

UNDERSTANDING SELF-CARE PRACTICES FOR AFRICAN-AMERICAN WOMEN  
WITH TYPE 2 DIABETES

By

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A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL  
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT  
OF THE REQUIREMENTS FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2010

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To my God that sustains me, my ancestors who paved the way, my family who love me, the mentors who encourage me, my daughter Saree Abigail Young and my husband Mark Tefari Young who hold my heart , and to all the women who took the time to share their stories to advance the cause of research, this is for you.

## ACKNOWLEDGMENTS

I thank my Lord and Savior Jesus Christ for lighting my path, bearing my burdens, and showing me that this work is more about serving others and less about me. I am extremely blessed to have obtained help and support from many people during my doctoral study. I would like to convey my appreciation to my chair Dr. W. William Chen for his unending support and shining example as a mentor and person. I am indebted to Dr. Sheu for his instruction in methodology and for the countless hours of guidance and support through the details of this work. My sincere appreciation extends also to Dr. Dodd for her great example of a female Ph.D. I thank my health services research and policy mentor Dr. R. Paul Duncan for his expertise, guidance, and support. I am tremendously grateful to Dr. Duncan for opening my life and work to such great possibilities and opportunities and whose time, patience, advice, and instruction were priceless. I am also indebted to Dr. Lutz for being an amazing mentor and supporter whose encouragement and instruction were immeasurable.

I am particularly grateful to my unofficial committee members: Dr. Hall, Dr. Bridgett Rahim-Williams, Dr. Simpson, Dr. Sanders, Dr. Pigg, and Dr. James, and Dr. E. Newton Jackson Jr. whose encouragement helped with various parts of the research process, and for their role as student advocates. I would also like to thank Dr. Behar-Hornstein for her class on dissertation writing.

Blessed am I to have been chosen by God to be the daughter of Heron and Marjorie Dale whose love means the world to me, and whose prayers, support and guidance have been my rock unflinching. I am so thankful that in spite of my faults they loved me, believed in me and prayed for me even when I did not believe in myself.

I am so thankful to be blessed with wonderful in-laws, Michael and Jacqueline Young for embracing me into their family with open arms; you all are incredible. For the constant love, support, frank criticism, yet subtle encouragement, I salute my brothers, Robert, Bion, and Drury Dale and I love you all with all my heart. I am also grateful to my sisters- and brothers-in-laws LeAnne and Damian, and Sanya and Gavin, and Anjule. To my sister Jeanne-Marie Hudson, and my niece Kaiyu, I am better for knowing you.

Though you are not physically here with me, Grandma Davis, I know that you are working diligently as one of God's angels to keep me forever wrapped in unconditional love and abounding grace. Thank you for loving me and for teaching me about God and his love, a love that constantly encircles me with an unperturbed focus that helps me persevere and keep going forward. Grandma Young, thank you that, at 92, you still remember every step of my journey to keep me accountable and on track.

To all my family, especially the matriarchs, Aunt Alden and Aunt Lena, and the patriarch, Uncle Denzil Southwood-Smith, for keeping me connected to where I came from. Also to my Godmothers Elizabeth, Hertha, and Gloria, and my adopted mother, Aunt Gloria Norwood, who keep me grounded and constantly embrace me with love. To Uncle Claude and Aunt Marcia, Uncle Carl and Aunt Lois, Uncle Norris, Aunt Yvonne, Aunt Nella, Aunt Marlize, Aunt Jean, Aunt Molly, Uncle Carlyle, Aunt Philis and Aunt Helen, your love constantly warms my heart. To my deceased forefathers, and my aunts and uncles who I lost along this journey: Uncle John and Aunt Missie, Uncle Johnnie, and Uncle Terrence, you will forever be in my heart.

My sincere gratitude is also extended to my church family and friends, for their prayers, love, and constant support. Thanks to my prayer partners, Robin and Claire, I love you. I am particularly grateful to the sisters and brothers in Christ at the Gainesville Christian Church, my baby sitters and Ms Gladyse, my mother's prayer group and daddy's walking group in Jamaica for their constant encouragement and support. Words cannot express the immense appreciation I feel for the support and encouragement from my friends and colleagues Dr. Danielle Hyles-Rainford, the future Dr. Keava Thompson, Dr. Amrobeth, Dr. Haun, my cousins Shana-Kae Davis, Nadine Killibrew LLB, Dr. Helen Norwood, Vanessa Norwood, Sonya Killibrew, Dr. Daryl McCartney, Donna Southwood-Smith, Paul, David, Kevin and family, Dean and Michelle and all of my other cousins and in-law cousins, Miguel Hastings and Tricia for tears and/or times of commiseration. I am also grateful to Dr. John, Dr. Wilder, Dr. Manohar, Dr. Cox, Dr. Lyles, Dr. Largo Wight, Dr. Wirth, Dr. Melissa Morris-Howard, the future Dr. Kimberly Elliot, Dr. Georgia Bianchi, Lilly Bell, Holly, Samantha, and for their support and example throughout this process.

A special thank you to people who, though our paths crossed for only a short time, made such an indelible mark on me: my marriage dynamics classmates at the Gainesville Christian Church, Dr. Jia, Jane and Lino Stanchich, Ted Emanuel, Dr. Bono. To Dr. Paul Logan and Ms. Sally McCoy at Howard University who always showed me such love and encouragement and helped me find my way, and my cousin Alicia who led me to such great people, I love you all. Many thanks also to my department program assistants Sheri and James P. Milford for all that you do and who you are. To the dearest and best editor, Margaret Joyner, you are my unsung heroine. My thanks are

also extended to my previous co-workers the Florida Medicaid Reform Evaluation team members and RORC group for their support. I am also grateful to all those who support and sustain my family. I thank God for offices and staff like the Office of Graduate Minority programs at the University of Florida and the leadership of Dr. Alexander without which much of my work would have not been supported financially.

To my darling daughter, Saree Abigail Young, you helped me more than you will ever know. Finally to my husband, Mark Tefari Young, for his unending support and love, you have been my world and my voice of reason, I love you more than words are able to express. To all my family and friends that I have not specifically named, please know that your help, support and prayers have helped made my journey possible.

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## LIST OF DEFINITIONS

- CRISIS THEORY** Focuses on how individuals cope with a major life crisis and transition (Moos, 1977).
- DIABETES MELLITUS** A chronic disease due to either or both insulin deficiency and resistance to insulin action, and associated with hyperglycemia (elevated blood glucose levels). Over time, without proper preventive treatment, organ complications related to diabetes develop, including heart, nerve, foot, eye, and kidney damage; problems with pregnancy also occur (National Institute of Diabetes and Digestive and Kidney Diseases, 2005).
- LENGTH OF TIME WITH DIABETES** The length of time diagnosed, which is greater than one year upon entering the study.
- GLYCEMIC CONTROL** The typical levels of blood sugar more specifically glucose in an individual with diabetes, greater than or less than 70–120 mg/dL [3.89–6.67] of their glucose level or calculated as the proportion of HbA1C less than 7%. (Rothman, Malone, R., Bryant, B., Wolfe, C., Padgett, D.A., et al., 2005; Koro, Bowlin, Bourgeois, and Fedder, 2004)
- LEVEL OF EDUCATION** This is the years of education that is less than a four year college degree
- LEVEL OF INCOME** Refers to diabetic women whose annual individual income is less than \$25,000 at the time of the study (CDC, 2002).
- SELF-CARE/SELF-MANAGEMENT** Activities undertaken by individuals to promote health, prevent disease, limit illness, and restore health (Schoenberg and Drungle, 2001)
- SOCIOECONOMIC STATUS** Will only refer to low income women and those with less than a high school degree (CDC, 2002) and those with less than a four year college degree.
- TYPE 2 DIABETES MELLITUS (T2DM)** Occurs when the body does not make enough insulin or cannot use the insulin it makes effectively (NIDDKD, 2005).
- VULNERABLE POPULATION** Vulnerable populations are social groups who have an increased relative risk or susceptibility to adverse health outcomes (Flaskerud and Winslow, 1998).

Abstract of Dissertation Presented to the Graduate School  
of the University of Florida in Partial Fulfillment of the  
Requirements for the Degree of Doctor of Philosophy

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August 2010

Chair: W. William Chen  
Major: Health Behavior

Diabetes is a significant public health problem and a leading cause of disability and death in the United States. The purpose of this study was to assess diabetes knowledge and self-care activities and explore experiences of African-American women with type 2 diabetes mellitus (T2DM). This mixed method study used a quantitative correlational design and a qualitative descriptive design. The data was collected using surveys and semi-structured individual interviews and analyzed using SPSS 17.0 and Atlas ti 5.2. Data were transcribed verbatim and examined for emergent themes.

The sample included fifty-two African-American women between the ages of 40-64 from the North Central Florida region. The mean age for the sample was 55 years. Approximately 55.8% of the participants had higher than the average knowledge for diabetes. Results showed no associations between the respondent's level of knowledge about diabetes and certain self-care activities. However there were positive significant correlations between knowledge about diabetes and the years of education ( $\rho=.24$ ) and some self-care activities namely (a) specific diet ( $r=.28$ ) and (b) foot care ( $\rho=.40$ ).

Participants' experiences with diabetes varied and most were aware of at least one factor that contributed to their diabetes. Thematically, their experience and perceptions organized around dealing with diagnosis of T2DM and management of T2DM with various factors influencing both. Influential factors for a) dealing with their diabetes included perceived long term consequences, past experiences, seminal events, level of awareness and support; b) managing their diabetes included difficulties (concerns with treatment, lifestyle changes, personal barriers and inadequate resources) and facilitators (improved awareness, supports, past experiences, religious beliefs, and adapting new strategies for care).

Limitations to note when interpreting the results were that there was a convenience sample, attrition, and a small sample size. Though significant associations were identified, they should not be used to predict behavior. More interventions are needed to help improve the diabetes self-care behaviors for African-American women when first diagnosed and motivate them to get consistent, flexible care throughout their lifespan to help alleviate increasing diabetes morbidity and mortality.

## CHAPTER 1 INTRODUCTION

Chronic illnesses such as diabetes claimed the lives of approximately 35 million people in 2005 and are also the leading causes of death worldwide (World Health Organization (WHO), 2005). If not controlled, projected deaths from chronic illnesses will increase by 17% in 2015 (WHO, 2005). Chronic illnesses cannot be prevented by vaccination and they do not eventually just go away. Rather, effective prevention, treatment, and health promotion initiatives reduce mortality, and with just a 2% reduction in chronic illness death rates annually, as many as 36 million lives can be saved (WHO, 2005). In America, more than 1.7 million, or seven of every ten, people die of a chronic illness (CDC, 2005) and chronic conditions account for approximately 75 percent of the more than \$2 trillion health care expenditure (CDC, 2009).

In 2005, approximately 180 million people worldwide had diabetes and 1.1 million died from this condition (WHO, 2006). In addition, 23.6 million people, or 7.8 percent of the American population, has diabetes, of which 17.9 million people know they have diabetes and 5.7 million people go undiagnosed (National Institute of Diabetes and Digestive and Kidney Diseases, 2008). In addition, almost half of diabetes deaths occur in people under 70 years of age. Fifty-five percent of diabetes deaths are women and this number will increase by more than 50 percent in the next 10 years if urgent action is not taken (WHO, 2006). Diabetes mellitus, therefore, is a significant public health problem and is one of the leading causes of disability and death in the United States (National Institute of Diabetes and Digestive and Kidney Diseases, 2005).

Type 2 diabetes mellitus (T2DM), some may argue, is the “mild diabetes”, however, this is not in keeping with the facts, especially because complications from

diabetes are the leading cause of blindness among adults. Additionally, about one-fifth of persons with diabetes develop nephropathy which requires renal dialysis treatment or transplantation. Additionally 30% of lower limb amputations are consequences of diabetes, and diabetes patients have an almost three-fold risk of heart disease and stroke (van den Arend, Stolk, Krans, Grobbee, and Schrijvers, 2000). In 2006, diabetes was the seventh leading cause of death in America (Xu, Kochanek, Murphy, and Tejada-Vera, 2007). Another co-morbidity is pregnancy complications (Powell, Hill, Clancy, 2007; Thackaray, Merrill, Neiger, 2004). Diabetes is also associated with continually changing symptoms, severity, perceived stigma, and future risk, all of which affect adherence to health-promoting behaviors (Elliot, Ross-Degnan, Adams, Safran, Soumerai, 2007). It is evident that the diabetes disease burden is great.

Nationally, the United States also sets goals reported in Healthy People 2010, a report on the nation's health objectives for the coming decade. Goals for diabetes in Healthy People 2010 include (a) increasing diabetes education from 45% to 60% (through prevention programs), (b) reducing the disease and economic burden of diabetes, and (c) improving the quality of life for all persons who have or are at risk for diabetes. In addition, reducing the diabetes death rate and increasing the proportion of adults with diabetes who perform self-blood-glucose-monitoring at least once daily are other important goals for the nation (Centers for Disease Control and Prevention (CDC), Disease Prevention and Health Promotion (DPHP), and U. S. Department of Health and Human Services (USDHHS), 2008). The American Diabetes Association (ADA) also developed standards of for patients with diabetes that guides healthcare providers and patients through the complex process of managing diabetes (ADA, 2002).

Above and beyond the goals set by the nation as a whole, individuals have to set their own goals for their diabetes care. The good news regarding diabetes is that it can be managed. However, managing T2DM involves two interacting levels: the treatment, consisting of self-care behavior and medical treatment, and the monitoring of the disease, consisting of self-control and medical control (van den Arend et al., 2000). Throughout this document, the terms diabetes self-management and diabetes self-care (Schoenberg and Drungle, 2001) will be used interchangeably.

The primary goal of T2DM self-management is to lower blood glucose levels. Reduced levels help to prevent the onset or progression of long-term complications, as well as improve the cardiovascular risk profile to prevent the symptomatic cardiovascular disease. However, various factors impact effective diabetes self-care. These factors include limited access to care, low socioeconomic status, and low health literacy. Literacy, as well as health literacy, impacts the ability of the nation to reach its diabetes goals. In the United States, an estimated 44 million Americans are functionally illiterate, and more than 90 million have inadequate literacy skills (American Medical Association, 1999; Rothman, Malone, Bryant, Wolfe, Padgett, DeWalt, Weinberger, Pignone, 2005). Both limited literacy and health literacy are also prevalent among patients with diabetes, and are associated with poorer knowledge of the illness and its complications, worse glycemic control, and higher rates of retinopathy (Powell et al., 2007). In addition, past research showed that comprehensive diabetes disease management programs, with educational strategies appropriate for low-literate patients, were of greater benefit to patients with low literacy than those with higher literacy (Rothman, Malone, Brayant, Horlen, DeWalt, Pignone, 2004).

Since one of the primary goals for diabetes, is self-care, T2DM demands that individuals have knowledge about their condition, specifically regarding how to treat it and its various symptoms (Rothman et al., 2005). In addition, knowledge of the individual is critical to assess the impact of diabetes education and interventions, as well as recognize diabetes education's intermediary role to improve patient outcomes. Further, despite diabetes education, various studies indicate that knowledge deficits are evident with low literate diabetics. Hence, individuals with low literacy have trouble reading prescriptions, following their healthcare provider's instructions, understanding their diseases, and, lack resources to help them find answers to questions. Low literacy may translate to low disease health literacy, which ultimately results in a lack of ability to care for specific illness such as diabetes. In addition, understanding why individuals do not practice self-care even though they are disproportionately affected needs to be studied more.

Further, in order to achieve goals in diabetes care for specific minority groups who share the burden of this disease, a greater understanding is needed of the experiences of those affected by diabetes, as well as their levels of knowledge for managing their condition. Hence, a major call to action is that researchers, practitioners, and individuals need to collectively identify their role in ensuring that diabetic individuals receive the appropriate and adequate patient education, particularly for self-management skills, to manage their condition, as well as prevent adverse health outcomes. To answer this call to action, more research has been devoted to diabetes self-management for various populations. Furthermore, the empirical literature highlights the success of self-management of chronic illnesses as being related to better health outcomes. This brings

us to a question that health educators try to negotiate: How do we translate health education into behavior? Specifically for this research, the guiding question is why do individuals fail to properly manage their diabetes, thus undermine their well-being?

### **Significance of the Study**

Though usually a life-long condition, diabetes can be managed. Achieving a good outcome means changing an individual's lifestyle to promote positive diabetes care. However, explanations of poor self-management include several interacting patient characteristics: knowledge, attitude, motivation, and personal skills (van den Arend et al., 2000) are important steps toward managing diabetes. Knowledge gaps exist for individuals regarding diabetes self-care and it is important to identify how these gaps impact individuals' self-care practices. In addition, a central tenet for changing patient behaviors and lifestyles is health education and promotion because one of its key assumptions is that helping individuals allows them to help themselves (van den Arend et al., 2000). It is imperative, to improve health education for disease-specific conditions, such as diabetes, in research and practice, because inadequate knowledge of the effect of diet and weight on diabetes and blood pressure and a lack of knowledge of the symptoms of hypoglycemia and its treatment may be life-threatening (Williams, Baker, Parker, Nurss, 1998). Since past research showed that comprehensive diabetes disease management programs were of greater benefit to patients with low literacy than those with higher literacy (Rothman, Malone, Brayant, Horlen, DeWalt, Pignone, 2004), it is even more compelling to address the diabetes burden, in part by education. However, the reality is that knowledge does not translate to action, and behavior modifications are the most difficult to achieve since individuals are asked to make changes in lifestyle patterns established over many years.

The ADA recommends that people with diabetes visit their healthcare providers every three to four months (Florida Department of Health, 2005). However, once individuals have seen the healthcare practitioner, they are in control of the recommendations they choose to implement or ignore. Individuals need to be continuously targeted for effective diabetes self-management skills, education, and promotion, especially because diabetes treatment regimens are complex and require making significant lifestyle changes that are not easy. Factors that translate knowledge into behaviors for this specific population also need to be improved.

In the past, most traditional health professional training was based on a medical model designed to treat acute healthcare problems. Today, new approaches that take into consideration the cultural world of the patients are increasingly necessary. These approaches also need to recognize patients' control and responsibility for the daily self-management of diabetes and that to succeed, a self-management plan needs to fit patients' goals, priorities, and lifestyles (Funnell and Anderson, 2003).

Further, patients are the experts on their own lives, and are the primary decision-makers in the control of their daily diabetes self-management (Funnell and Anderson, 2003). Unfortunately, many diabetic individuals either do not understand the importance of the self-management practices for their long-term survival or cannot be bothered with the regimens. Despite their reasons, since the consequences of the diabetics' decisions accrue directly to individuals, it is even more important that they take responsibility to manage diabetes in a way that is best suited to the context and culture of their lives (Funnell and Anderson, 2003).

A factor that inhibits the growth of the self-management literature is that patients or users of the healthcare system do not have as great a voice as they need in decisions about research and practice. To achieve a healthcare system that helps patients it is imperative that individuals do have a voice. Sofaer and Firmigner (2005) summed it up best: "If we are truly to achieve a health care system that is patient-centered, we must continue to search for creative ways to elicit and heed the voice of the patient". Further, individuals' desires for information and the extent that they want to be involved in making decisions about their health has been discussed more and studied less (Blenkinsoopp, Bashford and Dickinson, 1998; Granas and Bates, 2005). The literature also indicates that patients with low literacy need to be questioned orally about the degree of involvement they desire or are capable of, in the management of their diabetes, as well as the confidence they have in disease self-management (Powell et al., 2007). This study will add to the research base, and individuals from vulnerable populations may be given the opportunity to present their diabetes plight.

Past research indicates that more studies are needed to examine the experiences of vulnerable populations with poor health status, particularly because this group has more extensive health needs and higher utilization (Mason et al., 2002). Though the chronically ill may only be a small segment of health plan enrollees, they generate an outsized proportion of its healthcare expenditures, and concerns about the quality of care provided to them warrant a better understanding of their experiences (Mason, Scammon, Huefner, 2002). The current healthcare system, does not reward preventive care or continuity of care. Neither does the system reward early diagnosis, interdisciplinary care, emotional counseling, or patient and caregiver education.

