2DM for specific aim 1 and specific aim 2 to explore 3 specific topic areas: 1) Personal and diabetes-related information, 2) Diabetes self-management and motivation information, and 3) Diabetes self-management program information. The first topic area included personal and diabetes-related information that consisted of general information as hobbies and interest, transitioned into self-rated health, and specific questions about their definition of diabetes, initial emotions upon being diagnosed with diabetes. The second topic area explored participants self-management experiences and their definition of motivation, their motivations to self-manage their diabetes, and struggles with self-managing diabetes. The third topic area explored their perception of diabetes self-

management education programs including their familiarity of the diabetes self-management education programs, factors that could motivate them to attend a diabetes self-management education program, and way in which attending at diabetes self-management education program might help the participants.

Table 3.2 Sample Interview Questions for African American Men

Topic of Interest	Sample Questions
Personal questions and diabetes-related questions	<ul style="list-style-type: none"> <li>• Tell me some things about yourself (hobbies, work, and family).</li> <li>• How would you describe your health? Excellent, Very Good, Good, Fair, or Poor?</li> <li>• When were you diagnosed with diabetes?</li> <li>• How did being diagnosed with diabetes make you feel</li> <li>• What does the word diabetes mean to you?</li> </ul>
Diabetes self-management and motivation	<ul style="list-style-type: none"> <li>• How do you feel about self-managing your diabetes?</li> <li>• Have you always taken care of your diabetes?</li> <li>• What is a typical day in your self-management of diabetes?</li> <li>• How would you define motivation?</li> <li>• What motivates you to self-management your diabetes?</li> <li>• What are some of the things that you struggle with daily in self-managing your diabetes?</li> </ul>
Diabetes self-management programs	<ul style="list-style-type: none"> <li>• Are you familiar with diabetes self-management education programs?</li> <li>• Tell me what you know about diabetes self-management programs, and how do you feel about attending a diabetes self-management program</li> <li>• What are some things that would motivate you to attend a diabetes self-management education program?</li> <li>• Are there any reasons that have prevented you from attending a formal diabetes self-management education program?</li> <li>• If you were to attend a formal diabetes self-management education program, how do you think it would help you to self-manage your diabetes?</li> <li>• What are some things that would keep you on track in self-managing your diabetes?</li> </ul>

The interview guides were specifically developed to explore the definition of motivation, motivations for managing diabetes, what healthcare providers who treated African American men with T2DM felt about their motivations for managing diabetes, the role of the healthcare provider in assisting African American men with T2DM, and what would motivate them to attend a diabetes self-management education program using a Self-Determination Theory as a framework. Additional strategies to develop the interview guide, sequence the interview questions, explain the role of the interviewer and interviewee, and set parameters of the interview were derived from Kvale and Brinkmann (2009). DSME programs incorporate open ended and closed-ended question gathering strategies such as interviews, focus groups, and surveys to attain behavior specific data on the factors that influence poor self-management from members of the target population (Sarkisian, Brown, Norris, & Mangione, 2003).

### **Instrumentation**

The Modified Intrinsic Motivation Inventory (IMI) (Appendix A) was modified from the Self-Determination Theory (Deci & Ryan, 2011). The IMI has been extensively tested in many areas in the behavioral sciences with the SDT framework (Williams, et al., 2009; Williams, et al., 2006). The IMI is a multidimensional measurement device intended to assess participant's subjective experience related to a target activity in laboratory experiments and has been used over several decades. The interest/enjoyment subscale is a self-report measure of intrinsic motivation, and the subscale (McAuley, Duncan, & Tammy, 1987) that assesses intrinsic motivation (Self-Determination Theory, 2018). The IMI was modified for this study to be used as adjunct, descriptive data to measure the participant's level of intrinsic motivation for attending and participating in a

diabetes self-management class. The IMI was modified to an 8-item, 7-point scale with values from 1 (not at all true) to 7 (very true).

Table 3.3 Sample Interview Questions for Healthcare Providers

Topic of Interest	Sample Questions
Personal questions and diabetes-related questions	<ul style="list-style-type: none"> <li>• Tell me some things about yourself (hobbies, work, and family).</li> <li>• Where did you go to medical school?</li> <li>• How long have you been practicing?</li> <li>• What is your particular are of interest?</li> <li>• How would you describe your health? Excellent, Very Good, Good, Fair, or Poor?</li> </ul>
Diabetes self-management and motivation	<ul style="list-style-type: none"> <li>• Do you treat many African American men with T2DM?</li> <li>• Estimate the percentage of African American men with T2DM do you treat?</li> <li>• Do you refer African American men to diabetes self-management education program? Why or Why not?</li> <li>• What do you think your role is in helping individuals with diabetes to manage their diabetes?</li> <li>• Overall, how do you think your diabetes patients managed their diabetes?</li> <li>• More, specifically, how do you feel that your African American men manage their diabetes?</li> <li>• Do you think that your African American men with type 2 diabetes are motivated to manage their diabetes?</li> <li>• What are some strategies that you think would help African American men to manage their diabetes?</li> <li>• What are some things that you think African American men struggle with in their day to day self-management of their diabetes?</li> </ul>
Diabetes self-management programs	<ul style="list-style-type: none"> <li>• Do you think that attending a formal Diabetes Self-Management Education program helps your African American men self-manage their diabetes?</li> <li>• Do you know what exactly is being taught at the diabetes self-management classes?</li> <li>• Are there any cases of African American men and poor self-management of their diabetes that stand out?</li> </ul>



## **Data collection**

After the participants had been identified by the health ministry coordinators and men's ministry leaders, their contact information was given to the primary investigator.

The primary investigator contacted potential participants by telephone to give further information on the study and set up their interview if they were still interested.

Additional data used in analysis included investigator memos, field notes, reflections, and NVivo 10 software for initial storage of transcribed interviews prior to data analysis.

The interview guide was specifically developed to explore the definition of diabetes, the experience of living with diabetes, and self-management behaviors of African American men with T2DM. After interviews were completed and throughout the data analysis process, the primary investigator contacted participants via phone as necessary to gain clarity in their interview statements and verify and affirm that their statements from the interviews were accurate.

## **Data analysis**

Data analysis was an intentionally repetitive, reiterative, and continuous process that began in the early stages of data collection and continued throughout the study (Bradely, Curry, & Devers, 2006). Initial phases of analyzing qualitative data requires immersion in the data to gain a complete understanding (Pope, Ziebland, & Mays, 2000), and consisted of the initial coding of the data and continuously exploring, reviewing, comparing, and incorporating field notes, reflections, memo writing, query, and analyzing (NVivo, 2015). NVivo 10 was used as qualitative analysis software to assist

with the storing of the data, but the organization of the data development of themes to address the outlined research questions was performed by the primary investigator.

The transcription process was conducted in three overlapping phases and was rigid and consistent throughout the entire process. Half of the in-depth interview were transcribed by a study team member with extensive training in data collection and analysis, and the primary investigator re-listened to each interview and corrected the initial transcription draft by comparing it to the audio file. The primary investigator was responsible for the final verification of each transcript. In the initial transcription phase, each in-depth interview was transcribed by a study team member or the primary investigator to produce the first transcribed rough draft of the interview. The majority of the text that was uploaded from VoiceBase was unintelligible and required several revisions that consisted of meticulously comparing the current version of transcription to the original audio file. The high amount of unintelligible text could possibly be attributed to difficulty of the voice recognition program to recognize untrained voices on the original audio recording and quality of the audio files.

For the second phase of transcription, a second draft was produced by comparing the initial draft of the transcription line-by-line to the original audio file to improve the quality, clarity, and accuracy. Significant detail was utilized to transcribe exactly what was spoken, including partial words, repetitions, pauses, and chuckles. The interviewer's spoken words were designated as an "I" and the respondents spoken words were designated as "R" on the transcript. During this phase, unintelligible words were highlighted for further review by the primary investigator. For example, raw text that presented as "Farm dee" was corrected to read "Pharm D" (Doctor of Pharmacy).

In the final phase of transcription, the primary investigator verifying all 28 in-depth interviews by repeating the steps in phase two of by comparing the previous draft of the transcription line-by-line to the original audio file to gain additional quality, clarity, and accuracy. Verified transcriptions were labeled and saved in a password protected computer. For example, Verified DRS1 April 26, 2016 (Verified Diabetes Subject 1). The verified transcripts were then uploaded into NVivo 10 for further analysis.

Transcription was an exhaustive and time-consuming process with an estimated ratio of time being 4:1, that is, for every hour of interview time, there is an estimated 4 hours of transcriptionist cost and time (Stuckey H. , 2014; Markle, West, & Rich, 2011). It is estimated that the primary investigator spent 5-6 hours on each transcribed interview and the other study team member spent an average of 2 hours on each interview.

All interviews, investigator memos, and field notes were reviewed by the primary investigator to inform development of the initial codebook (DePoy & Gitlin, 1998). The initial codebook was developed based on the first 3-5 interviews and organized in NVivo. After the preliminary codebook was developed, data from each subsequent interview were continuously reviewed and compared to it to further develop themes. After several interviews were coded and the corresponding information stored in nodes, queries were conducted in NVivo to allow subsets of data to be analyzed, reviewed, and compared.

The transcribed and verified interviews, in the form of Word documents, were uploaded and stored in NVivo 10 folders called nodes, which are locations that contain information that is deemed as similar. The primary investigator arranged the nodes into a hierarchy of categories for the purpose of developing common themes on: the definition

of diabetes and motivation, experiences living with diabetes, motivations, diabetes self-management behaviors, motivations for managing diabetes, motivations for attending diabetes self-management education classes, the perception that African American men had for their healthcare providers, and the perceptions that healthcare providers had for African American men with T2DM that they treat on their motivation and their motivation to self-manage diabetes, and the perceived roles of healthcare providers in assisting African American men to manage their diabetes.

After the data was reviewed and a preliminary understanding of the data evolved, initial coding began. Coding is the process of grouping evidence and labeling ideas so that they reflect increasing broader perspectives (Creswell & Plano Clark, 2011, p. 208), and it provides a formal system to organize the data, uncovering and documenting additional concepts that were described in the data (Bradely, Curry, & Devers, 2006). As data was analyzed, initial coding, and emergent themes evolved. A codebook was developed on the first 3-5 interviews and organized into NVivo. After the preliminary codebook was developed, the data from each subsequent interview was compared to the preliminary codebook, NVivo 10 and existing codes.

NVivo 10 was used to conduct coding queries on data stored in nodes to allow subsets of data to be analyzed, reviewed, and compared to test ideas, explore patterns, and see the relationships between topics and themes (NVivo, 2015). Further development and analysis of themes, codes and codebook development strategies recommended by Creswell and Clark (2011) and Braun and Clark (2006). Braun and Clark (2006) recommend that following steps to analyze the data: 1) become familiar with the data, 2) generate initial codes, 3) research reading throughout each transcript to become immersed

in the data, 4) review themes, 5) define and name themes, and 6) produce the final document. Some of the interviewee responses could be attributed to more than one category, and thus were coded in each of those categories.

Thematic analysis is a process that searches for emerging themes that are important for description of the phenomenon being studied (Daly, Kellehear, & Gliksman, 1997) and consists of pattern recognition of the of the data set in which emerging themes produce categories for analysis (Fereday & Muir-Cochrane, 2006). Thematic analysis was used to analyze data for specific aim 1 and specific aim 2. For specific aim 2, the modified Intrinsic Motivation Inventory (Appendix A) was used as adjunct, descriptive data and defined in the instrumentation section. Thematic analysis is a widely-used qualitative data analysis method that can be used to identify patterns of meaning across a dataset. It has been widely used across the social, behavioral and applied sciences. Patterns are identified through a rigorous process of data familiarization, data coding, and theme development and revision. It can be used within different frameworks to answer different types of research questions (The University of Auckland, 2017).

### **Data confidentiality**

Guidelines from the Office of Research Integrity of the U.S. Department of Health and Human Services (Coulehan & Wells, 2018) were used to protect and maintain confidentiality of participants and data. Study codes were used for the modified Intrinsic Motivation Inventory. Participants were assigned an identification code when they turned in their surveys. Their identification codes were entered on a sheet and stored in a separate locked file cabinet. The identification code sheet was stored separately from the

completed questionnaires. An original document that contained the name of the participants, the date of the interview, and code number to provide anonymity and privacy was saved on a password protect computer. For example, “John Doe, Diabetes Research Subject 1, April 9, 2016. Recorded interviews and reflections were downloaded into MP4 audio files and saved on a password protected computer.

Interviews were digitally recorded and conducted in a private conference room at a local church, in a private room in the participant’s home, or in the office of the healthcare providers. One of the healthcare provider interviews was held at a café. After each in-depth interview was completed, the digital recording was transferred from the digital recorder to a password-protected computer hard drive and saved for reference purposes. All recordings were erased from the digital recorder, and all identification information was removed from transcripts that will be used for analysis. The original transcribed interviews were stored in a locked-safe for reference purposes. As a safe-guide for recording equipment failure, all in-depth interviews were dually recorded via mini-disc digital recorder and smart phone. After each in-depth interview was recorded, the audio files were saved as MP4 format. The audio files were then uploaded into a free, online automated speech recognition service program called VoiceBase. VoiceBase converts audio files to generic text files (VoiceBase, 2016).

### **Validity**

To enhance the credibility and validity of qualitative research, several strategies such as multiple data gatherers, triangulation, saturation, reflexivity, member checks, audit trails, and peer debriefing were used (DePoy & Gitlin, 1998; Creswell & Plano Clark, 2011). Twenty-eight participants were interviewed for this research project.

Triangulation was used by implementing the use of two data collection strategies by using an in-depth interview that was supplemented by the modified Intrinsic Motivation Inventory in specific aim 2 to further explore the responses of participants concerning factors that motivate individuals to self-manage their diabetes, and factors that would motivate participants to attend a DSME program.

### **Feedback and Member Checking**

Member checking was used throughout the data collection process. Member checking is a technique in which the investigator checks an assumption or a particular understanding with one or more informants, and it aims to affirm a particular revelation from a research participant to strengthen the credibility of the interpretation and to decrease the potential of introducing investigator bias (DePoy & Gitlin, 1998). Member-checking also consist of the investigator taking summaries of the findings back to the key participants in this study to asks them whether the findings are accurate reflections of their experiences (Creswell & Plano Clark, Designing and conducting mixed methods research, 2011).

Member checking was performed during and after data collection and analysis via a series of regularly scheduled check-up meetings or telephone calls with an expert reviewer to gain feedback and confirm findings of the study, get input and review the data collection process from research experts familiar with the research protocol and process. Typically, check-up meetings and calls were scheduled on a weekly basis, but there several non-scheduled and impromptu meetings. These meetings consisted of reviewing interviewing strategies, data collections strategies, and proccession information gathered via NVivo 10 software.

Additional member checking was incorporated in this study by conducting follow up phone calls to the African American male participants and healthcare providers. Brief follow up telephone conversations were held with 6 out of the 22 African American men and 4 out of the 6 healthcare providers to clarify portions of their interviews to verify or gain clarity in particular responses in their depth interview or verify information on their demographics sheet. All of the follow-up calls were less than 10 minutes. In 5 cases, participants requested follow up conversations through their health ministry coordinator because they wanted to ensure that that they had included particular information in their in-depth interviews. The follow up dialog with healthcare providers was mainly conversations concerning their interest to improve their practice as related to treating patients with T2DM or an interest of the issues that the other healthcare providers expressed in their interviews.



## CHAPTER 4

### RESULTS

This chapter will provide the study results divided into two manuscripts.

4.1 EXPERIENCES OF AFRICAN AMERICAN MEN IN SOUTH  
CAROLINA BETWEEN THE AGES OF 40 AND 85 LIVING WITH  
TYPE 2 <sup>1</sup>DIABETES

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<sup>1</sup> Walker, A.Q., Blake, C., Watkins, K., Wilcox, S. and Moore, J. To be submitted

## ABSTRACT

**BACKGROUND:** Type 2 diabetes mellitus (T2DM) is a chronic disease that poses many challenges to those living with it. African Americans are disproportionately affected by T2DM and are also an underserved and understudied population. Understanding how African Americans with T2DM define and live with diabetes is important for developing effective, culturally sensitive interventions that are tailored to improving diabetes self-management behaviors.

**OBJECTIVE:** To explore the definitions of diabetes, experiences of living with diabetes, and diabetes self-management behaviors of African American men.

**METHODS:** In-depth qualitative interviews were conducted with 22 African American men between the ages of 40 and 85 years diagnosed with T2DM. Interviews focused on participants' definition of diabetes, experiences living with diabetes, and self-management behaviors. In-depth interviews were transcribed and analyzed using NVivo 10 with thematic analysis and an emergent and thematic coding technique.

**RESULTS:** When defining diabetes, many participants responded with the actual physical effects of diabetes and what causes diabetes, using words such as "sugar" or "glucose." Many participants described their experience living with diabetes negatively, with phrases such as "a lot of trouble," "a dangerous disease," and "a bad, nasty disease" but indicated that if they were compliant with their medication and maintained a proper diet, they could live a relatively normal life. Most of the participants said that they did not exercise or maintain a proper diet, but all of them reported that they had been to their

primary care physician within the last six months. Many participants reported an awareness of health complications that could be caused by diabetes, such as amputations, diabetic comas, and even death. Participants' reactions when first diagnosed included disbelief, shock, and denial. Participants' emotional experiences of living with diabetes included apathy, shame and guilt, fatalism, fear, denial, and avoidance. Many participants expressed respect for and confidence in their healthcare providers, although a few expressed feelings of distrust and being uninformed. Many participants had self-management behaviors that included a routine of taking medications, relying on family support for encouragement, maintaining a proper diet, and dealing with the cost of diabetic medications and supplies.

**CONCLUSION:** Diabetes is a complicated disease that affects African American men disproportionately. Living with diabetes can be very challenging emotionally, physically, and mentally. Understanding the experiences of older African American men living with diabetes and how they define and self-manage diabetes is an important step in the ongoing process of developing and implementing interventions to help these individuals improve their quality of life.

## BACKGROUND

Diabetes mellitus is a group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, decreased production of insulin, or both and can affect multiple systems throughout the body (Kueh, Morris, Borkoles, & Shee, 2015; U.S. Department of Health and Human Services, 2016; American Diabetes Association, 2004). The three types of diabetes are types 1 and 2 and gestational, with type 2 (T2DM) accounting for 95% of cases in adults (U.S. Department of Health and Human Services,

2016). Diabetes has a tremendous impact at both the national and state levels. In South Carolina, more than 450,000 adults live with T2DM, and the mortality rate attributable to T2DM has increased over the last 10 years in SC. One of every five hospitalized patients have diabetes, and one in every 10 emergency room visits in SC is diabetes-related, costing more than \$4.2 billion in 2010 (Heidari, Myers, & Hermayer, 2013).

Diabetes is the seventh leading cause of death nationally but the fifth leading cause of death among African Americans (Heidari, Myers, & Hermayer, 2013). The risk of diabetes is 1.7 times higher among non-Hispanic blacks than non-Hispanic whites (American Diabetes Association, 2015), with 13.2% of non-Hispanic black adults in the United States living with T2DM compared to 7.6% of non-Hispanic white adults (American Diabetes Association, 2015; Center for Disease Control and Prevention, 2014). Diabetes can have a significant influence on quality of life and life expectancy. When compared to non-Hispanic white adults diagnosed with T2DM, African Americans with T2DM are more likely to experience complications from diabetes such as end-stage renal disease, lower extremity amputations, and hypertension (U.S. Department of Health and Human Services, 2016). African Americans also experience a significantly higher death rate and more years of potential life loss than non-Hispanic whites (South Carolina Department of Health and Environmental Control, 2009; U.S. Department of Health and Human Services, 2016). In particular, African American men are both disproportionately affected by T2DM and are an underserved and understudied population (U.S. Department of Health and Human Services, 2018; U.S. Department of Health and Human Services, 2016). In addition, older adults represent one of the fastest growing groups of the diabetic population (Kalyani, Golden, & Cefalu, 2017).

Effective self-management of T2DM can have major benefits, such as improving health on the individual, community, state, and national levels and reducing healthcare costs by delaying/preventing the onset of diabetic retinopathy, amputations, diabetes-related comorbidities, and kidney disease (Funnell, et al., 2011; Funnell, Tang, & Anderson, 2007). The United Kingdom Prospective Diabetes Study Group showed that a 1% reduction in mean HbA1c level was associated with a 21% risk reduction for endpoints related to diabetes overall, a 21% reduction in deaths related to diabetes, a 14% reduction in myocardial infarction, and a 37% reduction in microvascular complications (Stratton, et al., 2000). In most instances, if diabetes is managed appropriately, individuals can lead a relatively normal life (Zimbudzi, et al., 2016). Thus, with the known benefits of effective self-management of T2DM, understanding the knowledge and experiences of older African American men living with T2DM is vital for informing efforts designed to reduce morbidity and mortality and improve quality of life among this group. Further exploration of the self-management strategies of African American men may offer insight on how to reduce diabetes-related complications in this population and improve their quality of life.

Participation in diabetes self-management education programs is a critical component of care for individuals with, and those at risk for, diabetes and for preventing or delaying complications from diabetes (Standards Revision Task Force, 2014; Standards Revisions Task Force, 2017). Although addressing disparities in chronic diseases has been a public health initiative for decades (U.S. Department of Health and Human Services, 2000; U.S. Department of Health and Human Services, 1996), racial

disparities remain in the rate of diabetes, the rate of complications associated with diabetes, and decreased access to health care (American Diabetes Association, 2017).

In attempts to combat these disparities, hospitals and public health entities have implemented diabetes self-management education programs in underserved communities (American Diabetes Association, 2011; U.S. Department of Health and Human Services, 2016). Despite these efforts, the participation of African American men in these programs remains low (Tripp-Reimer, Choi, Kelley, & Enslein, 2001; Collins-McNeil, et al., 2012; Funnell, et al., National standards for diabetes self-management education, 2011; American Diabetes Association, 2017). Development of culturally sensitive diabetes self-management education programs that are relevant for African American men requires an understanding of their perceptions and experiences of living with T2DM (Eakin, Bull, Glasgow, & Mason, 2002; International Diabetes Federation, 2011; U.S. Department of Health and Human Services, 2018; American Diabetes Association, 2017; Sherman, McKyer, Singer, Larke Jr, & Guidry, 2014).

The purpose of this study was to address the following research questions: 1) how do African American men between the ages of 40 and 85 years with T2DM define diabetes; and 2) how do African American men between the ages of 40 and 85 years with T2DM describe their experiences living with diabetes, including their self-management behaviors? By exploring these research questions, it is hoped that additional knowledge will be gained to continue to help improve how African American men self-manage diabetes.

## METHODS

### **Study Setting and Recruitment**

This qualitative study was conducted in the Piedmont area of South Carolina and included participants from Spartanburg, York, Lancaster, and Chester counties. The Piedmont area is one of the most populated areas in the South Carolina Conference of the South Atlantic Episcopal District (SAED). Because many African American men participate in church activities and men's ministry activities, and because faith-based organizations have been successfully used in research to recruit African Americans (Streaty-Wimberly, Braithwaite, & Taylor, 2001; Campbell, et al., 2007), participants for this study were recruited from the SAED of the African Methodist Episcopal Zion (AMEZ) church. Permission to officially recruit members from the South Carolina Conference of the SAED of the AMEZ was granted by the presiding bishop during the 2008-2016 term. The recruitment team was comprised of the primary investigator, local health ministry coordinators, and men's ministry leaders of local AMEZ churches in Rock Hill, SC. The inclusion criteria for participants were: 1) African American men between the ages of 40 and 85 years with, 2) a diagnosis of T2DM, and 3) affiliated with an AMEZ church in the Piedmont area of South Carolina. Local health ministry coordinators and men's ministry leaders identified potential participants from their congregations and communities, and the primary investigator contacted potential participants to schedule participant interviews.