Vulnerable populations are relatively overlooked by previous research that reports the general population is satisfied and have high utilization of health plans in managed care (Mason et al., 2002). Hence, new investigators have a responsibility to study vulnerable populations in an effort to better target these priority populations with the scarce prevention dollars available.

Various studies also indicated that low literacy is associated with poor disease knowledge and self-management practices (Williams et al., 1998; Weiss, Hart, McGee, D'Estelle, 1992; Schillinger, Grumbach, Piette, Wang, Osmond, Daher, Palacios, Sullivan and Bindman, 2002; Powell et al., 2007). It is especially important to conduct this research, because assessing diabetes knowledge for self-care issues and identifying the specific behaviors of individuals with low levels of literacy may lead to more targeted interventions (Powell et al., 2007). Unfortunately, limited research has been done on low-literate populations and behavior change (Nath, 2007). One behavior specific to diabetes care is preventing further complications and eventual mortality that can occur due to ineffective or absent self-management. Preventative health behaviors are defined as behaviors by which individuals actively improve or maintain their health status (Cowther, Green, Armstrong, 2004). For example, in 1992, Duelberg conducted a study among African-American women and found that they were less likely than white women to practice preventative health behaviors. It is important to identify and add to the gap in the literature to promote prevention messages that meet established planning goals for the chronically ill of the nation. The specific needs of particular communities are also important to highlight to better serve them.

Past research has also increasingly looked at diverse populations and refined instruments, such as knowledge scales to be culturally appropriate (Vincent, Clark, Zimmer, Sanchez, 2006). Further knowledge scales have also been developed with the underserved population in mind, but limitations exist in these scales developed because they have focused on closed-ended multiple-choice questions. However, Rothman and colleagues in (2005) indicated that individuals with low literacy sometimes have a difficult time answering multiple choice questions. They developed a new knowledge scale to more effectively measure diabetes knowledge among individuals with diabetes, and specifically those with low literacy.

For a number of reasons, Florida is an important state to look at when assessing diabetes self-care knowledge for African-American women. Based on the reported estimates, Florida is the fourth most populous state in the nation, with 67 counties and 18 million people (U.S. Census Bureau Statistics, 2005). Florida also has approximately 51% females and 49% males in the population and three major ethnic groups in, whites (80%), Hispanics (19.5%) and African-Americans (15.7%) (U.S. Census Bureau, 2007). In Florida, more than 8% of adults have diabetes (FDH, 2005), although only an estimated 1 million adults know they have diabetes based on an official diagnosis (FDH, 2005), while approximately 300,000 Floridians are still unaware of their diabetes status. In addition, similar to most states, Florida also recognizes certain disparities regarding minorities who share a disproportionate burden of diabetes.

Despite past studies regarding understanding diabetes self-care practices, the use of more culturally appropriate instruments, and attention in research to minority populations, the escalating burden of diabetes in the African-American female

population still disproportionately affects these individuals. In 2004, Rahim–William’s conducted a study seeking to understand health behaviors, beliefs support systems, and access to care and their combined impact on diabetes self-management and glucose control. This study was not designed to capture participant’s life experiences with managing diabetes. Further, this study included women within a wide age range, up to 87, and education level, up to doctoral degree. The present study measured the participants, knowledge about diabetes and its self-care, as well as captured each participant’s story of their long-term living with and managing diabetes and limited the recruitment of women to a certain age range and educational level, which makes it more specific and tailored to further explore, understand and corroborate diabetes self-care knowledge and practices that augment Rahim-William’s (2004) study.

### **Statement of the Research Problem**

Among some of the major challenges facing the healthcare system is helping the increasing number of individuals diagnosed with diabetes control their condition. A challenge specifically for diabetics is that they have not received necessary self-management interventions (Fisher, Brownson, O’Toole, Anwuri, and Shetty, 2007) because as many as 60 to 70% go without this intervention (Austin, 2006). In 2002, of the 15.7 million people with diabetes, more than 8.1 million of those were women (CDC, 2002). Furthermore, approximately 95% of all persons diagnosed with diabetes and almost 100% of all persons with undiagnosed diabetes have T2DM (CDC and U. S. Department of Health and Human Services, 2008), while type 1 accounts for about 5% of individuals with diabetes (NIDDKD, 2005). In addition, the chance of having T2DM are increased by (1) having a family history of diabetes, (2) being a member of an ethnic group, such as African-American, (3) being overweight or obese, (4) having had

diabetes while pregnant (gestational diabetes), (5) having high blood pressure, (6) having abnormal cholesterol (lipid) levels, and (7) having limited physical activity (FDH, 2005).

The diabetes epidemic also disproportionately affects women. In diabetes care, positive outcomes depend on individual lifestyles, such as individual self-management, for example, appropriate diet and use of medications (Elliot et al., 2007). On average, individuals with diabetes will spend a few hours yearly in a physician's office, but more than 8760 hours yearly on their own (Fisher et al., 2007). It is therefore important to improve self-management practices across a diverse population regardless of the diabetic's health literacy or socioeconomic status. In short, those in racial and minority groups are disproportionately affected by diabetes. It occurs two to four times more often among African-Americans, Hispanics, Native Americans, and Asian-Pacific women than among white women (CDC, 2002).

The most common complication of diabetes is the risk of heart disease. Women with diabetes who suffer a heart attack have poorer subsequent quality of life and lower survival rates than men in the 25 to 44 year age bracket (CDC 2002). Another burden for women with diabetes is that death rates for these women are three times the rate for women without diabetes. In addition, middle-aged women with T2DM tend to have less education, lower income, and are less likely to be employed when compared to women without diabetes (CDC, 2002). Furthermore, social and economic issues leave many older women living alone and poor, and in Florida 28.5% of women in the 45 to 64 age bracket with diabetes have an annual family income of less than \$10,000 and more than half, have less than \$20,000 (CDC, 2002).

The extent of low literacy and health literacy levels for people with diabetes regarding essential diabetes knowledge coupled with the need to accurately measure diabetes knowledge were instrumental factors that motivated Rothman and colleagues (2005) to develop a scale to measure this knowledge for self-care for a low literate population. Previous knowledge scales had certain limitations. For example, they were often lengthy or too complicated for individuals with limited educational backgrounds and low literacy (Rothman et al., 2005; Speight and Bradley, 2001) and could be outdated, since many were developed in the 1980s (Speight and Bradley, 2001). Hence, continued use of scales such as the one developed by Rothman and colleagues that specifically target low literate individuals will better address this population regarding diabetes self-care practices.

This study differs from previous studies in two significant ways. First, the investigator obtained a picture of daily self-care struggles for those who have not necessarily been in an intense control program for their diabetes and have compounding factors that make them particularly vulnerable to increased morbidity, defeatist perceptions, and poor self-care behaviors. Second, the goal of this study is to apply a modified model for understanding the crisis of physical illness using a mixed methodology to identify key elements that seek to improve self-care practices for a socioeconomic group that have for the most part, low literacy and poor behavioral outcomes and is less studied.

### **Purpose of the Study**

The purpose of this study was to assess diabetes knowledge and self-care activities and explore experiences of African-American women with T2DM. Specifically, this study (1) assessed knowledge about diabetes in African-American women; (2)

explored the associations between African-American women's knowledge of diabetes and (a) income level, (b) years of education, (c) length of time with diabetes, (d) glycemic control, and (e) self-care activities; (3) explored experiences of African-American women about managing their diabetes as well as their understanding of diabetes. This study also used a mixed methodology to examine a modified model for understanding the adaptation to a physical illness.

### **Research Questions**

#### **Quantitative**

- 1) What knowledge level do African-American women with diabetes have about their diabetes?
- 2) Was African-American women's knowledge level about their diabetes self-care associated with income, year of education, length of time with diabetes, and glycemic control?

**Null Hypothesis H01.** Respondent's knowledge scores had no associations to a) income, b) years of education, c) length of time with diabetes, and d) glycemic control.

- 3) What were the associations between African-American women's levels of knowledge for diabetes self-care and their self-care activities?

**Null Hypothesis H02.** There were no associations between respondent levels of knowledge for diabetes self-care and their self-care activities.

#### **Qualitative**

- 4) What were African-American women's experiences managing their diabetes? What adaptive tasks and coping skills did they use?
- 5) How did African-American women perceive their diabetes? What did diabetes mean to them?

### **Delimitations of the Study**

The following delimitations should be considered in this study.

1. Study participants included African-American women with diabetes who were recruited primarily from the Gainesville community and surrounding area health

clinics, low-income communities, churches, low-income programs, and beauty salons.

2. Data collection was during the 2009–2010 academic year.
3. Demographic data were collected using a questionnaire to obtain self-reported participant characteristics.
4. The study used an embedded mixed methods-correlational model with a quantitative correlational design and a descriptive qualitative research design only.
5. The age range was appropriate for the study purpose.

### **Limitations**

1. The counties chosen for the study may not represent all African-American women in the state of Florida.
2. The participants in this study were all from the North Central Florida community (Alachua, Putnam, and Levy counties)
3. Participants' knowledge assessment, self-care activities, and perceptions represented one point in time and may not account for any changes as their diabetes condition evolved or the healthcare system changes.
4. Demographic information obtained from study participants did not capture all relevant information about participants.
5. Data collected during the 2009–2010 academic year may vary from data collected during other periods of time.
6. Interview guides may not identify all associated perspectives.
7. Use of qualitative research design limited measurable data analysis for that component of the study.
8. Diabetes knowledge and self-care activities, for this study was measured by self report.
9. Threats to internal and external validity were: a) limitations for interpreting the findings, b) potential threats to the study, c) limitations of the researcher-constructed interview guide and d) limitations of recruiting participants.

### **Assumptions**

1. Interview guides developed for use were adequate to answer the research questions.

2. Data collected during the academic year 2009–2010 were considered adequate for the purpose of the study.
3. Demographic data obtained from the participants were adequate for the purposes of the study.
4. Participants provide accurate information that answered the research questions.
5. Collecting data using a valid and reliable diabetes knowledge assessment, self-care activities measure, and an interview guide were considered adequate tools for collecting data for the purpose of this study.

### **Summary**

Chronic illnesses are the leading cause of death worldwide, and nationally. In addition, more than 8% of Florida adults have diabetes (FDH, 2005). Diabetes is a chronic illness that requires patient education for self-management to adequately control the condition as well as prevent adverse health outcomes that are in large part due to an individual's lifestyle. Further, good outcomes in chronic illness are promoted by good self-care behaviors. Diabetes as a chronic illness is a significant public health problem.

Literacy and health literacy are primary indicators of one's health status. Low health literacy is prevalent among patients with diabetes and associated with a poorer knowledge of the illness and its complications, for example, worse glycemic control and higher rates of retinopathy (Powell et al., 2007). However, barriers to a patient's education will remain unless health educators, nurses, and other providers make a conscious effort to simplify care, tailor education, and reduce the perceived complexity of the healthcare system (Nath, 2007).

The goals of Healthy People 2010 (CDC, DPHP, and USDHHS, 2008) that addresses diabetes and the ADA agendas, if achieved, will improve health outcomes. However, prevention efforts do not effectively meet the needs of those who are low

income and have low literacy. Therefore, more research is needed, especially because diabetes is a condition that touches almost everyone's life; most individuals know someone who has this ongoing and life-long disease. Moreover, worldwide 36 million lives could be saved through an annual 2% reduction in chronic disease death rates (WHO, 2005). Consequently, it is important to identify populations particularly at risk and give them a voice. Health educators also need to better target vulnerable populations to help them develop proper diabetes self-management skills. The objective of this study was to assess a representative group of African-American women with T2DM regarding their knowledge of diabetes and their self-care activities, and to explore their experiences with their diabetes self-care instruction and practices.

## CHAPTER 2 LITERATURE REVIEW

This study focused on the assessment of diabetes knowledge and self-care activities among African-American women in North Central Florida. Their perceptions and understanding of diabetes, particularly with respect to managing their condition, were also explored. This is the first study that applied the model for understanding the crisis of a chronic illness to (1) assess diabetes knowledge and self-care activities in low- income African-American women and (2) explore their experiences with self-care practices from a quantitative and qualitative data collection methodology. Identifying the factors and processes by which individuals adapt and improve self-care behavioral practices by surmounting a series of crisis provides a shift in the conceptual lens through which diabetes care and treatment programs are viewed today (Misra and Lager, 2008).

A limited number of studies have reported, from the patient's view, the process nature of learning to manage their diabetes care (Ellison and Rayman, 1998; Hernandez, 1995; Price, 1993; Rayman and Ellison, 2004). In early self-management regimens, one study found that individuals set aside their personal preferences despite lifestyle disruption and negative body responses, and were more motivated to follow the prescribed self-care practices (Price, 1993), while another study illustrated comparable results in that individuals were adhering to professional advice about their care practices (Hernandez, 1995). In a similar light, another study showed that women, described as good self-managers by their providers, described their early times of learning self-management as chaotic and very difficult (Ellison and Rayman, 1998). However, in more recent studies, a qualitative study that described the early experiences and day-

by-day reality of learning to self-manage T2DM among women in an intensive control program (Rayman and Ellison, 2004) sought to identify some of the reasons for this chaos, because understanding the problems incurred in the early time of self-management is necessary to the design and timing of positive intervention management.

### **Defining Chronic Illness and Diabetes**

According to the World Health Organization (WHO), the term “chronic disease” includes heart disease and stroke (cardiovascular disease), cancer, chronic respiratory diseases, diabetes, and visual and hearing impairment. In ancient Greece, Hippocrates distinguished diseases that were acute (abrupt, sharp, and brief) from those that were chronic (Shiel and Stöppler, 2008). The term “chronic” comes from the Greek *chronos*, time, and means lasting a long time. Various definitions exist for chronic illnesses. For this study, chronic illness is defined as a disease that has one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care (Federal Trade Commission and Department of Justice, 2004).

The diabetic chronic illness was the focus for this study. Diabetes is a group of diseases marked by high levels of blood glucose resulting from defects in insulin production, insulin action, or both. Diabetes can lead to serious complications and premature death, but people with diabetes can take steps to control the disease and lower the risk of complications (National Institute of Diabetes and Digestive and Kidney Diseases, 2005). There are two types of diabetes, type 1 and 2. Type 1 diabetes, formerly called juvenile diabetes, results when the body’s immune system attacks and

destroys its own insulin-producing beta cells in the pancreas (NIDDKD, 2005). On the other hand, T2DM, formerly called adult-onset diabetes, usually develops in adults over the age of 40, but is increasingly prevalent in younger age groups, including children and adolescents. It occurs when the body does not make enough insulin or cannot use the insulin it makes effectively (NIDDKD, 2005). Type 2 diabetes mellitus will be the focus of this study.

### **Chronic Illness and the Health Care System**

The Institute of Medicine's (IOM) report "Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century" (IOM, 2001) outlined six specific aims for improvement in the health and functioning of Americans, one of which is patient-centered care. Patient-centered care is defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM, 2001). This is important because a healthcare system that achieves patient-centered care, in part, would more effectively meet their needs (IOM, 2001). Patient-centered care is a goal of the IOM, and some patients feel that this represents a move from a disease focus to the "whole person." Health education is an integral part of meeting patient's needs within the healthcare system. Hence, it is particularly important to examine gaps in health education for individuals with diabetes, within the context of clinical services.

For the twenty-first century, the challenge therefore is to design a system that meets the needs of those with serious and potentially disabling chronic illness and reduce the progression of disability and improve functional status and quality of life. To accomplish this, the Chronic Illness Care Improvement Act of 2000 amended Title XVIII of the Social Security Act, to include the intention to bring about excellence to the care

of chronic illness and help America move forward in identifying proactive strategies to prevent complications and disability (U.S. Congress, 2000). Despite this agenda and the complex care needed for the chronically ill, due in part to diverse service needs delivered by multiple providers in numerous settings, delays in care and worsened conditions exist (Ireys, Thronton, Mckay, 2002).

In addition, challenges exist for Medicaid enrollees recruited as part of the population of interest. Chronically ill Medicaid enrollees also face additional burdens because, this population bears the brunt of disparities for health care since they are disproportionately affected by various chronic conditions, such as diabetes. The impact of worse conditions means that larger portions of budgets, including the Medicaid budget, are spent on these needs.

Medical advances also impact the growing need for diabetes education for self-care because the twentieth century medical discoveries have dramatically prolonged the life expectancies of persons with all types of chronic illnesses, transforming many illnesses from rapidly disabling conditions to chronic conditions that people can live with for a long time. For the twenty-first century therefore, the challenge is to reduce the progression of disability and improve the functional status and quality of life of persons with chronic illness.

### **Individual's Key Role in Chronic Illness Care**

Despite attempts to encourage, cajole, and persuade patients to perform self-care tasks, practitioner frustrations mount when patients are unwilling or unable to follow advice and achieve desired outcomes (Funnell and Anderson, 2003). Traditionally, the success of patients to manage their diabetes has been judged by their ability to adhere to a prescribed therapeutic regimen. Unfortunately, this approach does not match the

reality of diabetes self-care. Individuals need more information and in-home guidance about their condition, especially because of the serious and chronic nature of diabetes, the complexity of its management, and the multiple daily self-care decisions required of those with diabetes. In this regard, adhering to a predetermined care program is generally not enough to manage diabetes over the course of a person's life (Funnell and Anderson, 2003); the care needs to be flexible, yet consistent.

### **Increasing Health Care Costs**

Today the economic burden in our society of chronic conditions is great. Chronic conditions account for approximately 75% of the \$2+ trillion healthcare expenditure (CDC, 2009). Contrary to many Americans' belief that acute care consumes all the healthcare system dollars, treating chronic conditions is the real culprit, affecting people of different ages, income levels, and geographic regions (Anderson and Knickman, 2001). Chronically ill individuals are expensive to treat within the healthcare system and are a key driver of medical care costs. In addition, total health care and related costs for the treatment of diabetes runs about \$132 billion annually (NIDDKD, 2005). Various trends and factors impact a diabetic's self-care, including limited insurance coverage, medical advances, an increasing aging and obese population, greater longevity, and limited prevention and health promotion efforts, such as diabetes education. Limited health insurance coverage is one of the greatest challenges facing people. It specifically affects the poor and disabled, such as those on Medicaid, especially those who are chronically ill (Anderson and Knickman, 2001; Ireys et al., 2002). Therefore some argue that these trends exacerbate the consequences of chronic illnesses to the individual especially because they purport that healthcare system is designed to deliver acute symptom-driven crisis management care, it is less effectively configured to financially

contribute to diabetes self-care through health promotion, particularly regarding the development of a collaborative daily self-care plan.

### **The Role of Literacy and Health Literacy in Diabetes Care**

Since 2003, health literacy has received increasing attention (Weiss, 2005). According to the National Health Literacy Act of 2007, health literacy is an individual's ability to obtain, process, and understand basic health information and services needed to make appropriate healthcare decisions (U.S. Congress, 2007). It is clear that health literacy involves not only understanding health information, but also how to obtain services to integrate care practices, particularly for diabetes self-care. The difference between health literacy and general literacy is that general literacy is the basic ability to read, write, and compute, without regard to the context in which the reading and writing occur, while health literacy specifically incorporates the context of health care and assumes that the reading and understanding occurs within the healthcare context (Weiss, 2005).

The Agency for Health Care Research and Quality (AHRQ) recently indicated that only 1 in 10 adult Americans have all the skills needed to manage their health, and 12% have the skills to manage their own health care proficiently (AHRQ, 2007). For example, a generally literate individual may have inadequate functional health literacy capabilities in the healthcare environment (Consumer Health Advisory Committee, 2000). The National Adult Literacy Survey (NALS) primarily estimates general literacy in the overall population, but also obtains data on select subpopulations. The elderly and racial and ethnic minority groups were subpopulations included in the study, and poorer literacy, which disproportionately affected them, had prevalence as high as 80%. The NALS also indicated that the African-American population had an illiteracy rate of over 41% as

compared to 22% in the general U.S. adult population (Weiss, 2005). Ultimately, this low general literacy seems to cross over, thus translating into poor health literacy in African-American populations.

To identify the state of the science for overcoming inadequate literacy in diabetes self-care, in a review of the literature between 1990 and 2006, health literacy was found to be a stronger predictor of health status than socioeconomic status, age, or ethnic background (Nath, 2007). The review focused on studies that identified literacy as a factor in self-management outcomes, highlighting effective strategies to overcome barriers posed by inadequate literacy. In addition, studies of both indigent and Medicare populations indicate that health literacy is lower among older adults (Gazmararian, Williams, Peel, and Baker, 2003). Further, other research suggested that system, provider, and patient factors also contribute to health literacy (Weiss, 2005).

Low literacy is associated with poor disease-related knowledge and self-management strategies, worse self-reported health status, poor adherence to treatment, and a 30 to 50% increased risk for hospitalization (Powell et al., 2007; Schillinger et al., 2002; Weiss et al., 1992; Williams et al., 1998). Furthermore, research also suggests various factors for measuring health literacy. Contributing factors to measuring health literacy levels consist of reading fluency, prior knowledge, barriers, oral complexity, complexity of health information, culture, and social norms (Baker, 2006). In addition, depending on the context and setting, health literacy aptitude does not rest only on general reading ability, but also on years of education.

One of the first studies to measure the functional health literacy skills of non-indigent patients with chronic disease evaluated the relationship of literacy to patients'

knowledge of disease and self-management skills and outcomes, and confirmed that individuals with inadequate health literacy know less about their disease (Gazmararian et al., 2003). That study on health literacy and knowledge of chronic disease used a cross-sectional survey and measured health literacy using the Short Test of Functional Health Literacy in Adults (S-TOFHLA). The sample consisted of 653 Medicare enrollees 65 and older. Results indicate that, overall, 24% of patients had inadequate and 12% had marginal health literacy skills. Respondents with inadequate health literacy knew significantly less about their disease than those with adequate literacy. Multivariate analyses indicated that health literacy was independently related to disease knowledge (Gazmararian et al., 2003).

Gazmararian and colleagues (2003) further indicated that there are many opportunities to improve patients' knowledge of their chronic diseases, and efforts need to consider their health literacy skills. Knowledge therefore remains an important goal of patient education programs, and the results showed that many patients with inadequate functional health literacy, even those who had attended formal diabetes education programs, did not know the basics of their disease and good self-management skills (Williams et al., 1998).

Past research has shown high rates of limited health literacy among older adults and even after adjusting for measures of cognitive dysfunction, an association between limited health literacy and age has been found (Baker, 2000). Low-income older adults in some studies had reading skills at or below the fourth-grade level, had difficulty understanding information provided by their providers, and learned information from television instead of the healthcare system. Other studies indicate that both lower and

upper socioeconomic strata older adults have low literacy (Baker, 2000). In persons with limited education, low literacy is present. Hence, those with limited education also have high rates of limited general literacy, with more than 80% of those not finishing high school as reported on the NALS having poor reading skills (Weiss, 2005).

Various studies also identify the relationship between health literacy and other factors, such as diabetes knowledge, self-efficacy, and self-care. For example, Sarkar and colleagues (2006) reported an association between self-efficacy and self-management that persisted across ethnic groups and health literacy levels. This finding suggests that carefully designed self-management interventions targeting self-efficacy may be effective in populations with low literacy. This leaves key questions as to how to mobilize and involve patients in their own care and guide them in learning about their diabetes. Several factors contribute to self-efficacy and improve education outcomes for adults with diabetes, such as providers involving patients in their own care and guiding them in actively learning about the disease.

In addition, Skelly and colleagues (2000) indicated that preliminary work must be done to identify concepts that are important to the particular group under study. This call has been answered in other studies that focused not only on African-Americans, but Mexican Americans and Puerto Ricans, in developing culturally appropriate messages. However, studies such as the present one are needed to continue this research endeavor because the diabetes epidemic continues to rise disproportionately in minority populations.

In the healthcare setting, literacy has been measured by the two most widely used instruments: the Rapid Estimate of Adult Literacy in Medicine (REALM, available only in

English) and the Test of Functional Health Literacy in Adults (TOFHLA, available in English and Spanish) (Weiss, 2005). Specifically, the REALM is a word-recognition test where individuals read from a list of progressively more difficult medical words and the maximum difficulty level at which words can be read and pronounced correctly defines their health literacy. The TOFHLA is an inherently more difficult test than the REALM, because it involves reading appointment slips, interpreting prescriptions, and filling in missing words on a consent form (Weiss, 2005).

Regarding diabetes care, there are complex regimens that need to be followed, and such layered problems such as language, exist to achieve this care, culture, and an intricate healthcare system that is difficult to navigate (Nath, 2007). All these factors can make the self-care burden for diabetes overwhelming, especially to someone with inadequate literacy.

### **Diabetes, Literacy, and Health Outcomes**

Seminal works have defined the effect of literacy on health outcomes in the United States. First, the IOM report (2001) concluded that most health professionals and policymakers lack understanding about the barriers posed by inadequate health literacy. Second, an AHRQ report (2007) found an association between inadequate literacy, as measured by reading skills, and several adverse health outcomes, including increased incidence of chronic illness, relatively poor intermediate disease markers, and suboptimal use of preventive health services (Nath, 2007). Past intervention studies within a group setting have tried to meet the needs of diverse groups, such as combining those with diabetes type 1 and 2, combining males and females, and including individuals from wide age ranges and diverse ethnic backgrounds (Brown,

1999). However, separating groups based on characteristics and keeping groups small has resulted in better compliance (Brown, 1999).

Though successful diabetes care includes such needed factors as two-way communication between healthcare providers and patients and involvement of patients in treatment decisions, the active participation of patients in self-care and goal setting are key. Those with inadequate health literacy however may lack the skills to accomplish such tasks, and find it difficult or impossible to access and understand healthcare information and instructions or to implement recommended behaviors (Nath, 2007).

In 2000, Skelly and colleagues developed and tested culturally sensitive instruments, for African-American women, with T2DM. The purpose was to present a method for developing new instruments and/or modifying existing instruments to identify and measure important sociocultural constructs that influence self-care practices by these women. Results from this study indicate that perceptions of self-efficacy were high among group members for certain diabetes self-care activities (e.g., administering medication, home blood glucose monitoring), yet participants felt least confident about their diet and physical activity practices (Skelly, Samuel-Hodge, Elasy, Ammerman, Headen, and Keyserling, 2000).

Knowledge of diabetes among group members was limited; for example, several participants expressed uncertainty about the meaning of blood glucose values and the rationale for treatment recommendations, particularly those relating to diet. (Skelly et al., 2000). Moreover, questions were raised about the most fundamental areas of self-care. It was found that many participants had received inadequate diabetes education or the

effectiveness of the diabetes education they had received was limited by lack of comprehension of basic terminology often used by healthcare providers (Skelly et al., 2000). In the large review of intervention studies commissioned by AHRQ, Pignone and colleagues (2005) found several interventions related to knowledge outcomes, but few dedicated to health behaviors, such as dietary patterns. In addition, self-efficacy, a term based on social cognitive theory, suggests that patients' confidence in their ability to perform health behaviors influences which behaviors they will engage in (Bandura, 1986). This is reinforced by past research that indicates personal evaluation of health is a complex process not fully understood (Silverman, Smola and Musa, 2000; Idler, 1999), and the cognitive complex process of assessing one's health changes as factors in one's illness experience change (Silverman et al., 2000).

### **Vulnerable Populations and African-Americans**

Vulnerable populations are defined as social groups who have an increased relative risk or susceptibility to adverse health outcomes (Flaskerud and Winslow, 1998) evidenced by increased morbidity, premature mortality, and diminished quality of life. These vulnerable groups are the poor and persons subject to discrimination, intolerance, subordination and stigma, politically marginalized, disenfranchised and denied human rights, and typically include women and children, ethnic people of color, immigrants, gay men and lesbians, the homeless, and the elderly (Flaskerud and Winslow, 1998). For example, on average, African-Americans are 1.8 times more likely to have diabetes as non-Hispanic whites of similar age. Thirteen percent of African-Americans aged 20 years and older have diabetes (NIDDKD, 2005).

Until the twentieth century, most Americans of African ancestry lived in the south without any formalized system of health care. Today, in the twenty-first century, the

advent of health clinics and Medicaid and Medicare have made those who traditionally have had limited access to and experience with the healthcare system receive care and use services, although poverty and inadequate health care continue to be a problem in health care delivery. Further disparities in health status are discussed extensively since lifestyle, reduced access to health care resources, lack of health insurance, limited knowledge of health promotion disease prevention behaviors and practices, and certain genetic variables contribute to disparities in health status (Ashley, 1999).

Further, individuals from different races are not homogeneous. Slavery, despite what some think, was not the beginning of differences in African-Americans as a group (Ashley, 1999); rather these differences existed above and beyond that experience because of migration to the United States. Hence, great diversity within the general population as well as those in the African ancestry exists about attitudes, behaviors, and beliefs. Compared to other groups in the United States, African-Americans lag behind on most health indicators, particularly for diabetes. Further, African-Americans are more susceptible to cancer, heart disease and stroke, death by homicide and unintentional injuries, infant mortality, and substance abuse (Ashley, 1999).

Unfortunately some of these disparities go unaddressed, and one of the main goals of Healthy People 2010 today is reducing disparities in health. Diabetes is one disease that disproportionately affects minority populations. The fact that the gap exists today suggests that social factors, for example, inadequate education and public access to healthcare, to name a few, still play a significant role in health outcomes with sociocultural and behavioral lifestyle issues being highly correlated with these disparities (Ashley, 1999).

It is therefore evident that meanings applied to health by various ethnic groups also vary substantially. For example, a study of 114 Medicare community dwellers of older African-Americans and whites with chronic illnesses by Silverman et al. (2000) found participants frequently assigned the attribute of the presence of functional capacities as being healthy. African-Americans, more than whites, mostly attributed the absence of medical and physical symptoms as being healthy. In addition, African-Americans did not mention psychological attributes for being either healthy or not healthy while whites did so when defining the meaning of healthy. Whites also generally identified more attributes when characterizing the condition of not being healthy. Similar to other literature, this study suggested that health is a multidimensional construct, but it also highlighted that healthy may be more connected to ones' total life experiences than is a designation of not healthy.

With regard to the elements of achieving successful programs in communities, such as low income, low literate African-American communities, need assessments, program plan development, implementation, and evaluation are essential (Ashley, 1999). Although health education is an effective tool to potentially improve the health status of Americans, more needs to be done. Furthermore, in African-American communities, a lack of health education still plays a key role, especially since the most elementary information about disease and disease prevention very often is deficient in this population (Ashley, 1999).

Further, though chronic illness is not the exclusive domain of older adult's age plays an important role in the development of chronic illness, and approximately 80% of older adults have at least one chronic disorder (Holmes, 2006). Hence, as the

population ages, and obesity becomes more prevalent, the need for diabetes education and self care is urgent (Lewis, 2007). In addition, the prevalence of diabetes among adults in Florida has also continued to increase (Florida Department of Health, 2005). The prevalence of obesity among people with diabetes is 44.6%, more than twice the rate of those who do not have diabetes (FDH, 2005). Among race, the prevalence of obesity varies; non-Hispanic blacks have a higher prevalence of obesity (62.1% than non-Hispanic whites (42.6%). The prevalence of obesity among non-Hispanic black women is significantly higher (70.9%) than that for non-Hispanic white women (44.1%) and non-Hispanic white men (41.2%) (FDH, 2005). The prevalence also significantly differs by age. People between 45 and 64 years have a higher prevalence (55.7%) of obesity than adults 65 years and older (34.7%) (FDH, 2005).

For the purpose of this study, African-American women with diabetes will be the vulnerable population of interest. This population was chosen not only because of the increasing prevalence of diabetes in this population, but also because greater insight will be obtained into gaps in self-management practices to better guide future interventions and policies for health promotion and prevention, and to improve treatment initiatives for this population.

### **Importance of Culture in Diabetes Self-care**

The diabetes and behavioral change literature emphasizes the importance of understanding an individual's cultural beliefs, attitudes, and perceptions because these factors are also important determinants of the ways in which people with diabetes behave with respect to their self-care (Skelly et al., 2000; Maillet, D'Eramo, Melkus and Spollett, 1996). It is therefore imperative that prevention of worsening conditions and promotion of ongoing care are a constant focus for improving the system. In addition,

limited work addresses the unique needs of sicker patients from their perspective; researchers suggest that more studies examining the experiences of vulnerable populations with poor health status are needed, particularly because this group has more extensive needs and higher utilization (Mason et al., 2002). Further, the Silverman et al. (2000) study suggested that health is a multidimensional construct, and, as such, may be more connected to an individual's total life experiences than would be a designation of not healthy.

In addition, past research has provided limited information on the sociocultural factors that influence self-care practices among African-Americans with diabetes. For this study it is also anticipated that various factors, including but not limited to, sociocultural factors may emerge from the data. This will be important to add another dimension to the literature by identifying those factors that help future researchers to find ways to measure the sociocultural variables that affect self-care practices in minority populations.

### **Management of Diabetes and the Role of Self-Care**

The consumer shift in health care, which advocates for patients taking more active roles in medical encounters and engaging in increased self-care, has gained increasing momentum since the 1980s and has spurred growing research attention to chronic illness self-management research (Gallant, 2003). Self-management of chronic illness refers to the daily activities that individuals undertake to control their illness, minimize its impact on physical health status and functioning, and cope with the psychosocial process of the illness (Clark, Beker, Janz, Lorig and Rakowski, 1991; Gallant, 2003). Consequently, self-management entails a high level of control on the patients' part, and

some independence regarding adjusting the regimen is essential and requires deliberate decision-making and problem-solving (Gallant, 2003).

Diabetes self-management education plays a specific role in diabetes care because it is an ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care (Funnell et al., 2009). This education incorporates the needs, goals, and life experiences of the diabetic for the ultimate outcomes of 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., 2009).

Successful self-management requires the mastering of three sets of tasks: (1) making informed decisions about care, (2) performing activities aimed at management of the condition, and (3) applying the skills necessary for maintaining adequate psychosocial functioning (Clark et al., 1991). In addition, Clark and colleagues (1991) indicated that although self-management tasks are specific to an illness, for example, measuring blood glucose for diabetes, there are also core self-management tasks that are common to all illness categories that include physical activity, smoking cessation, maintaining diet, recognizing and responding to symptoms, and taking medications properly, to list a few.

For many vulnerable populations, increased barriers to self-care exist. They may include a lack of financial resources, unawareness that services even exist, fear or distrust of large (or small) institutions, lack of transportation, and low health literacy. Although communities may have various diabetes self-management education

programs, these target populations may not take advantage of them or fail to incorporate them into their daily lives.

Increasingly, empirical research indicates that successful self-management of chronic illness is related to better overall physical and psychological health outcomes (Clark et al., 1991; Gallant, 2003; Fisher, Arfken, Heins, Houston, Jeffe, Sykes, 1997). Further, Gallant (2003) indicated that a full understanding of the social context of chronic illness self-management may result in key implications for the design of interventions that seek to enhance self-management behavior, as well as for the health and well-being of individuals with chronic illness.

Randomized controlled trials of self-management educational interventions have been shown to influence positive health outcomes for individuals with heart disease, arthritis, asthma, and other illnesses (Bailey et al., 1990; Bartholomew et al., 1997; Clark et al., 1997; Clark, Janz, Dodge, Schork, Fingerlin, Wheeler, Liang, Keteyian, Santinga, 2000; Gallant, 2003; Lorig and Holman, 1993).

### **Factors Affecting Diabetes Self-care**

Correlates of knowledge for diabetes self-care include socioeconomic status, length of time with disease, glycemic control, and self-care activities. Evidence from previous research highlights these factors in the literature that illustrate these associations. Table 2-1 indicates the variables used in the study.

#### **Socioeconomic Factors**

In 2000, the U.S. Centers for Disease Control assessed the socioeconomic status (SES) of women with diabetes from data from the Behavioral Risk Factor Surveillance System (BRFSS). The findings indicated that women with diabetes in 2000 had markedly lower SES levels than women who did not have diabetes (CDC, 2002).

Though SES incorporates factors such as income, size of household, marital status, employment status, and living arrangements, for the CDC study women were classified as having a low SES if they did not complete high school or lived in a household with an annual income of less than \$25,000. Findings suggest that a higher educational level may influence a woman's decision-making, while those women with higher income may have better access to health care, higher living standards, and other material benefits that have a positive impact on health (CDC, 2002). Similarly, in this present study, SES will refer to low income women (annual household income  $\leq$  \$25,000) and mostly those with less than a high school degree as well as women with less than a four year college degree.

### **Level of Income**

A woman with diabetes, whose annual individual household income was less than or equal to \$25,000 at the time of the study, was regarded as low income. It is important to identify if level of income in the literature is associated with factors such as glycemic control for other populations where race and gender were the same and the population was more homogenous. Other studies did not identify a relationship between glycemic control to socioeconomic status or access to medical care in racial or ethnic groups studied (Harris, Eastman, Cowie, Flegal and Eberhardt, 1999). The function of identifying level of income will be to describe any association that may emerge from women with low SES with their diabetes knowledge for self-care.

### **Level of Education**

Numerous studies confirmed an association between (1) inadequate health literacy and adverse outcomes in patients with diabetes and (2) a poor match between readability of printed materials, internet offerings, and interactive multimedia and the

population for which the materials are intended (Nath, 2007). In addition, depending on the context and setting, health literacy aptitude does not rest only on general reading ability, but also on years of education (Consumer Health Advisory Committee, 2000). The literacy category used the level of education, which represented the years of education that was less than a four-year college degree. Further, determinants of health literacy also include age, language, race, ethnicity, employment, SES, and environment (Pawlak, 2005). One study using a qualitative study, explored how older adults with multiple illnesses make choices about medications and results indicated that there was no evidence of “adherent” personalities. However, a limitation to the study was that educational attainment was not determined. As previously discussed, education, specifically level of literacy was a strong predictor of self-care behaviors. Health education is a prerequisite for effective self-management of diabetes, but previous research corroborates that knowledge does not necessarily predict outcome (Nath, 2007). Therefore, in populations that have large knowledge deficits, even a small increase in knowledge may contribute to improved self-care (Nath, 2007).

### **Length of Time with Disease**

Other factors, such as duration of disease, may be stronger predictors of metabolic control (Nath, 2007). This has been used in previous work regarding its impact on glycemic control. It will also be used in this study and referred to as length of time diagnosed with diabetes, which is greater than one year upon entering the study.

### **Glycemic Control**

Testing of HbA1C values is now the main way to measure and track glycemic control in diabetics, and patients knowledge of these values may be useful as a precondition for their involvement in their diabetes self-management (Harris, Piette,

Spencer, Kiefer, Vijan, 2005). Therefore achieving metabolic control requires improved diabetes self-management, especially because it helps to reduce diabetes complications, as well as improve quality of life (Misra and Lager, 2008). The single most important clinical characteristic of the individual with diabetes is the blood glucose level because this defines the disease and is a major risk factor for complications of diabetes (Harris, Eastman, Cowie, Flegal and Eberhardt, 1999). Further, Harris and colleagues (1999) conducted one of the first studies that evaluated glycemic control in a representative sample of U.S. adults with T2DM. They found that most patients had not self-monitored and the use of multiple daily insulin injections was more common in whites than non-Hispanic African-Americans, non-Hispanic whites, and Mexican-Americans. Glycemic control in a general sense refers to the typical levels of blood sugar, more specifically, glucose, in an individual with diabetes. This is a factor used repeatedly in the literature as a variable of interest for selection of subjects for various studies. In addition, an extensive review of intervention studies commissioned by AHRQ, DeWalt and colleagues in 2004 looked at interventions that examined an independent relationship between reading ability and metabolic outcomes.