## **Data collection**

In-depth interviews with participants were completed over a six-month period beginning in January 2016. All interviews were conducted either at the participant's home or in the conference room of the participant's church. All participants also provided self-reported demographic information. Before and after the interview period, the investigators engaged in extensive dialog about T2DM and the experiences of African American men with clergy from participating churches, diabetic educators, and healthcare providers that treated African American men with diabetes in several cities in South Carolina between 2014 and 2016. Additional data used in analyses included investigator memos and field notes.

The interview guide for African American men with T2DM (Appendix A) was developed with questions adapted from Stuckey (2013) and organized into three topic areas: personal topics, diabetes self-management, and addressing barriers and factors for success in diabetes self-management. The interview guide was developed specifically to explore the definition of diabetes, the experience of living with diabetes, and self-management behaviors of African American men with T2DM. After interviews were completed and throughout the data analysis process, the primary investigator contacted participants via phone as necessary to gain clarity in their interview statements and verify and affirm that their statements from the interviews were accurate.

## **Data analysis**

Each in-depth interview was transcribed by the primary investigator or a study team member with extensive training in data collection and analysis. The primary investigator re-listened to each interview and corrected the initial transcription draft by comparing it to the audio file. The primary investigator was responsible for the final verification of each transcript.

Data analysis was aided by NVivo 10 software for data management and storage. All interviews, investigator memos, reflections, and field notes were reviewed to inform development of the initial codebook (DePoy & Gitlin, 1998). The codebook development began with coding the first three to five interviews organized in NVivo. After the preliminary codebook was developed, data from each subsequent interview were compared to it. After several interviews were coded and the corresponding information stored in nodes, queries were conducted in NVivo to allow subsets of data to be analyzed, reviewed, and compared.

## **RESULTS**

Twenty-two African American men diagnosed with T2DM participated in this study Table 4.1 shows participant demographic information.

### **Definition of diabetes**

Many of the participants acknowledged that diabetes was a disease that could cause serious health consequences. The participants defined diabetes in several ways but generally had a basic understanding that it was a serious disease (e.g., “bad, nasty

disease”) that affected sugar or glucose levels. One participant described diabetes very vividly:

Table 4.1 Research Study Demographics for African American Men

<b>Participant Characteristics (n=22)</b>	<b>Mean (range) or n (%)</b>
Age (years)	63.8 (47-81)
Education level	
Grade 1-8	1 (4.5)
Grade 9-11	2 (9.1)
High school graduate	5 (22.7)
1-3 years college	5 (22.7)
College graduate	9 (40.9)
Average income	
<\$10K	3 (13.6)
\$10-15K	1 (4.5)
\$20-25K	4 (18.2)
\$25-35K	3 (13.6)
\$50-75K	3 (13.6)
>\$75K	7 (31.8)
Age diagnosed with diabetes (years)	51.4 (31-70)
Duration of illness (years)	12.6 (2-34)
Last doctor’s appointment	
Within past 3 months	17 (77.3)
Between 3-6 months	5 (22.7)
Have health insurance	22 (100)
Self-rated health	
Poor	0 (0)
Fair	8 (36.4)
Good	11 (50.0)
Very Good	3 (13.6)
Excellent	0 (0)
Height (inches)	69.7 (66-75)
Weight (pounds)	218.4 (148-330)
Body mass index (kg/m <sup>2</sup> )	31.0 (21.0-44.0)
Marital Status	
Single	1 (4.5)
Married	14 (63.6)
Widower	1 (4.5)
Divorced	5 (22.7)

“[Diabetes is] a disease that attacks your body, your blood cells, your heart and anything that’s in you...it just attacks you...in a way that’s if not controlled it could...you know, it could just take your life, your limbs, anything...your eyesight and everything. It’s just a bad, nasty disease.”

Another patient stated:

“It means that my body has a concern in glucose management. Be it the resistance to insulin, or just doesn't produce any insulin. So, that my blood doesn't have enough glucose to produce and provide the energy that my body organs needs to provide comfortable quality of life, and what I mean by that is energy, and also not being nervous and not being sleepy and things of that nature.”

### **Experiences living with diabetes**

Participants’ descriptions of their experiences living with T2DM included initial reactions when first being diagnosed, emotional experiences, general perspectives on diabetes, and perceptions of their healthcare providers.

*Initial reaction:* Participants’ initial reactions when they were diagnosed with diabetes covered a wide spectrum. Anger, disbelief, shock, and denial were common reactions, as represented in statements such as “I was like this can't be. This can't be real” and “I was shocked.” Some participants expressed feelings of anger, with one participant saying:

“I was angry. I was very angry because especially when I discovered how close I was to death. I was very angry. I was angry with myself after I discovered that what I thought I was doing right, eating right and so forth in this sort of thing was the cause of some of my issues with my health.”

Many of the participants expressed and explained feelings of fear or concern when they found out that they had diabetes. One participant said:

“[It was] scary, scary...that sh#! [diabetes] was up there...that sh#! [glucose level] was up there. I was dizzy as heck.”

Another said:

“Well, I think it made me feel concerned. We have had that type of situation in my family you know. My great grandmother...I used to give her injections when I was growing up. So, I knew about diabetes, and I knew what you can do, the symptoms and also the effect that it has on the human body, and I knew that...I must take care [of myself] if I want to have a good quality of life, and I definitely want to have that as long as I can.”

*Emotional experiences of living with diabetes:* Participants expressed various emotions about living with and managing diabetes, including apathy, shame and guilt, fatalism, fear, denial, and avoidance. When explaining why he did not adhere to taking medication and checking glucose levels, one participant stated:

“...it's like I guess for me it's like a lot of things you just choose to ignore stuff until it just gets to a time where you got to do something about it.”

Some participants expressed guilt and shame, believing they were at fault for acquiring diabetes or there was something they could have done to prevent it. One participant felt guilty because his weight might have contributed to his diabetic condition:

“You know you feel bad, and you go to the doctor and doctor tells you, you're borderline. You know I always been a heavy guy, and say if you lose a little weight, you can control it and get rid of it.”

Only one participant reported using an insulin pump. He expressed shame and a need to explain to others why he uses the pump:

“...and then, what I found out from people when they find out that I do have the pump, they say, oh I didn’t know your diabetes is that bad. Well, I am like you don’t understand, this is a better way for me to manage my diabetes.”

Many participants expressed fatalism. They felt that acquiring diabetes was inevitable because it is hereditary and that they were going to get diabetes regardless of what they did. One participant iterated:

“...but, uh, it runs in my family, so I just guess it wasn’t no way around it...hereditary I guess. I guess some people don’t believe that, but, you know, if it runs in your family, 9 times out of 10 you going to get it anyway.”

One participant had a very vivid, firsthand experience of how devastating diabetes could be because he had witnessed a friend having all four extremities amputated:

“I had a church member and friend, who had diabetes so bad that he had to have all of his limbs cut off. All four of his limbs over a few years! This made me feel really bad. He was my friend. He passed away a few years ago.”

Most of the participants expressed having a fear of needles. One participant explained his fear of needles by stating:

“I can’t stand needles. People can give me shots, and that is well and fine, but I had to witness my dad take insulin shots and stuff like that, and I don’t want to have to do that.”

Although many participants expressed that they had their diabetes “under control,” a few described a fear of serious health complications, such as diabetic comas. One participant described his fear in the following manner:

“Yeah, [I] can go into hypoglycemia or whatever you call it, and you get to shaking and sweating...happened to me. Almost, got me yesterday...I hadn’t eaten breakfast and you know, and we were gone a long time [shopping with wife]...and I felt my sugar dropping on me...you can feel it coming on me.”

Although many participants acknowledged their concern at the possibility of serious health complications, some participants noted a fear of dying from diabetes, with one participant stating:

“Oh yes, we have had people with diabetic comas...people die because of being diabetic, cannot maintain glucose... it will kill you...and I like to be around for a while until the Lord calls me home.”

Some participants conveyed a sense of denial when they received a diagnosis of diabetes. Some participants were apprehensive about the diagnosis of pre-diabetes or borderline diabetes:

“Well, I mean the fact that I was told...I was first told that I was borderline diabetic. I mean through my such thinking, there is no such thing as borderline diabetic...either you are or aren’t.”

Although all of the participants were very willing to speak about their diabetic condition in the interview process, some participants avoided this topic in their daily life:

“Well, I really haven’t talked to nobody like that. Well, no, no, no. To sit down and talk about something like that [diabetes], no.”

*General perspective on diabetes:* Participants had a wide range of general views about diabetes. Some participants indicated that they had been cured or were no longer diabetic and that they had reached a point where they no longer had to take medication. The concept of convenience was a common theme among participants, and many participants reported that managing diabetes could be time consuming:

“The obstacle I had... I worked so they wanted to do it during the week, and I couldn't make it during the week. So, we had uh...they had a program that was going on Saturdays and it was in [name of town]. So, being that they had that flexibility that helped me to make my meetings. So, I schedule, did my meetings on Saturdays.”

*Participant perceptions of healthcare providers:* Participants expressed different opinions of their healthcare providers. Either they had a great deal of respect for their healthcare providers or they espoused feelings of distrust, but the majority were pleased with the care and services provided. A few participants reported feelings of skepticism about having to take medications and wondered why they had to take medication because, as one participant stated, “I don't feel like I have it [diabetes].” A few participants perceived the care and information they received from their healthcare providers as inadequate. They felt as if they had been misdiagnosed with diabetes and were taking medication for no reason. One participant conveyed that some African Americans are diagnosed with diabetes when they do not have the disease:

“Why do doctors try to diagnose black Americans with diabetes when they don't have it? My mother and one of my brothers...she was up in the hospital. I forgot what she was up there for. I think, one of them doctors, my sister said...tried to



diagnose her with diabetes and was wanting to put her on medication for diabetes. My sister happened to be up there, and she wouldn't let them do it. So, when she got out, my sister carried her to her family doctor, and he checked her and said he did not see any trace of diabetes in her blood.”

Similarly, a few participants expressed concerns of treatments for diabetes not being geared towards African Americans:

“...and I guess I've been concerned that each doctor seems to...did not have a magic bullet of how to treat the actual problem that I had. Everybody tried different things, and I'm not sure if it's because of in the black race...since medications are not typically geared towards Afro-Americans specifically in clinical trials that they really [do not] have a handle on what is necessary...you know to treat Afro-Americans relevant to, in my opinion, for diabetes”

In addition, some participants believed that they could be cured:

“I'm off [medication]. I did the exercise and lost weight and so my numbers went back down by going through the education process and doing whatever they said. I got away from diabetes. I'm not...I'm not diabetic no more.”

Although a few participants expressed distrust in their healthcare providers, the majority had a great deal of respect for their providers. One participant described his admiration for his healthcare provider in the following manner:

“I have a great relationship with my doctor, great relationship. I had to begin to develop issues about my sex life. I had no problems going to him. He helped guide me through that with medication, in fact, two boxes I got in my house, two boxes, and I haven't used them, I didn't take it.”

Many of the participants developed cordial relationships with their healthcare providers and appreciated their patient-healthcare provider relationship:

“My doctor... I wouldn't take nothing for my doctor. He, he, he my doctor he's straight up with me. He told me look, ‘If you don't do this you are going to die. If you want to live, this is what you have to do, if you not going on dialysis, it's up to you.’ He's...he's a real straight-up type of guy I like. Ok, I'm [the doctor] telling you what you got to do and that's it. You know. It is up to you. So, he holds no punches”

Many participants spoke very highly of their healthcare providers, but one participant acknowledged a special bond that he developed with his provider because his provider took the time to explain results and give him a call:

“...both of them [his doctors] would be an “A” because first of all, Dr. [name], would call me. You know, when my numbers were actually out of whack. I mean I get my blood sugar done. I get my blood work done every three months or so, and we actually sit and explain everything to me. And then, when [I] went to the specialist, they actually sat [down with me]. You know it wasn't a typical fifteen minutes. I mean, I would be with [name] for an hour. You know. I would be with them up to like thirty minutes. And she was going over everything was going over my numbers you know. All my blood work. You know them giving me the tools and everything and taking the time and explaining everything to me. So, that's why I gave them an ‘A’.”

## **Participant diabetes self-management techniques**

There were many factors that influenced how participants managed their diabetes, and different barriers seemed to be integrated into their diabetes self-managing strategies. Participants expressed that they managed to live with diabetes by finding ways to afford diabetes self-management, trying to achieve good health and wellness, and relying on family support. Participants also discussed their opinions on diabetes self-management classes.

*The cost of managing diabetes can be high:* Diabetes tests strips, glucose monitors, medication, medical appointments, and travel cost to get to appointments all factor into the financial responsibility of managing diabetes. Many participants discussed this financial aspect, with some acknowledging that managing diabetes was costly and describing having to find ways to pay for medications and test strips:

“I had doctors who actually helped me out as far as giving me like the free things. Like right now on my Invokana, I mean for the last three years, I mean it's been free because I come in like a trial. And, so my doctors keep giving me [samples] like these.”

The cost of test strips sometimes influenced participants' consistency in monitoring their glucose levels:

“...and, by checking every two hours, most people don't check every two hours because of expense of buying those hah, buying that kit [laughing]...it is [covered by insurance] but it's still expensive. So, by using that tool, I can see where I am at and what I'm eating.”

The one participant that had an insulin pump said that it was convenient for him but very expensive:

“...for me last year, I spent ten thousand dollars but...yes, because with my pump...the pump and co-pays, and the medication. You know, once I hit my co-pay, I was good. But, my co-pay on three months’ supply of insulin...now, is like two hundred dollars for three-month supplies. So, if you look at that times say what? Four?”

Although all of the participants in this study reported that they had insurance and had been to their doctor within the past six months, they expressed that lack of money or insurance could be a factor that keeps other African American men from going to the doctor:

“They [African American men with diabetes] may not have the money, to go get tested. You know sometimes we put off going to the doctor because we don't have that green stuff to go pay them.”

Another participant expressed his concerns about a friend who has diabetes but no insurance:

“I got a friend...he had insurance, but now he doesn't have insurance [now], he's skeptical about going to the doctor because of the high cost of medicine and doctor bills.”

Some participants expressed how fortunate they were to have insurance to help with the cost of managing their diabetes:

“I mean it's a good thing I had insurance...you know with my company. You know I think one of the biggest things that probably would stop the

persons...from really taking care of their diabetes as, far as not getting the right knowledge or anything, is the cost. It is a very expensive disease. Very expensive [chuckle].”

To manage diabetes properly, it is recommended that diabetic individuals maintain a consistent regimen of glucose monitoring and medication adherence. A few participants were very consistent and detailed with monitoring their glucose and taking their medication:

“Pretty much a set routine within a certain range of plus or minus an hour because you know...like I said, in the morning I get up and do this. At lunchtime, I do this. Before dinner, I do this. Before going to bed, I do this. It's just a routine every day that I started so that I can have this data. It is just like if you were running a reaction to create a medication in a chemical plant. There's a protocol that you have to follow. And if you don't follow that protocol the same every time, you're not going to produce the same medication. So, if I don't if I don't do the same protocol with a plus and minus, I am not going to have good information to chart and understand where I am in diabetes management.”

Conversely, some participants did not see the importance of these self-management techniques. One participant indicated that he was not consistent in monitoring his glucose and felt that it was a waste of time to manage his condition:

“...and, you you're just poking yourself [and your] finger twice a day ain't gonna do nothing about it anyway. I'm taking my medication. If I ain't doing nothing stupid, I should be alright...I start getting some symptoms that are out of the way,

of course I'll check it, but, not every day for two times a day. I think that's a waste of time."

*Nutrition and exercise:* The importance of nutrition, diet, and exercise was a consistent theme with most participants. Trying to adhere to healthy habits such as proper nutrition and exercise was very challenging for many. Many participants mentioned that they had poor dietary habits, had to change their diets after being diagnosed with diabetes, implemented a portion-control system with meals, and had "holiday diets" and "go-to" foods or snacks for when their glucose levels were low. Nearly all participants viewed exercise as important, but few exercised on a regular basis. Although they realized the importance of nutrition, some participants reported poor dieting habits that were difficult to break. One individual, who prided himself on being disciplined, revealed:

"Let me say this. I'm proud military. I was in the United States Air Force, and before then back in the day, we ate basically what we wanted to eat. What was cooked at home. I'm from the old school, pinto beans, black eye peas, squash, and green beans, corn bread, and fatback. You know we raised our own hogs and killed them and took the cows to the slaughterhouse, to be slaughtered. So, we basically didn't have no idea that one day this would cause us to be diabetic and it runs in my family a little bit also."

Another participant indicated that he would overindulge in drinking juices and eating popsicles:

"Gatorade, apple juice, grape juice and you know a lot of these have a lot of sugar. And I was eating these doggone popsicles. I used to love these little

popsicles. I'd take four of them with me every time I sit down and eat all four of them...three or four times you know an evening. So, I go through twelve thirteen of them, you know an evening. And, basically, they're all sugars. So basically, basically feeding this monster more and more and more. And I didn't realize it, so I once I cut all of that out and went down to drinking just water and using the pills that they gave me that time and it brought it down considerably.”

The majority of the participants realized that they had to change their diets to manage their diabetes. One patient compared his previous diet habits to his current diet:

“[Now] I get up and eat breakfast. Well, now you know an egg, a slice of toast and some coffee [Chuckles when explaining what his breakfast used to consist of] Man! Grits, bacon and everything...the whole works! Yeah, you know, but kind of slowed down on that stuff man. I mean grits and eggs, all that is good but you can't eat the whole pot.”

Many of the participants mentioned that portion control was an important component in managing their diabetes. They stated that this was one of the main things mentioned in the diabetes education classes and by their healthcare providers:

“So, basically the whole idea was that they'd rather see me eating smaller portions more often during the course of a day because, say again, if I am eating correctly there is no more than 3 or 3 and a ½ hours in between eating that you should have something to eat.”

Another participant expressed that he had to change his diet:

“Ok, I stopped eating a lot of my stuff [chuckle]. Um, I stopped eating sausage, I stopped eating bacon, and...uh, I stop eating. Now, I ate it today, but I stopped

eating fast food. I don't know how that affects that. And, I look at everything now like my sugar content. Stuff like that. No ice cream. I eat sorbet.”

A few participants mentioned that they experienced moments in which their glucose levels were out of control and resulted in unsafe situations:

“I brought that on myself. You know I told you that I take insulin before I go to bed at night. And I take two kinds of insulin, I take Humalog which is a fast-acting insulin and I take Lantus which is was a slow acting and I accidentally to a took a dose of Humalog thinking that I had taken Lantus, and that put me into a coma...The family had to call 911; I had to go to the hospital... Three days.”

Another participant mentioned that he fell in the yard after his glucose level went too low:

“If its low [or]going low, I can tell when it’s going to do that you can’t see. It deals with your eyes, and then it off balances you. You can’t walk, and you going to fall because I stayed out there yesterday too long, and I fell before I got back in the house.”

Many participants revealed that they had “go-to” foods to manage hypoglycemia or moments where they felt their glucose levels were out of control:

“I would have to say peanut butter. You know it gives you proteins as well as it releases calories at a very low rate, and if I want to do it [raise glucose levels] instantly, I take an orange juice or something like that.”

Many participants indicated that that they knew the benefits of maintaining proper dieting habits but had many reasons for not adhering to the proper diets:



“You know, I knew it was going to be a little high because I was eating. You know Halloween. There was Thanksgiving. There was Christmas. There’s was you know Veterans’ Day, holidays period [He chuckles. Participant is in military]. I knew I was eating little bit. You know, but you know, we must have had probably 5 pot lucks at work. So, I hadn't been going to the gym regularly during that period. So, I knew I was there a little bit [high glucose level], but I didn't know it was going to be that much.”

As with dieting, all participants indicated that they knew the benefits of exercise, but only a few exercised on a regular basis. One patient described his challenges with exercising:

“It's kind of hard to exercise, but you know your mind wants to, but your body is weak...but your mind wants to but you can't. So, you have to kind of discipline yourself to do those things.”

Another individual expressed his desires to exercise:

“You know, I need to do more exercise and stuff like that. “

One participant described his eating and exercise habits in the following manner:

“I could do a much better job of managing. I mean you know in terms of what I eat and exercising. Since I've retired, especially, you know I have gained weight which you know doesn't help anything. Uh, although, I tend to pay attention, I could do a much better job than what I'm doing. You know in terms of eating and exercising especially. “

Although technology in monitoring diabetes is becoming more prevalent, only a couple of participants relied on such tools to manage their diabetes. Only one participant used a

pump, and he noted that it helps him socially and with the management of his diabetes, and it keeps him from having to use needles:

“So, with the pump, I don't have to do that [give injections] because I don't mind you seeing it [because it] looks like a pager. You know, and I just can put in and check my blood sugar, and I can put in how much I'm going to eat. It does calculations for me and make the adjustments. And, its gonna keep me in my range.”

There was only one participant, a chemical engineer, who plotted his glucose readings and had them monitored by a software program at his medical office:

“I do it [monitor glucose levels] on a chart... I monitor it. I plot it... put it down on the chart. My unit [monitor] for glucose has a program on it for glucose levels. And it tells you... ask you what time of day it is... it tells you is it before breakfast? After breakfast? Before exercise? After exercising? I chart it that way, but for my blood pressure. I do it manually.”

*Family support and managing diabetes:* The majority of participants indicated that they had family support in managing their diabetes, for example, in helping with meal preparation and encouragement. The participants reported that their wives gave the most assistance in managing their diabetes. One participant described managing his diabetes by highlighting the teamwork between himself and his wife, who is also diabetic:

“Well, you know by working together means... You both [are] trying to stay on top of it. It that means you won't be neglecting yourself because you've got to, you

know, help each other and that means that you maintain yourself as well as maintaining hers too...you helping her with hers.”

Although the participants’ wives were important, other family members and healthcare providers helped keep the participants accountable in their diabetes management:

“My family helps keep me on track. My doctors keep me on track...So, I have a lot of people keeping me constantly aware that I need to do a better job of managing my diabetes.”

*Diabetes self-management classes:* The participants had varying opinions on diabetes self-management education classes. Many participants expressed that although they felt the classes were informative, they were too long:

“I think they [diabetes self-management education classes] have some good information on some of [diabetes] you know. It's just time consuming... I think...the nutrition programs are good, some had some nutritional programs that tell you what you can eat, when you eat, and how much. Too long...you had to go to so many of them...it was kind of like a repetition type thing. It, it, got boring...and I'm the type person you know...I don't feel like I need to be preached to.”

## DISCUSSION

Diabetes is a significantly growing public health issue that affects all races and ethnicities and places a tremendous burden on our healthcare systems, but it has affected the African American community disproportionately (U.S. Department of Health and Human Services, 2016; U.S. Department of Health and Human Services, 2018). Thus, it is important to study this underserved population to gain further insight on how African

Americans with diabetes define and describe their condition, their lived experiences and self-management strategies of diabetes, their opinions of their healthcare providers, and their feelings about diabetes self-management education. Individuals living with diabetes face many challenges, including comorbidities and adjusting to a multitude of diabetes self-management issues that can be improved with a greater understanding of their lived experiences and self-management behaviors.