One study in part sought to describe the changes in glycemic control among the adult U.S. population diagnosed with T2DM between 1999 and 2000. Their data supported the key public health message of early and aggressive management of diabetes (Koro, Bowlin, Bourgeois and Fedder, 2004). Further, Koro and colleagues (2004) also illustrated that treatment regimens of diet and exercise, plus proper self-administration of insulin, or oral hypoglycemic agents have been shown to improve glycemia, but more disease management that includes greater patient self-participation is needed and

recommended. In past studies glycemic control rates were calculated as the proportion of individuals with T2DM with an HbA1C level of less than 7% (Koro et al., 2004). Other studies also calculated glycemic control as the proportion of HbA1C less than 7%. (Koro, Bowlin, Bourgeois, and Fedder, 2004; Rothman et al., 2005). For this study, glycemic control is the typical levels of blood sugar, more specifically glucose, in an individual with diabetes, between than or less than 70 and 120 mg/dL [3.89–6.67] of their glucose level.

In 2003, a qualitative study of problem-solving and diabetes control in T2DM self-management was conducted with 186 low income African-Americans to explore and compare diabetes-related problem-solving in this urban population in good and poor diabetes control (Hill-Briggs, Cooper, Loman, Brancati and Cooper, 2003). Two focus groups were studied, one with participants with good control and the other with participants with poor control. HbA1C value was measured within last three months. Primary types of problems with diabetes self-management were similar in the good control and poor control groups (Hill-Briggs et al., 2003). Further, predominant problem-solving themes in the good control group reflected a positive orientation toward diabetes self-management and problem-solving, a rational problem-solving process, and a positive transfer of experience. However, those in the poor control group revealed a negative orientation, careless and avoidant problem-solving processes, and a negative transfer of past learning to new situations (Hill-Briggs et al., 2003). However, improved knowledge alone does not correlate with improved glycemic control, and evidence show that providing more information is not enough to motivate patients (Heisler, Piette,

Spencer, Kieffer, Vijan, 2005). Rather, this study measured knowledge for particular self care in a less studied population.

In sum, although research has shown that various factors impact people with diabetes, such as self-efficacy, stress management, goal setting, and decision-making, improve metabolic control, it is not known if these factors are similarly effective in low literacy populations with diabetes (Nath, 2007).

### **Knowledge for Diabetes Self-care**

Both limited literacy and health literacy are prevalent among patients with diabetes, and are associated with poorer knowledge of the illness and its complications, worse glycemic control, and higher rates of retinopathy (Powell et al., 2007). In addition, past research showed that comprehensive diabetes disease management programs, with educational strategies appropriate for low literate patients, were of greater benefit to patients with low literacy than those with higher literacy (Rothman, Malone, Brayant, Horlen, DeWalt, Pignone, 2004).

Since one of the primary goals for diabetes management is effective self-care of T2DM, thus individuals must have and apply knowledge about their condition, specifically regarding its various symptoms and how to treat it (Rothman et al., 2005). In addition, the knowledge an individual assimilates is critical to assess the impact of diabetes education and interventions, as well as recognize diabetes education's intermediary role to improve patient outcomes. Further, despite diabetes education, various studies indicate that knowledge deficits are evident in low literate diabetics. Knowledge gaps exist for individuals regarding diabetes self-management care, and it is important to identify how these gaps impact individuals' diabetes self-management practices. Although knowledge alone does not motivate action, particularly for self care

activities, this will be used as a measure to assess if this holds true for our less studied population and the identified assessment will be further explored in the qualitative component of the study. The qualitative component will help to explore patient's values, motivations, and goals that have been shown to be more effective in addressing barriers to improving self care activities (Heisler et al., 2005).

### **Self-Management Activities**

Clark and colleagues (1991) indicated that, although self-management tasks are specific to an illness, for example measuring blood glucose for diabetes, there are also core self-management tasks that are common to all illness categories. These include physical activity, smoking cessation, maintaining diet, recognizing and responding to symptoms, and using medications, to list a few.

The summary of the diabetes self-care activities (SDSCA) measure has been administered as a self-completion questionnaire, and is one of the most widely used self-reporting instruments for measuring diabetes self-management in adults (Toobert, Hampson, Glasgow, 2000). The key activities included in this measure are diet, exercise, blood sugar testing, foot care, and smoking.

### **Measures in Diabetes**

Various scales are available to measure diabetes-related issues. These include, but are not limited to, the Diabetes Health Belief Model scale (DHBM), Diabetes Knowledge Test (DKT), Diabetes Risk Improvement Scale, and the Diabetes Self-Management Tool (D-SMART), the Spoken Knowledge in Low Literacy Diabetes scale (SKILLD), and the Summary of Diabetes Activities measure, to name a few. The DKT is a 14-item general multiple choice test, and a 9-item insulin use subscale is used to assess patients' diabetes-related knowledge. The DHBM scale is an 11-question health

beliefs questionnaire that operationalizes the health belief model for individuals with diabetes (Powell et al., 2007).

The Diabetes Risk Improvement Scale allows either the patient to fill out the scale and score it or scores are entered into a provider database to help identify patients in need of care by the practitioner. D-SMART is a patient self-report instrument that captures the assessment information on diabetes health status, knowledge, skill, confidence, barriers, and current self-management behaviors. For the purpose of this study, the SKILLD will be used to assess African-American women's knowledge about their diabetes self-care issues.

The SKILLD is a 10-item oral questionnaire that measures diabetes knowledge about self-care issues (Rothman et al., 2005). This scale was a recently validated scale, developed to combat some of the concerns with past scales that used multiple-choice questions, and will be used to measure diabetes knowledge specifically as it relates to self-care issues. In the past, close-ended questions that were typically multiple choice made it particularly difficult for those with low literacy to navigate through the responses.

The diabetes activities measure is a multidimensional measure of diabetes self-management with internal and test-retest reliability and evidence of validity and sensitivity to change, revised in the last few years; it consists of a core set of 11 items (Toobert, Hampson, and Glasgow, 2000). An extended version of the scale also exists but for the purpose of the study, the core items will be used. The scale also consists of five areas around which questions are organized and include diet, exercise, blood sugar testing, foot care, and smoking.

## **Diabetes Education**

Diabetes education contributes to how different behaviors and choices affect health outcomes—both for better and worse—and can help address incorrect assumptions and learning (CDC, 2005). Importantly, health education helps impart knowledge about strategies that improve a patient’s ability to identify effective diabetes care action plans, as well as adopt self-management behaviors. Prolonged planning and routine monitoring, prevention, coordination of care, education, and self-management are constantly needed for those with chronic illnesses. However, far too often, prevention and health promotion is shortchanged despite the fact that chronic diseases, such as heart disease, hypertension, and diabetes, are among the most prevalent and costly, yet are the most preventable of all health problems (CDC, 2005).

In a review of the diabetes education literature, a comparison of findings reported prior to the 1990s, to findings since 1990, recent changes and patterns in diabetes self-management education exist, such that trends in interventions involving diabetes self-management education have evolved from education only, to include behavioral models and with more attention to interventions for specific minority populations (Brown, 1999). This is a positive step in the right direction, but the increasing rates of diabetes morbidity and mortality and the disease burden of this chronic illness, particularly for low income, low literate African-American populations, suggest that education is needed that actually helps translate knowledge into self-management skill practices.

In 2007, the American Association of Diabetes Educators took steps to outline what diabetes educators must do by officially defining diabetes education, also known as diabetes self-management training (DSMT), as a process that requires collaboration through which people with or at risk for diabetes, gain knowledge and skills needed to

modify behavior and effectively manage the disease and its related conditions (Funnel et al., 2007). The step aims to achieve optimal health status, better quality of life, and a reduction in the need for costly health care. Further, diabetes education has seven self-care behaviors that are deemed essential for improved health status and quality of life and they include healthy eating, being active, monitoring, taking medication, problem solving, healthy coping, and reducing risks. This is an encouraging step for diabetes educators who seek to educate and empower those with diabetes. However, factors that contribute to the gap between actual delivery of these skills taught and their implementation need to be further explored, identified, and improved (Funnel et al., 2007). The current study documented some of this target populations experiences with their diabetes, their self-management practices and the gaps as perceived by these participants in adapting the self-care education from the healthcare system into practical use in their homes.

Past studies have also identified the importance of improving patient-provider communication as a key strategy for advancing patient involvement in setting a patient's own goals. For example, (Nath, 2007) identified some of these techniques to improve communication between providers and patients who had inadequate literacy. These techniques included more frequent use of oral and visual instructions; limiting instructions to essential information only; making instructions interactive with patients to demonstrate their understanding of the topic; and encouraging the assistance of surrogate readers. The "teachback" strategy is an interactive educational strategy in which patients paraphrase their understanding of information (Nath, 2007).

## Summary

An improved paradigm for high quality chronic illness care is urgently needed and this care should seek to promote increased understanding of patients' lives and preferences. Regardless of cultural background, race, or level of education, the effects of inadequate diabetes knowledge and self-care activities are detrimental to the individual and society. It is vital that researchers continue to assess knowledge and self-care activities for diabetes particularly because, if diabetes is managed effectively, you get positive outcomes. This literature review not only defined chronic illnesses but also looked at how chronic illnesses are placed within the health care system and the people's role in their care. The literature review also highlighted the increasing health care costs associated with chronic illnesses, the role of culture and health literacy in diabetes self-care. A brief focus on the vulnerable population of interest and their role in diabetes self-management was also highlighted. Common factors associated with diabetes that will be used to make associations in the current study were also explored. The various scales used to measure aspects of diabetes self-care were also covered, focusing ultimately on the scales that were appropriate for this current study.

Increasing healthcare costs, medical advances, obesity, and age however, all impact diabetes, especially for minority women, and increased self-care skills and practices are needed by this population. In addition, the healthcare system has been deemed to lack patient-centered care, and the literature reports that patients need to be given more of a voice in research efforts and education targeted to improve their care and self-care.

In addition, only limited research addresses the unique needs of sicker patients from their perspective, and in many ways the health system does not appear patient-

centered or coordinated. Consequently, it is also imperative that investigators explore the meanings assigned to chronic illnesses and how they impact various self-care behaviors. These study data will provide direction for diabetes health educators and researchers to better target the needs of vulnerable populations.

Table 2-1. List of variables for Quantitative study

<u>Variable</u>
Explanatory
Background and Personal Factors
Socioeconomic status
Literacy level (level of Education)
Illness-Related Factors
Length of time with disease (diabetes)
Glycemic control
Outcome
Outcome of the Illness
Knowledge for diabetes self-Care
Diabetes self-care activities (includes: general diet, specific diet, exercise, blood sugar testing, foot care and smoking)

## CHAPTER 3 METHODOLOGY

The purpose of this study was to assess diabetes knowledge and self-care activities and explore the experiences of African-American women with type 2 diabetes mellitus (T2DM). This study used a correlational embedded mixed methods design and provided applications to different parts of a modified model for understanding the crisis of a physical illness. Specifically, the study was designed to (1) assess knowledge about diabetes in African-American women; (2) explore the associations between African-American women's knowledge for diabetes and (a) income and year of education, (b) length of time with diabetes, (c) glycemic control, and (d) self-care activities; and (3) explore experiences of African-American women in managing their diabetes, as well as their understanding of diabetes.

This chapter describes the methodology used to conduct this study. Each of the following areas will be presented and discussed: (1) theoretical perspective; (2) research design, (3) research methods, which include (a) settings and participants, (b) instrumentation, (c) scientific integrity, (d) data collection and recruitment plan, (4) data analysis, (5) limitations, and (6) summary.

### **Theoretical Perspective**

#### **Model for Understanding the Diabetic Illness—Quantitative Study**

Caplan's 1964 crisis theory, one of the first, was inspired by Erikson's (1963) formulation of "developmental crises" at transition points in the life cycle. Caplan's theory dealt with the impact of disruptions on established patterns of personal and social identity (Moos, 1982). Since a person cannot remain in an extreme state of disequilibrium, within a period of time, some resolution, no matter how temporary, must

be found and equilibrium reestablished. The crisis experience evokes a new balance achieved, or a transitional period or turning point that may be a healthy adaptation with personal growth and maturation or a maladaptive response with psychological deterioration or decline that impacts an individual's long-term ability to meet future crises (Moos, 1982).

The theoretical perspective that guides this study is the model developed by Rudolph Moos and Vivian Tsu in 1977 to understand the crisis of a physical illness. This crisis theory has provided a conceptual framework for preventive mental health care and for dealing with severe physical illness or injury, where the crisis of a physical illness is an unusually potent stressor that may extend over a long period of time and lead to permanent changes among patients and their families (Moos, 1982). In addition to diabetes, the model has been used in the past for studies on impairment, disability, slow recovery from illness, chronic pain, Alzheimer's disease support groups, bereavement, and crisis intervention for children and families. In 1996, the model was used to explore the quality of life, life experiences, and characteristics relevant to quality of life of Thai women living with diabetes (Puavilai, 1996). This study would be the first to apply the Moos model for low-income African-American women within a specified age range living in North Central Florida. The model (Fig. 1-1) helps to frame the present study, which identifies the diabetes illness experience, especially in the time just after diagnosis, as a crisis.

The Moos-Tsu (1977) model for understanding the crisis of a physical illness is considered appropriate for this study for several reasons: 1) it identifies factors relating to the illness experience: a) background and personal factors (precursors), b) illness-

related factors, c) and the physical and social environment of the individual during the lifetime of the stressful chronic illness, then d) links them to the outcomes illustrated in the literature; 2) it illustrates that, from this crisis, an individual's cognitive appraisal of a disease's significance puts in motion basic skills and experiences, including adaptive tasks that result in the application of various coping skills; and 3) it identifies the successful resolution of the crisis, which in this case is diabetes knowledge about self-care and diabetes activities for self-care. Their model was also particularly useful to this study because it appropriately explained variables used in this study as they are associated with outcomes in the literature, and that were anticipated for this study as well. In addition, their model was relevant to this study in that it can be focused on the individual living with her diabetes, a chronic lifetime illness perceived as a crisis, and the diabetes knowledge outcomes that may or may not be present in this population.

In the Moos-Tsu model, serious physical illness or injury is understood as a life crisis. The life crisis of a major, chronic physical illness upsets the equilibrium of people, here women with diabetes, precipitating a crisis and need for adaptation to restore equilibrium. Further, the severity of a crisis stems from an unexpected diagnosis and the pervasive threat to the essence of an individual's life and adaptation, typically existing for a lengthy time, affecting permanent changes in the individual and family life (Moos, 1982; Puavilai, 1996). The current study applied and augmented factors included in their model. In the case of this study, it was assumed that diabetes is a chronic physical condition that causes crises in the lives of the African-American women in our study. The term crisis may seem overly dramatic, but was used because the increasing rates of diabetes in this population point to ignorance about the causes of the disease,

inadequate or too infrequent instruction and follow up on diabetic self-care, and resistance by many individuals to adaptation to diabetes resulting in maladaptive responses and further crises. Also the changing nature of an individual's diabetes over time can result in repeated disequilibrium or disorganization in diabetics' lives (Puavilai, 1996). These crisis periods may be transient, but occur throughout the rest of the life cycle of women with diabetes, their severity often depending on the quality of their self-care.

For the purpose of this study the conceptual model for understanding the crisis of physical illness was modified as in the Puavilai study in 1996 and categorized into three components. The categories were viewed slightly different from the previous study when it was applied to Thai women with diabetes (Puavilai, 1996). The components are: (1) precursors, (2) skills and experiences, and (3) outcomes of the crisis. See Figure 3-1 for the modified version of the Moos model. Precursors are the first component of the model and will include three factors: background and personal factors, illness-related factors, and physical and social environmental factors. All these factors impact skills and experiences that ultimately influence the negative or positive outcomes of the crisis. The first component was the focus of the primary quantitative study as it relates to outcomes. This model was valuable to the study because it focused on a diabetic woman's illness experience of living with a lifetime chronic condition. Through the components of the model, women with diabetes learn how to live with their chronic condition and the outcome is either positive or negative depending on their ability and willingness to engage in good self-care.

### **Precursors-Background and personal characteristics**

This included age, gender, socioeconomic status, intelligence, cognitive and emotional development, ego strength and self-esteem, philosophical or religious beliefs, and previous illnesses and coping experiences. Only age, gender, and socioeconomic status were obtained from the self-report survey by the participant. Ego strength and self-esteem were not identified in either the qualitative or quantitative data sets, but philosophical or religious beliefs, and previous illnesses and coping experiences were considered when analyzing the findings for the qualitative study. These factors determine the meaning that the illness carries for an individual and affect the psychological and the intellectual resources available to meet the crisis (Moos & Tsu, 1977; Moos, 1982). In this study, the proxy for intelligence, outlined in the original model, was level of education attained. According to the original model, another important aspect of the background and personal characteristics was timing of an illness in the life cycle, as individuals who were diagnosed with the disease later in life may have more maturity and draw from experiences to cope with the illness that threatens life goals and established roles (Moos & Tsu, 1977; Moos, 1982). This was considered under the following section illness-related factors, when describing the relationship of variables for this study and duration of disease was used to capture the length of time with diabetes.

### **Precursors-Illness-related factors**

According to the model for understanding the crisis of a physical illness, these include the type and location of symptoms, a key component in defining the exact nature of the tasks the individuals faced and their adaptive responses. Different organs and functions may have a psychological significance not pertaining to the biological

factors related to survival (Moos & Tsu, 1977; Moos, 1982). For example, loss of vision in an eye from diabetes may have more psychological significance than a severe diabetes hyperglycemic crisis that if left untreated may directly threaten life. For the purpose of this study, a modification was made regarding time since diagnosed with diabetes, which was placed in this section referred to in this study as length of time with diabetes.

### **Precursors-Physical and social environmental factors**

These factors specifically affect the adaptive tasks patient's family's face and the choice and outcome of the coping skills used including the aesthetics of the surroundings, the amount of personal space available, and the degree of sensory stimulation which may influence a person's cognitive functioning, mood, and general morale; the social or human environment consisting of the relationships of patients and their family, features of the work settings, social supports in the wider community and sociocultural norms and expectations (Moos & Tsu, 1977; Moos, 1982). For the purpose of this study, a modification was made to this section and referred in this study as social support, primarily collected from the qualitative component of the study.

### **Skills and experience**

The second component of the model was the women's skills and experience and includes appraisal and activation, major adaptive tasks, and major types of coping skills. The skills and experience section of the model was best illustrated from the qualitative study and addressed in the findings section. The factors that comprise the skills and experiences component: appraisal and activation, major adaptive tasks, and major types of coping skills are explained below.

**Skills and experience-cognitive appraisal.** This was defined as the way in which the potential stressor was perceived, and may or may not be a mediating factor. Activation or arousal occurred when the environment was appraised as necessitating a response, which fosters efforts to adapt and cope. The nature of these tasks was affected by the meaning of the illness, by personal factors, and by the selection of relevant coping skills that were influenced by environmental factors. The result of adaptation and coping may affect the outcome of the crisis. From this crisis, an individual's cognitive appraisal of its significance puts in motion basic adaptive tasks that result in the application of various coping skills (Moos, 1982).

**Skills and experience-adaptive tasks.** The adaptive tasks included two key categories, illness-related tasks and general tasks. The illness-related tasks included dealing with symptoms, environment and treatment procedures, and relationship maintenance with healthcare staff. General tasks included being able to preserve (a) reasonable emotional balance, (b) satisfactory self-image, and sense of competence and mastery, (c) relationships with family and friends, and (d) preparation for an uncertain future (Moos, 1982).

**Skills and experience-coping skills.** These consisted of mental and behavioral components of an individual, viewed as positive and teachable, which may be used individually, consecutively, or in various combinations. The coping skills are seven adaptive tasks typically used: (a) denying or minimizing the seriousness of the crisis; (b) seeking information about the illness, treatment procedures, and probable outcomes; (c) learning specific illness-related procedures, such as giving self insulin injections or running a home dialysis machine; (d) maintaining a regular routine and setting concrete

limited goals; (e) managing self-presentation and ability to request needed reassurance and support; (f) preparing self mentally and rehearsing potential alternative outcomes; and (g) finding a general purpose or pattern of meaning in the course of events. This component of the model was also applied based on the qualitative data obtained. The skills and experiences were important for the ultimate phase, the outcome (Moos, 1982). Combined, the two components, precursors, then skills and experiences, determine the outcome of the crisis (Moos & Tsu, 1977).

### **Outcome**

The third component of the model is the outcome of the illness, and represents either a healthy adaptation that promotes personal growth and maturation or a maladaptive response which signifies psychological deterioration and decline (Moos, 1982). For this study, both knowledge about self-care as well as performing diabetes self care activities determined the outcome of the illness for the individual.

In sum, the adapted model for understanding a physical illness was reworked. The first section was grouped under the general heading of precursors which include background and personal characteristics, illness related factors and physical and social environmental factors which collectively influence one another and affect the self-care skills and experiences of a person which subsequently impacts their self-care knowledge and self-care activities.

### **Explanatory Model**

The explanatory model was used to construct the interview guide for the qualitative portion of the study. Using this model was important because explanatory models incorporate factors about an episode of sickness and its treatment employed by all those engaged in the clinical process (Kleinman, 1980). Explanatory models also

explain sickness and treatment that guides choices among available therapies and therapists and gives personal and social meaning to the experience of sickness. Kleinman distinguished explanatory models from general beliefs about sickness and health care, in that general beliefs belong to the health ideology of the different healthcare sectors and exist independent of and prior to a given episode of illness. An individual's explanatory model, in addition to drawing on these belief systems, are marshaled in response to particular illness episode (Kleinman, 1980).

Individual explanatory models were anchored in a different explanatory system and social structural arrangement comprising the separate sections of a local healthcare system (Kleinman, 1980). This explanatory model therefore was invaluable for constructing the semi-structured interview guide to obtain the perceptions and experiences of the participants for the qualitative arm of the study.

### **Research Design**

To address the research questions, this study used a primary data source, a community sample from a North Central Florida community. The design that represented the best option to answer the research questions in this study was an embedded mixed method design (Creswell & Clark, 2007). This design had both a quantitative and a qualitative component. The qualitative data played a supportive role to the quantitative data and was collected during the same time frame.

The chosen design was appropriate for this study because it allowed different sets of research questions to be answered without necessarily merging the data sets. Using this design, applications to different parts of the model of understanding the crisis of a physical illness were also possible, identifying perceived factors that impeded

knowledge that could promote behavior change may help better target healthcare needs.

The quantitative data was used to answer the following research questions in the correlational design:

- 1) What knowledge level do African-American women with diabetes have about their diabetes?
- 2) Was African-American women's knowledge level about their diabetes self-care associated with income, years of education, length of time with diabetes, and glycemic control?

**Null Hypotheses H01.** Respondent's knowledge scores had no associations to a) income, b) years of education, c) length of time with diabetes, and d) glycemic control.

- 3) What were the associations between African-American women's level of knowledge for diabetes self-care and their self-care activities?

**Null Hypothesis H02.** There were no associations between respondent's level of knowledge for diabetes self-care and their self-care activities.

The qualitative data, embedded within the correlational design, answered another set of research questions:

- 4) What were African-American women's experiences with managing their diabetes? What adaptive tasks and coping skills did they use?
- 5) How did African-American women perceive their diabetes? What was their perceived meaning of diabetes?

The reason for collecting this qualitative data was to provide support for the primary data and delve into various perceptions, skills, and experiences that impact the diabetes knowledge or knowledge gap of the participants. In the quantitative study, the assessments themselves would not adequately capture the necessary information to answer the research questions.

This design was used to illustrate the modified version of the crisis of a physical illness. Moreover the mixed methods study most appropriately allowed for the assessment of diabetes knowledge and self-care activities through the quantitative study and self-care practices and the diabetes illness experience for this group of women through the qualitative study. Quantitative and qualitative studies though consist of similar elements, in that they have a purpose, pose a problem, define a research population, collect and analyze data, and present outcomes, they are different individually, and as research methods they have inherent value as well as deficiencies. Quantitative research is concerned with the measurement of outcomes using numerical data under controlled, organized, and standardized conditions using formal instruments (Portney & Watkins, 2000). However, certain things are not particularly easy to measure. Hence, qualitative studies rely on inductive reasoning, help interpret and structure the meanings derived from data, distinct from the quantitative deductive inquiry processes. Thorne (2000) summarized this distinction by stating that inductive reasoning uses the data to generate ideas (hypothesis generating), whereas deductive reasoning starts with an idea then uses the data to confirm or negate the idea (hypothesis testing). In addition, qualitative approaches are essential for pinpointing key issues and concepts related to people's thoughts and actions (Skelly et al, 2000). Therefore qualitative data has value because of its ability to reveal complexity not obtained from quantitative surveys (Elliot et al., 2007).

Mixed methods research involved the mixture of qualitative and quantitative approaches in collecting, analyzing, and mixing data in a single study or series of studies (Creswell, 2003). As a research methodology, mixed methods is relatively new,

but has gained increasing popularity over the past 25 years. This momentum has occurred, in part, because of the weaknesses that limit each methodology. Mixed methodology addresses, but does not resolve, some concerns specific to the two competing paradigms.

Quantitative research falls short in understanding the context or setting in which people live, and the voices of participants are not directly heard. Qualitative research was thought to make up for this weakness. Qualitative research does not focus on things inherent to the quantitative research process, such as charts, figures, tables, percentages, measures of association, or tests of statistical significance. Rather, the objectives of qualitative research are to discern themes, understand texture, provide context, and allow for in-depth attention to detail, context, and nuance (Patton, 2002) that may ultimately help inform quantitative analyses. An assumption of qualitative research was that reality is socially constructed, thus variables are complex, interwoven, and difficult to measure. In addition, qualitative research is more concerned with subjective, narrative information based on open-ended questions in interviews in an effort to capture the context of the data to better understand individual's experiences (Portney & Watkins, 2000). This method also facilitated looking at a broad range of experiences for a smaller number of people.

Over the years this mixed methodology has gained increasing recognition, especially because all the tools of data collection are used, rather than being restricted to the weaknesses of data collection typically associated with either the quantitative and qualitative methodology (Creswell, 2003). Combining both approaches provides a better understanding of research problems than either approach can alone. Using mixed

methodology was also practical for this study, because individuals tend to solve problems by combining inductive and deductive thinking and employing skills in observing people as well as recording behavior (Creswell & Clark, 2007). It was natural then to employ mixed methods research as the preferred way to address the research problem.

The qualitative arm of the study proved invaluable in that the study participants presented their experiences and perceptions living with diabetes, and their views are legitimate representations of their own experiences. For this study, the qualitative data was embedded in the larger quantitative data set and collected concurrently. Though it can be a challenge to differentiate between a study using an embedded design and one using another mixed design, the embedded design is different in that it employs one data type in a supplemental role to another. For this study the qualitative data played this role. This design can use either a one-phase or two-phase approach for the embedded data. A one-phase approach was used for this study because it was the most feasible modality to recruit the required sample. Therefore, the qualitative results had great value when considered within the quantitative study design (Creswell, 2003).

### **Methods**

This section describes the instrumentation, the participants, the strategies that were used to recruit participants for data collection, and the methods that were used for the analysis. This mixed methods study employed an embedded strategy, using a quantitative correlational design then a qualitative descriptive design. This design allowed the investigator to assess diabetes knowledge through the quantitative study, then identified the self-care practices and the diabetes illness experience for this group of women through a qualitative study.

In the embedded correlational design, researchers collect qualitative data as part of their correlational study to help explain how the mechanisms work in the correlational model (Creswell & Clark, 2007). For example, within the larger embedded correlational design, the qualitative interviews about perceptions, beliefs, and experiences of individuals' self-care practices were embedded within the diabetes knowledge level assessment for low literate African-American women with diabetes. The embedded study helped explain possible associations or identified various moderating factors.

Challenges existed using the embedded design. To address these challenges, the study's purposes were clearly outlined, each with its own goal, to ensure that distinctions were made to avoid confusion. According to Creswell (2003), distinct from the triangulation design that seeks to merge two different data sets, the quantitative and qualitative data sets, to answer the same question, so it was possible to bring the data sets together in the concurrent approach and interpret them in the form of a discussion for the analysis (Creswell & Clark, 2007).

### **Setting and Participants**

The population of interest for this study were adult African-American women with T2DM who lived in Alachua County and the surrounding areas, between the ages of 40 to 64 who had had less than four years of college. The study protocol was submitted to the UFIRB for approval and approval was obtained.

### **Sample**

The goal for this study was to recruit a purposive sample, but due to difficulties with recruitment initiatives, a convenience sample was used. The inclusion criteria for this study were participants who were (a) non-pregnant African-American women; (b) aged between 40 and 64 years; (c) self-reported that they had had a clinical diagnosis

of T2DM; (d) had had diabetes for at least 1 year prior to entering the study; (e) had no mental health co-morbidities that incapacitated them from communicating logically with the interviewer; (f) were low income, on Medicaid, poor, uninsured, or underinsured; and (g) self-reported as having less than four years of college. Further, participants were excluded from the study if they had type 1 diabetes, were pregnant, reported having as anything other than African-American ancestry, and were too disabled or mentally ill that they could not appropriately respond in an oral interview. Diabetics who had had diabetes for less than one year were also excluded from the study because those individuals had limited experience in taking care of their diabetes. The age range for this study focused on participants eligible for Medicaid, because older individuals would be put in another care category and eligible for Medicare. Study participants who met the inclusion criteria were recruited from various UFIRB approved sites, including the University of Florida and other clinics, churches, low-income community residencies, hair dressing salons, and service facilities in Alachua County and surrounding areas and invited to participate in the study.

For the quantitative arm of the study, a power analysis using G\*-Power was performed based on the effect size found from this study, statistical procedures used in the study, type I error, and number of the sample. The effect size is the strength of the relationship between variables in this study, while the power of a statistical test depends on alpha level or type 1 error rate, effect, and sample size. In addition, for the qualitative study, another goal of the research was to identify from the participants surveyed for the larger quantitative study, a subset of individuals to participate in a face-to-face 35 to 60 minute oral in-depth semi-structured qualitative interview. In past

qualitative studies with a similar population's (Rayman and Ellyson, 2004), obtaining an adequate sample size was determined once saturation was achieved and for this study participants were also recruited until saturation was achieved. Individuals for the qualitative interviews were also recruited based on convenience, since some individuals who met the initial goal of the study (to draw the higher and lower scoring individuals on the quantitative assessment knowledge for diabetes scale) did not want to participate, or did not provide follow up contact information. In sum, snowball sampling was used to obtain additional participants. Interviews took place at a location convenient to the participant.

All participants in this sample signed an informed consent approved by the University of Florida Internal Revenue Board. The informed consent was done prior to using any of the instruments. Each participant was given a copy of her signed informed consent for future reference.

### **Instrumentation**

A variety of data collection methods were used for the mixed methods design, a quantitative survey as well as a semi-structured interview guide, and the investigator developed these protocols using specific, detailed, and systematic methods. Four instruments were used in this study. The demographic information questionnaire was used to collect biographic information (Appendix A); the Spoken Knowledge in Low Literacy Diabetes Scale (SKILLD) was used to measure diabetes knowledge (Appendix B); the Summary of Diabetes Self-Care Activities (SDSCA) was used to determine current self-care activities or behaviors (Appendix C); and the interview guide (Appendix D) was used to explore life experiences, knowledge, and understanding of diabetes and how women with diabetes manage their chronic illness.

Validity concerns pertain to the extent to which an instrument measures what it is supposed to measure (Portney & Watkins, 2000). This is done to ensure adequate inferences from scores on the instruments used in the study. The validity was addressed below in the section appropriate to each instrument specified.

### **Demographic information Questionnaire**

Demographic information was obtained from the participants using a questionnaire administered before the interview began, primarily to obtain sample characteristics and gain a broader picture of the participants. This questionnaire consisted of 12 questions based on study purpose and literature review and included information about the participants self-reported diagnosis of diabetes, last blood sugar reading at home, length of time with T2DM, annual personal income, annual household income, residency status, race, age, and mental illness status. The questionnaire was administered orally by the interviewer because all the other instruments were given orally to accommodate those whose reading skills might have been minimal.

### **Spoken knowledge in low literacy diabetes scale (SKILLD)-quantitative study**

For the quantitative study, the SKILLD scale document (Rothman et al., 2005) was used to collect the data. This scale assessed knowledge about diabetes and self-care activities and consisted of ten questions. Further, the participant's knowledge of diabetes was correlated with education level achieved, both personal and household incomes, length of time with diabetes, glycemic control, and self-care activities. When measuring diabetes knowledge in vulnerable patients with possible low literacy, the SKILLD instrument is brief, well validated, easy to use, and well accepted by patients (Rothman, et al., 2005). The reliability and internal consistency of the scale was examined using the Kuder-Richardson coefficient of reliability, which is a variant of

Chronbach's coefficient for items that are dichotomous. The coefficient of internal reliability for all the items was 0.72, which suggested adequate reliability. A principal factors analysis and principal components analysis to confirm scale validity and examine possible scale reduction analysis were done. The factors retained for the analysis were done using a scree test and Varimax and Promax rotation. Questions were kept if they had consistently high loadings with rotation ( $>0.3$  or  $<0.3$ ). Factor analysis was also forced on specified factors to examine question loading. In the factor analysis, a single factor dominated (eigenvalue 2.95) in principal components factor analysis, with question three and seven having high loadings to the factor (Rothman, et al., 2005).

### **Scoring SKILLD**

The SKILLD survey was scored by assigning 10 points to each of the 10 questions for a potential total of 100 according to the specifications in Rothman and colleagues 2005 study. The scores were summed and a variable created for total score. This total score was then used to do the appropriate analyses to answer the research questions.

### **Summary of diabetes self-care activities measure-quantitative study**

The summary of diabetes self-care activities measure (SDSCA) was used to measure diabetes self-management in adults. The SDSCA measurement is an eleven item questionnaire that includes sections pertaining to specific activities, diet, exercise, blood sugar testing, foot care, and smoking. This questionnaire is one of the most widely used self-report instruments for measuring diabetes self-management in adults and is promoted in the literature to be used with other samples and is in the public domain. In addition, the strength of the scale was its brevity and ease of scoring (Toobert et al., 2000). The quantitative study also obtained the knowledge level about

diabetes to make associations with the diabetes self-care activities measure. The SDSCA has been administered as a self-completed questionnaire in paper and pencil form, touch screen computer, and over the internet (Toobert, et.al, 2000). For this study, the SDSCA was given orally to compensate for the target population's self-reported years of school, which was usually low. It is also a brief, yet reliable and valid, self-report measurement of diabetes self-management (Toobert et.al, 2000).

### **Scoring SDSCA**

The SDSCA scale was scored by averaging the scores for the individual sections pertaining to general diet, specific diet, exercise, blood sugar testing, and foot care. The number of cigarettes smoked per day was summed to determine the smoking score. The scores for each section were determined and associated with the total knowledge score obtained from the SKILLD score. Only one question was reverse coded and that related to specific diet.

### **Interview guide-qualitative study**

In the qualitative study, a semi-structured interview guide that consisted of seven questions with various probes was used to collect data. It was developed using past interview guides presented in the literature, specifically, the Kleinman (1980) explanatory model's eight standard questions. Kleinman's questions are very useful to obtain participants' explanatory models of their illness experience. However, in practice, laymen often either do not volunteer an explanatory model to health professionals or, when they do, it is a short, single-phrase explanation. This may be because individuals are embarrassed about revealing their beliefs in formal healthcare settings, and fear being ridiculed, criticized, or intimidated because their beliefs appear mistaken from a professional medical viewpoint. Accordingly, Kleinman indicated individual's explanatory

models are more easily elicited in homes by a researcher not involved in the delivery of medical care to the patient, and who expresses a genuine, non-judgmental interest in the patient's perspective. Consequently, this research was conducted in a convenient location for the participant, for example, the patient's home or a safe, comfortable place (Kleinman, 1980).

In sum, the study had various components that were given orally: 1) informed consent (then signed); 2) demographic information questionnaire; 3) SKILLD and SDSCA; and 4) face-face semi-structured individual interviews. Only the individuals asked to participate in the individual, semi-structured interview, also signed the audio portion of the consent form.

### **Scientific Integrity**

The research was also meticulously documented so as to allow other researchers to replicate the process. Qualitative assessment of validity was distinct from the determination of quantitative validity. For qualitative validity, the focus was on identifying a degree of congruence between explanations and the realities of the world, the consistency with using the interview guide, as well as the content validity of the interview guide. Further, reliability in qualitative studies meant the degree of consistency with which an instrument or rater measures a variable (Portney & Watkins, 2000). Consistency in the use of the interview guide was achieved by using the same interviewer for each interview. Using other data from previous studies to confirm results were used to enhance the reliability of the research. Although Patton (2002) indicates that no formula exists for transforming data obtained from qualitative analysis (p. 432), the results were analyzed using thematic analysis. This study employed a number of techniques promoted by McMillan & Schumacher (2006) to ensure that the researcher

captured the meanings of what was being said by using voice recorders to tape the interviews and transcribe them verbatim, using an expert panel to guide the analysis process, ensuring consistency between interviews by using the same researcher, as well as looking for negative or discrepant data that will modify patterns found in the data.

Reliability in quantitative studies means the extent to which a measurement was consistent and free from error, and was conceptualized for reproducibility or dependability (Portney & Watkins, 2000). In the case of this correlational study, the reliability correlation was important because reliability reflects the degree of association between two sets of data, or the consistency of position within the two distributions. The statistic most often used for internal consistency is Chronbach's coefficient alpha (Portney & Watkins, 2000).

### **Protection of Human Subjects**

Prior to undertaking this study, the study protocol was approved by the UFIRB. Informed consent was obtained from each participant in the study. In a designated interview area, agreed upon by the participant, an informed consent was administered orally and signed before the various components of the study were conducted. A thorough explanation and description of the study purpose, method, potential risks and benefits for participation in the study, and the protection of confidentiality were told to eligible participants in this study as part of the informed consent process. Those individuals who could read were also given the informed consent orally and were asked to review the form on their own to corroborate what the principal investigator explained. If the individual could not read, then they were asked to repeat the information that they

understood back to the principal investigator before they were allowed to sign the informed consent to ensure that they understood the study.

Additionally, approval from all other required parties was obtained. Women were given the opportunity to ask questions, and decline, or accept participation in the study. All data were made anonymous by assigning codes to the data. No identifying information was included in the data report and all recordings were stored in an encrypted file and will be destroyed according to the stipulations by the UFIRB. The phone number and address of the investigator and the chair of the dissertation committee were given to participants so they could address questions or concerns related to the study. The phone number for the UFIRB was also included.

The participants in this research did not suffer any health risk because of participation in this study. Informants were told of their freedom to answer or not answer questions, and that the interview could be stopped at any time without penalty. Since the study was focused on a vulnerable population with the chronic illness of diabetes, every effort was made to keep these individuals anonymous. Hence measures were taken to exclude all names and locations from the data to ensure confidentiality and anonymity. There were no direct benefits for the participants; however, since they were being directly affected by diabetes they may have been motivated to make their voices heard regarding issues associated with their self-care practices.