Historically there has been relatively little research aimed specifically at African American men with T2DM, but over the last decade research has increased in exploring the lived experiences of this population (Jack, Jr. L. , 2004; Sherman, McKyer, Singer, Larke Jr, & Guidry, 2014; Marshall, Jr., 2005; Balls-Berry, et al., 2015). In this study, participants defined diabetes in several ways, but most believed that it was a serious disease that had a significant impact on the body. Generally, the participants had a basic understanding that diabetes is something that affects their “sugar” or glucose levels. Consistent with previous research (Sherman, McKyer, Singer, Larke Jr, & Guidry, 2014), most of the participants also described health complications related to diabetes, such as limb amputations and kidney disease, and stated that if they did not properly manage their diabetic condition, it could cause further health issues. Although participants were aware of these possible complications, the results did not show that participants linked these consequences to reasons behind diabetes self-management behaviors. However, Newsom et al. (2012) studied patterns of behavior change following diagnosis and showed that the majority of individuals diagnosed with a new chronic condition do not adopt healthier behaviors and do not show any significant increases in exercise for any health condition.

In describing their emotional experiences living with diabetes, participants spoke of their initial reactions when they were first diagnosed with diabetes, their emotional experiences living with diabetes, and their general perspective on diabetes. Participants expressed various emotions when they were initially diagnosed, including apathy, shame and guilt, fatalism, fear, denial, and avoidance. Participants who described feeling apathy tended to think they did not truly have diabetes, and so there was no need to manage a condition they did not have. Participants that felt shame and guilt indicated that if they had taken better care of themselves, they would not have diabetes. Fatalism was also described by some participants as the belief that because of their genetics, they were predestined to get diabetes regardless of what they might do to prevent it. Participants expressing denial described similar feelings to those who felt apathy, stating that they did not have any symptoms of diabetes, even though they had been diagnosed with the condition. Fear was prevalent among all participants, including fear of needles, fear of losing limbs, and even fear of not being around to see their children and grandchildren accomplish dreams.

Although participants revealed various emotions during their initial reaction to being diagnosed with diabetes, depression, which is prominently discussed in the literature (Xiang, 2016; Ward & Mengesha, 2013), was not mentioned or discussed by any participants. However, this is fairly consistent with most literature noting that African American men do not utilize mental health services. Xiang (2016) concludes that diagnosis of a chronic illness may present the healthcare practitioner with a teachable moment for behavior change, but the behavior-changing effect may be smaller with individuals with major depression. This may have a greater effect in the African

American community because African American men face a number of risk factors related to depression, but evidence suggests that these individuals do not use mental health services (Ward & Mengesha, 2013). However, if there is undetected depression that accompanies the diagnosis of diabetes, diabetes self-management strategies may have to be altered to address multiple needs.

Among some of the issues revealed when participants described their general perspective on living with diabetes was the revelation that many did not share their diagnosis with others, and for many, this research study was the first time that they openly discussed their condition. When discussing diabetes, men have a tendency to be more private than women (Mathew, Gucciardi, De Melo, & Paula, 2012). A few of the participants stated that they could be cured of diabetes with proper exercise and medication, and one participant adamantly stated that he had been cured. Participants expressed a wide range of opinions about their healthcare providers, with most stating that they had a good relationship with their providers and appreciated their role. However, a few participants expressed distrust and felt as if their healthcare provider did not spend adequate time with them, and some participants described receiving a diagnosis of diabetes without any explanation. One participant wondered whether medications to treat diabetes are effective for African Americans.

Most of the participants felt that they could successfully self-manage their diabetes and generally did not report trouble in taking their medications. In previous studies, individuals with T2DM often alluded to their struggles managing diabetes (Jack, Jr. L., Diabetes and men's health issues, 2004). Although many participants in this study did allude to missing scheduled medication times, not taking insulin regularly, or

improper dieting, they did not see this as a “struggle.” This could possibly compound issues with self-managing their diabetes in that diabetes not managed appropriately in the initial stages after diagnosis may lead to onset and progression of diabetes-related complications. Participants varied in how they self-managed their condition, with some very strictly and precisely managing their diabetes via computer programs, charts, and devices that reported to their physician’s office. Others were inconsistent and regularly and knowingly skipped daily glucose checks and medications because of cost, hesitancy to prick fingers, and simply forgetting. Although all participants reported that they had insurance, most of them reported that their diabetes self-management techniques were influenced by the cost of supplies such as test strips, glucose monitoring devices, and doctor’s visits. Many of the participants reported that they either had friends or knew individuals that had no insurance and were thus not able to go to the doctor or get medication.

All participants acknowledged the importance of proper nutrition and exercise in controlling and preventing diabetes, but only a few said that they had an intentional physical activity program or adhered to a proper diabetic diet. Participants struggled with giving up foods they like; for example, one participant had difficulty giving up “freezies” (popsicles) and red velvet cake, and another had a problem giving up fried foods even though acknowledged that eating such foods could be counterproductive in self-managing their condition.

This study is consistent with previous research in that participants reported family support as being either positive (supportive) or negative (nagging). Previous studies have shown that family support has an influence on the self-management of diabetes. Family

support can have a positive influence by increasing a patient's self-esteem and encouraging optimism (DiMatteo, 2004). Although this type of positive or instrumental family support can help the patient manage his or her diabetes, obstructive family support can have negative consequences (Mayberry, Harper, & Osborn, 2016). Indeed, reporting more obstructive behaviors by family members is associated with less adherence-related motivation and self-efficacy (Cardenas, Vallbona, Baker, & Yusim, 1987; Pamungjas, Chamroonsawasdi, & Vatanasomboon, 2017). Therefore, nagging, or obstructive support, can have a negative influence on individuals that self-manage their diabetic condition.

Although participants in this study reported having family support, it varied in forms and frequency, with the majority of participants reporting positive family support, including the majority of married participants. For example, one married couple relied on encouraging each other to take medications, attend doctor's appointments, and remaining physically active. However, some patients who reported positive family support still did not adhere to proper diabetes self-management strategies. One participant noted that his wife was upset with him because he became dizzy and fell in the yard because he was not taking his medication properly.

African American families with low socioeconomic status managing diabetes can often experience both supportive and obstructive support from the same individual (Mayberry, Harper, & Osborn, 2016). However, in this study, the majority of the family support was supportive and came from the participant's wife or significant other. An important factor that may have influenced these reports of positive support might have been that that 45.4 % of participants reported an income over \$50,000, and 63.6 %



attended at least one year of college. Thus, their socioeconomic status is significantly higher than that of the participants reported in Mayberry, Harper, and Osborn (2016).

Most of the participants believed that they could benefit from diabetes education classes, but participants' opinions varied on the best setting for these classes, i.e., individual versus group setting. Participants also believed that diabetes education classes were inconvenient with respect to time and location, consistent with previous research (Gucciardi, DeMelo, Offenheim, & Stewart, 2008). However, a few stated that if the classes were incorporated into their workplace, attending would be easier. A few participants said that they thought diabetes self-management classes were boring. One participant stated that he would not attend a diabetes self-management class because he was still not convinced that he had diabetes. Most participants reported that portion control and proper dieting were heavily enforced in the diabetes self-education classes.

*Strengths and limitations:* The limitations of this study included restrictions on the inclusion criteria, potential research bias, and limited generalizability to a larger population. The inclusion criteria—African American men with T2DM between age 40 and 85 years and affiliated with the SAED of the AMEZ church—restricted the participants to a specific population and geographic region of South Carolina. The selection criteria were purposeful and did not allow for the exploration of diabetes in other ethnicities, age groups, genders, or geographic regions. However, limiting the study to African American men with T2DM was necessary to explore their definitions of diabetes, specific lived experiences with diabetes, opinions on diabetes self-management strategies, and perceptions of diabetes self-management classes in this underserved and

understudied population. As with most research, potential research bias is present in all stages of research (Pannucci & Wilkins, 2010; Smith & Noble, 2014).

There were several strengths to this study. Although qualitative research may not be generalizable to a larger population, it allows for exploration of in-depth thoughts and feelings of the research participants, which can allow for an understanding of the lived experiences of a particular population or group (Sutton & Austin, 2015). This study allowed for African American men with T2DM to express their experiences living with diabetes and their motivations to self-manage diabetes and attend diabetes self-management classes. Additional strengths of this study were the initial dialog between the primary investigator and the health ministry leaders, in-depth interviews in a comfortable environment, and information gathered from an underserved and understudied population.

Many studies have indicated that there is a benefit in peer and community informants in reaching at-risk populations (Eakin, Bull, Glasgow, & Mason, 2002; Sarkisian, Brown, Norris, & Mangione, 2003; Sokol & Fisher, 2016; Fisher, et al., 2017). The initial dialog between the primary investigator and the health ministry leaders was important for establishing the relationship that led to participant recruitment because the health ministry leaders were trusted by their congregants, and were thus, more effective at recruiting participants. Conducting interviews in a comfortable setting of the participant's choice reduced the opportunity for external interference and provided a place of familiarity for the participant.

*Implications of the study:* African American men with T2DM comprise an understudied and underserved population, and it is important to gain access to this

population to explore their definition of diabetes, their experiences living with diabetes, their opinions of their healthcare providers, and their diabetes self-management strategies. Exploring this population will continue to add to the existing literature about the experiences of African American men living with diabetes and the ways they self-manage their condition.

As with some previous research, recruitment of African American men (Spence & Oltmanns, 2011; Ledric & McKyer, 2015) for this study was not productive initially. Once the participants realized the purpose of the study and understood that their participation could help other African American men, they began to tell others about the study. Although this only occurred on an individual basis, this type of study could lead to greater dialog between individuals with T2DM or diabetes support or education groups among these men, which promote not only discussion of diabetes self-management behaviors but possibly expand to prevention strategies as well. Furthermore, although there seem to be initiatives for research in the university or academia setting, continuing to develop community initiatives important among understudied populations such as African American men.

Results of the study indicated that the African American men with T2DM who participated knew the consequences of having diabetes. However, there seemed to be a disconnect between the seriousness of the consequences of the disease and importance of diabetes self-management. Because this study had a supportive faith-based setting (SAED of the AMEZ church), there may be opportunities to introduce recommendations and implement information campaigns about the importance of managing diabetes in this setting. This information campaign could include consistent and intentional

announcements at church-related events from the leadership of global and national religious denominations to the local the health ministry leaders. This campaign could also include establishment of social media agendas and possible creation of grassroots movements and health initiative movements with health and men's ministries in South Carolina.

Future research should continue to explore the best ways to reach this population and focus on the best strategies to improve their diabetes self-management while also promoting prevention. Implementing effective programs to disseminate information on free diabetes clinics and services could also benefit non-insured individuals with diabetes. Additionally, further exploration of ways to improve and promote a positive relationship between African American men with T2DM and their healthcare providers may also help in improving diabetes self-management strategies.

## CONCLUSION

Individuals living with diabetes face many daily challenges, including strategies to cope with their emotions about having diabetes, associated health concerns, diabetes management (including cost, family support, and lifestyle changes), and possible declines in quality of life. Diabetes affects racial and ethnic minorities disproportionately, and disparities in healthcare quality and access are issues of concern that contribute to many African Americans not seeking appropriate care to manage their diabetes. African American men are an underserved population in research and working to understand the issues that they face when living with diabetes can have major implications in implementing new and effective strategies to help with diabetes self-management among this population. The findings of this study can be used to supplement data indicating a

need for continued research in further understanding African American men living with T2DM.

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4.2 EXPLORATION OF MOTIVATIONS AMONG AFRICAN AMERICAN MEN  
AND PERCEPTIONS OF HEALTHCARE PROVIDERS REGARDING  
MANAGEMENT OF TYPE 2 DIABETES USING SELF-DETERMINATION  
THEORY AS A<sup>2</sup> FRAMEWORK

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<sup>2</sup>Walker, A.Q., Blake, C., Watkins, K., Wilcox, S. and Moore, J. To be submitted

## ABSTRACT

**BACKGROUND:** Diabetes disproportionately affects minority groups and can have deleterious effects on an individual's quality of life. Managed appropriately, individuals with diabetes can reduce the risk of associated health complications and comorbidities and improve their health and quality of life. Gaining a perspective on how African American men and healthcare providers view motivations for managing T2DM is critical in improving and targeting effective diabetes management strategies.

**OBJECTIVE:** The purpose of this study was to explore motivations to self-manage T2DM in African American men between the ages of 40 and 85 years using Self-Determination Theory as a framework and understand the factors that they and their healthcare providers believe influence motivations to manage diabetes and attend diabetes self-management education classes.

**METHODS:** In-depth interviews were conducted with African American men (n=22) between the ages of 40 and 85 with T2DM and healthcare providers (n=6). Interview questions focused on participants' definitions of diabetes and motivation, how they manage their diabetes, and their motivation to manage diabetes and attend diabetes self-management classes. Healthcare provider interviews focused on their role in African American men's diabetes management and their opinion of what motivates these men to manage their diabetes. Interviews were transcribed verbatim, and NVivo 10 was used for data storage and management. Data were analyzed using thematic analysis and an emergent coding technique.

**RESULTS:** Participants stated that they knew appropriate strategies to manage their diabetes, such as monitoring their diet, exercising, and checking glucose levels. However,



most admitted that they did not consistently practice those strategies. Participants defined motivation in various ways, but overall definitions included, "to achieve something without external pushing", or having "drive", or a "goal." Most participants described family or children as their primary motivation for diabetes management. None of the patients expressed true intrinsic motivation, such as doing it for joy, for their diabetes management. Two participants were amotivated, in that they did not care about managing their diabetes, and most had extrinsic motivation, e.g., family or not wanting to have to deal with needles or finger pricks. Most healthcare providers viewed their role as a "cheerleader," "coach," "role model," or "lifestyle changer." Healthcare providers described using fear tactics to motivate participants to manage their diabetes, such as making them aware of possible erectile dysfunction or other comorbidities. Healthcare providers believed that participants would be more motivated to attend diabetes management classes if the classes were more interesting, convenient, involved family, cost less/were free, empowered individuals, and were culturally sensitive. Healthcare providers also believed that being able to spend more time with diabetic patients would be helpful.

**CONCLUSION:** For individuals with T2DM, managing diabetes is critical to improving quality of life and decreasing healthcare costs and medical visits. Understanding the motivations for managing diabetes in African American men, the types of motivation they exhibit, what healthcare providers believe motivates them to manage diabetes, and strategies to improve attendance at diabetes self-management education programs can assist in designing and improving these important programs.

## BACKGROUND

Diabetes mellitus is a chronic disease that currently affects the US population at epidemic levels, and the effects of diabetes continue to be a major healthcare concern nationally and globally (WHO, 2016). Some of the primary risk factors for T2DM are being overweight, decreased physical activity, age over 45, and having a familial history of diabetes (U.S. Department of Health and Human Services, 2016). As with many chronic diseases, diabetes disproportionately affects racial and ethnic minorities. Many initiatives to decrease healthcare disparities and improve accessibility to diabetes care have attempted to address this issue in the US (U.S. Department of Health and Human Services, 2012; U.S. Department of Health and Human Services, 2016), but African American men remain an understudied population (U.S. Department of Health and Human Services, 2018; Sherman & J.McKyer, 2015), with little existing research on what motivates them to manage their diabetes.

Diabetes Self-Management Education (DSME) programs are designed to provide participants with knowledge and skills for diabetes self-management. Such programs address the needs, goals, and life experiences of the individual with diabetes. DSME programs are guided by evidence-based standards, aiming to support informed decision-making, self-care behaviors, problem solving, and active collaboration with the healthcare team to improve clinical outcomes, health status, and quality of life (Funnell, et al., 2011; Standards Revisions Task Force, 2017). DSME programs can help individuals with diabetes improve their health outcomes (American Diabetes Association, 2017; Funnell & Piatt, 2017), and having culturally sensitive and appropriate programs is

vital to improving diabetic education strategies among high-risk populations, including African American men (Collins-McNeil, et al., 2012).

Using 2000-2010 age-adjusted data, African Americans' participation in DSME programs was 57.8%, which is between the rates seen in European Americans (58.7%) and Hispanics (45.8%) (Centers for Disease Control and Prevention, 2014). Although the percentage of African American men ever attending a DSME program is slightly lower than that of European Americans, it remains important to study ways to improve DSME program attendance among all racial and ethnic minorities.

It is of particular importance to improve DSME program participation rates among African American men. Although some previous studies have addressed the lived experiences of African American men with T2DM, there has been very limited research on the motivations of these men regarding self-management of their diabetes and attendance at DSME classes. In addition, little work has explored the perceptions of both African American men with T2DM and healthcare providers regarding the role of the healthcare provider in assisting with T2DM self-management and reasons behind the success or failure of self-management techniques, including attendance at DSME classes. To increase participation in DSME programs, it is important for healthcare providers who treat African American men with T2DM to understand motivations behind attending or not attending DSME programs. Such insights may lead to more effective and targeted interventions that improve participation rates of African American men in DSME programs that are designed to address specific areas to improve diabetes self-management strategies.

Self-Determination Theory (SDT) (Deci & Ryan, 1985) specifically addresses distinct types of motivation, such as intrinsic motivation versus extrinsic motivation, and underlying constructs that might influence motivation. SDT (Deci & Ryan, 1985) has been used since the mid-1980s to study motivation in many areas, including physical activity, tobacco cessation, and obesity (Deci & Ryan, 2008). SDT is based on the concept that humans have innate psychological needs for autonomy, competence, and relatedness and contends that behavioral regulation towards an activity can be amotivated, extrinsically motivated, or intrinsically motivated (1985).

According to Deci and Ryan, amotivation is the state of lacking the intention to act, and when amotivated, people either do not act at all or act without intent. Extrinsic motivation is doing something because it leads to a separable outcome. Intrinsic motivation is the performance of an activity for its inherent satisfactions rather than for some separable consequence, in other words, doing something because it is inherently interesting or enjoyable (Ryan and Deci 2000). Understanding the motivations and types of motivation of African American men related to diabetes self-management and attending diabetes self-management classes is important in tailoring DSME programs to address their specific modes and areas of motivation. By exploring these factors, interventions to improve diabetes self-management strategies and DSME program attendance can be implemented based on what motivates African American men.

It is also important to understand the relationship between individuals with diabetes and their healthcare providers, as these relationships can affect patients' motivation and practices in managing their diabetes. As the primary gatekeepers to the healthcare systems, healthcare providers have a critical role in motivating, encouraging,

and assisting individuals with T2DM. However, there has been a history of distrust and apprehensiveness among African Americans in previous research initiatives, due in large part to such events as the Tuskegee syphilis experiment and the Charleston drug testing for prenatal mothers (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Freimuth, et al., 2001; Sankare', et al., 2015; Paul-Emile, 1989). Thus, having a positive and trusting relationship with a healthcare provider could provide a patient with increased confidence in his or her ability to manage a diabetic condition. Understanding what healthcare providers and African American men perceive as the healthcare provider's desired role could allow for further strategies to approach African American men with T2DM to improve their outcomes in self-managing their diabetes.

This study addressed six specific research questions. 1) How do African American men between the ages of 40 and 85 years with T2DM define motivation? 2) How does this population describe self-management of their diabetes? 3) What type of motivation do individuals in this population exhibit in managing their diabetes, as related to SDT? 4) What do African American men with T2DM and healthcare providers think influences motivation to manage T2DM in this population, including attending diabetes self-management classes? 5) What do healthcare providers view as their role in assisting their patients manage diabetes? 6) What motivates African American men between the ages of 40 and 85 with T2DM to attend DSME programs?

## METHODS

### **Study Setting and Recruitment**

Interview participants were from four counties of the Piedmont region of South Carolina (Spartanburg, York, Lancaster, and Chester) and were affiliated with the South

Carolina Conference of the South Atlantic Episcopal District (SAED) of the African Methodist Episcopal Zion (AMEZ) church. Many African American men participate in church activities and men's ministry activities, and faith-based organizations have been successfully used in research to recruit African Americans (Streaty-Wimberly, Braithwaite, & Taylor, 2001; Campbell, et al., 2007). The recruitment team was comprised of the primary investigator, local health ministry coordinators, and men's ministry leaders of local AMEZ churches in Rock Hill, SC. The inclusion criteria for participants were 1) African American men between the ages of 40 and 85 years with 2) a diagnosis of T2DM and 3) affiliated with an AMEZ church in the Piedmont area of South Carolina. Local health ministry coordinators and men's ministry leaders identified potential participants from their congregation and community, and the primary investigator contacted potential participants to schedule participant interviews. Word of mouth emerged as an important recruitment tool.

There was a total of 28 participants: 22 African American men with T2DM and six healthcare providers participated in qualitative interviews. The healthcare providers included two male African American family practice physicians, two male European-American family practice physicians, one female European-American nurse practitioner, and one female African American doctor of pharmacy. These six practitioners were chosen because they provide treatment to African American men between the ages of 40 and 85 years with T2DM in or near the Piedmont area of South Carolina and have at least eight years of experience in their field. There was a conscious effort to include healthcare providers from various disciplines, genders, and ethnicities, and all healthcare providers who were asked to participate in the study agreed to participate.

## **Data collection**

Interviews with participants and healthcare providers were completed over a six-month period beginning in January 2016. After obtaining oral consent and explaining the purpose of the research, participants filled out a demographic information sheet and the modified Intrinsic Motivation Inventory (Appendix A). The modified Intrinsic Motivation Inventory (IMI) used in this study is an eight-item questionnaire that uses a Likert scale to score participants' motivation to participate in DSME classes. In-depth interviews were conducted after participants completed the questionnaires. The interview guide for the African American men with T2DM, located in Table 4.2 and Appendix E, included questions adapted from Stuckey (2013) and was organized into three topic areas: personal, diabetes self-management, and barriers and factors for success in self-management. Table 1 includes sample questions from the participant interview guide. Interviews with participants were conducted either at the participant's home or in the conference room of the participant's church. Before and after the interview period, the investigators engaged in extensive dialog about T2DM and the experiences of African American men with clergy from participating churches, diabetic educators, and healthcare providers that treated African American men with diabetes in several cities in South Carolina between 2014 and 2016.

The interview guide was used for the 22 African American men with T2DM to explore 3 specific topic areas: 1) Personal and diabetes-related information, 2) Diabetes self-management and motivation information, and 3) Diabetes self-management program information. The first topic area included personal and diabetes-related information that

consisted of general information as hobbies and interest, transitioned into self-rated health, and specific questions about their definition of diabetes, initial emotions upon

Table 4.2 Sample Interview Questions for African American Men

Topic of Interest	Sample Questions
Personal questions and diabetes-related questions	<ul style="list-style-type: none"> <li>• Tell me some things about yourself (hobbies, work, and family).</li> <li>• How would you describe your health? Excellent, very good, good, fair, or poor?</li> <li>• When were you diagnosed with diabetes?</li> <li>• How did being diagnosed with diabetes make you feel</li> <li>• What does the word diabetes mean to you?</li> </ul>
Diabetes self-management and motivation	<ul style="list-style-type: none"> <li>• How do you feel about self-managing your diabetes?</li> <li>• Have you always taken care of your diabetes?</li> <li>• What is a typical day in your self-management of diabetes?</li> <li>• How would you define motivation?</li> <li>• What motivates you to self-manage your diabetes?</li> <li>• What are some of the things that you struggle with daily in self-managing your diabetes?</li> </ul>
Diabetes self-management programs	<ul style="list-style-type: none"> <li>• Are you familiar with diabetes self-management education programs?</li> <li>• Tell me what you know about diabetes self-management programs, and how do you feel about attending a diabetes self-management program?</li> <li>• What are some things that would motivate you to attend a diabetes self-management education program?</li> <li>• Are there any reasons that have prevented you from attending a formal diabetes self-management education program?</li> <li>• If you were to attend a formal diabetes self-management education program, how do you think it would help you to self-manage your diabetes?</li> <li>• What are some things that would keep you on track in self-managing your diabetes?</li> </ul>



being diagnosed with diabetes. The second topic area explored participants self-management experiences and their definition of motivation, their motivations to self-manage their diabetes, and struggles with self-managing diabetes. The third topic area explored their perception of diabetes self-management education programs including their familiarity of the diabetes self-management education programs, factors that could motivate them to attend a diabetes self-management education program, and way in which attending at diabetes self-management education program might help the participants.

Interviews with five of the six healthcare providers were conducted at the offices of the healthcare provider, and one was held at a café. The interview guide for healthcare providers (Table 2 and Appendix C) also included questions adapted from Stuckey (2013) and was slightly amended from the participants' interview guide to gain the perspective of healthcare providers that treat African American men with diabetes, focusing on motivational strategies to encourage management of diabetes and the provider's role in treating and supporting individuals with T2DM. Table 2 shows sample questions from the provider interview guide. Additional data used in analyses included investigator memos, reflections, and field notes.

### **Data analysis**

The data analysis process was an intentionally repetitive, continuous process that began in the early stages of data collection and continued throughout the study (Bradely, Curry, & Devers, 2006). Each interview was transcribed by a study team member with extensive training in data collection and analysis or the primary investigator. The primary

investigator then re-listened to each interview and corrected the initial transcription draft by comparing it to the original audio file. The primary investigator was responsible for the final verification of each transcript.

Table 4.3 Sample Interview Questions for Healthcare Providers

Topic of Interest	Sample Questions
Personal questions and diabetes-related questions	<ul style="list-style-type: none"> <li>• Tell me some things about yourself (hobbies, work, and family).</li> <li>• Where did you go to medical school?</li> <li>• How long have you been practicing?</li> <li>• What is your particular area of interest?</li> <li>• How would you describe your health? Excellent, very good, good, fair, or poor?</li> </ul>
Diabetes self-management and motivation	<ul style="list-style-type: none"> <li>• Do you treat many African American men with T2DM?</li> <li>• Estimate the percentage of African American men with T2DM do you treat.</li> <li>• Do you refer African American men to diabetes self-management education programs? Why or why not?</li> <li>• What do you think your role is in helping individuals with diabetes to manage their diabetes?</li> <li>• Overall, how do you think your diabetes patients managed their diabetes?</li> <li>• More specifically, how do you feel that your African American men manage their diabetes?</li> <li>• Do you think that your African American men with type 2 diabetes are motivated to manage their diabetes?</li> <li>• What are some strategies that you think would help African American men to manage their diabetes?</li> <li>• What are some things that you think African American men struggle with in their day-to-day self-management of diabetes?</li> </ul>
Diabetes self-management programs	<ul style="list-style-type: none"> <li>• Do you think that attending a formal Diabetes Self-Management Education program helps your African American men self-manage their diabetes?</li> <li>• Do you know what exactly is being taught at the diabetes self-management classes?</li> <li>• Are there any cases of African American men and poor self-management of their diabetes that stand out?</li> </ul>

Data analysis was aided by using NVivo 10 software for data storage and management. Thematic analysis was used to analyze the interviews for content related to the specific aims and associated research questions of the study. Collecting and analyzing data was an integrated and concurrent process in which interview transcripts and reflections were transcribed and reviewed to gain a greater understanding of the data in terms of how the data correlated and addressed the research questions. The initial codebook development began with coding of the first three to five interviews. All interviews, investigator memos, reflections, and field notes were reviewed to inform development of the final codebook (DePoy & Gitlin, 1998).

Data from the eight-item modified IMI were analyzed using Microsoft Excel, where the Excel average function was used to attain answers from each African American male with T2DM (n=22) for each of the questions posed. The participants answered each question using a Likert scale with answers ranging from 1 (not at all true) to 7 (very true), with a middle response of 4 (somewhat true).

The purpose of the modified IMI (Appendix A) was to provide adjunct, descriptive data via measuring the level of intrinsic motivation of African American men with T2DM to attend and to participate in a DSME program. For this study, the original 22-item IMI was modified to contain eight items, which were graded on a 7 point Likert scale and were aimed specifically at addressing intrinsic motivation as related to participants' attending and participating in a DSME program. For the modified IMI, responses ranged from 1 (not at all true) to 7 (very true).

## RESULTS

Twenty-two African American men diagnosed with T2DM and six healthcare providers who treat African American men with T2DM participated in this study. Table 4.4 shows participant demographic information for the African American men. Results of the study provided insight into 1) how African American men between the ages of 40 and 85 with T2DM defined motivation, 2) how individuals in this population described diabetes self-management techniques, 3) how individuals in this population exhibited different types of motivations (i.e., external/intrinsic motivation, amotivation), 4) what individuals in this population and healthcare professionals providing care to T2DM patients believe will motivate patients to better manage their diabetes, including attending DSME classes, 5) what healthcare providers view as their role in assisting patients with diabetes management, and 6) what motivates African American men between the ages of 40 and 85 to attend DSME classes?

### **Definitions of motivation**

Most participants described motivation as “a drive” or acting to “accomplish a goal.” Some of the major themes that emerged from questions on definitions of motivation that were specifically related to diabetes self-management included longevity, being there for families, seeing kids and grandchildren grow up, not wanting to lose limbs, and not wanting to have to use needles. One participant defined motivation as:

“Definition for motivation? To me, it would be the drive that keeps me...that makes me want to do better for myself and for my family.”

Table 4.4 Research Study Demographics for African American Men

<b>Participant Characteristics (n=22)</b>	<b>Mean (range) or n (%)</b>
Age (years)	63.8 (47-81)
Education level	
Grade 1-8	1 (4.5)
Grade 9-11	2 (9.1)
High school graduate	5 (22.7)
1-3 years college	5 (22.7)
College graduate	9 (40.9)
Average Income	
<\$10K	3 (13.6)
\$10-15K	1 (4.5)
\$20-25K	4 (18.2)
\$25-35K	3 (13.6)
\$50-75K	3 (13.6)
>\$75K	7 (31.8)
Age diagnosed with diabetes (years)	51.4 (31-70)
Duration of diabetes (years)	12.6 (2-34)
Last doctor's appointment	
Within past 3 months	17 (77.3)
Between 3-6 months	5 (22.7)
Have health insurance	22 (100)
Self-rated health	
Poor	0 (0)
Fair	8 (36.4)
Good	11 (50.0)
Very Good	3 (13.6)
Excellent	0 (0)
Height (inches)	69.7 (66-75)
Weight (pounds)	218.4 (148-330)
Body mass index (kg/m <sup>2</sup> )	31.0 (21.0-44.0)
Marital status	
Single	1 (4.5)
Married	14 (63.6)
Widower	1 (4.5)
Divorced	5 (22.7)

Another participant defined motivation as:

“Well (chuckle), putting an emphasis on doing something and trying to achieve something. You know. For whatever reason. A goal, you're seeking a goal. I say it could be from a positive point of view, and sometimes it could be from a negative

point of view. You put forth the effort to achieve something, or to do something, or stop something. I mean different things can motivate you for different reasons.”

A few participants described motivation as having discipline:

“Motivation, motivation, motivation is self-discipline to get up and do...you know. Do what you got to do without hesitation.”

Another participant described motivation as not letting anything stop him from staying on top of managing diabetes:

“Well, I define motivation in that...I can't let nothing stop me or separate me from doing what I would have to do in order to...stay on top of my diabetes. And what motivate(s) me? I don't want to be sitting around sluggish and dragging, you know. I know the things I need to do, so I stay consistent with what I do. And, really that motivates me to want to do good in whatever I do and manage whatever I do.”

One participant compared motivation to his job and playing golf:

“Motivation is an element of life that makes you want to accomplish something. And, anytime that I have a goal. And, I do set goals. When I worked, I had projects, and you have to plan around that project to accomplish it. And, usually with projects, you've got a deadline... and my deadline, relative to my diabetes is to feel great the next morning and throughout the day. For all the activities that I'm anticipating to perform, especially playing golf or going walking or usually, when I was playing tennis...that as well because that motivates me to make sure I do the things I need [to do].”

### **Motivation types: intrinsic/extrinsic motivation and amotivation**

*Intrinsic motivation:* Intrinsic motivation is doing an activity simply because one finds it enjoyable. Although most participants scored highly on the modified IMI (see Table 4.5), their interview responses centered mainly on extrinsic motivation and amotivation. Of note, no range is reported for some questions in Table 4 because all respondents answered in the same way, e.g., for the question “I felt relaxed while participating in the Diabetes Self-Management Education program,” 100% of participants answered 7 (very true), and so no range is reported in the table.

The results from the modified IMI indicated that most of the respondents thought that participating in a DSME program would be fun and felt that they were not or would not feel pressured while participating in a DSME program. All participants stated that they were or would feel relaxed participating in a DSME program, they did or would enjoy participating in a DSME program very much, they were not or would not be anxious to participate in a DSME program, participating in a DSME program was not or would not be boring, participating in a DSME program was or would be very interesting, and they did not or would not feel like they had to participate in a DSME program.

*Self-determined extrinsic motivation:* Many participants exhibited self-determined extrinsic motivation, for example, where their motivation for managing their diabetes was to be there for their family, kids, and grandchildren. Some participants said they wanted not only to be present for their families but also to be in good health and live longer.

Table 4.5 Quantitative Results from the Modified Intrinsic Motivation Inventory<sup>a</sup>

<b>Modified Intrinsic Motivation Inventory</b>	<b>Average score (range)</b>
I believe that participating in a Diabetes Self-Management Education program would be fun.	5.77 (4-7)
I felt relaxed while participating in the Diabetes Self-Management Education program.	7.00
I think I would enjoy participating in the Diabetes Self-Management Education program very much.	7.00
I would be anxious to participate in a Diabetes Self-Management Education program.	1.00
I think that participating in a Diabetes Self-Management Education program would be very boring.	1.00
I think that participating in a Diabetes Self-Management Education program would be very interesting.	7.00
I think I would feel pressured while participating in the Diabetes Self-Management Education program.	2.14 (1-6)
I feel like I have to participate in a Diabetes Self-Management Education program.	1.00

<sup>a</sup>Participants responded to each item using a Likert scale

One participant noted that his father passed at age 38 from diabetic complications and missed all of the participant’s childhood activities. The participant did not want his children to experience the same thing:

“That's what motivates me. You know. Knowing that, that...I want to be around here for my kids. Like I say, when my dad died at thirty-eight, I knew if he were to keep better care of himself, then he would be around to see his grandkids and...like I said, he died when I had just graduated from high school. He didn't get to see none of the things that I accomplish in life, you know [like] when I went to service. I mean, he didn't get to see that. So, that's a definite motivation



for me. You know to be around, or as long as God is willing to let me be around. I want, I want to do everything I can to do, you know...to be here..."

Another participant revealed his motivation was to be there to see his granddaughter:

"And my granddaughter, I have a granddaughter now, and I like to see her grow up as long as I can. So, that motivated me to try to exist in this world what is the best quality of life that I can."

The majority of participants relied on some form of family support as motivation for self-managing their diabetes. Participants indicated that family members motivated them by urging them to take medications, assisting in meal preparation, and encouraging proper nutrition:

"She helps me with the pills. I mean my wife, wife, wife [helps]...getting the medicine. Make sure, she thinks I slip and eat something but I don't...no I don't slip. My daughter...she takes me places that I need to go and all doctor's appointments."

In describing how family support helped him with managing diabetes, another participant mentioned:

"My family keeps me on track, my doctors keep me on track, and so I have a lot of people keeping me constantly aware that I need to do a better job of managing my diabetes."

Two participants stated their wives also had diabetes. However, these two couples had significantly different methods for managing their diabetes. One participant noted that he and his wife worked together:

“Well, you know by working together means...you both [are] trying to stay on top of it. It means you won't be neglecting yourself because you've got to, you know, help each other and that means that you maintain yourself as well as maintaining hers too...you [are] helping her with hers. And, now we just...try to keep a regular routine.”

The other participant whose wife had diabetes was adamant that he and his wife manage their diabetes separately and independently:

“[We] Do our own thing [diabetes management]. She is educated like I am. We know what to do...Education plays a big part of it.”

One participant jokingly noted that he was motivated to manage his diabetic condition to keep from having to hear about it from his three daughters and wife:

“Being in the house with all women, (laugh) quite a bit...and very, very strong (family influence) because they watch everything that I do and ready to complain at any given moment.”

Many participants expressed that wanting to live a long life was their motivation to keep up with self-management. One participant stated:

“Well, the main reason is health. I mean...having a long, healthy lifestyle. I mean, to be honest with you more than anything else. You want to live, or at least me, I want to live as long as I possibly can and as healthy as I can.”

Most participants mentioned fear as a motivating factor in managing their diabetes. These fears included amputations, developing other health issues, fear of needles, and erectile dysfunction. When expressing fears of amputations, one participant stated:

“And I remember him [grandfather] having the bottom half of one of his legs cut, amputated. And, later on a couple of toes on the other foot and everything. I remember as a kid they talked about burying his leg. And you know as a child, that leaves a deep impression on you, but I didn’t understand the whole focus of it.”

One participant who was very active stated that he would rather die than have an amputation:

“The fear of losing a leg or arm, or you know something like that. You know...Again, like I said, I would rather die straight out than, you know, be in the hospital because of my leg, my arm. You know. I see people at work all the time have diabetes, and you know they are in excessive level [diabetic condition]. You know they've got the bands on their legs and you know the pressure socks.”

One participant explained his other health issues in the following manner:

“Well, I can’t, ah do a lot of things, ‘cause I got several things uh wrong, I got a pace maker...I already got diabetes. I go to a psychiatrist, and I go to a kidney doctor, and I go to my regular doctor... did I say heart doctor?”

All the participants who were sexually active mentioned the fear of erectile (or sexual) dysfunction as a major motivating factor for managing their diabetes. One participant stated:

“...and most of all I have to control my diabetes because I’m married, and thing about it [is] that I have to take care of my wife [sexually]. You know...because they [doctors] told me, man that it messes with your sex drive and all that...you

know whatever is going to interfere with that you know I need to keep it in check!

So, that's [sex] a motivating factor...that's [sex] number one motivating [factor].”

Most participants indicated that a fear of needles motivated them to manage diabetes. In the words of one participant:

“For me, I guess, if you want to say one other motivating thing too is, I can't stand needles. People can give me shots, and that is well and fine, but I had to witness my dad take insulin shots and stuff like that, and I don't want to have to do that. And, even in spite of knowing all of that, I don't do as good as I should do, but that is something that I just don't want to have to do.”

Although many participants did not completely adhere to all recommended lifestyle behaviors, most expressed that their motivation for managing diabetes was to maintain a healthy lifestyle. In discussing why maintaining a healthy lifestyle was a motivating factor, one participant stated:

“Now, like I say what motivates me is my health. So, I am trying to maintain my health, and seeing other people that have been affected by it [diabetes]. I think motivates me more than anything else because I watched one or two that was doing ok with it, with their limbs, then all of a sudden, it got to a point that gangrene set in, and they had to lose a leg. That is what motivates me to want to stay on top of it.”

*Amotivation:* Two participants expressed amotivation, meaning that nothing would motivate them to manage their diabetes or attend a diabetes self-management class. One participant was very adamant about expressing that he did not need diabetes self-management classes and stated:

“No other reason [to attend a diabetes self-management class]. I just feel like I don’t need to.”

One participant emphatically opposed attending a diabetes self-management class:

“Yes, I know that they are [diabetes self-management education classes] out there, and I know that they are available. My doctors mentioned it before, but I think as I mentioned earlier, I’ve kind of balked at it a little bit. It’s not because I think I’m smarter than anybody, or smarter than these guys are professional to sit there and tell you anything. I just...I’m not hugely interested. I don’t think they can tell me anything that’s going to change my attitude or change my behavior. They can give me the facts. You know and I know they’re right I know one hundred percent they’re right. I know that. No doubt in my mind, but that’s not going to change my behavior. When [mentions his name] sees that piece of, you know, red velvet cake that he wants to try you know. I got to do that, you know, on my own, and they can’t do that [change his behavior].”

Another patient was adamant in expressing that although he knew that healthcare providers were very knowledgeable about diabetes, diabetes self-management classes would not benefit him or change his behavior:

“Well. Oh, I know about them [diabetes self-management classes], and I don’t doubt that they probably would be good for me and in my best interest. The one that I did attend after a few sessions, I kind of felt like it was a more of a waste of time because I wasn’t being told anything to do that I wasn’t already doing.”

## **Diabetes self-management strategies**

Participants described that a typical day managing their diabetes consisted of eating a healthy diet, monitoring portion size, exercising, and checking their glucose levels. Some participants noted that they did not do anything differently after being diagnosed with diabetes than before their diagnosis. One patient directly stated:

“I don’t check it [glucose levels].”

Many patients reported that meal portion size was emphasized by healthcare providers and in diabetes self-management programs:

“You got to eat portions, you I found that out. You can eat anything you want to as long as it is in portions and it’s the right thing. You know not no saturated pork or noting like that, but you can eat anything in portions. I had a doctor to tell me: you are a diabetic you are not supposed to go a long time without eating. You eat many times...you eat little amounts many times a day. That is what I was told.”

Some participants noted that they managed their diabetes but were not very compliant:

“Well, I don’t do the best job. I could do a much better job of managing. I mean you know in terms of what I eat and exercising. Since I’ve retired, especially, you know I have gained weight, which you know doesn’t help anything. Uh, although, I tend to pay attention, I could do a much better job than what I’m doing. You know in terms of eating and exercising especially.”

Some participants did have a consistent schedule in managing their diabetes. One participant described his management of diabetes in the following manner:

“I have a regiment that I take in the morning. Have medication and blood pressure medication...cholesterol [medication]. I take one half pill for my

diabetes in the morning and one-half pill in the afternoon. But, you know I told you about me trying to stay busy [physically active]. I know, to me, not just exercise and not just exercising like walking and whatever else people do. Exercise, I think sometimes just being busy and being on the go instead of just sitting around and laying around. I think that has more effect on your health too.”

Although the majority of patients indicated a basic knowledge of diabetes, many did not indicate an urgency to manage their diabetes:

“Like I say the biggest thing I say that I don't do is, like I say, is paying attention to eating in a much better manner and in exercising as much as I should.”

A few participants made no lifestyle changes to manage their diabetes. One participant stated:

“Well I just...I didn't know too much about diabetes, but I didn't feel bad or nothing. Just taking my medication. I ain't changed nothing from what I've been doing. I'm doing everything I [have] been doing.”

### **How to improve motivation to manage diabetes and attend self-management classes:**

#### **Participant and healthcare provider viewpoints**

*Participant views:* Some participants indicated that they were motivated to attend diabetes management classes to seek information. As stated by one participant:

“What motivates me to do that [attend diabetes self-education classes] is because I seek information. I like to have knowledge of...you know...being an analytical chemist, we always feel that there is a means in which you can get to the end. There are many ways to skin a cat, so having more information is a plus, and I would love to know more because of some of the things I'm doing may not be the

best way of doing it. I don't think that knowledge about Afro American relative to diabetes is a clear-cut regiment of how to treat it yet.”

Some participants said they would be more motivated to attend diabetes education classes if class times and locations were more convenient and were located at their job site and if classes were more interesting. One participant indicated that he was able to attend a diabetes self-management class because the classes offered flexibility in location, as well as a weekend class:

“Well, the only thing was...the obstacle I had... I worked so they wanted to do it during the week. And, I couldn't make it during the week. So, we had uh...they had a program that was going on Saturdays, and it was in Matthews (NC). So, being that they had that flexibility that helped me to make my meetings. So, I schedule, did my meetings on Saturday.”

*Healthcare provider views:* Healthcare providers discussed many things that may improve their patients' motivation to self-manage diabetes and attend diabetes self-management classes, such as 1) reaching African American men in areas they frequent, 2) involving family, 3) combating cost, 4) empowering patients, 5) making classes more convenient, 6) cultural awareness, 7) the ability to spend more time with patients, and 8) emphasizing prevention.

Most healthcare providers believed that a key to motivating African American men to manage their diabetes is to first reach them in areas that they frequent, such as sporting events, communities, and churches:

“I think you've got to go where they are. Most African American men that I see are at sporting events...they love sporting events. And, you know they're active.



They're working in the yards. They are cutting grass. They're going to be the guys that are involved in their families. And, this is just from my practice, but you know, I think that if you can meet them at work and make it a community event wherever they are. I think that this applies not just African Americans but applies to everyone. “

Most healthcare providers also believe that involving the families of African American men with T2DM would motivate them to better manage their diabetes:

“I want to say the ones that seem to be the most motivated are the ones that bring (their) wife in here with them. So, I don't know if the wife is motivating them, or they are actually motivated to do it.”

One healthcare provider suggested that bringing a significant other to medical appointments would improve motivation by helping with retention of information and applying it at home:

“It's hard when I'm talking to them [African American men with T2DM]. When you're anxious, you don't hear what's being said. And, so they bring their wives, the wives hear also, and a lot of not just African American men, but a lot of women are doing all the cooking and all of that you know. So, they're the ones around to try to adjust the diet. And, I'm always suggesting to [them] you know the whole walk with them and exercise with them as it helps. Men on the whole, whether they're African American or not, don't like to come to the doctor's office, and that's why, when a man comes in here sick, I take them much more seriously than a woman because they don't come in for the most part.”

Similar to the African American men with T2DM, all of the healthcare providers recognized that the cost of diabetes can negatively influence diabetes self-management.

One healthcare provider noted the “astronomical” cost of managing diabetes:

“There is actually [an] astronomical cost with diabetes, again this is probably one of the most expensive, most intensive disease processes in medicine even up to this date. It is very, very time consuming, but cost is probably the number one factor that most people, and African Americans included are not able to get a good grip on this disease process.”

Most healthcare providers indicated that empowering African American men with T2DM was a key strategy in motivating them to self-manage their diabetes:

“...And, one of the things [we] are trying to do is incorporate patients into their care. Let them know that they're active participants in the management [of diabetes]. This is not just a one-sided affair. This is something that we both take on. Usually, even when I discuss treatment plans I say “we,” not “me” or “I,” but “we” are going to go ahead and take care of this. “We” are going to help control these sugars because it's a team approach, and what I mean by team is that the patient is part of that team.”

All the healthcare providers realized that making diabetes self-management classes more convenient may have an important role in increasing the motivation for patients to attend:

“Our outside diabetic education [program], which we have used, is probably [a] more open schedule, but you have to travel somewhere. And, then there's still there's a lot of cost involved because it's usually not all that well covered by, by most insurances. And, then our free access is our doctor of pharmacy here, and

that's a very good educational program, but it's again Monday, Wednesday, and Friday mornings. And, again most of my people are working in jobs that, that need them there. They you know they don't have the flexibility of... you know, a manager or something who are typically the ones I deal with. They just can't get in on a drop of a hat. So, so that's [what] I think time is one issue. It's a huge issue. Cost is another. And, then the third would be somehow motivate them that this is going to help.”

All the healthcare providers recognized the importance of understanding general cultural behaviors, such as typical routines:

“...and there are cultural kind of approaches to this...you know and I know we're focusing in on an African Americans, but it kind of goes out to other cultures. But, when you're looking at forty or older, you know that means that somebody has been on some kind of routine for, you know, maybe twenty to thirty years. And, so you're going to that age where you're finally seeing the sugar go up. So, one of the barriers is that the routine that they've just gotten used to over time. You know that's one thing, and that can be cultural as well...a certain way you eat, certain diets. You know, and it could be even from the different areas that we live in the country, right?”

Another healthcare provider spoke of culture in terms of the perception of African American men going to the doctor, as well as the access African American men have to healthcare:

“I think coming from a cultural aspect [an issue] could be access to healthcare. [Individuals] may not be in a culture that is prone to go to the doctors unless

something is wrong, and so that may lead to the higher A1C upon diagnosis than someone that's been managing and tracking along the way.”