### **Data Collection and Recruitment**

Data collection was quantitatively and qualitatively driven and complemented with demographic data. The data was collected during 2009 and 2010 using a convenience sample. The informed consent, quantitative surveys, and qualitative interview were conducted orally.

## **Recruitment and Reimbursement**

The investigator met with the person in charge of the facility from which individuals were recruited and informed them about the study. This individual, such as the head nurse or doctor of the clinic, the head of the church, the manager of the hair salon, or the local community liaison were briefed about the study and sample recruitment needs. Next, the research investigator asked the appropriate individual in charge of the facility to give out flyers to make initial contact with women and introduce the study to interested participants who met the inclusion criteria. In addition, the investigator put up flyers at UFIRB approved sites and recruited interested parties from clinics, at churches, and in low income housing communities. To supplement the recruitment process, snowball sampling was employed as needed, to obtain an appropriate sample for the study. The participants were not financially compensated for their time. A reminder phone call if possible was made before each interview.

## **Data Collection**

The data was collected during 2009-2010. All the instruments, including the informed consent were conducted orally. For the quantitative study, participants were asked to respond to the demographic information questionnaire and the SKILLD survey. The SKILLD survey was particularly appropriate for use with the participants because it was given orally in an effort to avoid problems with reading comprehension (Rothman et al. 2005). The quantitative surveys lasted approximately 20 minutes. The SDCSA was also administered orally.

For the qualitative study individual interviews lasted between 35 to 60 minutes. Open-ended semi-structured questions for the individual interviews were used in this study. Using open-ended semi-structured individual interviews is a common method for

data collection to gather data from various participants (Kvale, 1996). Understanding constructed realities meant that the investigator interacted and talked with participants about their views, perceptions, and experiences (Maxwell, 2005). Further, interviews allowed the researcher to go beneath the surface of the described experience, stop and explore a statement or topic, request more detail or explanation, ask about participants' thoughts or feelings, restate, validate the participants' humanity, and use observational and social skills to enhance the discussion (Charmaz, 2006).

In qualitative research the sample size is typically small (Crabtree & Miller, 1999) because as Patton (2002) indicated, though a small sample is used in qualitative inquiry, high quality, detailed descriptions of each case (key for documenting uniqueness) and important shared patterns (emerging out of heterogeneity) are beneficial. Guest and colleagues (2006) indicated that selecting sample size typically relies on the concept of "saturation" or the point at which no new information is observed in the data, since no published guidelines or test of adequacy for estimating the sample size exists. Patton (2002) indicated that sampling to the point of redundancy was an ideal that works best when choosing the participants. Therefore data collection continued until saturation was achieved, which was the point at which no new information emerged.

### **Data Analysis Process**

Data collection was primarily quantitatively driven, with an embedded qualitative design using concurrent data collection and analysis. The goal of the data analysis process was first to, analyze each of the quantitative and qualitative data sets and second, to identify the women's descriptions of their experiences and show how the experiences helped them manage their diabetes.

Creswell and Clark (2007) proposed several guidelines for the concurrent embedded design analysis. This study first employed Stage 1, which involves conducting separate initial data analysis for the quantitative and qualitative data sets. Unlike the triangulation design where both data sets are merged to present a complete picture developed from both data sets, for the embedded design the supportive data set (qualitative) reinforces or refutes the results of the primary data set (quantitative). Hence the data analysis was guided by the question, What additional information was obtained during the correlational study from the qualitative data? To answer this question, Stage 2 of the concurrent embedded design was implemented whereby the data was compared by a discussion using the (qualitative) data to reinforce or refute the results of the primary data set (quantitative). The results for both stages of this analysis process are presented in chapter 4.

A study that includes both quantitative and qualitative methods without explicitly integrating the data derived from each is simply a collection of multiple methods (Creswell & Clark, 2007), which is not the intention of this study. For this study, though both methodologies were used to answer different research questions, they had common goals: (1) to identify knowledge and behaviors regarding self-care practices of African-American women with T2DM and (2) to apply the model for understanding the crisis of physical illness through the different data collection strategies. Further, this study employed a rigorous and strong mixed-method design that addressed key factors (such as timing and weighting of data, explained previously) in integrating data analysis decisions.

For the embedded design-correlational model used in this study, the embedded data may be either one- or two-phased (Creswell & Clark, 2007). Conceptually, a one-phased approach was used to embed data at the design level and connect data from data analysis to data collection. Decisions regarding timing, weighting, and mixing the data are also important in mixed-methods data analysis. Timing refers to the time the data sets are collected and describes the order in which the researchers use the data within a study, classified in one of two ways, concurrent or sequential (Creswell & Clark, 2007). This study used a concurrent data collection and analysis procedure. Concurrent timing occurs when the researcher implements both quantitative and qualitative methods during a fixed time of the research study. This means that the data are collected, analyzed, and interpreted during the same time period (Creswell & Clark, 2007), even though they were collected at different times during this period.

Weighting refers to the emphasis of the approaches in the study, that is, the relative importance or priority of the quantitative and qualitative methods in answering the study questions (Creswell & Clark, 2007). There are two options, giving equal weight or unequal weight. Equal weighting suggests that the investigator assumed each method played an equally important role in addressing the research problem. Unequal weighting means one of the methods will have a greater emphasis within the study than the other method. The unequal weighting was more appropriate for this study for a number of reasons. First, unequal weighting best addressed the research questions and goals. Since limited work has been done to determine the state of diabetes knowledge among these specific adult women, it is important to identify the knowledge level for these individuals. Historically, more work has been done regarding identifying

individuals experiences with diabetes self-care. Hence it was more of a priority to give weight to assessing the knowledge level for these individuals. Further, practical considerations for using this method also made it more appropriate for this study. Since it takes more resources to implement a study that gives equal weight to the two methods, this study prioritized the unequal method. Concurrent data analysis first involved procedures that involved conducting a separate initial data analysis for each of the qualitative and the quantitative data sets (Creswell & Clark, 2007). Hence coding, theme development, and the interrelationship of themes were done.

Next, the concurrent data analysis allowed the quantitative and qualitative data sets to be used, the supportive data set (qualitative) reinforcing and supplementing the results of the primary (quantitative) data set. This allowed the researcher to answer the research questions for the quantitative and qualitative studies through a discussion (Creswell & Clark, 2007). The qualitative study sought to provide contextual information to supplement the quantitative study and allow for a more appropriate application of the theoretical guide for this study, the model for understanding the crisis of a physical illness. In addition, the investigator consistently used the following key question proposed in Creswell and Clark, 2007, to guide the research analysis process: What additional information is obtained during the correlational quantitative study from the qualitative data?

**Quantitative study.** The quantitative study used descriptive statistics, including frequencies, percentages, sample mean, median, and standard deviation, to analyze the personal characteristics of the sample participants, the SKILLD scores of women with diabetes and the SCSCA scores. For this correlational study, explanatory and

outcome variables (Table 2-1) were level of income, level of education achieved, length of time with diabetes, and glycemic control. Knowledge about diabetes also served as both an explanatory variable and an outcome variable. For the associations between knowledge level of diabetes and self-care activities, knowledge about diabetes was the explanatory variable. However, knowledge about diabetes care was the outcome variable for associations made with income, education level attained, length of time with diabetes, and glycemic control. These variables were particularly important because they have each been correlated with knowledge about diabetes self-care in previous empirical evidence (Rothman et al., 2005). In this study, socioeconomic status was broken down into level of personal and household income and level of education achieved, both measured as a continuous variable. As the outcome variable the level of diabetes knowledge was measured by a composite score from the SKILLD. Knowledge was examined as a continuous variable (total SKILLD score of 0–100%) when regarded as the explanatory or outcome variable. Single item knowledge results were compared to SKILLD knowledge scores (range 0%–100%) and compared to incomes, education (continuous variable), length of time with diabetes (continuous variable), and glycemic control, which was also a continuous and ordinal variable (greater than or less than 70–120 mg/dL [3.89–6.67] of their glucose level).

Total SKILLD knowledge scores using Pearson correlation coefficients and *t*-tests. In addition, SKILLD knowledge scores (range 0%–100%) were compared to the scores from the SDSCA scores using Pearson and Spearman correlation coefficients, and *t* tests.

**Qualitative study.** The qualitative research used semi-structured, open-ended interviews (Swandt, 1997). Open-ended questions asked during these interviews allowed the participants to supply answers in their own words. For the qualitative data analysis, aggregating the words or images into categories of information and presenting the diversity of ideas gathered during data collection (Creswell & Clark, 2007 was the modus operandi). Computer assisted software is particularly useful for organizing and storing large quantities of data (Hatch, 2002, p. 208), and in this study Atlas ti 5.2 was used. The qualitative interviews were transcribed verbatim, labeled with numbers for identification, converted to a rich text file and uploaded in Atlas ti 5.2. Thematic analysis refers to analyzing transcripts in an effort to reduce the mass of qualitative data to make sense of the material and identify core consistencies and meanings (Patton, 2002). Here thematic analysis identified emergent themes. Free line-by-line coding was done and codes obtained were used to generate categories. This helped develop themes, ultimately proposing plausible relationships among concepts and sets of concepts. Subsequently, the data was taken to an expert panel of qualitative researchers to further guide the data analysis process and to ensure that the themes were plausible and the quotes matched the appropriate themes identified. This analysis was rigorous and allowed the data to be examined a number of times to derive the best way to present the mass of data obtained in the study, which fostered a systematic approach to analysis. Lastly, the report writing was done. This was not separated from the analytical process, since summarizing data and selecting descriptors that reflect the intricacy of the data was key in completing the analysis. The presentation of the results was

prefaced with a section that illustrated who the participants were based on the suggestion of the expert panel.

### **Summary**

This chapter described the methodology that was used to conduct this study. Data collection was primarily quantitatively driven, with an embedded qualitative design using a one-phased correlational concurrent embedded design for the data collection and analysis. This study used a mixed methodology to examine a modified model for understanding adaption to a physical illness. This is the first study to have illustrated that African-American women with T2DM adapt and improve self-care practices by surmounting a series of crisis. Further, the present study not only applied the model to understand the crisis experienced after the onset of a physical illness, but it also measured knowledge for diabetes and self-care activities and explored African-American women's experiences and perceptions about diabetes. This study therefore also used methodologically different approaches to apply the various parts of a similar model (the model for explaining model for understanding the crisis of a physical illness) using a correlational embedded mixed-methods design.

The theoretical framework was the conceptual model for understanding the crisis of physical illness (Moos & Tsu, 1977) used to explain the correlations between the predictor and explanatory variables. The explanatory model was used to develop the interview guide (Kleinman, 1980) for the qualitative development of the interview guide. Thematic analysis was done. All data were recorded and interviews transcribed verbatim. The quantitative and qualitative studies used a convenience sampling method. Interviews were conducted in a specified location by the participant . Validity and reliability were ensured in each aspect of the research process. This study was

designed to explore some of this target population’s experiences with their diabetes, assess their diabetes knowledge and self-care practices, and explore their experiences and perceptions to identify ways that African-American women translate the education obtained from the healthcare system into practical use in their home and lives.

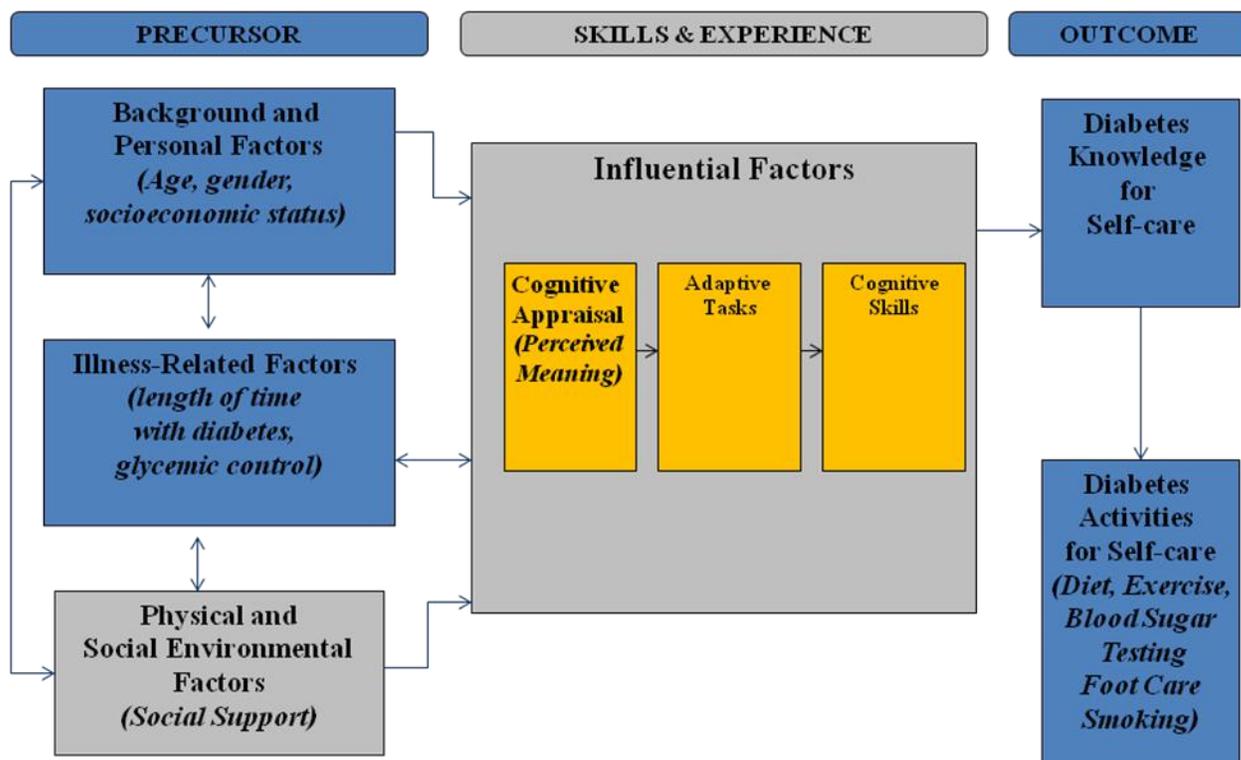


Figure 3-1. Adaptation of a conceptual model for understanding the crisis of a physical illness. (From “Coping with Acute Health illness.” By R.H. Moos, 1982 In T. Milton, C. Green, and R. Meagher (Eds.), *Handbook of Clinical Health Psychology* (pp. 129-151).

## CHAPTER 4 RESULTS, DISCUSSION, RECOMMENDATIONS

### **Introduction**

The purpose of this study was to assess diabetes knowledge and self-care activities and explore experiences of African-American women with type 2 diabetes mellitus (T2DM). The specific aims of this study were to (1) assess knowledge about diabetes in African-American women; (2) explore the associations between African-American women's knowledge of diabetes and (a) income level, (b) years of education, (c) length of time with diabetes, (d) glycemic control, and (e) self-care activities; (3) explore experiences of African-American women with managing their diabetes as well as their understanding of diabetes.

This chapter is organized first with the quantitative then the qualitative study results followed by a discussion of the results. Findings presented in this chapter follow the research question it answers. The discussion section includes not only a discussion of the study findings, but also the study limitations, implications and suggestions for future research.

### **Participant Characteristics/Demographics**

The sample consisted of 52 participants who met the study criteria. Study participants were recruited from UFIRB-approved sites, including clinics, churches, low-income community residential facilities and healthcare service facilities in Alachua County and the surrounding areas. Flyers were used to invite women who met the criteria to participate in the study. The flyers and snowball sampling of respondents were the primary methods used to select participants. Interviews took place in a private location convenient for the participant. Informed consent was explained and each

participant signed hers. All instruments: the informed consent form, the demographic information questionnaire, the SKILLD and SDSCA were orally administered to each participant and her responses written down.

The mean age of the sample was 55 years ranging from 40 to 64. Participants had known they had had diabetes for an average of approximately 9 years ranging from 1 to 32 years; the mean blood sugar reading was 136, with a minimum reading of 70 and a maximum of 263. Based on participants' self report of their last blood sugar reading, eight participants did not disclose this reading due to inability to remember their last reading (Table 4-1). Participants reported their education as high as 15 years and as low as 7 years, with a mean of 11.97. Approximately 42.3 percent of the participants had personal incomes of \$10,000 or less and 25 percent reported personal income between \$10,000 and \$20,000. When asked about the total household income, 32.7 percent of the participants reported \$10,000 or less, 25 percent reported household income between \$10,000 and \$20,000 (Table's 4-2 and 4-3). The majority of the participants were from Alachua County (86.5%), while 11.5% and 1.9% were from Levy and Putnam counties respectively (Table 4-4). Over half the sample (61.5%) participated in some form of diabetes education classes (53.8%) or got information from doctors (7.7%), while 38.5% of the participants had no formal diabetes classes or education (Table 4-5).

A power analysis was performed based on the effect size found from this study, statistical procedures used in the study, type I error, and sample number. By securing 52 participants along with the highest strength of association found in this study (0.40), the actual statistical power is estimated favorable (0.92) based on two-tailed hypothesis

and type I error at 0.05. In a more conservative estimate when 0.3 is used as an average medium correlation coefficient, the power is also acceptable (0.82). From the 52 participants surveyed, 14 individuals participated in a face-to-face 35–60 minute oral in-depth semi-structured qualitative interviews. The following results are presented based on the research questions and hypotheses set forth in the study.

## **Results of Individual Research Questions**

### **Research Question #1**

What knowledge level did African-American women with T2DM have about their disease?

The total SKILLD score was determined by computing the participant responses on each individual item of the survey, with each question having a point value of ten. Descriptive statistics indicated that the mean SKILLD score of the participants was 57.31 and the Standard Deviation (SD) was 17.50. Overall, the respondents answered more than half the questions correctly, some scoring as little as 20, and others as high as 100 out of a possible 100 points with a range of 80, and the most commonly occurring score (the mode) was 70 (Table 4-6). Forty-four percent of the participants scored 50 or less on the SKILLD score (Table 4-7).

### **Research Question #2**

Were African-American women's knowledge levels about their T2DM self-care associated with income, years of education, length of time with T2DM, or glycemic control?

**Null Hypotheses H01.** Respondents' knowledge scores were not associated with (a) income, (b) years of education, (c) length of time with T2DM, or (d) glycemic control.

**Results.** To ascertain that the normality assumption is met before conducting a Pearson Correlation, the Kolmogorov-Smirnov Z score (K-S Z) was calculated over the continuous variables. A  $p$  value equal or higher than 0.05 indicates the normal distribution assumption is met for the tested variable (Corder & Foreman, 2009). Also, if some variables were not continuous, then a Spearman rank correlation test was deemed more appropriate. Before testing the association between SKILLD scores and income, normality assumptions were examined for the following variables: (1) SKILLD, (2) income (personal and total), (3) years of education, (4) length of time with T2DM, and (5) glycemic control. The K-S Z scores were the following: (1) SKILLD score = 1.09 with  $p = 0.19$ ; (2) income: personal income = 1.87 with  $p = 0.00$  and total income = 1.4 with  $p = 0.04$ ; (3) years of education = 2.13 with  $p = 0.00$ ; (4) length of time with T2DM = 1.60 with  $p = 0.01$ ; and (5) glycemic control = 1.22 with  $p = 0.10$ . SKILLD score and glycemic control were considered normally distributed. However, total and personal incomes, years of education, and length of time with diabetes had a  $p$  value less than 0.05 and cannot be treated as normal distributions (Table 4-8).

**SKILLD scores and income.** Normality assumptions were examined prior to testing the association between SKILLD scores and incomes. SKILLD scores can be treated as a normal distribution, but total and personal incomes cannot be treated as normal distributions. Since one variable was continuous and one ordinal, a Spearman's rank order correlation was used to examine their association. Positive non-significant correlations were found between SKILLD scores and both income variables: personal income ( $\rho = 0.24$ ) and total household income ( $\rho = 0.21$ ). The findings confirm the

null hypothesis that there were no associations between SKILLD scores and personal and household incomes (Table 4-9).