Healthcare providers also expressed that talking to others and having help can promote a positive attitude and may provide motivation for managing diabetes:

”...And then, I think just kind of as a society, you know, I talk to my patients about stories. So, talking to family members, or talking to people at church. [You] don't really ever hear about people's good days with diabetes. You always hear about the negative days. So, a lot of patients come in already the first thing they will say is, 'I don't want to go on insulin because someone is on dialysis and they went on insulin or someone lost a foot when they went on insulin.' So, they [already] have different negative connotations associated with the treatment and therapy that I'm trying to initiate for their care.”

All healthcare providers expressed a desire to spend more time with diabetic patients and said that spending additional time with their diabetic patients may increase patients' motivation to manage their diabetes:

“Mainly because I only have fifteen minutes with them in the office. And, so time is always a factor. If time wasn't a factor, I think we would have to refer less [to diabetes self-management classes], and we can educate them here in the office. But, when we are talking about diabetes, it is such a complicated disease process. It's probably the most complicated chronic disease that we manage. We're talking about a disease process that affects every organ of the body. There is no way a fifteen, twenty, thirty minutes now to the point it could actually justify that. There are tons of questions that may come up. There are some specialists that's doing

really, really good job on it. But, you know I think the self-management part of it is actually part of the key to treatment and better outcomes for patients.”

Healthcare providers realized that there is so much to explain to their diabetic patients but so little to time in an office visit:

“I think when you get somebody who is non-compliant, you have to kinda dig deep to see why, most of the time there’s a reason. Nobody wants to say, ‘Hey, look I got diabetes and have poor prognosis and want to die early, or have end stage organ damage.’ There is usually a reason. Sometimes financially and sometimes they don't understand how the medicines work. Sometimes they don't know how much exercise to do. Sometimes they don't know, which is a big one, what to eat and that's probably the biggest one. All those things got to be considered so you have to take the time and slow down. Really say well why aren't you taking your insulin? What foods are you really eating?”

### **Healthcare providers’ self-perceived roles**

Many healthcare providers perceived their role as a “coach,” “cheerleader,” and “lifestyle changer.” Healthcare providers indicated that their role could be influential to their patients who are trying to self-manage their diabetes in that they encourage patients and work towards “giving them the tools and training” to accomplish their goals. One healthcare provider indicated that he motivated African American men with diabetes by being their cheerleader:

“Part of my role is I’m the cheerleader. You can do this, you can get this weight, and you can get more exercise, you can eat correctly.”

Another healthcare provider indicated that he motivates African American men with diabetes by being a coach:

“You know what I think of myself as, as a coach who is...who is trying to, you know, teach my diabetic athlete [comparing diabetes to coaching an athlete] to you know what, what’s necessary to do well...to give them the tools and training to accomplish those goals. To periodically test to see if they're where they are in relation to those goals. And, also somewhat of a cheerleader. Honestly, to say, ‘Hey, you know hey you're not there, but look what changes you've made’.”

Some healthcare providers believe that simply being a role model helps to motivate African American men with T2DM. One healthcare provider indicated:

“I think us, as providers, we should practice what we preach, and you know, ‘Will I be the perfect person?’ No, but I think I can serve as a role model from practical experiences and personal experiences when it comes to dealing with the difficulties of being healthy.”

One healthcare provider thought that he could motivate African American men by anonymously taking diabetes education classes to get a perspective from the patient’s point of view:

“The people there [at the diabetes self-management education class] did not know I was a physician, and I just sat in on a class, and it really opened my eyes to [the] patient’s perspective on diabetes. One of the things that I noticed was things that I would assume were mentioned in the physician-patient conversation, patients were not grasping or understanding because a lot of them had questions on basic things about diabetes. Everything from how to test, to what to eat, what not to eat,

what does it mean to have diabetes, what does it affect, what parts of the body does it affect. So, I then bring that to the patients [and] say well I sat in on this class. You know, similar class. And there's a lot of good information that can help you better control the blood sugars.”

Most of the healthcare providers indicated that empowering and encouraging African American men with diabetes by letting them know that they are not alone in managing their diabetes, they can still live a normal life if their diabetes is managed properly, and they can control their diabetes is an important motivating strategy:

“So, one, they say ok I am not in this by myself, and I know there are other people who look like me. They also can understand that, wow, I can still live my life with diabetes.”

“So, I like to tell people don’t let diabetes dictate your life, you dictate what diabetes is going to do, by take control and that's where these classes I think help as a motivating factor. Oh, I [the patient] can do this!”

“I think you have to take ownership of the disease process. So, if you have a cold before you go see your doctor, you are going to try to prevent that cold from getting worse. Right? That's what we teach patients. The same thing applies to diabetes. Before you see your doctor, even as a follow up, you should have the tools to do as much as you possibly can to prevent further worsening of the disease.”

One healthcare provider used motivational interviewing strategies as a method to encourage her patients with diabetes:

“I try to utilize motivational interviewing. So, putting them at the center of the conversation having everything, the suggestions or recommendations come from them instead of from me, and so kind of present options and then give them the choice of which path to go down. Whether if they have options for different medications, or...kind of give them the say [choice] of what they choose to start on. Or, if it’s just diet and exercise, kind of base it again on what they would normally be doing and help them identify any areas that they could improve on.”

All healthcare providers used fear tactics to motivate African American men with T2DM to manage their diabetes. Additionally, all healthcare providers agreed that sex and sexual performance were major concerns for this population and something their patients deemed an important part of their lives. One healthcare provider described how he approached addressing sexual dysfunction in this population:

“Now the disease process does affect sexual dysfunction because you're dealing with a small vessel disease. Which supply innervation or blood to all vessels, all organs, including sexual organs, and so that’s why I usually approach and say look, we've got to get on top of this, and we don't want the sexual dysfunction down the road.”

Healthcare providers admitted relying on horror stories to motivate African American men to manage their diabetes and based their fear tactics on real-life stories. One healthcare provider described her approach in the following manner:

“...and they're true stories, and I don’t make them up. But, I also say you know, if you don't do this you're increasing your risk of heart attack heart disease or stroke. Men particularly [if I] want to get their attention, I tell them it can cause



erectile dysfunction. And usually wham! I get a lot of attention at that moment when I say that because some of these guys are forty. I mean, I mean even sixty-five years old still don't want to have that happen, but it really...I think it helps.”

All healthcare providers acknowledged that although DSME classes and education are important, prevention is the most important strategy:

“I always tell them my goal is prevention. If I can prevent you from developing neuropathy or going to dialysis, that is my goal.”

## DISCUSSION

Diabetes is a global and national epidemic that affects all populations, ethnicities, and socioeconomic classes, but affects that racial and ethnic minorities at disproportionately. African American men are an underserved and understudied population, and exploring how they define motivation, the types of motivation they exhibit in self-managing their diabetes, their motivation to attend diabetes self-management education programs/classes, and the perception that they have of their healthcare providers and their healthcare provider of them, is important in developing effective diabetes self-management strategies for this population. African American men with T2DM in this study defined motivation as “a drive,” “to accomplish a goal,” or “being disciplined.” The results yielded some consistent themes on what motivates African American men with T2DM between 40 and 85 years of age to self-manage their diabetes, such as desire for longevity, being there for their families, seeing their kids and grandchildren grow up, not wanting to lose limbs, and not wanting to have to use needles. Participants differed in the ways they described their diabetes self-management techniques. Many participants described that healthy eating, physical activity, and

glucose monitoring were important parts of their self-management routine. However, some participants acknowledged that they could do a better job of managing their diabetes, with participants saying “I don’t do the best job” or even stating directly “I don’t check it” (glucose levels), and some stated that they did not feel any particular urgency to change their lifestyle.

In the Self-Determination Theory, an individual’s motivation is influenced by his or her levels of autonomy, relatedness, and competence. Generally, as these factors are increased, an individual’s motivation also increases. Because this was a qualitative study, autonomy, relatedness, and competence were not measured objectively, but through examination of the interview responses, it was determined that autonomy was present, in that most of the participants had positive associations with their healthcare providers and reported that they controlled and were responsible for diabetes self-management. This is consistent with research that an autonomy-supportive environment from physicians is strongly associated with autonomous motivation and effective self-management of T2DM (Koponen, Simonsen, & Suominen, 2017). Participants also exhibited competence via feeling confident and knowledgeable about their diabetes self-management, and they exhibited relatedness in feeling they were responsible for their own self-management and in understanding their connection to their diabetic condition and the relationship and importance of properly managing their diabetes.

In examining the types of motivation that participants used to self-manage their diabetes, we found that participants generally relied on a mixture of both intrinsic and extrinsic motivation, with a few participants reporting amotivation, which is consistent with an SDT framework. However, the results from the modified IMI and in-depth

interviews differed. It is important to note that although Likert-type rating scales are important in research, there is evidence that the scale format can influence response distribution (Weijters, Cabooter, & Schellewaert, 2010). Data from the modified IMI indicated that all or practically all participants thought that participating in a DSME program would be fun, they would feel relaxed, they would enjoy it very much, they would not be anxious to participate, it would not be boring, it would be interesting, they would not feel pressured to participate, and they did not feel as if they had to participate. Contrarily, many of the participants indicated in their in-depth interviews that DSME classes were boring, covered the same information, were too long, and were inconvenient.

The differing findings that were observed here could perhaps be explained by responder bias, unreliability of self-reported data, and social desirability of certain responses. These biases may exist when individuals tend to present a favorable image of themselves on questionnaires (Mortel T. v., 2008). To control for social desirability response bias, future studies could include a self-report social desirability scale, such as the Crowne-Marlowe Social Desirability Scale (Crowne & Marlowe, 1960). The modified IMI was adapted for populations with diabetes but would benefit from further testing with African American men with T2DM to ensure that it indeed measures the degree of intrinsic motivation with this specific population. Another point to consider is that not all DSME programs are homogenous in orientation, curriculum, and setting, with some participants having attended classes held by certified diabetes educators, some having been educated by their healthcare providers, and some having only been given

materials to read. In addition, responder bias might have played a role, in that respondents wanted to answer questions in a positive manner.

There are a few other factors that may have contributed to the differences in the high levels of intrinsic motivation reported in the modified IMI and the lack of intrinsic motivation reported in the interviews, in addition to responder bias, problems with self-report data, and social desirability. Although the modified IMI has been tested over several domains, such as tobacco cessation, sports, weight management, and diabetes management, it has not been specifically tested with older, African American men with T2DM. An important factor that must be taken into consideration is that the modified IMI asked questions that were specifically related to attending and participating in a diabetes self-management education class, whereas the in-depth interviews addressed diabetes self-management classes but also explored many other aspects of diabetes management, such as struggles with diabetes self-management, motivations to self-manage diabetes, relationships with healthcare providers, and family support. Thus, future studies could match specific interview questions to the items contained in the modified IMI, which might offer results that are specifically related to the level of intrinsic IMI for attending diabetes self-management classes.

While the data from the qualitative interviews exploring intrinsic motivation differed from the modified IMI, it is important to note that the interview guide was specifically designed to explore 3 specific topic areas for 22 African American men with T2DM: 1) Personal and diabetes-related information, 2) Diabetes self-management and motivation information, and 3) Diabetes self-management program information. The purpose of the modified IMI was to provide adjunct, descriptive data via measuring the

level of intrinsic motivation of African American men with T2DM to attend and to participate in a DSME program. Thus, it is important to note that the two instruments provided information on 2 different phenomena.

Although the data obtained from the interview guide and the modified IMI differed in the levels of intrinsic motivation that they reported, it perhaps raises an interest finding that there are different types of motivation in the daily self-management of diabetes compared to the motivations to participate and attend a DSME. Previous research note that diabetes self-management can be influenced by socioeconomic factors (Weaver, Lemonde, Payman, & Goodman, 2013) and social resources (Newton, Asimakopoulou, & Scambler, 2015). This inherently places more variables in the daily diabetes self-management behaviors that may include family, financial obligations, medications, physical activity, and dietary concerns that will have to be managed for a lifetime. On the other hand, participants expressed high levels of intrinsic motivation for attending and participating in diabetes self-management education classes may not view them as permanent or something that they had to do. This is important, but it reveals that motivation is just not a “one size fits all” philosophy when implementing strategies to improve diabetes self-management strategies and strategies to improve DSME attendance and participation by older African American.

Our results show that many participants felt that personal motivation is not sufficient to manage their diabetes successfully: when reporting external motivation factors, the importance of family support was frequently mentioned by participants as a key to successful diabetes self-management. In this study, there were two situations in which participants and their spouses were both dealing with self-managing T2DM. The

two couples were distinctly different: one worked together and managed their diabetes as a team, whereas the second couple was totally independent in managing their diabetes. The participant that managed his diabetes independently noted that he and his wife were both college educated and did not need to depend on each other to self-manage their diabetes. The participant that co-managed his diabetes with his wife noted that they encourage each other and stated that they both had other health ailments.

Although this study examined African American men only, it is interesting to note gender differences in the perceptions and responses to family support. In previous research, women reported family support less often than men and reported family barriers to self-care more often than men, and nearly 80% of women reported that family members nagged or criticized them about their illness care (Rosland, Heisler, Choi, Silveira, & Piette, 2010). In the current study, most participants reported positive family support, and it is important to identify and incorporate positive family support in DSME interventions and strategies to enhance motivation and behavior skills. It is particularly important that family members not interfere with an individual's diabetic self-care efforts (Mayberry & Osborn, 2012).

These findings on the assistance family members provide provokes further thought on areas that future research may address concerning the motivations and intentions of the family members of African American men with T2DM. Many participants in this study mentioned wanting to be there for their children, and some participants did have the support of their wives, but the motivations of family members were not explored. Supportive family behaviors have been associated with adherence to

various self-care behaviors, and obstructive family behaviors have been associated with less adherence to these behaviors (Mayberry & Osborn, 2014).

There is a positive and significant relationship between social support and adherence to diabetes treatment (Miller & DiMatteo, 2013). It is clear that social support has a vital role in improving adherence to diabetes self-management strategies (Powers, et al., 2015), but it is important to identify what positive family support comprises, what types of social support family members are capable of providing, what type of support an individual with diabetes is willing to receive, and the types of motivations behind family members' actions. Future research could aim to identify the various types of social support interventions that promote adherence and the motivations behind social support.

One participant had three daughters and a wife and jokingly admitted if he did not manage his diabetes appropriately, he would have “no peace in the house.” Sometimes family members' non-supportive behaviors can have a negative impact on individuals that are self-managing their diabetes. In situations as these, Mayberry and Osborn (2014) concluded that involving family members in an individual's diabetes management may compromise self-care and glycemic control if family members demonstrate obstructive behaviors. Although family members may perceive their actions as ways to motivate an individual to remain consistent with diabetes self-management, they could ultimately be curtailing the individual's efforts and motivations to manage his or her diabetes by providing the wrong type of family support.

Benefits of physical activity (Colberg, et al., 2010) and medical nutrition therapy (MNT) are well documented (MacLeod, et al., 2017). The results of our study indicated

that participants realized that physical activity and maintaining proper diets were key components in diabetes self-management, but the majority of them still did not adhere or engage in consistent physical activity or proper dietary recommendations for individuals with T2DM. As related to motivation for dieting and physical activity, monitored exercise and dietary programs have shown that long term interventions can improve motivation in terms of intrinsic regulation of and improving autonomous motivation (Saavedra, Garcia-Hermosa, Escalante, & Dominguez, 2014). Since being overweight is a risk factor for developing T2DM (Geyen, 2012), it is important for individuals with T2DM to incorporate physical activities into the activities of daily living and adhere to proper diabetic diets.

Physical activity and maintaining proper diabetic nutritional and dietary strategies are critical components of diabetes self-management education and support programs (Standards Revision Task Force, 2014; Standards Revisions Task Force, 2017). Certified diabetes self-management education programs include MNT, which is an evidence-based application of the nutrition care process provided by registered dietitian nutritionist and includes an individualized nutrition assessment, nutrition diagnosis, intervention and monitoring, and evaluation (Powers, et al., 2015). Many participants mentioned that one of the main points that they retained from their diabetes self-management education programs was the importance of portion control with each meal. It is important to continue to emphasize portion control and ways to motivate individuals with T2DM to adhere to portion controlled diets because it can aid in weight loss and weight reduction (Foster, et al., 2013).



The findings of our study revealed that while the majority of the participants cited the importance of physical activity and proper dieting in self-managing their diabetes, only a few indicated that they were compliant in maintaining proper physical activity and diet regiments. As related to motivation and in correlation with the SDT (Deci & Ryan, 2000; Deci & Ryan, 1985), dieting and weight-related behaviors, individuals are more likely to be compliant with significant behavior changes if they feel competent and autonomous about their participation (Teixeira, Silva, Mata, Palmeira, & Markland, 2012). Improving dietary concerns and healthy eating for older adults sometimes requires implementing dietary self-regulation and self-control (Naughton, McCarthy, & McCarthy, 2015). However, it must be noted that these are similar issues and barriers that are associated with improving motivation in the participants in this study and in diabetes self-management education programs (Funnell, Tang, & Anderson, 2007; Purcell & Cutchen, 2013).

In further examining the results of this study, it is evident that the majority of the participants were not mildly motivated to implement or maintain a consistent physical activity or a healthy diet regiment even though it could possibly help their diabetic condition. Possible reasoning for their lack of motivation to implement physical activity or healthy diet regiments could center around barriers associated with physical activity such as lack of time, lack of physically active role models, decreased energy, lack of convenient facilities, lack of safe walking areas, and lack of knowledge about proper physical activity (Joseph, Ainsworth, Keller, & Dodgson, 2015); and barriers associated with healthy dieting such as time to prepare food, cost of healthy, and changing to a healthy diet (White, et al., 2017). As one of the healthcare providers reasoned, it is much

cheaper to get a combination meal at a fast-food restaurant than to get a healthy meal. It is more cost efficient to get can goods that can last for months than to purchase perishable items that may last for only a few days. As with previous research, diagnosis of a chronic illness does not necessarily motivate dietary and lifestyle changes among men (Er, et al.). These issues illustrate the needs to implement efficient programs, or restructure and promote current programs to educate older African American men about physical activity and healthy dietary choices, and also explore ways to make healthy eating more affordable.

Our results indicated that there were some commonalities between African American men with T2DM between the ages of 40 and 85 years and healthcare providers that treat African American men with diabetes on many issues surrounding the management of diabetes. Participants and healthcare providers spoke about the importance of outside support. Two participants noted that golfing outings gave them an opportunity to address diabetes issues with their peers. Some healthcare providers encouraged their patients to bring their wives to their doctor's appointments, with the rationale that in most households, the wife is the one doing the cooking or preparing the meals. Therefore, if both the patient and his wife are educated in good self-management techniques, especially as related to diet, the chance of successful diabetes management may be increased. African American men with T2DM and healthcare providers both recognized that the cost of managing diabetes and the inconvenience of the times and locations of the DSME classes were barriers to increasing motivation to self-manage diabetes.

While patients in the study reported fears of that may accompany improperly managed diabetes and healthcare provider acknowledged using fear tactics such as possible erectile dysfunction, amputations, or comorbidities, this did not necessarily lead to a sustainable behavior change in the participant's diabetes self-management strategies. There is research that indicates that the use of fear tactics may not be effective and strategies that include understanding and increasing the individuals reason for change by noting negative consequences for initial behavior change but emphasizing positive sources of motivation may aid to maintain long-term health behaviors (Sabourin & Pursley, 2013).

Indeed, fear tactics as motivation have been used for decades in public health advertising and in healthcare provider relationships (Leventhal, 1971; Wright, Yelland, Heathcote, Ng, & Wright, 2009). The use of fear as a motivation tactic has produced some conflicting findings, with some studies reporting that fear can be ineffective in promoting or achieving a particular behavior change (Job, 1988). However, in certain public health areas, such as HIV/AIDS, early research states that the use of fear arousal can promote behavioral change when implemented with other strategies, including self-efficacy (Green & Witte, 2006). Diabetes self-management education programs have transitioned from a medical model that emphasized treatment of acute health care problems in which goals were set by health professionals to an empowerment model which is patient-centered and tailored to match the goals of their diabetes care (Funnell, Tang, & Anderson, 2007; Funnell & Anderson, 2004). Thus, while it should be part of the education process to make patients aware of the consequences of diabetes, emphasis

should be placed on empowering individuals with diabetes to manage their diabetic condition.

Although African American men with T2DM and healthcare providers both indicated that fear was a motivating factor in diabetes self-management, this idea was conceptualized in different ways. African American men expressed a fear of detrimental consequences, such as amputations and having to use needles, as motivation for managing T2DM.. Most of the healthcare providers in this study reported using fear as a motivating factor by educating their patients that improperly managing their diabetic condition could lead to further complications such as amputations, retinopathy, neuropathy, kidney disease, hypertension, and erectile dysfunction. From the healthcare providers perspective, and from the participants' reports, the possibility of erectile dysfunction was a topic that was commonly used as a fear tactic by healthcare providers and was a motivation strategy for participants. It is difficult to determine the impact that fear tactics may have when motivating African American men to properly self-manage their diabetes, as healthcare providers and patients may differ in what they believe improves adherence (Brundisini, Vanstone, Hulan, DeJean, & Giacomini, 2015).

In addition to fear tactics, one healthcare provider reported using motivational interviewing, as well as allowing patients to have ownership of their management plans and encouraging patients to play an active role in their diabetes management. Healthcare providers noted that repetition and continuous reinforcement are critical components in motivating African American men between the ages of 40 and 85 with T2DM to good self-management of their condition. Additionally, there was a sense that healthcare providers need to “dig deeper” to see if there are other underlying factors influencing

individuals in self-managing their diabetes. Healthcare providers noted that discovering some of the obstacles or barriers that hinder motivation of African American men with T2DM could allow them to address the underlying causes. For the most part, healthcare providers perceived that lifestyle changes and changing routines influenced self-management motivation. One provider stated that T2DM typically comes on during middle age, and it is difficult to change a routine or a lifestyle when you have been doing something for 30 years.

The healthcare providers that treat African American men with T2DM between the ages of 40 and 85 viewed themselves as having a significant role in assisting and educating this population. Many viewed themselves as a coach, cheerleader, motivator, and lifestyle changer. They viewed themselves as a role model in the sense that you have to “practice what you preach.” All healthcare providers viewed their role as significant in helping their patients self-manage their diabetes.

*Strengths and limitations:* The limitations of this study included sample size, restrictions on the inclusion criteria, and possible research bias. Although the sample size was appropriate to attain saturation of the data (n=22 African American men with T2DM and n=6 healthcare providers), it does not allow for the findings to be generalizable to a larger population. The inclusion criteria—African American men with T2DM between 40 and 85 years of age and affiliated with the SAED of the AMEZ church and healthcare providers from diverse disciplines and ethnicities—restricted the African American participants with T2DM to a specific population residing in the Piedmont region of South Carolina. Additionally, healthcare providers were restricted to those practicing in the Piedmont region of South Carolina and in areas of North Carolina bordering this region.

Because the selection of participants was purposeful, it did not allow for the exploration of diabetes in other ethnicities, age groups, genders, or geographic regions. Biases can exist in all research study designs and can manifest throughout all phases of a study, and attempts to minimize biases in this study included attention to methodological criteria and design to address the study aims, rigorous data collection, acknowledging researcher bias of any personal prejudices or experiences (positive or negative) that may influence the study, and incorporating multiple levels of analysis (Maxwell, 2005; Creswell & Plano Clark, 2011; Smith & Noble, 2014).

The modified IMI was used for descriptive data only, but further pilot testing of this questionnaire for reliability and specificity could improve its accuracy in future studies of African American men with T2DM. Although the healthcare providers were from various disciplines, genders, and ethnicities, including just six healthcare providers treating African American men in a specific geographic region does not allow for generalizability to a broader population. However, it does provide the unique perspectives of the different disciplines involved.

This study had several strengths. One strength is that although qualitative research may not be generalizable to a larger population, it allows for exploration of in-depth thoughts and feelings of the research participants, which can allow for an understanding of the lived experiences of a particular population or group (Sutton & Austin, 2015). Additional strengths of this study were the initial dialog between the primary investigator and health ministry leaders, in-depth interviews in a comfortable environment, and information gathered from an underserved and understudied population. Many studies have indicated that there is a benefit in peer and community informants when attempting

to reach at-risk populations (Eakin, Bull, Glasgow, & Mason, 2002; Sarkisian, Brown, Norris, & Mangione, 2003; Sokol & Fisher, 2016; Fisher, et al., 2017). The initial dialog between the primary investigator and the health ministry leaders was important for establishing the relationships that led to participant recruitment, as the health ministry leaders were trusted by their congregants and were thus effective at recruiting participants.

Conducting interviews in a comfortable setting of the participant's choice was also a strength of this study because it reduced the opportunity for external interference and provided a place of familiarity for the participant. This study also explored and could add to the limited literature on the mode of motivation of African American men with T2DM. The inclusion of healthcare provider interviews also allowed for additional information about the role these individuals can play in supporting diabetes self-management, which has the potential to greatly improve our understanding of the myriad factors that may contribute to successful diabetes self-management programs.

*Implications of the study:* African American men with T2DM comprise an understudied and underserved population, and it is important to gain access to this population to explore their definition of motivation, self-management strategies, modes of motivation in managing their diabetes, and opinions on ways to improve their motivation, including attending DSME classes. The results of this study revealed that although the participants self-reported that they would be intrinsically motivated (i.e., doing an activity for joy) to manage their diabetic condition and also attend diabetes self-management classes, the responses from their interviews expressed mostly extrinsic motivations (doing something for a separable outcome). These findings indicate that

although strategies intended to improve motivations to self-manage diabetes are needed, it is important to address what types of motivations are necessary when implementing DSME classes and when attempting to motivate African American men with T2DM to improve their self-management behavior strategies.

There were several themes that arose from this study that have may have implications for future practice in researching African American men with T2DM such as emphasize gaining trust by listening, emphasizing the effectiveness of evidence-based DSME programs in self-managing diabetes, varying the levels of intensity of the classes, and being aware of the roles of family members in diabetes self-management education. Although limited time with patients was a common theme for healthcare providers, it is critical that patients feel that they have adequate time listening and explaining treatment strategies because not doing this can consequently lead to mistrust in older African Americans (Hansen, Hodgson, & Gitlin, 2016).

Research has long relied on faith-based organizations to recruit African Americans for research (Whitt-Glover, Borden, Alexander, Kennedy, & Goldmon, 2016; Reed, Foley, Hatch, & Mutran, 2003), and faith-based organizations should continue to remain an area of recruitment for African Americans. Previous research have included faith-based organizations and barbershops/salons to study phenomena of African Americans (Balls-Berry, et al., 2015; DeHaven, Hunter, Wilder, Walton, & Jarett, 2004; Streaty-Wimberly, Braithwaite, & Taylor, 2001). However, there is a need for future research to continue emphasize initiatives that unite and educate various religious denominations that have significant African American representation about the benefits of participating in research and easing the negative stigma and issues distrust that are



sometimes held by African Americans concerning research. As health initiatives continue to be integrated into the platforms of faith-based organizations, encouraging collaboration between research initiatives and the leadership of various faith-based organization to adopt strategies to forge a combined, research-friendly agenda could continue to educate the importance of reaching this underserved and understudied population.

Eliminating healthcare disparities and improving access to healthcare are known issues facing underserved and understudied populations. Additionally, it is not enough for programs just to reach targeted populations. In the case of diabetes self-management education programs, the programs need to be tailored and culturally sensitive to improve the efficacy of diabetes self-management education programs. There has been success in replicating diabetes self-management programs in primary care settings (Peros, James, Nolan, & Meyerhoff, 2016). Current standards of diabetes self-management education and support (Standards Revisions Task Force, 2017) outlines and emphasizes several standards that include individualization to design services using person-centered practices that focus on the individual's priorities and values throughout the diabetes self-management process. These programs are vital, but still need to be made more readily available to underserved and understudied populations such as African American men.

While the results of our study indicated that most of the participants received positive support, individuals with diabetes have reported feeling stigmatized and blamed by friends, family, colleagues, and even healthcare professionals for their diabetic conditions (Browne, Ventura, Mosely, & Speight, 2013). This could possibly lead to individuals with diabetes withdrawing and not actively managing their diabetes. What this also warrants is a need to educate the public on the actual causes of diabetes to

debunk stigmas and stereotypes about diabetes sometimes these stereotypes are associated with individuals, higher A1C and body mass index, who need diabetes self-management education the most (Liu, et al., 2017).

This study revealed some of the common dilemmas of recruiting older, African American men. Our initial intention was to recruit participants through their primary care practitioners or directly through DSME programs. Because there were not any established relationships between the research team and primary care facilities, it was difficult to gain entry to these facilities beyond the initial introductory stages. Initial contact with the primary care facilities was via the front office. Most of the facilities responded positively when the possibility of participating in research was introduced. However, after the initial contact, several attempts to set up further meetings with individuals who could approve the study were unsuccessful. In all, six DSME programs (three hospital-based and three independently operated) and ten primary care facilities were initially contacted. Some valuable information on how DSME programs were operated came from the hospital-based DSME programs, but being approved in a timely manner from the hospital-based DSME programs was not possible. Although no specific reasons were given for the inability to work with the primary care facilities, it appears that the reluctance stemmed from the fear of placing more demands on busy staff members. All contact persons from the primary care facilities asked about any extra responsibilities for their staff but were assured by the primary investigator that the only work needed by staff members would be identifying participants that fit the inclusion criteria. It was communicated that the research team would be responsible for any extracurricular work.

However, after months of being unable to enroll participants in the study through primary care facilities and/or DMSE programs, the focus of recruitment turned to the African Methodist Episcopal Zion Church and the South Carolina Conference of the South Atlantic Episcopal District. For this study, the research plan was presented and approved by the Presiding Bishop of the SAED of the AMEZ church, 2008-2016. Once approved, the purpose of the research was disseminated throughout the AMEZ in the Piedmont area of South Carolina via the help of the health ministry leaders and men's ministry leaders. Details about the study and the purpose of the research were presented during church announcements and during events sponsored by the men's ministry at multiple churches. As health ministries continue to grow, and as their platforms and agendas grow, the use of social media and technology to reach potential research participants will be an important recruitment tool. Even if older participants are not on social media, reaching family members that could inform them of possible research participation opportunities would be a valuable recruitment tool. There are advertisement campaigns that target all populations with T2DM. As with any information campaigns, they must be culturally sensitive to the specific groups that they target.

There are national campaigns that aim to bring attention to the diabetes epidemic via use of advertisement and marketing to reach individuals with T2DM. The use of technology, social media, and faith-based organizations will be critical in not only raising awareness of T2DM, but also in making interventions easier and more convenient to implement. For example, video appointments are becoming more prominent primary care physicians for routine medical issues. While video appointments would increase convenience, the services would have to be available to at-risk and underserved

population. As faith-based organizations continue to be used in conjunction with research, it is important that academia works with them to implement strategies to help with gaining access and improve trust to underserved populations.

Having sufficient time with patients can be an issue with healthcare providers, (Abdulhadi, Al-Shafae, Wahlstrom, & Hjelm, 2013; Yarnall, et al., 2009), and healthcare providers from all disciplines in this study indicated that a lack of time or high workload demand was a factor in treating diabetic patients. However, primary care physicians that had access to a doctor of pharmacy that could provide additional one-on-one diabetic counseling after a visit provided opportunity for immediate feedback. Where feasible, this might be a model to consider when time with a primary care physician is limited. Two healthcare providers anonymously attended diabetes self-management classes to learn what was being taught and see things from the patient's point of view. Structured programs that permitted diabetes educators to conduct formal trainings regarding the material taught in DSME classes may improve efficiency and rapport between the healthcare provider, the patient, and diabetes educators. Because diabetes is a leading contributor to cardiovascular disease and stroke, implementing an additional education section on cardiopulmonary resuscitation (CPR) certification or with annual competencies for healthcare providers may also be warranted.

It is important to understand how healthcare providers perceive the motivation and self-management strategies of their patients with T2DM, as well as their perceived roles in their patients' diabetes self-management strategies. Future research should continue to explore the best ways to reach African American men with T2DM and focus on ways to improve their diabetes self-management strategies, as well as tailoring

programs to address modes of motivation and also promote prevention (e.g., via healthy lifestyle). Additionally, further exploration of ways to improve and promote a positive relationship between African American men with T2DM and their healthcare providers may help in improving diabetes self-management strategies.

## CONCLUSION

Properly managing their condition can help individuals with T2DM maintain a good quality of life (Kueh, Morris, Borkoles, & Shee, 2015; Zimbudzi, et al., 2016). There are many factors that influence motivation to self-manage diabetes and understanding various modes of motivation can help increase the effectiveness of diabetes self-management education programs. Diabetes affects racial and ethnic minorities disproportionately, and healthcare disparities and healthcare access are issues of concern that may contribute to many African Americans not seeking appropriate care to manage their diabetes (U.S. Department of Health and Human Services, 2018).

African American men are an underserved population in research, and efforts to understand what motivates African American men to manage their diabetes and what they and healthcare providers believe contribute to the successful management of diabetes and attendance at diabetes self-management classes can have major implications for implementing new and effective strategies to help this population with diabetes self-management techniques. The findings of this study can supplement current data on the need to continue understand what motivates African American men to manage their diabetes and understand the importance of their relationships with their healthcare providers.

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## CHAPTER 5

### DISCUSSION

The purpose of this study was to explore an understudied and underserved population, African American men, their experiences living with type 2 diabetes (T2DM) and to get their explicit account of how they defined diabetes and described their diabetes self-management behaviors. Additionally, using the Self-Determination Theory as a framework, this study explored their definition of motivation, their motivations for managing diabetes, and their motivations for attending diabetes self-management classes. Finally, the study explored the relationship between African American men with T2DM and healthcare providers from various disciplines that treated African American men with T2DM, how older, African American men viewed the role of their healthcare providers in assisting them with T2DM, and what healthcare providers thought would motivate African American men with T2DM to manage their diabetes and attend a diabetes self-management education program.

Having been raised in a rural community in South Carolina that had a high rate of diabetes, I experienced firsthand the deleterious consequences of “sugar diabetes”, as diabetes was often referred to by older members of my church and community. At the time, I did not realize how much of a lifestyle changer having diabetes could be, but working in the healthcare field, being involved with individuals with T2DM on a frequent basis, and my interest in public health has given me a peripheral account of the impact diabetes can have on individuals. This research project is a product of the passion and



interest that has developed and evolved over that timeframe. Preliminary ideas on this research study arose from a keen interest of health concerns for geriatrics, and more specifically about older African American men. Continuing to promote health behaviors and initiatives to educate African American men with diabetes, can decrease, and hopefully, one day eradicate these health care disparities as well as improve their current self-management strategies.

In this chapter, the following is presented: 1) a summary of the major findings of the study, African American men's definitions and descriptions of diabetes, their initial reactions when first being diagnosed with diabetes, their experiences living with diabetes, their diabetes self-management behaviors, their definitions and descriptions of motivation, their motivation to manage diabetes as related to the Self- Determination Theory, their perceptions of their healthcare providers, what healthcare providers who treat African American men with T2DM think motivates African American men to manage their diabetes and to attend diabetes self-management education classes, 2) strengths and limitations of this study, 3) importance of methodology, and 4) implications for research and practice.

### **Summary of Major Findings**

By the use of in-depth interviews, rich information was gathered from the participants. Two specific aims with associated research questions were devoted to exploring these phenomena.

**Specific Aim 1:** To explore the definitions of diabetes, experiences living with diabetes, and diabetes self-management behaviors of African American men between the ages of 40-85 with T2DM.

Research Questions:

- 1) How do African American men between the ages 40-85 with T2DM define diabetes?
- 2) How do African American men between the ages of 40-85 with T2DM describe their experiences living with diabetes?
- 3) How do African American men between the ages of 40-85 describe their diabetes self-management behaviors?

Results from specific aim 1 are presented in manuscript one, *Experiences of African American men in South Carolina between the age of 40-85 living with type 2 diabetes*. Data was gathered and themes evolved on the following topics: 1) participant's definition of diabetes, 2) their experience living with diabetes, and 3) participant's diabetes self-management behaviors.

Diabetes continues to have an enormous impact on our entire population, but disproportionately effects racial and ethnic minority groups (Peek, Cargill, & Huang, 2007; U.S. Department of Health and Human Services, 2018; U.S. Department of Health and Human Services, 2016). Thus, it is important to study this underserved population to gain further insight on how African Americans with diabetes define and describe their condition, their lived experiences and self-management of diabetes, their perceptions of

their healthcare providers, and their feelings about diabetes self-management education. Individuals living with diabetes face many challenges, including comorbidities and adjusting to a multitude of diabetes self-management issues that can be improved with a greater understanding of their lived experiences and self-management behaviors.

Participants defined diabetes vividly as a “big nasty disease” that “attacked your body and if not controlled it could just take your life, your limbs, eyesight and everything because it’s a bad nasty disease.” Participants generally described living with diabetes with various reactions such as disbelief, anger, and being scared when first being diagnosed with diabetes. Participants emotional experiences living with diabetes involved a wide spectrum of emotions including denial, shock, fatalism, apathy, guilt, fear, and distrust.

Many participants were in denial and shock when they were first diagnosed with diabetes. This may be a reason that many of them did not take the diagnosis of diabetes seriously. Other studies (Eborall, Davies, Kinmonth, Griffin, & Lawton, 2007) have also shown that participants experience a process of psychological adjustment as they progressed through a diabetes screening process and downplayed the seriousness and the individual risk of having diabetes. While these emotions are similar, previous research (Low, Tong, & Low, 2014) identified mixed feelings of positivity and negativity as related to the domain of quality of life. These types of feelings may lead to compromise in managing diabetes because individuals do not see it as an immediate danger. Some participants mentioned that diabetes is a “silent killer” and “it is not like cancer” indicating that they may not take it as seriously because they did not view it as posing and immediate threat. While the “silent killer” expression is typically associated with

hypertension (CDC, 2016), diabetes has also been referenced as a “silent killer” (Riaz, 2009).

Fatalism was a common theme with many participants believing that they were predestined to get diabetes regardless of what they may do. Fatalism, or a sense of hopelessness in having diabetes, is often experienced with individuals living with diabetes (Walker, et al., 2012). Many participants believed that getting diabetes was related to hereditary, and since their parents or siblings had it, they would get it too. Recent research suggests that, while there is still a need to explore the relationship between religiosity and fatalism, addressing fatalistic attitudes may be a useful strategy for diabetes management (Berardi, Bellettiere, Nativ, Hovell, & Baron-Epel, 2016). This could lead to a great opportunity for health ministry leaders to address fatalistic attitudes. If individuals with T2DM believe that they are ultimately going to get diabetes and suffer from complications associated with diabetes regardless of what preventive measures they pursue, then these individuals need to be identified immediately after their diagnosis to educate them on the importance of diabetes self-management and that they can benefit from proper self-management strategies (American Diabetes Association, 2017; Standards Revision Task Force, 2014).

The notion of distrust in research agendas and the healthcare community has long been a concern in the African Americans (Freimuth, et al., 2001; Jacobs E. A., Rolle, Ferrans, & Whitaker, 2006), and continues to be a significant barrier (Scharff, et al., 2010). Current research indicates that perceived health care discrimination is associated with poorer glycemic control among black men (Assari, et al., 2017). In this research study, distrust was an interesting theme that evolved. On an individual level the majority

of the participants actually thought highly of their primary healthcare provider, but still felt a lack confidence in the overall healthcare system as related to with their diabetic condition. A few of the participants questioned why they were not told of “pre or borderline” diabetes, and one participant noted that he was falsely diagnosed with diabetes.

Fear was a common theme mentioned when participants were describing living with diabetes. Participants frequently mentioned fear of amputations, fear of needles, fear of erectile dysfunction, and fear of declining health. Participants’ experiences of seeing others with amputations left vivid pictures in participants’ minds of possible consequences of improperly managed diabetes. Another prominent fear for participants was the fear of needles or having to take insulin injections. Fear of needles and injections is common and has been associated with healthcare avoidance (Wright, Yelland, Heathcote, Ng, & Wright, 2009). Many participants recalled unpleasant experiences of having to watch loved ones get insulin injections. Erectile or sexual dysfunction was a major concern for all participants, and fear of erectile dysfunction and possible decreased intimacy received the most animated responses, “You know whatever is going to interfere with that [sex] you know I need to keep it in check!” All men mentioned that anything that effected sexual performance was a serious concern. There is evidence that erectile dysfunction is prevalent in the men with T2DM, but research is addressing ways that counseling and adjunct therapy can improve sexual function (Corona, Glorda, Cucinotta, Guida, & Nada, 2016).

Participants managed to live with their diabetic condition by finding ways to pay for medications and diabetes test kits, trying to achieve good health and wellness, and

relying on family support. For most of the participants, cost was identified as a barrier, and this is consistent with current literature (American Diabetes Association, 2017; Li, et al., 2013; Zhuo, Zhang, Albright, Thompson, & Gregg, 2014). While most individuals in the study were concerned with the cost of managing diabetes on an individual basis, the systemic cost of managing complications was rarely mentioned but that could be reflective of how this research study emphasized the individual components instead of institutionalized components. For example, some participants simply would not consistently check their glucose levels because of the cost of test strips, but contrarily, some participants indicated that their test strips were free or that they could be given a supply of test strips by their healthcare provider. This indicates that there is a need for consistency on educating individuals on the availability of cost-effective items that can assist with managing their condition.

This study is consistent with previous research in that participants reported family support as being either positive (supportive) or negative (nagging). Previous studies have shown that family support has an influence on the self-management of diabetes. Family support can have a positive influence by increasing a patient's self-esteem and encouraging optimism (DiMatteo, 2004). Although this type of positive or instrumental family support can help the patient manage his or her diabetes, obstructive family support can have negative consequences (Mayberry, Harper, & Osborn, 2016). Indeed, reporting more obstructive behaviors by family members is associated with less adherence-related motivation and self-efficacy (Cardenas, Vallbona, Baker, & Yusim, 1987; Pamungjas, Chamroonsawasdi, & Vatanasomboon, 2017). Therefore, nagging, or obstructive support, can have a negative influence on individuals that self-manage their diabetic condition.

Although participants in this study reported having family support, it varied in forms and frequency, with the majority of participants reporting positive family support, including the majority of married participants. For example, one married couple relied on encouraging each other to take medications, attend doctor's appointments, and remaining physically active. However, some patients who reported positive family support still did not adhere to proper diabetes self-management strategies. One participant noted that his wife was upset with him because he became dizzy and fell in the yard because he was not taking his medication properly.

African American families with low socioeconomic status managing diabetes can often experience both supportive and obstructive support from the same individual (Mayberry, Harper, & Osborn, 2016). However, in this study, the majority of the family support was supportive and came from the participant's wife or significant other. An important factor that may have influenced these reports of positive support might have been that that 45.4 % of participants reported an income over \$50,000, and 63.6 % attended at least one year of college. Thus, their socioeconomic status is significantly higher than that of the participants reported by Mayberry, Harper, and Osborn (2016).

Family and social support are crucial components of diabetes management and adhering to diabetes self-management (Miller & DiMatteo, 2013). Most of the participants stated that family support was important in helping them to manage their diabetes. In most instances, it was their wife or children that either encouraged them to be consistent in taking their medication or reminded them of the consequences of not taking their medications such as amputations, blindness, and using needles for injections. A few individuals noted that that they did not need any support, and that they could manage

diabetes on their own. Since many of the participants indicated that they were motivated by family support, finding ways to incorporate positive family support into DSME programs could possibly lead to improved motivation and improved outcomes.

Self-management behaviors varied among participants. Most of the participants who believed that they had diabetes did take their medications and believed that they needed to remain consistent with their medications to manage their diabetes. Many times individuals with T2DM have other conditions such as hypertension, cardiovascular disease, cerebrovascular diseases, obesity, and hyperlipidemia (American Diabetes Association, 2011; Centers for Disease Control and Prevention, 2015), and despite measures to control glycemic levels, research suggest that glycemic goals are achieved by less than 50% of individuals and this may be associated with decreased adherence to therapies or having 3 or more chronic conditions (Garcia-Perez, Alvarez, Dilla, Gil-Guillen, & Orozco-Beltran, 2013).

Research indicates that lifestyle and behavior changes such as promoting healthy dieting strategies and increasing physical activity can aid in combating and controlling T2DM (Mohammad, 2014; Nelson, Reiber, & Boyko, 2002; Colberg, et al., 2010). While many of the study's participants acknowledged that health and wellness consisted of proper dieting and exercising, the majority of the participants did not exercise or eat properly. Most participants admitted that they often practiced improper dieting habits in which they ate foods they were advised to avoid. Many did not participate in an active exercise program, but some did note that they participated in activities such as walking and yardwork to remain active. Some were just not motivated to exercise which is consistent with previous research (Praet, Rooij, Wijtvliet, & et al., 2008). The American



College of Sports Medicine and the American Diabetes Association recommend that individuals with T2DM participate in at least 150 minutes of moderate exercise weekly which should include resistance training 2 to 3 times a week (Dugan, 2016).

Many individuals with T2DM do not meet the recommended levels of physical activity and many do not have access to behavior change programs that support lifestyle changes, but use of technology such as mobile applications, social media, and games offers avenues to help individuals with T2DM change exercise behaviors (Tate, Lyons, & Valle, 2015). Since the participants in this study were older, many did not use technology to assist with managing diabetes, but all except one had access to a mobile phone. This could be an area where younger family members and spouses who embrace modern technology could help individuals with T2DM to improved adherence to physical activity and self-management with diabetes (Beverly & Wray, 2010).

Involving and integrating technology is becoming increasingly important with apps to monitor, track, and educate individuals with T2DM, and future will have a greater familiarity and comfort level of using the technologies to help manage diabetes which may lead to possible automated treatment systems (Ramchandani & Heptulla, 2012). It was not within the scope of this study to assess participants familiarity with technology or smartphones, but further research is needed to analyze the effectiveness of new technologies that can aid with diabetes self-management (Shaw & Garg, 2015). Text messaging has been used with different levels of success in the context of clinic-based quality improvement initiative to assist with diabetes self-management. The results have varied with success in clinically significant weight loss in individuals with prediabetes (Fischer, et al., 2016), but with no statistical difference between a control group and an

intervention group as related to change in A1C (Capozza, et al., 2105). Obviously, owning a cell phone, the degree of cellular coverage, and efficacy of an electronic mobile program is critical for the success of an electronic mobile program (Van Olmen, et al., 2016). Despite the technological advances, lifestyle and behavior change and modes of motivation will still ultimately remain up to the individual. For example, one participant acknowledged the benefits of DSME programs, but adamantly admitted that he could be given all of the knowledge about diabetes “in the world”, but it would not matter until he decided to change his behavior.

There continues to be barriers to diabetes self-management education and individuals having a lack of knowledge of target blood glucose and blood pressure (Onwudiwe, et al., 2011; Osborn & Fisher, 2008; Agency for Healthcare and Research Quality, 2016). Sometimes, individuals who do not practice healthy behaviors are perceived negatively as if they do not care about their health and that adherence problem is their fault, or that healthcare is available and accessible to them (Tripp-Reimer, Choi, Kelley, & Enslein, 2001). With access to healthcare still being a major issue for minorities (U.S. Department of Health and Human Services, 2016; Peek, Cargill, & Huang, 2007), it is important that these attitudes are curtailed and do not negatively influence treatment of individuals with chronic illnesses or any illness.