**SKILLD scores and education.** Normality assumptions were examined before testing the association between SKILLD scores and education. To identify the association between two continuous variables, where SKILLD scores were normally distributed, but years of education were not a Spearman's rank correlation was calculated. There was a positive significant correlation ( $\rho = 0.24$ ) between SKILLD scores and the years of education. Results showed participants with more years of education were more likely to have better knowledge about T2DM (Table 4-10). The findings refute the null hypothesis.

**SKILLD scores and length of time with diabetes.** Normality assumptions were examined before testing the association between SKILLD score and education. The SKILLD score was normally distributed, but the length of time with T2DM was not. A Spearman's rank correlation was done to identify the association between two continuous variables, SKILLD score and the length of time with T2DM. There was a negative non-significant correlation ( $\rho = -0.11$ ) between SKILLD score and length of time with T2DM (Table 4-11).

**SKILLD scores and glycemic control.** Only 44 participants of the 52 were able to recall their last blood sugar reading. Prior to examining the association between SKILLD scores and glycemic control, the normality assumption was tested on the variable of blood sugar reading. The SKILLD scores and latest blood sugar reading were treated as normal distributions. Hence, the association between two continuous variables, SKILLD scores and blood sugar reading, was identified using a Pearson

correlation, where both variables were normally distributed (Table 4-12). There was a positive non-significant correlation between SKILLD scores and glycemic control with diabetes ( $r = 0.17$ ).

An independent sample  $t$  test was also done to examine the SKILLD scores between the participants who controlled their glycemic level well and those who did not. Since the SKILLD score was normally distributed, inferences were done to compare the SKILLD mean scores. Sixteen of the 44 participants (36.4%) who reported their blood sugar levels were well controlled while 28 (63.6%) did not control well. Those who controlled well had a mean SKILLD score of 55 and a SD of 18.97 while those who did not control well had a mean of 60 and a SD of 17.43 (Table 4-13). The independent  $t$ -test indicated no statistically significant difference in SKILLD score between the two groups in glycemic control ( $t = -0.89$ ,  $df = 42$ ,  $p = 0.38$ ) (Table 4-14).

### **Research Question #3**

What were the associations between the African-American women's level of knowledge of T2DM and their self-care activities?

**Null Hypothesis H02.** There were no associations between respondent's level of knowledge of T2DM self-care and their self-care activities.

**Results.** The association between SKILLD scores and self-care activities were done after normality assumptions were examined for the following variables: (1) SDSCA-general diet, (2) SDSCA-specific diet, (3) SDSCA-exercise, (4) SDSCA-blood sugar testing, and (5) SDSCA-foot care. A one-sample K-S Z test was performed for each of the variables. The K-S Z scores were as follows: (1) SDSCA-general diet = 0.83 with  $p = .49$ ; (2) SDSCA-specific diet = 1.25 with  $p = 0.09$ ; (3) SDSCA-exercise = 1.09 with  $p = 0.19$ ; (4) SDSCA-blood sugar testing = 1.70 with  $p = 0.01$ ; and (5) SDSCA-foot

care = 1.41 with  $p = 0.04$ . SKILLD as well as SDSCA-general and specific diet and SDSCA exercise were normally distributed. However, SDSCA-blood sugar testing and foot care had  $p$  values less than 0.05 and cannot be treated as normal distributions (Tables 4-15).

**SKILLD scores and SDSCA-general diet.** Before testing the association between SKILLD scores and SDSCA-general diet, normality assumptions were examined. A one-sample K-S Z test was performed. The variables of interest SKILLD scores and SDSCA-general diet were both continuous, both SKILLD scores and SDSCA-general diet were normally distributed. General diet was considered as following a healthful eating plan within the last seven days and the month. The association between SKILLD scores and SDSCA-general diet was identified using a Pearson correlation. Knowledge for SKILLD scores and SDSCA-general diet were positively correlated ( $r = 0.003$ ) but it was not significant statistically (Table 4-16). This supported the null hypothesis that there was no association between the SKILLD scores and SDSCA-general diet.

**SKILLD scores and SDSCA-specific diet.** Before testing the association between SKILLD scores and SDSCA-specific diet, normality assumptions were examined. An SDSCA-specific diet was considered as having, within the last seven days, greater than or equal to five servings of fruits or vegetables or high fat foods, such as red meat or full-fat dairy products. Both SKILLD scores and SDSCA-specific diet were normally distributed. Hence, the association between SKILLD scores and SDSCA-specific diet was identified using a Pearson correlation. SKILLD scores and SDSCA-specific diet were positively correlated ( $r = 0.28$ ) with statistical significance. The results

showed participants who tend to engage in eating more fruits and vegetables and less high-fat foods, such as red meat or full-fat dairy products, within the week prior to questioning had more knowledge about T2DM than their counterparts (Table 4-17). This association refuted the null hypothesis.

**SKILLD scores and SDSCA-exercise.** Before testing the association between SKILLD scores and SDSCA-exercise, normality assumptions were examined. Both SKILLD scores and SDSCA-exercise were normally distributed. Hence, the association between SKILLD scores and SDSCA-exercise were identified using a Pearson correlation. Knowledge for SKILLD scores and SDSCA-exercise were negatively correlated ( $r = -0.07$ ), and it was not significant (Table 4-18).

**SKILLD scores and SDSCA-blood sugar testing.** Before testing the association between SKILLD scores and SDSCA-blood sugar testing, normality assumptions were examined. The SKILLD scores variable was normally distributed, but SDSCA-blood sugar testing was not. A Spearman correlation was used to identify this relationship. SKILLD scores and SDSCA-blood sugar testing were positively correlated ( $\rho = 0.09$ ) and the results were not significant. The results showed, with no statistical significance, participants who tend to engage more in self-care activities by blood sugar testing had more knowledge about T2DM than their counterparts (Table 4-19).

**SKILLD scores and SDSCA-foot care.** Before testing for the association between SKILLD scores and SDSCA-foot care, normality assumptions were examined. The SKILLD scores variable was normally distributed, but SDSCA-foot care was not. Hence, a Spearman correlation was used to identify this relationship. SKILLD scores and SDSCA-foot care were positively correlated ( $\rho = 0.40$ ) and were statistically

significant. The results showed that participants who tend to engage in foot care self-care activities during the last seven days by checking their feet and inspecting the inside of their shoes, had more knowledge about T2DM than their counterparts (Table 4-20).

**SKILLD scores and SDSCA-smoking.** Since the SKILLD scores were normally distributed, inferences concerning means were done to compare the SKILLD scores mean scores between those who did or did not smoke. All participants in the study reported their smoking status. Seven were smokers and 45 were non-smokers. Those who smoked had a mean score of 55.71 and a SD of 16.18, while those who did not smoke had a mean score of 57.56 and a SD of 17.86 (Table 4-21). The independent *t*-test indicated no significant difference in SKILLD scores between the two groups, smoking status ( $t = -0.89$ ,  $df = 42$ ,  $p = .38$ ) (Table 4-22).

#### **Research Question #4.**

What are African-American women's experiences with managing their T2DM?  
What adaptive tasks and coping skills did they use?

#### **Research Question #5**

How do African-American women perceive their T2DM? What is their perceived meaning of T2DM?

There were many experiences expressed by the African-American women in this study. The qualitative research questions four and five were answered together because an individual's perception of T2DM seemed similar to their description of their experience with T2DM and it was difficult to distinguish the two based on their responses. To better understand who these women were, a magnified illustration of the different types of experiences that these women had during their life with T2DM was presented in the section titled Portrait of the African-American Woman with Diabetes in

This Study below. Their experiences and perceptions seemed to fall into two distinct thematic categories, namely (1) dealing with the diagnosis of T2DM and (2) management of T2DM, with a number of consistent and unique factors influencing both categories.

### **Portrait of the African-American Woman with Diabetes in This Study**

This section presents a description of these women as diabetics. The women's beliefs about the causes and meaning of T2DM, as well the role their past experiences played provide insight into how the women eventually dealt with their own diagnosis of T2DM and ultimately their self-care. It was important to distinguish the women's initial beliefs and reactions from their current attitudes and beliefs about T2DM, because their initial beliefs and reactions were altered by various influences and subsequent experiences.

**Their perceived meaning and cause of diabetes.** For the most part, the women were aware of factors that contributed to their T2DM. These factors included having a genetic predisposition, being physically at risk (obese), having physical co-morbidities (high blood pressure, high cholesterol, stress), and having bad habits relating to eating and exercising. Not engaging in preventative health measures, inadequate health care practices, and poverty were also indicated as possible contributing factors to T2DM.

These beliefs were illustrated best in the following quote:

[Diabetes] just means to me that it's something that come down through the blood genes of the family . . . and I've been told that you live long enough that you will get it if it runs in your family. (P7).

To a lesser extent, T2DM was also believed to be linked to a particular culture, as was expressed most succinctly in the following quote: "Well [I've] always heard that it run strongly in African-American women, and [diabetes] done been through the whole

family.” All these perceptions set the context for the women’s lives and helped the researcher understand just how they perceived their condition.

Most participants knew the causes of T2DM or had their own perception of the disease, while other participants were unaware or unsure of what caused their T2DM as indicated in the quote: “You know, I really don’t know.” Some women were mistrustful of their doctors and felt that they were misdiagnosed and had received incorrect treatment by their doctor that led them to have T2DM. These bad experiences with doctors impacted their self-management:

I have had experience with bad doctors, who just told me what was normal, what was in the book, but they never evaluated me. . . . The lack of perfect medications and of easily prepared foods also made it difficult. (P1)

Obtaining good medical care could be a problem for these disadvantaged women. It was heart rending when one woman, crying, expressed her gratitude to me in just allowing her to talk about her experience with T2DM because she felt that she had no support and no one who took the time to listen, including her doctor.

Misconceptions about treatment were evident. For example, one individual expressed that only taking the gel from the aloe vera plant would help treat her T2DM. Many of them mentioned being “cured” or “beating diabetes,” by which they meant that God would one day cure them if they had enough faith. Only a few of them were aware that T2DM had no cure, but if it was managed well, they could live a healthy life. Many women, were unaware of the power of self-care and its role in helping them live a long and healthy life. Another experience of the women was that many of them were in constant pain and some had physical conditions that had never been diagnosed.

Reflected in their past reactions to their diabetes was the inherent sorrow that many women experienced when they were first diagnosed. They were frustrated that

they had become diabetic, resentful that, despite all they did to help their family members who had T2DM, they still got the disease themselves, and fearful of what could happen to them. These reactions could manifest themselves in denial or avoidance of diabetic self-care activities. Particularly notable when they were first diagnosed with T2DM was that many of the women perceived this to mean a type of illness “causing death.” The general perception of the women that diabetes meant death was illustrated below:

I know it's a chronic disease and it takes you a long time to get into it, but it takes you a longer time to get out of because of the things that go on with your body. And I know it take a lot longer, you have to control your eating habits, your exercising. . . . So when you say diabetes . . . I know people that have had diabetes and have died. (P1)

**Past experiences.** The women made references in large part to childhood experiences that impacted their self-care behaviors. Childhood reflections impacted their view of what having T2DM meant. So their childhood experiences with people with T2DM tainted their view of someone with the disease. Not only was diabetes something that caused death, but it was suppose to be a disease that affected older people. One woman expressed this best because when she found out she had T2DM an image was brought to her mind:

[Diabetics] couldn't walk, they usually had a cane, or they were still in a wheelchair. Usually they were very large. They always had something swollen, especially their feet. Their feet was always swollen. . . . They was always coughing . . . so as a child I remember diabetes was one step from death . . . so you treat people like that because they may die any minute (P1).

Lack of financial resources was another challenge for these women. Though some women accepted their condition, not having the money to care for T2DM affected their self-management. Many of the participants stated that they grew up in a situation where

going to the doctor for preventative care was not typical. Most women who reflected on their childhood experiences indicated that they were not given foods that were healthy for them; and their meals were not planned growing up. As a result, childhood experiences with diet also impacted their self-care practices as adults. Present diets were indicated by a few of the women to be a reflection of their upbringing and how they were taught to cook “lots of fat, salt, and lots of everything.” This is illustrated best in the following quote:

As a child I was never taught proper eating skills. We did not concentrate on what was good to eat, we ate what was available, whatever was given to us, and that practice continued until adulthood (P1).

Despite such physical ailments as poor circulation, fatigue, and an inability to do activities they were used to doing, many ignored their T2DM and did not go to the doctor for months or even years because they did not want to hear anything the doctor had to say about their diagnosis. This helps explain why the women who did not accept their diagnosis when they first heard it had serious problems due to noncompliance. Attempts to acknowledge and do something about their condition eventually occurred, as can be seen from their current experiences. For those who could not accept their condition, their T2DM was not monitored until a seminal event happened and real change occurred in their lives. These events included physical deterioration that caused them to suffer great pain, loss of a foot or leg, go blind, or suffer kidney failure.

The women’s experiences are extreme examples of an array of events, their common denominator being their eventual journey back to acceptance and the highs and lows associated with trying to walk the intricate path of diabetic self-care. Regarding dealing with T2DM, despite where they started, most of the women had a hope of living, not only for themselves, but for their loved ones:

Well, now, what helps me to really try and encourage me to try and do better is, I have three kids that need me, I need to be healthier for myself, and then I have 3 kids that I adopted and um that need me to be there for them, and I can't be there for them if I don't take care of myself, and I have a sick husband that also depends on me so I got to take care of me in order to take care of any of them. (P 11)

Most of the women had been intimately acquainted with the loss of loved ones due to diabetes or had had someone in their family who suffered with diabetes, which led to the strong culture of caring for others for these diabetic women. One woman's plea to her granddaughter was to lose some weight so that she would not have to endure the negative aspects of diabetes. Despite the fact that she was obese and in constant pain, her first thoughts were for her granddaughter before herself. Because thinking of others was such a large part of who these women were, reflecting on their experiences to make recommendations to others was a joy for them. The irony for many of the women was they gave the best advice, but they had not followed this advice themselves from the very beginning when they were initially diagnosed with diabetes. Many felt it important to tell others to face reality because they felt it an imperative stance if they wanted to live. Many admitted that, had they followed their advice, today they would be in much better physical condition and living a more pain- and stress-free life. These recommendations included managing diabetes well, which meant learning everything they could about diabetes, not to ignore the diagnosis, do all they could to live with it, and follow the treatment by doctors to manage diabetes. The women's recommendations are best indicated in the following quote:

I tell everybody, it's a do or die situation, you either manage it properly, or it manages you. [Diabetes] will meet you if you meet it, . . . so I'm dragging myself into submission, (P2)

Some women were very resilient. For example, I had the most difficulty scheduling an interview with one woman who had bilateral above the knee amputations because she was always on the move and did not allow her condition to stop her from doing the things she wanted to do.

Past experiences also intimately acquainted them with the loss of loved ones due to diabetes. The ways in which they talked about family or friends whom they had lost due to diabetes showed wisdom gained from experience, and they were eventually better for the experience though many had long periods of denying their condition or distancing themselves from self-care.

As time passed and they had had diabetes longer, they became more hopeful and rallied their belief in God and their vitality to live for their grandchildren and began to perceive diabetes as something they could overcome. In addition, the women who initially accepted their condition seemed to embrace this hope for their diabetes from the very beginning. The few that accepted their condition when initially diagnosed, had overcome other serious illnesses such as cancer or seemed to have more support when they were first diagnosed that help them tackle diabetes from the very beginning.

The women living with diabetes in general tried to have positive attitudes about having diabetes, but this did not stop some women from being particularly candid about how they felt. Some expressed having real fears about diabetes because of how it had affected others they knew or because they just did not have enough information to know better or they resented diabetes for happening to them despite all they did to help others who had diabetes in their past. Some women felt that they were the support systems for their family, but it was not reciprocated. They feared going on dialysis or

getting their limbs amputated. Feeling stigmatized specifically indicating feeling judged by family, their bosses, and doctors, because of their diabetes, was also noted by a few women.

Taking care of their diabetes was challenging because it meant being constantly vigilant about their self-care. Hence, the women struggled with the process of self-care as indicated best in the quote that follows: “I’ve had a struggle trying to find the right medication, trying to find the right exercise program, trying to even find the right combination of foods that work for me.” Ultimately, they believed that because diabetes affects various parts of the body, it was difficult to manage the intricate nature of taking care of their diabetes:

diabetes affects everything, and so you got to watch out for everything, your whole body and that’s a big job that’s a big thing to do and that’s a hard thing to do, because you concentrate on your eyes, then your feet go, if you concentrate on your feet then your circulation goes . . . it’s just hard to do unless you are at the top of your game, you know, 24/7, and I don’t think anyone can do that but we just have to do the best we can. (P1)

Currently, the women were, for the most part, hopeful. Some had trouble finding a physician who would listen to their concerns. Physicians the patients felt comfortable with who recommended different things for care and most importantly, did not stereotype or talk down to them, but recognized them as a person who just wanted to be heard. In addition, family support caregivers, especially husbands, sisters, and nieces were invaluable and helped them manage their diabetes. Establishing routine, planning meals, reading relevant literature, and gaining knowledge was also important in helping the women adapt to diabetes.

Although each participant had a unique story, the African-American women's experiences with diabetes are summarized in the following sections titled Dealing with a Diagnosis of T2DM and Management of T2DM.

### **Dealing with a Diagnosis of Type 2 Diabetes Mellitus**

Each African-American woman in this study described her life with diabetes. Dealing with the diagnosis was divided into two parts: (1) reaction to a diagnosis of diabetes and (2) influential factors that impacted how she dealt with her diagnosis. There were three general reactions to being told "You had diabetes": denial, avoidance, or recognition and acceptance. The influential factors clustered around (1) past experiences, (2) seminal events, (3) perceived long term consequences, (4) level of awareness or understanding or misunderstanding, and (5) support.

**Reactions.** From examining each woman's life experience with diabetes, their initial responses to their diagnosis of diabetes fell into one of three reactions: they denied, avoided and ignored it or accepted it. Six participants accepted their diabetes diagnosis when they were first diagnosed. Of the six, one participant accepted her diagnosis, but a tragedy occurred in her life that led her to ignore or avoid doing the necessary self-management practices required. Seven participants all ignored, avoided, or denied that they had diabetes, which led to various forms of lack of self-management until some significant life event, crisis, or realization occurred that impelled them toward a better diabetes self-management lifestyle.