Most of the participants believed that they could benefit from diabetes education classes, but participants’ opinions varied on the best setting for these classes, i.e., individual versus group setting. Participants also believed that diabetes education classes

were inconvenient with respect to time and location, consistent with previous research (Gucciardi, DeMelo, Offenheim, & Stewart, 2008). However, a few stated that if the classes were incorporated into their workplace, attending would be easier. A few participants said that they thought diabetes self-management classes were boring. One participant stated that he would not attend a diabetes self-management class because he was still not convinced that he had diabetes. Most participants reported that portion control and proper dieting were heavily enforced in the diabetes self-education classes.

**Specific Aim 2:** To explore motivations of African American men between the ages of 40-85 with T2DM to engage in diabetes self-management behaviors, using a Self-Determination Theory as a Framework.

Research Questions:

- 1) How do African American men between the ages of 40-85 years with T2DM describe self-management of their diabetes?
- 2) How do African American men between the ages of 40-85 years with T2DM define motivation?
- 3) What type of motivation do African American men between the ages of 40-85 years with T2DM exhibit in managing their diabetes as related to the Self-Determination Theory?
- 4) What do African American men think about the healthcare providers involved in managing their diabetes?
- 5) What do healthcare providers think influences motivation to manage their diabetes in African American men between the ages of 40-85 years with T2DM?

- 6) What motivates African American men between the ages of 40-85 years to attend diabetes management classes?

Results from specific aim 2 are presented in manuscript two, *Exploration of motivation among African American men regarding management of type 2 diabetes using Self-Determination Theory as a framework*. Data was gathered and themes evolved on the following topics: 1) the participant's definition of motivation, 2) participants motivation for managing their diabetes, 3) participants perceptions of their healthcare providers, 4) healthcare providers perception of their roles in treating African American men with T2DM, 5) what African American men with T2DM and healthcare providers that treat African American men with T2DM believe motivates them to self-manage their diabetes, and 6) what African American men with T2DM and healthcare providers that treat African American men with T2DM believe motivates them to attend diabetes self-management education classes.

Participants defined motivation in various ways but overall their definition of motivation was consistent with having a “drive,” a “goal,” or “to achieve something without external pushing.” For most participants, being there for family or children were their primary motivating factors. As related to the motivation and the theoretical framework of the Self-Determination Theory, none of the participants stated in their interviews anything that could be considered true intrinsic motivation for managing their diabetes or attending DSME classes for the joy of the activity. A few participants were amotivated, not really caring about managing their diabetes, and a most had extrinsic motivation of managing their diabetes such as being there for family, seeing grandchildren grow up, or not wanting to have to deal with needles or finger pricks

In the Self-Determination Theory, an individual's motivation is influenced by his or her levels of autonomy, relatedness, and competence (Deci & Ryan, 2000). Generally, as these factors are increased, an individual's motivation also increases. Because this was a qualitative study, autonomy, relatedness, and competence were not measured objectively, but through examination of the interview responses, it was determined that autonomy was present, in that most of the participants had positive associations with their healthcare providers and reported that they controlled and were responsible for diabetes self-management. This is consistent with research that an autonomy-supportive environment from physicians is strongly associated with autonomous motivation and effective self-management of T2DM (Koponen, Simonsen, & Suominen, 2017). Participants also exhibited competence via feeling confident and knowledgeable about their diabetes self-management, and they exhibited relatedness in feeling they were responsible for their own self-management and in understanding their connection to their diabetic condition and the relationship and importance of properly managing their diabetes.

In examining the types of motivation that participants exhibited to self-manage their diabetes, results indicated that participants generally relied on a mixture of both intrinsic and extrinsic motivation, with a few participants reporting amotivation, which is consistent with an SDT framework. However, the results from the modified IMI and in-depth interviews differed. It is important to note that although Likert-type rating scales are important in research, there is evidence that the scale format can influence response distribution (Weijters, Cabooter, & Schellewaert, 2010). Data from the modified IMI indicated that all or practically all participants thought that participating in a DSME

program would be fun, they would feel relaxed, they would enjoy it very much, they would not be anxious to participate, it would not be boring, it would be interesting, they would not feel pressured to participate, and they did not feel as if they had to participate. Contrarily, many of the participants indicated in their in-depth interviews that DSME classes were boring, covered the same information, were too long, and were inconvenient.

One point to consider is that the modified IMI only asked participants about their motivation to attend DSME classes, which is just one aspect of diabetes self-management. The in-depth interviews probed deeper into diabetes self-management in general, including DSME class attendance. Although the modified IMI and in-depth interviews each had a slightly different focus, and thus some variation may be expected in responses, we would expect the results from the two to be fairly consistent. The differing findings that were observed here could perhaps be explained by responder bias, unreliability of self-reported data, and social desirability of certain responses. These biases may exist when individuals tend to present a favorable image of themselves on questionnaires (Mortel T. v., 2008). To control for social desirability response bias, future studies could include a self-report social desirability scale, such as the Crowne-Marlowe Social Desirability Scale (Crowne & Marlowe, 1960). The modified IMI was adapted for populations with diabetes but would benefit from further testing with African American men with T2DM to ensure that it indeed measures the degree of intrinsic motivation with this specific population. Another point to consider is that not all DSME programs are homogenous in orientation, curriculum, and setting, with some participants having attended classes held by certified diabetes educators, some having been educated by their

healthcare providers, and some having only been given materials to read. In addition, responder bias might have played a role, in that respondents wanted to answer questions in a positive manner.

There are other possibilities to consider when explaining the different results rendered by the in-depth interviews and the modified IMI. While the data from the qualitative interviews exploring intrinsic motivation differed from the modified IMI, it is important to note that the interview guide was specifically designed to explore 3 specific topic areas for 22 African American men with T2DM: 1) Personal and diabetes-related information, 2) Diabetes self-management and motivation information, and 3) Diabetes self-management program information. The purpose of the modified IMI was to provide adjunct, descriptive data via measuring the level of intrinsic motivation of African American men with T2DM to attend and to participate in a DSME program. Thus, the in-depth interviews and the modified IMI provided information on 2 different phenomena. The interview guide sought to explore personal information on diabetes, aspects of diabetes and motivation to self-manage diabetes information, and general information on diabetes self-management education programs, whereas, the modified IMI sought to provide descriptive information on the level of intrinsic motivation that participants experienced during their actual participation in a DSME program and motivations to attend a DSME.

Although the data obtained from the interview guide and the modified IMI differed in the levels of intrinsic motivation that they reported, it perhaps raises an interest finding that there are different types of motivation in the daily self-management of diabetes compared to the motivations to participate and attend a DSME. Previous

research reveals that diabetes self-management can be influenced by socioeconomic factors (Weaver, Lemonde, Payman, & Goodman, 2013) and social resources (Newton, Asimakopoulou, & Scambler, 2015). This inherently places more variables in the daily diabetes self-management behaviors that may include family, financial obligations, medications, physical activity, and dietary concerns that will have to be managed for a lifetime. On the other hand, participants that expressed high levels of intrinsic motivation for attending and participating in diabetes self-management education classes may not view them as permanent or something that they had to do as compared to their daily self-management of diabetes. This is important, but it reveals that motivation is just not a “one-size-fits-all” philosophy when implementing strategies to improve diabetes self-management strategies and strategies to improve DSME attendance and participation by older African American.

There are a few other factors that may have contributed to the differences in the high levels of intrinsic motivation reported in the modified IMI and the lack of intrinsic motivation reported in the interviews, in addition to responder bias, problems with self-report data, and social desirability. Although the modified IMI has been tested over several domains, such as tobacco cessation, sports, weight management, and diabetes management, it has not been specifically tested with older, African-American men with T2DM. An important factor that must be taken into consideration is that the modified IMI asked questions that were specifically related to attending and participating in a diabetes self-management education class, whereas the in-depth interviews addressed diabetes self-management classes but also explored many other aspects of diabetes management, such as struggles with diabetes self-management, motivations to self-manage diabetes,



relationships with healthcare providers, and family support. Thus, future studies could match specific interview questions to the items contained in the modified IMI, which might offer results that are specifically related to the level of intrinsic IMI for attending diabetes self-management classes.

The results of this study indicated that participants realized that physical activity and maintaining proper diets were key components in diabetes self-management, but the majority of them still did not adhere or engage in consistent physical activity or proper diets. This is consistent with previous research with general population not adhering to physical activity or dietary recommendations. As related to motivation for dieting and physical activity, monitored exercise and dietary programs have shown that long term interventions can improve motivation in terms of intrinsic regulation of and improving autonomous motivation (Saavedra, Garcia-Hermosa, Escalante, & Dominguez, 2014).

Benefits of physical activity (Colberg, et al., 2010) and medical nutrition therapy (MacLeod, et al., 2017) are well known, and because being overweight is a risk factor for developing T2DM (Geyen, 2012), it is important for individuals with T2DM to incorporate physical activities into the activities of daily living and adhere to proper diabetic diets. Physical activity and maintaining proper diabetic nutritional and dietary strategies are critical components of diabetes self-management education and support programs. Certified diabetes self-management education programs include Medical Nutritional Therapy (MNT), which is an evidence-based application of the nutrition care process provided by registered dietitian nutritionist and includes an individualized nutrition assessment, nutrition diagnosis, intervention and monitoring, and evaluation (Powers, et al., 2015). Many participants mentioned that one of the main points retained

from diabetes self-management education programs was the importance of portion control in their diets. It important to continue to emphasize portion control and ways to motivate individuals with T2DM to adhere to portion controlled diets because it is can aid in weight loss and weight reduction (Foster, et al., 2013).

The findings of this study revealed that while the majority of the participants cited the importance of physical activity and proper dieting in self-managing their diabetes, only a few indicated that they were compliant in maintaining proper physical activity and diet regiments. As related to motivation and in correlation with the SDT (Deci & Ryan, 2000; Deci & Ryan, 1985), dieting and weight-related behaviors, individuals are more likely to be compliant with significant behavior changes if they feel competent and autonomous about their participation (Teixeira, Silva, Mata, Palmeira, & Markland, 2012). Improving dietary concerns and healthy eating for older adults sometimes requires implementing dietary self-regulation and self-control (Naughton, McCarthy, & McCarthy , 2015). It is important to note that these are similar issues and barriers that are associated with improving motivation in the participants in this study and in diabetes self-management education programs overall (Funnell, Tang, & Anderson, 2007; Purcell & Cutchen, 2013).

In further examining the results, it is evident that the majority of the participants were not mildly motivated to implement or maintain a consistent physical activity or a healthy diet regiment even though it could possibly help their diabetic condition. Possible reasoning for their lack of motivation to implement physical activity or healthy diet regiments could center around barriers associated with physical activity such as lack of time, lack of physically active role models, decreased energy, lack of convenient

facilities, lack of safe walking areas, and lack of knowledge about proper physical activity (Joseph, Ainsworth, Keller, & Dodgson, 2015). Typical barriers that are associated with healthy dieting include time to prepare food, cost of healthy, and changing to a healthy diet (White , et al., 2017). As one of the healthcare providers reasoned, it is much cheaper to get a combination meal at a fast-food restaurant than to get a healthy meal, nutritious meal. It is more cost efficient to get can goods that can last for months than to purchase perishable items that may last for only a few days. As with previous research, diagnosis of a chronic illness does not necessarily motivate dietary and lifestyle changes among men (Er, et al.). These issues illustrate the needs to implement efficient programs, or to restructure and promote current programs to educate older African American men about physical activity, healthy dietary choices, and to explore ways to make healthy eating more affordable.

The results of this study show that many participants felt that personal motivation is not sufficient to manage their diabetes successfully. When reporting external motivation factors, the importance of family support was frequently mentioned by participants as a key to successful diabetes self-management. In this study, there were two situations in which participants and their spouses were both dealing with self-managing T2DM. The two couples were distinctly different: one worked together and managed their diabetes as a team, whereas the second couple was totally independent in managing their diabetes. The participant that managed his diabetes independently noted that he and his wife were both college educated and did not need to depend on each other to self-manage their diabetes. The participant that co-managed his diabetes with his wife noted that they encourage each other and stated that they both had other health ailments.

Although this study examined African American men only, it is interesting to note gender differences in the perceptions and responses to family support. In previous research, women reported family support less often than men and reported family barriers to self-care more often than men, and nearly 80% of women reported that family members nagged or criticized them about their illness care (Rosland, Heisler, Choi, Silveira, & Piette, 2010). In the current study, most participants reported positive family support, and it is important to identify and incorporate positive family support in DSME interventions and strategies to enhance motivation and behavior skills. It is particularly important that family members not interfere with an individual's diabetic self-care efforts (Mayberry & Osborn, 2012).

These findings on the assistance family members provokes further thought on areas that future research may address concerning the motivations and intentions of the family members of African American men with T2DM. Many participants in this study mentioned wanting to be there for their children, and some participants did have the support of their wives, but the motivations of family members were not explored. Supportive family behaviors have been associated with adherence to various self-care behaviors, and obstructive family behaviors have been associated with less adherence to these behaviors (Mayberry & Osborn, 2014).

There is a positive and significant relationship between social support and adherence to diabetes treatment (Miller & DiMatteo, 2013). It is clear that social support has a vital role in improving adherence to diabetes self-management strategies, but it is important to identify what comprises positive family support, what types of social support family members are capable of providing, what type of support an individual

with diabetes is willing to receive, and the types of motivations behind family members' actions. Future research could aim to identify the various types of social support interventions that promote adherence and the motivations behind social support.

One participant had three daughters and a wife and jokingly admitted if he did not manage his diabetes appropriately, he would have “no peace in the house.” Sometimes family members' non-supportive behaviors can have a negative impact on individuals that are self-managing their diabetes. In situations as these, Mayberry and Osborn (2014) concluded that involving family members in an individual's diabetes management may compromise self-care and glycemic control if family members demonstrate obstructive behaviors. Although family members may perceive their actions as ways to motivate an individual to remain consistent with diabetes self-management, they could ultimately be curtailing the individual's efforts and motivations to manage his or her diabetes by providing the wrong type of family support.

The results of this study indicated that there were some commonalities between African American men with T2DM between the ages of 40 and 85 years and healthcare providers that treat African American men with diabetes on many issues surrounding the management of diabetes. Participants and healthcare providers spoke about the importance of outside support. A few participants noted that golf outings provided them an opportunity to address diabetes issues with their peers in a friendly environment. Some healthcare providers encouraged their patients to bring their wives to their doctor's appointments, with the rationale that in most households, the wife is responsible for cooking or preparing the meals. The rationale of the healthcare provider was that if both, the patient and his wife, are educated in proper self-management techniques, especially as

related to diet, the chance of successful diabetes management would be increased.

African American men with T2DM and healthcare providers both recognized that the cost of managing diabetes and the inconvenience of the times and locations of the DSME classes were barriers to increasing motivation to self-manage diabetes.

While patients in the study reported fears of what may accompany improperly managed diabetes and healthcare provider acknowledged using fear tactics such as warning patients of possible erectile dysfunction, amputations, or comorbidities, this did not necessarily lead to a sustainable behavior change in the participant's diabetes self-management strategies. There is research that indicates that the use of fear tactics may not be effective, and even though individuals may use negative sources of motivation to initiate behavior change, positive sources of motivation may better aid in maintaining long-term health behaviors (Sabourin & Pursley, 2013). Indeed, fear tactics as motivation have been used for decades in public health advertising and in healthcare provider relationships (Leventhal, 1971; Wright, Yelland, Heathcote, Ng, & Wright, 2009). The use of fear as a motivation tactic has produced some conflicting findings, with some studies reporting that fear can be ineffective in promoting or achieving a particular behavior change (Job, 1988). However, in certain public health areas, such as HIV/AIDS, previous research states that the use of fear arousal can promote behavioral change when implemented with other strategies, including self-efficacy (Green & Witte, 2006). Diabetes self-management education programs have transitioned from a medical model that emphasized treatment of acute health care problems in which goals were set by healthcare professionals to an empowerment model that is patient-centered and tailored to match the goals of their diabetes care (Funnell, Tang, & Anderson, 2007; Funnell &

Anderson, 2004). Thus, it should be part of the education process to make patients aware of the consequences of diabetes, but emphasis should be placed on empowering individuals with diabetes to manage their diabetic condition.

Although African American men with T2DM and healthcare providers both indicated that fear was a motivating factor in diabetes self-management, this idea was conceptualized in different ways. African American men expressed a fear of detrimental consequences, such as amputations and having to use needles, as motivation for managing T2DM. Most of the healthcare providers here reported using fear as a motivating factor by educating their patients that improperly managing their diabetic condition could lead to further complications such as amputations, retinopathy, neuropathy, kidney disease, hypertension, and erectile dysfunction. From the healthcare providers perspective, and from the participants' reports, the possibility of erectile dysfunction was a topic that was commonly used as a fear tactic by healthcare providers and was a motivation strategy for participants. It is difficult to determine the impact that fear tactics may have when motivating African American men to properly self-manage their diabetes, as healthcare providers and patients may differ in what they believe improves adherence (Brundisini, Vanstone, Hulan, DeJean, & Giacomini, 2015).

In addition to fear tactics, one healthcare provider reported using motivational interviewing, as well as allowing patients to have ownership of their management plans and encouraging patients to play an active role in their diabetes management. Healthcare providers noted that repetition and continuous reinforcement are critical components in motivating African American men between the ages of 40 and 85 with T2DM to good self-management of their condition. Additionally, there was a sense that healthcare

providers need to “dig deeper” to see if there are other underlying factors influencing individuals in self-managing their diabetes. Healthcare providers noted that discovering some of the obstacles or barriers that hinder motivation of African American men with T2DM could allow them to address the underlying causes. For the most part, healthcare providers perceived that lifestyle changes and changing routines influenced self-management motivation. One provider stated that T2DM typically comes on during middle age, and it is difficult to change a routine or a lifestyle when you have been doing something for 30 years.

The role of the healthcare providers varied with most healthcare providers seeing themselves as a “cheerleader,” “coach,” “role model,” and “lifestyle changers.” Most of the healthcare providers also realized that they had to hold themselves accountable and to “practice what they preached.” Healthcare providers believed that several things could possibly motivate individuals with diabetes attend diabetes management classes such as: making class information interesting, making classes convenient, involving family with the management of diabetes, reaching the individuals with diabetes “where they are,” decreasing cost of managing diabetes, empowering individuals, recognizing the importance of culture, and having more time to spend with diabetic patients. There is literature on what doctors and nurses feel are barriers with care of diabetes care (Abdulhadi, Al-Shafae, Wahlstrom, & Hjelm, 2013), but there is not any significant literature on African American men with T2DM and healthcare providers that treat them on their as related to their perceived roles and relationships between them and how they view motivation and motivation to self-manage diabetes. Previous research suggest that the patient-doctor relationship is important because if patients have a favorable viewpoint



of their healthcare providers, they are more likely to be compliant with being compliant with plan of care (Gensichen, et al., 2009; Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). In this study, most participants viewed their healthcare providers favorably and graded them highly. However, a few of the participants had negative opinions and expressed distrust in their healthcare providers. Future studies could explore if diabetes self-management correlated with the how African American men with T2DM perceived their relationship with their healthcare provider

All of the healthcare providers in the study perceived diabetes self-management education classes as beneficial and a critical piece in assisting with self-management of diabetes. However, many of them did not know the specifics that were being taught in the diabetes self-management classes. This could be an area of potential systemic improvement in the initial phases of diabetes education by taking measures to ensure that there is a consistent message being delivered by healthcare providers and DSME programs. Additionally, healthcare providers provided consistent themes that the high cost of treating and managing diabetes could be a major barrier for individuals with diabetes. The cost of test strips and medication, not enough time at office visits, and not believing in the seriousness of the disease were all concerns with promoting diabetes self-management. Many of the participants stressed that there needed to be more emphasis on pre-diabetes or borderline diabetes phases. All of the healthcare providers indicated that the goal is to prevent diabetes and greater emphasis should be place on preventative measures. This is consistent with past and current literature as diabetes prevention initiatives have been and continue to be implemented on a global (WHO, 2016), national

(U.S. Department of Health and Human Services, 2010), and state level (Myers, et al., 2011).

Healthcare providers and participants expressed a concern that a lack of access to DSME classes in terms of times and location prevented some from attending DSME classes. Both groups of participants consistently mentioned that the convenience factor could be improved if classes were offered in other setting such as their jobs. Access, availability, and convenience to DSME programs is vitally important (U.S. Department of Health and Human Services, 2016; Tripp-Reimer, Choi, Kelley, & Enslein, 2001; Centers for Disease Control and Prevention, 2015) because regardless of how effective the classes or programs are, they are not beneficial if they are not reaching this high-risk population.

Healthcare providers believed that decreased access to healthcare and inconsistent follow-up visits with health providers were factors that may lead to decreased effectiveness in diabetes self-management. They believed that many people may not have insurance or simply just might not have regular visits with their healthcare providers. However, for this study, all participants had visited their primary care physician within 6 months and most of them had visited their primary care physician within 3 months. This is different than what is represented in the literature, but it is a very important issue. Individuals with diabetes who do not have health insurance have fewer physician office visits and are prescribed fewer medications for diabetes than individuals with insurance coverage, but they also have more emergency department visits than people who have insurance (American Diabetes Association, 2017). In this study, factors that may have contributed to a high number of participants having health insurance and having recent

visits to their primary care physician may be due to the average age of this study being 63.8 years and many of the participants were eligible for Medicare, and that half of the participants were either college graduates or had attended 1-3 years of college.

All African American men in this study were affiliated with a faith-based organization. Community and church-based diabetes self-management interventions that are culturally targeted have been shown to improve outcomes for African American adults with T2DM (Collins-McNeil, et al., 2012). However, educating African American men with T2DM about their diabetic condition is still challenging and must reach various settings, or in the words of one of the healthcare providers, “reach them [individuals with diabetes] where they are.” Traditionally, there has been success with faith-based organizations being relied upon to reach the African American population (Streaty-Wimberly, Braithwaite, & Taylor, 2001; DeHaven, Hunter, Wilder, Walton, & Jarett, 2004), but not all African Americans are affiliated with faith-based organizations. Thus, research initiatives have to continue to recruit African Americans in traditional settings such as churches and barbershops but must also recruit in non-traditional areas beyond churches and barbershops.

In this study, community leaders and health ministry and men’s ministry leaders played a critical role in identifying the targeted research population. The majority of men in this study indicated that they were very willing to participate in the study, but they were not aware that African American men were needed for diabetes research until announced at their church or mentioned by their health ministry or men’s ministry leaders. Additionally, they did not realize that African American men were an understudied population and that they could contribute to research by their participation.

As with previous research (Tripp-Reimer, Choi, Kelley, & Enslein, 2001; Heisler, et al., 2009), incorporating community leaders, or as in this study health ministry and men's ministry leaders, was critical in the recruitment of African American men and making them comfortable and aware of the need to study older African American men with T2DM. This also identifies a need to improve dissemination of information to underserved and understudied populations such as African American men.

### **Strengths and Limitations**

Addressing the limitations of the study will consist of disclosing limitations, describing limitations, and describing directions and implications of future research similar to steps outline by Brutus, Aguinis, and Wassmer (2013). Limitations of the study included a sample size that could not be generalizable to a larger population, inclusion criteria, instrumentation, and research bias. The sample size for this study was n=22 for specific aim 1 and n=28 for specific aim 2, and participant selection was non-randomized. Although not generalizable to a larger population, the sample size was large enough to achieve saturation and adequately address the research questions that were posed. This study used specific inclusion criteria with African American men between the ages of 40 and 85 years old with T2DM affiliated with the AMEZ church in and the Piedmont region of South Carolina and healthcare providers that treat African American men with T2DM in the same region. Thus, this study does not reach African American men who are not in these geographic regions, not affiliated with the South Carolina Conference of the SAED, or with the AME Zion churches in these areas.

The modified IMI was used for descriptive data only, but further pilot testing of this questionnaire for reliability and specificity could improve its accuracy in future studies of African-American men with T2DM. Although the healthcare providers were from various disciplines, genders, and ethnicities, including only six healthcare providers treating African American men in a specific geographic region does not allow for generalizability to a broader population. However, it does provide the unique perspectives of the different disciplines involved.

While the primary focus of this study was to focus on motivations to self-manage diabetes and to attend DSME classes, it must be acknowledged that motivation is only one area that can influence adherence to diabetes self-management strategies. Schulman-Green, Jaser, Park, and Whittlemore (2016) identified five categories of factors that affect self-management of chronic illnesses: personal/lifestyle characteristics, health status, resources, environmental characteristics, and health care system with each entity having the ability to be a facilitator or a barrier. Some of the demographic data was self-reported such as income, height, and weight, and the modified IMI.

This study had several strengths. One strength is that although qualitative research may not be generalizable to a larger population, it allows for exploration of in-depth thoughts and feelings of the research participants, which can allow for an understanding of the lived experiences of a particular population or group (Sutton & Austin, 2015). Additional strengths of this study were the initial dialog between the primary investigator and health ministry leaders, in-depth interviews in a comfortable environment, and information gathered from an underserved and understudied population. Many studies have indicated that there is a benefit in peer and community informants when attempting

to reach at-risk populations (Eakin, Bull, Glasgow, & Mason, 2002; Sarkisian, Brown, Norris, & Mangione, 2003; Sokol & Fisher, 2016; Fisher, et al., 2017).

The initial dialog between the primary investigator and the health ministry leaders was important for establishing the relationships that led to participant recruitment, as the health ministry leaders were trusted by their congregants and were thus effective at recruiting participants. Improving the success rate of recruiting African American men to research seems to be influenced by tailoring culturally sensitive and respectful recruitment materials towards African American men (Bryant, Wicks, & Willis, 2014; Loftin, Barnett, Bunn, & Sullivan, 2005). With improved recruiting strategies, hopefully, African American men will be better represented in research that is aimed to benefit them.

Conducting interviews in a comfortable setting of the participant's choice was also a strength of this study because it reduced the opportunity for external interference and provided a place of familiarity for the participant. This study also explored and could add to the limited literature on the mode of motivation of African American men with T2DM. The inclusion of healthcare provider interviews also allowed for additional information about the role these individuals can play in supporting diabetes self-management, which has the potential to greatly improve our understanding of the myriad factors that may contribute to successful diabetes self-management programs

Many participants expressed that their willingness to participate in this study was because they felt it could benefit other African American men with diabetes. This provokes the thought that maybe increased and targeted marketing that emphasizes how important and beneficial it is for African Americans to participate in research could

possibly improve recruiting strategies for African Americans. At the end of the in-depth interviews, many of the participants indicated that they would be more inclined to talk to other individuals with diabetes. Some of them made personal pledges to talk to other African American men, not only about diabetes, but getting regular medical check-ups. There is a need for future research to continue to offer insight on ways to improve participation of African American.

### **Importance of the Methodology**

Researcher bias cannot be eliminated, but it can be identified and examined to attempt to understand the impact that it has on the data-collection and data-analysis process (DePoy & Gitlin, 1998; Pannucci & Wilkins, 2010). Consistent implementation of self-reflection and reflexivity throughout this study was utilized to recognize and reduce researcher-related biases. However, the primary investigator's affinity to study this population must be taken into account. Other aspects that could influence the data and participants in this study are the dynamics and scheduling of participants. For example, does conducting interviews at a church, public place, or a participant's home alter participants' responses? Does having all data being self-reported influence the results? Although the churches are in the same district/area, does the size of the church or influence of their health ministry influence participants?

### **Implications for Research and Practice**

Findings of this study are intended to contribute to the limited literature on an understudied and underserved population, African American men between the ages of 40-85 with T2DM. By exploring the real life experiences of individuals living with diabetes,

their definitions of diabetes and motivation, their diabetes self-management behaviors, their motivation for managing their diabetes, their perceptions of their healthcare providers, and what they and healthcare providers that treat African American men with T2DM believe would motivate them to manage their diabetes and attend diabetes self-management classes, obtaining rich data will continue to add to the existing literature on this population.

As with some previous research, recruitment of African American men (Spence & Oltmanns, 2011; Ledric & McKyer, 2015) for this study was not productive initially. Once the participants realized the purpose of the study and understood that their participation could help other African American men, they began to tell others about the study. Although this only occurred on an individual basis, this type of study could lead to greater dialog between individuals with T2DM or diabetes support or education groups among these men, which promote not only discussion of diabetes self-management behaviors but possibly expands to prevention strategies as well. Furthermore, although there seems to be initiatives for research in the university or academia setting, continuing to develop community initiatives is important to continue to understand understudied and underserved populations such as African American men.

The results of this study revealed that although the participants self-reported that they would be intrinsically motivated (i.e., doing an activity for joy) to manage their diabetic condition and also attend diabetes self-management classes, the responses from their interviews expressed mostly extrinsic motivations (doing something for a separable outcome). These findings indicate that although strategies intended to improve motivations to self-manage diabetes are needed, it is important to address what types of



motivations are necessary when implementing DSME classes and when attempting to motivate African American men with T2DM to improve their self-management behavior strategies.

This study revealed some of the common dilemmas of recruiting older, African American men. Our initial intention was to recruit participants through their primary care practitioners or directly through DSME programs. Because there were not any established relationships between the research team and primary care facilities, it was difficult to gain entry to these facilities beyond the initial introductory stages. Initial contact with the primary care facilities was via the front office. Most of the facilities responded positively when the possibility of participating in research was introduced. However, after the initial contact, several attempts to set up further meetings with individuals who could approve the study were unsuccessful. In all, six DSME programs (three hospital-based and three independently operated) and ten primary care facilities were initially contacted. Some valuable information on how DSME programs operate was attained from hospital-based DSME programs, but due to time constraints, it was not possible to include hospital-based DSME programs in this study. Although no specific reasons were given for the inability to work with the primary care facilities, it appears that the reluctance stemmed from the fear of placing more demands on busy staff members. All contact persons from the primary care facilities asked about any extra responsibilities for their staff but were assured that the only work needed by staff members would be identifying participants that fit the inclusion criteria. It was communicated that the research team would be responsible for any extracurricular work.

Results of the study indicated that the African American men with T2DM knew the consequences of having diabetes. However, there seemed to be a disconnect between the seriousness of the consequences of the disease and importance of diabetes self-management. Because this study had a supportive faith-based setting (SAED of the AMEZ church), there may be opportunities to introduce recommendations and implement information campaigns about the importance of managing diabetes in this setting. This information campaign could include consistent and intentional announcements at church-related events from the leadership of global and national religious denominations and is also passed down to the local the health ministry leaders. This campaign could also include establishment of social media agendas and possible creation of grassroots movements and health initiative movements with health and men's ministries in South Carolina.

There were several themes that arose from this study that have may have implications for future practice in researching African American men with T2DM such as emphasizing gaining trust by listening, emphasizing the effectiveness of evidence-based DSME programs in self-managing diabetes, varying the levels of intensity of the classes, and being aware of the roles of family members in diabetes self-management education. Although having limited time with patients was a common theme for healthcare providers, it is critical that patients feel that they have adequate time listening and explaining treatment strategies because not doing this can consequently lead to mistrust in older African Americans (Hansen, Hodgson, & Gitlin, 2016).

Research has long relied on faith-based organizations to recruit African Americans for research (Whitt-Glover, Borden, Alexander, Kennedy, & Goldmon, 2016; Reed,

Foley, Hatch, & Mutran, 2003), and faith-based organizations should continue to remain an area of recruitment for African Americans. However, there is a need for future research to continue emphasize initiatives that unite and educate various religious denominations that have significant African American representation about the benefits of participating in research and easing the negative stigma and issues of distrust that are sometimes held by African Americans concerning research. As health initiatives continue to be integrated into the platforms of faith-based organizations, encouraging collaboration between research initiatives and the leadership of various faith-based organization to adopt strategies to forge a combined, research-friendly agenda could continue to educate involved entities on the importance of reaching this underserved and understudied population.

As the majority of the participants in this study indicated, there is a willingness for African American men to participate in research that they believe will benefit other African American men. It is well acknowledged that faith-based organizations and barbershops/salons have been used when studying phenomena of African Americans (Balls-Berry, et al., 2015; DeHaven, Hunter, Wilder, Walton, & Jarett, 2004; Streaty-Wimberly, Braithwaite, & Taylor, 2001). While many African Americans are associated with faith-based organizations, it important to realize that not all African Americans are associated with faith-based organizations. Establishing a research coalition with faith-based organizations could have a significant impact on African American participation in research that extends beyond the boundaries of faith-based organizations and into other segments of the African American population. Additionally, placing an African American researcher in a role of recruiting African American participants does not necessarily

ensure participation of African Americans (Fowler, 2001), but having African Americans investigators throughout the research process could lead to establish trust (Herring, Montgomery, Yancey, Williams , & Fraser, 2004).

Eliminating healthcare disparities and improving access to healthcare are known issues facing underserved and understudied populations. Additionally, it is not enough for programs just to reach targeted populations. In the case of diabetes self-management education programs, the programs need to be tailored and culturally sensitive to improve the efficacy of diabetes self-management education programs for targeted populations. There has been success in replicating diabetes self-management programs in primary care settings (Peros, James, Nolan, & Meyerhoff, 2016). Current standards of diabetes self-management education and support (Standards Revisions Task Force, 2017) outlines and emphasizes several standards that include individualization to design services using person-centered practices that focus on the individual's priorities and values throughout the diabetes self-management process. These programs are vital, but still need to be made more readily available to underserved and understudied populations such as African American men.

While the results of our study indicated that most of the participants received positive support, individuals with diabetes have reported feeling stigmatized and blamed by friends, family, colleagues, and even healthcare professionals for their diabetic conditions (Browne, Ventura, Mosely, & Speight, 2013). This could possibly lead to individuals with diabetes withdrawing and not actively managing their diabetes. What this also warrants is a need to educate the public on the actual causes of diabetes to debunk stigmas and stereotypes associated with diabetes such as higher A1C and body

mass index because these are individuals who may benefit the most from diabetes self-management education (Liu, et al., 2017).

Future research should continue to explore the best ways to reach this population and focus on the best strategies to improve their diabetes self-management while also promoting prevention. Implementing effective programs to disseminate information on free diabetes clinics and services could also benefit non-insured individuals with diabetes. Additionally, further exploration of ways to improve and promote a positive relationship between African American men with T2DM and their healthcare providers may also aid in improving diabetes self-management strategies.

There are national campaigns that aim to bring attention to the diabetes epidemic via use of advertisement and marketing to reach individuals with T2DM. The use of technology, social media, and faith-based organizations will be critical in not only raising awareness of T2DM, but also in making interventions easier and more convenient to implement. For example, video appointments are becoming more prominent for primary care physicians to address routine medical issues. While video appointments would increase convenience, the services would have to be available to at-risk and underserved population. As faith-based organizations continue to be used in conjunction with research, it is important that academia works with them to implement strategies to help with gaining access and improve trust to underserved populations. The use of technology, social media, and faith-based organizations will be critical in not only raising awareness of T2DM, but also in making interventions easier and more convenient to implement.

While there has been a gradual increase of research devoted specifically to African American men with T2DM (Jack, Jr. L. , Diabetes and men's health issues, 2004;

Sherman & J.McKyer, 2015; Liburd, Namageyo-Funa, Jack, & Gregg, 2004; Marshall, Jr., 2005), there has not been much research done on what motivates African American men to self-manage diabetes or attend diabetes self-management classes or how African American men with T2DM perceive their healthcare providers, and how healthcare providers who treat African American men with T2DM believes motivates African American men. Additional research is needed to continue to improve current DSME programs and implement new, culturally-sensitive strategies (Collins-McNeil, et al., 2012).

Public health practitioners, educators, and clinicians are faced with a major task of controlling the diabetes epidemic. In order to fulfill this expectation, public health clinicians must continue to address demanding public health issues such as diabetes (Albright, 2008; American Diabetes Association, 2016). Developing effective DSME programs requires multi-level involvement of governments, healthcare professionals, and the community and general public to advocate and establish evidenced based DSME programs to address T2DM (Centers for Disease Control and Prevention, 2011; Funnell & Piatt, 2017). However, getting at-risk populations with T2DM to attend DSME programs or continuing to devise strategies to reach at-risk and underserved populations remain as top priorities in improving self-management of diabetes. Empowerment-based diabetes self-management support programs that are patient-centered and theoretically based are needed to continue to promote diabetes self-management skills after DSME programs (Funnell, Tang, & Anderson, 2007; Standards Revisions Task Force, 2017). For individuals that cannot attend or afford certified diabetes self-management classes, it is important to continue to have information-based community programs that may be

offered at community centers, churches, and at other events frequented by African American men.

As related to motivation and the Theory of Self-Determination (SDT), autonomy, competence, and relatedness are essential components. Incorporating an autonomy supportive environment into DSME curriculums based on addressing what factors influence motivation and the SDT will hopefully improve adherence and ultimately improve outcomes. Patient-centered collaborative model that emphasizes patient autonomy provides a more effective strategy to improve diabetes self-management (Delamater, 2006).

Recruitment efforts were far more productive when the focus of recruitment turned to African Methodist Episcopal Zion Church and the South Carolina Conference of the South Atlantic Episcopal District. The help of the SAED of Rock Hill District of the AMEZ church, health ministry coordinators, and men's ministry leaders of the AME Zion church were critical in recruiting and reaching African American men in their environment. Getting African American men with T2DM between the ages of 40-85 to willingly participate was critical in collecting valuable data that addressed the research questions posed in this study.

## CONCLUSION

Diabetes has an enormous impact on the U.S. health care system on a community and individual level, and while the face of diabetes does not discriminate, it affects racial and ethnic minorities disproportionately. This poses additional complications because disparities in healthcare quality and access are issues that contribute to many African Americans not attaining or seeking appropriate care to manage their diabetes. Properly

managing their condition can help individuals with T2DM maintain a good quality of life (Kueh, Morris, Borkoles, & Shee, 2015; Zimbudzi, et al., 2016). As with many of the diseases that our society faces, prevention and eradication are the primary goals that run concurrently with effective disease management. In the case of diabetes, self-management can improve diabetes outcomes and slow down the progression of the disease. Thus, it is important that DSME programs not only reach underserved populations such as African American men, but they must reach all underserved population and provide strategies that effectively address their needs.

Individuals living with diabetes face many challenges, including coping with their emotions about having diabetes, dealing with associated health concerns, diabetes self-management (including cost, family support, and lifestyle changes), and possible declines in quality of life. Continuing to explore the issues that they face when living with diabetes can aid in implementing new and effective strategies to help with diabetes self-management among this population. The findings of this study can be used to supplement data on understanding the lived experiences and motivations of African American men living with T2DM to self-manage and attend DSME classes. Additionally, these findings add to the limited research on African American men with T2DM and their perception of the relationships and roles that they and healthcare providers that treat African American men with diabetes share.



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## APPENDIX A

### MODIFIED INTRINSIC MOTIVATION INVENTORY (TASK EVALUATION QUESTIONNAIRE)

For each of the following statements, please indicate how true it is for you, using the following scale:

1	2	3	4	5	6	7
Not at all True		Somewhat True			Very True	

1. I believe that participating in a Diabetes Self-Management Education program would be fun.
2. I felt relaxed while participating in the Diabetes Self-Management Education program.
3. I think I would enjoy participating in the Diabetes Self-Management Education program very much.
4. I would be anxious to participate in a Diabetes Self-Management Education program.
5. I think that participating in a Diabetes Self-Management Education program would be very boring.
6. I think that participating in a Diabetes Self-Management Education program would be very interesting.
7. I think I would feel pressured while participating in the Diabetes Self-Management Education program.
8. I feel like I have to participate in a Diabetes Self-Management Education program.

## APPENIDIX B

### DEMOGRAPHIC INFORMATION SHEET

ID# \_\_\_\_\_

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Age \_\_\_\_\_ Height \_\_\_\_\_ Weight \_\_\_\_\_

1. Which one of these groups would you say best represents your race?  
 A) White  B) Black or African American  C) American Indian or Alaska Native  
 D) Asian  E) Chinese  F) Other  G) Refused
2. Are you: (Marital Status)  
 A) Married  B) Divorced  C) Widowed  D) Separated  E)  
Never married  F) A member of an unmarried couple  G) Refused
3. Do you have any kind of healthcare coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare, or Indian Health Service?  
 A) Yes  B) No  C) Don't know/Not Sure  D) Refused
4. About how long has it been since you last visited a doctor for a routine checkup?  
 A) Within past year  Last 3 Months  Last 6 Months  Last 9 Months  
 B) Within past 2 years (1 year but less than 2 years ago)  
 C) Within past 5 years (2 years but less than 5 years ago)  
 D) 5 or more years ago  
 E) Do not know/Not sure  
 F) Never  
 G) Refused
5. What is the highest grade or year of school you completed?  
 A) Never attended school or only kindergarten  
 B) Grades 1 through 8 (Elementary)  
 C) Grades 9 through 11 (Some high school)  
 D) Grade 12 or GED (High school graduate)  
 E) College 1 year to 3 years (Some college or technical school)  
 F) College 4 years or more (College graduate)  
 G) Refused

6. What Is your annual household income from all sources:
- A) Less than \$10,000
  - B) Less than \$15,000 (\$10,000 to less than \$15,000)
  - C) Less than \$20,000 (\$15,000 to less than \$20,000)
  - D) Less than \$25,000 (\$20,000 to less than \$25,000)
  - E) Less than \$35,000 (\$25,000 to less than \$35,000)
  - F) Less than \$50,000 (\$35,000 to less than \$50,000)
  - G) Less than \$75,000 (\$50,000 to less than \$75,000)
  - H) \$75,000 or more
  - I) Do not know/Not sure
  - J) Refused
  - K) Disabled

APPENDIX C  
RECRUITMENT LETTER



Anthony Q. Walker  
515 Grey Dove Lane  
Catawba, SC 29704

January 31, 2016

Dear [Recipient Name]:

My name is Anthony Q. Walker. I am a member of Catawba Chapel AME Zion church, and I am a doctoral student at the University of South Carolina. My dissertation topic is: *Use of the Theory of Self-Determination Framework to Explore the Motivational Factors in the Diabetes Self-Management Strategies of African Americans Males between the ages of 40-85 with Type 2 Diabetes.*

I am collecting data for my dissertation to explore attitudes, and perceptions related to self-management strategies of type 2 diabetes in African American males between the ages of 40-85. African American males are an understudied population, and I need your help to recruit individuals between the ages of 40-85 with type 2 diabetes from your congregation.

For those individuals who agree to participate in the study, they will complete a short questionnaire and participate in an audio recorded, semi-structured interview. Completion of the questionnaires and the interview should take approximately 40 minutes. The content of the questions will be related to diabetes, self-management strategies, and their feelings about attending formal diabetes self-management education program. I have attached a flyer that can be placed on your church's information/announcement board. Would you please announce the research study at your church, and collect the names and contact information of those willing to participate?

Sincerely,

Anthony Q. Walker

APPENDIX D  
RECRUITMENT FLYER

**How do you feel about self-managing your type 2 diabetes?  
Help us learn more about diabetes self-management!**



**You can play a key role by participating in a research study:**

**Who:** African American men between the ages of 40 and 85 who have a diagnosis of type 2 diabetes.

**Why:** Self-Management of Type 2 Diabetes education is important and by this study we hope to find out how do you feel about having type 2 diabetes and how do you feel about self-managing strategies of type 2 diabetes. This may help us to improve self-management strategies in individuals with Type 2 Diabetes.

**What:** For this research, you will complete a short survey and participate in a 20-minute interview. The questions will pertain to your motivation to perform diabetes self-management activities, your confidence in performing those skills, and how do you feel about your diabetes self-management strategies.

**Help us to understand motivational factors in diabetes self-management in individuals with Type 2 diabetes. To learn more contact:**

Dr. Christine Blake [ceblake@mailbox.sc.edu](mailto:ceblake@mailbox.sc.edu) 803-777-1484

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APPENDIX E  
INTERVIEW GUIDE FOR AFRICAN AMERICAN MEN

Key Questions

**Personal Question**

1. Mr.\_\_\_\_\_tell me some things about yourself (work, family, hobbies)
2. Would you say that in general your health is: Excellent, Very Good, Good, Fair, or Poor?
3. Have you ever attended a diabetes self-management education program? Why or Why not?
4. When were you diagnosed with diabetes? How old were you? What were your symptoms?
5. How did being diagnosed with diabetes make you feel?
6. What does the word “diabetes” mean to you?

**Diabetes Self-Management and Motivation**

7. How do you feel about self-managing your diabetes?
8. Have you always taken care of your diabetes? Can you tell me a more about that?
9. What is a typical day in your self-management of diabetes? What time do you wake up, eat, exercise, take you medication, check your blood sugar, and go to bed?
10. How would you define motivation? What motivates you to want to control your diabetes?
11. What are some of the things that you struggle with daily in self-managing your diabetes?

**Diabetes Self-Management Programs**

12. Are you familiar with Diabetes Self-Management Education Programs? Tell me what you know about them and how you feel about attending a Diabetes Self-Management Program?
13. Have you ever attended a Diabetes Self-Management Education Program?
  - a. What are some things that would motivate you to attend a Diabetes Self-Management Education program? Are there any reasons that have prevented you from attending a formal Diabetes Self-Management Education program?

14. If you were to attend a formal Diabetes Self-Management Education program, how do you think it would help you to self-manage your diabetes?
15. What are some things that keep you on track in self-managing your diabetes?
  - a. If you could describe your diabetes when you were first diagnosed in one sentence, how would you describe it? How would you describe it now

APPENDIX F  
INTERVIEW GUIDE FOR HEALTH CARE PROVIDERS

Key Questions

**Personal Questions**

1. Dr. \_\_\_\_\_ tell me some things about yourself:
  - a. Where did you go to med school?
  - b. How long you been practicing?
  - c. Do you have a particular area of interest?
2. Would you say that in general your health is: Excellent, Very Good, Good, Fair, or Poor?

**Diabetes Self-Management and Motivation**

1. Do you treat many African American men with type 2 diabetes?
2. Roughly, what is the percentage of African American men with type 2 diabetes that you treat?
3. Do you refer them to diabetes self-management education program? Why or Why not?
4. What do you think your role is in helping individuals with diabetes to manage their diabetes?
5. Overall, how do you think your diabetes patients managed their diabetes?
  - a. More, specifically, how do you feel that your African American men manage their diabetes?
6. Do you think that your African American men with type 2 diabetes are motivated to manage their diabetes?
7. What are some things or strategies that you think would help African American men to manage their diabetes?
8. What are some of the things that you think African American men struggle with in their day to day self-management of their diabetes?

**Diabetes Self-Management Programs**

1. Do you think that attending a formal Diabetes Self-Management Education program helps your African American men self-manage their diabetes?
2. Do you know what exactly is being taught at the diabetes self-management classes?
3. Are there any cases of African American men and poor self-management of their diabetes that stand out?

APPENIDIX G  
LOGISTICS OF STUDY

Item	Expenditure
RCA 400 Digital Voice Recorder	\$45.00
Remunerations	None
Transcription	Materials 150.00
Travel for Interviews and Recruitment	\$200.00