Of the seven participants who did not accept their condition when diagnosed, four used the term "denial" to describe how they initially dealt with their diabetes. For these women, "denial" meant that they did not acknowledge diabetes and this lasted for a period of time as is illustrated from the following quotes:

I didn't accept the diagnosis. I was in denial. . . . I didn't do anything. I refused to do the treatment . . . [for] about 6 months. (P1)

I was in denial. It's just like the doctors said. I'm a diabetic, but I really don't believe that and I don't have to be a diabetic and I'm not listening to what the doctor says. (P11)

Of those participants who chose to ignore or avoid their diabetes, one ignored or avoided her condition due to her "beliefs" that she was "misdiagnosed," that diabetes was an "old people disease," that she "didn't have the wisdom to deal with it," or that "as a child I remember diabetes was one step away from death." Another believed the doctor's diagnosis, but still ignored her condition, "Yes, I did [believe the doctor about having diabetes]. . . . You know, I just, really just, ignored [the diabetes]." Still another first denied her condition, refused conventional medicine, then moved to "ignore" her condition, choosing instead a folk medicine alternative:

At first, when they first gave me the medicine, I wouldn't take it because I didn't have it. And if I did have it, I just wanted to run some aloe and make it go away, because aloe is very good for diabetes. (P4)

Initially a few women accepted their diagnoses and were managing their diabetes well, but a turn of events caused them to revert to neglecting self-care. It was also found that participants diagnosed with the disease later in life seemed to move to acceptance far quicker than those who were diagnosed early in life. In addition, particular beliefs resulted in inadequate self-care, where one woman ignored her diabetes for a while. However, like all the women she eventually accepted her condition again:

When I was diagnosed around thirty years ago, I was on pills and I took the pills and stuff and the doctor told me if I eat right and do right and stuff and follow the restrictions that I would be you know borderline, and just come off of it, so you know for about three or four years, I did what the doctor said, I didn't have to take you know pills or nothing. . . . I went to controlling it very well, I went to exercising. . . . I said I was going beat this . . . then I had a tragedy in my life, I lost a seventeen-year-old son, you know I eat and just

didn't care. . . . I just wasn't taking care of the inside of my body the way I supposed to with my blood sugar (P5)

Some of the participants accepted their condition from the very beginning as indicated by participant 14, "I start taking care of it from the very beginning when I was diagnosed, [the doctor] had written a prescription for my meter . . . and my strips and all that and I started that the next day" (P14). Some participants accepted their diagnoses, but did not always adhere to the path of good self-care:

Right after I was diagnosed and I was checking everything and watching what I eat and keeping my weight at a normal level and then somehow I slipped and started doing what I really want to do. (P11)

In sum, less than half the participants initially accepted their diagnoses or were proactive in their self-care. The one participant who had initially accepted her diagnosis and was proactive in self-care activities, but had suffered the death of her son and had avoided and ignored her diabetes, was also currently caring for her diabetes. Interestingly, the women's experiences had a common denominator despite their initial reaction of avoidance or denial, their eventual journey back to acceptance of their diabetes particularly because the debilitating nature of their condition made them more concerned. Hence, at the date of the interviews, all participants accepted their condition and were in the process of caring for their diabetes. The above three reactions were clearly identified from the data and seemed to be processes that each woman went through in dealing with the diagnosis.

**Influential factors.** The participant's journey to self-care, were impacted by various influential factors when they were first diagnosed with diabetes. These included five major themes that reflected what influenced how the women dealt with their diagnosis: (1) past experiences, (2) seminal events, (3) perceived long-term

consequences, (4) level of awareness and understanding or misunderstanding, and (5) support.

**Past experiences.** The women's past experiences with treatment, physical ailments, and loss of family or friends were also important influential factors in how the women dealt with their diabetes. Their perception of how diabetes impacted the lives of family and friends was noteworthy:

It's really like not having a life, to have to be on the [dialysis] machine four hours of your day and then you free for a day and then you got to go back. It's a cycle. . . . if you happen not to be as blessed as my mom was to have kids to take you to dialysis, then you got to ride the bus to dialysis. . . . I sat there and I watched these people come off dialysis and they had to wait at least two hours before they could get a ride home. . . . I don't want to end up having to go up through all that. (P11)

Many women recognized and acknowledged the folly of their past actions. Hence, experiences with physical ailments helped the majority of women concede that they were not taking care of their diabetes. This process was illustrated best in the following quote:

I have retina disease in my eyes, that is a downfall of the diabetes because I wasn't taking care of the diabetes the way I was supposed to, so that's nobody's faults but mine, as long as I do what I supposed to do for the diabetes then I wouldn't have these faults, like you know a heart attack, a little mild stroke. [Before] now I never had high blood pressure, but now I have high blood pressure. . . . if I'd a start from when they first diagnosed me with the diabetes, of taking the pills, exercising, eating right, not doing what I want, doing what I suppose to do . . . I wouldn't a had these things. (P4)

Past loss was another influential factor regarding how some dealt with their diabetes. For example, losing a family member or friend who suffered prolonged problems due to diabetes reminded them to, at all costs, avoid the suffering they saw their loved ones endure, as was expressed below:

I see all that Momma went through . . . sometimes her sugar use to be so low she would go in a coma and when she went in a coma it seems like she blew up three times bigger than she was, cause my Momma was a heavy-set woman, and when she went in a coma they had to break the wall down to pull her through the window to bring her out because they couldn't get through the room door, because she so heavy, and then she had to blow up bigger and see all that she went through, you know suffer. I don't want to go through all of that. (P8)

Past experiences were potent reminders of what participants did not want for their own lives and so acted as motivators for self-care.

**Seminal events.** These major or seminal events occurred in several women's lives which significantly impacted how they dealt with their diabetes. These occurred because of altered beliefs or the role family members in their lives or physical ailments that impelled them to deal with their diabetes. Altered beliefs occurred for many women who simply had erroneous information about diabetic self-care, so once they got the information, they were able to change a fundamental error in their belief systems that led them to better self-care practices. Many of the women also had family members who were diabetics or who were very supportive to them, or both, and they did not have time to neglect their condition. Their family might call them daily, help them plan meals, or teach them how to test their glucose level and these events significantly altered their subsequent behaviors. In dealing with their diabetes, many women's beliefs were altered when their family, friends, or others enlightened them as soon as they were diagnosed with diabetes and one participant illustrated this best:

Fearful because I like to eat the wrong things, because I used to eat what I wanted . . . but knowing at the same time that it can cause kidney failure something like that and I be fearful for my sister always say. . . . Well, you're just going to die, might lose your kidneys, you might go blind, might lose one of your limbs, you won't necessarily just die. Kind of scared me, and knowing that it won't go lower, so I just follow, so it make you kind of fearful. (P7)

The role of family in their lives therefore impacted how they dealt with diabetes from the very beginning. For participant 7, it was her sister's scare tactics that really affected how she dealt with diabetes and promoted her self-care behaviors. Having a diabetic family member in their lives when they were initially diagnosed with diabetes proved instrumental in helping them deal with their diabetes and was later invaluable to helping them care for their diabetes. For example, "[My niece], the one got me started, she would come down and she wrote me a little menu to go by before. . . . I'm getting there" (P14).

Participant 5, on the other hand, lost a family member and this was another example of a seminal event that hindered her, in particular, from staying on a positive track for dealing with their diabetes. Unlike other women who experienced loss earlier in their lives, the loss was of older individuals who had diabetes. This participant however, the loss was of her son who did not have diabetes. Initially she accepted her diagnosis and, according to her view, dealt with it well. The death of her son, however, resulted in her feeling depressed and not wanting to have to deal with the fact that she had diabetes, as she related: "I handled [my diabetes] good, and like I said, I handled it good [but] 10 years later, you know, when my son died, it took a hold, it took a toll on me (P5).

In general, these seminal events in the women's lives changed their behaviors drastically, impacting how they initially dealt with their diabetes.

**Perceived long-term consequences.** These consequences of having diabetes impacted how the women dealt with their diagnoses. Long-term consequences expressed by a majority of the women when they were initially diagnosed with diabetes

related to concerns about lack of treatment, loss pertaining to kidney function and not wanting to go on dialysis, and loss of, limbs, sight, and family members. The paradox of their experiences is that some women, despite their diminished health, refused medication or ignored self-care activities. However, increasingly unbearable physical pain that they experienced impacted their decision to deal with diabetes because this pain forced them to go and get treatment since it either became too unbearable or they were fearful of increasingly negative outcomes.

Losing kidney function, for example, was perceived as a severe consequence for the majority of the women in this study. This was especially true because they had seen others affected in this way. Their actions regarding how they dealt with their diagnoses were therefore influenced and the majority of the women used their knowledge about the consequences to motivate themselves. One woman, encouraged to take her medication, said, “I don’t want to go on dialysis, so I just take my medication and keep my glucose checked, you know, as I should” (P14).

Experiencing the loss of a family member or friend from the consequences of diabetes helped them think about how they had to deal with diabetes. Despite their realization that diabetes resulted in death for many they knew, the women expressed hope regarding their condition as seen in the following representative quote:

A lot of my family members have died from it and so I’d be concerned about what it can cause in the body. And hopefully. . . . I don’t have to deal with it the rest of my life. . . . I’ll go another way besides diabetes. (P7)

**Level of awareness and beliefs or misunderstandings.** Though conceptually different, these three factors were put together because they relate to information. They were considered to be influential factors in how the women dealt with their diabetes. One participant reflected how her belief in God helped her deal with her diabetes since

she feels closer to God. “I care now [about dealing with diabetes] cause I’m closer to the Lord and back then I didn’t care. . . . Cause you know I’m with God now, and I done realize a lot of stuff, and I’m happy about that, and I can deal with [the diabetes] more” (P3).

For some women, various beliefs held by them indicated that they did not have a true understanding of their condition. The quote from participant 5 expressed this lack of understanding best: “So I figured if I didn’t have to take the pill then I could control it.” This quote indicates that she did not understand that to avoid taking the pill would contribute to exacerbating her diabetes, not make it better.

Some women were not aware of their lack of understanding, while others were not only aware of what they did not know, but expressed specific hopes based their belief in God or information they learned in the past about diabetes.

**Support.** This came from various sources in the women’s lives. Diabetes education classes helped improve awareness; family members who were diabetic and caregivers, especially close relatives, also provided help in dealing with a participant’s diagnosis. There were other factors that played key roles in how some women dealt with their diabetes. Those who were best informed and aware had the best outcomes. It is also notable that a few women mentioned that knowing they were helping others provided strength for them to deal with their diabetes.

The example below illustrates the role of the diabetes education class, which not only increased their awareness, but also supported their efforts to live with diabetes. The classes also helped them overcome some of the fears that they initially had about

the disease so they were able to better deal with their diagnosis of diabetes. The following quotes help illustrate:

When I was first diagnosed with diabetes, I took a class on nutrition, and they teach you all the things you need to know about how to eat, how much to eat, to read the food labels, how much salt you should have and all, all the things that what to do when your diabetes is low when it is too high, what to do when you have a sick day and they taught us all that in the class and it was really encouraging. (P11)

Because I didn't think I could give myself the shot, I was like, Oh, no, not a needle. But I went to my doctor's office and they showed me how to do it. First couple of weeks, I was like, Oh, my God, that was one of the dreaded things. But then I got use to it. She taught me how to do it and told me how to take it in my stomach area, told me how to do it and everything, and I started doing it. Now it's nothing. (P6)

These quotes captured how their initial exposure to classes really helped to relieve some of their fears and insecurities about taking the medicine using a syringe, and encouraged them to deal with their condition.

### **Management of Type 2 Diabetes Mellitus—Influential Factors**

Proactive and inactive represent the highs and lows of diabetes self-management for these women. Participants were regarded as proactive if they were currently caring for their diabetes and inactive if they ceased to care for their diabetes. Typically, once a participant acknowledged the importance of self-care, she became proactive in the management of her care. There were, however, times when some women chose not to manage, becoming inactive regarding their care. The themes for the management of T2DM involved various factors which either impeded or facilitated the women's management of T2DM.

## **Impediments**

These included treatment concerns, such as medication issues and concerns about their providers, and lifestyle changes, including implementing self-management, personal barriers, and inadequate resources.

**Treatment concerns.** For some, these included overcoming the difficulty of taking their first insulin by syringe (needle), finding the right medications, or finding the right doctor, as is illustrated in the quotes below:

The first shot I gave myself. . . . I was crying because I didn't want to shoot myself. (P4)

It's a struggle everyday, simply because there is so many things that you desire to do that you cannot do. There is always the, ah, ball and chain of your medicine . . . , and I am on the insulin and your insulin pretty much controls your life. . . . My biggest struggle was not just with my diet, but also getting the medical help that I thought I needed . . . and I do believe that a lot got to do with [that] because I am sure that a lot of the patients was black overweight women, and they judge us all on the same scale . . . and that's why they didn't listen. . . . Its been a struggle just finding someone that would finally listen to me. (P1)

The struggle to care for their diabetes was evident. However, to a great extent, the women seemed to feel that treatment concerns added additional concerns for them regarding their self-care practices. This is important to mention because, for many of the women, they had better treatment experiences the longer they had had diabetes.

**Lifestyle changes.** For many women, having to incorporate lifestyle changes to ensure that they managed their diabetes well, proved difficult at times. These difficulties included overcoming certain habits, personal barriers, and inadequate resources. Habituations, including culinary and food preferences, overcoming a lack of discipline, temptations, distractions, and attitudes that got in their way, as well as their inadequate

resources, were cited as things they had difficulties with, illustrated by the following quotes:

I was not and still am not as disciplined as I should be. . . . I contributed. I'm my own worse enemy. Oh, yes. Headstrong. Yes, very headstrong. I contributed to my own situation. You can't keep abusing the situation and expect everything to come up roses. It doesn't work that way. (P2)

And I'm not going to lie to you. Sometimes I see those commercials of Pepsi or something on TV and I say, "Um. I wish I had me a soda." (P6)

I still get that way [hardheaded] sometimes now, but I'm, I'm, I'm doing better. When I feel that, hey, you know, I got to do this, so I do it, sometimes I go and forget to take my shot cause I be running out in the morning, so now that I'm doing it good, I am doing it good now cause I take my shot at night, so I take it in the evening, so I take it before my last meal in the evening which is before 7 so I take my shot then. (P5)

Depending on, you know, what's going on with me, what I'm feeling I guess, I may eat it knowing I shouldn't eat it. . . . I have my weakness. (P13)

In addition to lack of discipline, to a certain extent, a few women indicated that they prioritized their co-morbidities because they were first diagnosed with a condition such as high blood pressure or they knew more about the other condition, so focusing on the first condition almost became a habit. Trying to add caring for diabetes as part of a health routine and making it a habit proved difficult at times:

The most important thing that I worried about back then was my blood pressure, and the doctor used to tell me, if you take care of your diabetes the way you take care of your blood pressure, you'll be all right, but I was hard headed and now I'm paying the price for it. (P5)

These findings illustrate the need to focus on overcoming the difficulties that were imperative for the majority of women to address in order to better care for their diabetes.

### **Facilitators**

Factors that helped these women manage their diabetes are referred to as facilitators, which are adaptive strategies and coping skills. These included improved

awareness or thinking, various types of supports, the role of past experiences, women's spiritual or religious beliefs, and their adopting new strategies for care.

**Improved awareness.** The most influential factor individuals mentioned in large part were that classes and experiences helped clear up misunderstandings, improve the way they thought about self-care, and increase their general understanding of diabetes self-care. This was evidenced by various individuals who acknowledged the importance of having knowledge about their diabetes, and due to diabetes education class, experiences at the doctor's office, and supplemental reading material, were better able to manage their diabetes.

What helped me the most? Knowing about diabetes is the biggest thing, you know, knowing the effect that diabetes can have on you, and um in following the doctor's instructions in what I need to do to stay in control of diabetes. (P13)

There is so much literature, . . . and I think that sometimes knowledge helps too, ah cause when I am experience something different, something may well click in my mind. Well I read this, this may be a new phase in my diabetes, . . . but the reading material out there is great, and what is great about it is that a lot of it is free [laughs], all you have to do is request it, or whether it's in the doctor's office or its in the clinics or whatever, you just pick it up and take it home and you just learn from that so that has helped a great deal . . . in the last few years. . . . Now I am more aware of the sickness, more aware of the fact that I've got to work to live longer, it's just not a given. (P1)

To a great extent, for most of these women obtaining this information made them concentrate more on their diabetes. Many admitted that they did not incorporate a lot of the information into their lives, but getting that information helped them know how to tackle various concerns or problems they had managing their diabetes. In addition some women indicated that they made good use of some of the information. For example, the information they read, helped them consider alternative places to test their glucose

levels, not just their fingers. Although not a strong motivator all the time, this information helped them care for their diabetes somewhat better.

**Support.** Family members and friends, who might or might not have been diabetic, all played a key role in helping the women manage their diabetes. The role the women's grandchildren played was also important because many of the women felt that living a long life for her family helped her care for her diabetes: "I want to live healthy and I want to live a long life and I want to be around for my children and grandchildren." (P5) In addition, losses of family members from diabetes had such an impact on them, it influenced them to take better care of themselves.

It was kind of scary because my grandmother died of diabetes, and I know the things she went through with diabetes, she lost one of her eyes, she lost both of her legs, and it incapacitated her from doing the things that, you know, she was use to doing, and I am just hoping that mine stay under control and it wouldn't get to that point. . . . I wouldn't want to lose a limb, lose my eyesight, or nothing, and I think with the experience and with the things that I knew about diabetes it helped me a lot to help myself with diabetes. (P13)

Living diabetic family members also supported the women when they were first diagnosed and subsequently impacted how they managed their T2DM. The following quote demonstrates how one participant's husband really helped her deal with her diabetes.

I had to bring my husband with me because they were going to explain to us the proper things to eat, the proper ways to eat, just information that would help us, the second day was more informational and I received my um meter the second day, he didn't have to go with me the second day. I mean, I learned a lot, it's probably been about 5, 6 years that I had, they scheduled me within that month or two. (P12)

Another woman found support from her sister:

P: My sister [who had developed it a long time before she did], she knows a lot about diabetes and everything. . . . We talk a lot.

I: So how did she help you when you first got diabetes?

P: She was constantly calling me. "Have you taken your meds? Are you eating the right things? You got to do this, you got to do that." She still do it right now. (P7 )

It was also notable that a few women mentioned how knowing they were helping others provided support for them to deal with their diabetes and manage it better.

If I go out and do something for some body and stuff, and I come back, then I feel good, as long as I feel good about myself, and, you know. I know I done did good. I know I got to take care of myself because there is somebody else out there that I got to go out there tomorrow, that I need to go out be there and be there for, you understand, and I need to be there for them, and I can't be down and I can't show them a negative side. I got to show them a positive side, you know, and stuff, and if I'm worrying about diabetes [it gets in the way]. (P5)

The role of family was very important to their self-care behaviors and levels of awareness. This ultimately affected their desire to manage their own diabetes. What was unclear was exactly how they followed through with these self-care activities, but it was clear that the various channels of support, at the very least, proved encouraging factors for engaging in beneficial self-care behaviors.

**Past experiences.** Past experiences seemed to help the women better manage their diabetes because they remembered what their diabetic family member had to endure and that motivated them to be proactive in their self-care or impelled them to learn about diabetes and how to better manage their diabetes care:

Yeah, see, my mother was a diabetic, too. Shoot she wasn't education 'bout stuff like they is now, back in them days. She had it so bad she used to end up going into seizures and comas and stuff, so that's what happen when you diabetic, you go through. She had one of her legs amputated, she went blind, and that's what I'm saying. I know I got to do something, my eyes getting so bad. This eye here hurting [points to eye], that's why I got to make me an appointment. (P9)

I wouldn't want to lose a limb, lose my eyesight, or nothing, and I think with the experience and with the things that I knew about diabetes, it helped, helped me a lot to help myself with diabetes. (P13)

I learned from [my mother] if you follow the guidelines, healthy eating, timely eating, taking your prescribed medications, that you manage your diabetes quite well. It doesn't really affect your life that much because it becomes a part of a routine, and she adjusted well to the routine. So I learned from her, but it didn't change my way of thinking about being a bit resentful [even though] my mom was not resentful. It was just a part of her health problems, and she was okay with it. She was okay with most things. I don't like a lot of change like that. (P2)

**Beliefs.** Spiritual or religious beliefs helped the women not only concentrate on dealing with their diabetes, but also influenced their day-to-day self-care practices. Their beliefs helped participants control their dietary intake: "During the Lenten season, I gave up adding salt to anything. I commissioned if it wasn't already added to the food when I got it, then I had to eat it like that" (P2), or belief that they had to follow the doctor's advice: "Sometimes you might get over it and, like, sometimes you might and sometimes you might not. It just depends on how you take care of yourself and do what the doctor say to." (P10) For many, the role of their belief system was instrumental in helping them to better care for their diabetes:

You're right, number one is having faith in God. Because I could have been lost, you know, and they say with wisdom comes understanding, and that's what I pray for. God give me the wisdom to know what kind of disease I am in and understanding what I need to do to take care of myself. (P6)

**Adopting new strategies for care.** Many women mentioned having to adopt new strategies for self-care. These included establishing routines, following treatment recommendations (or using folk medicine), and controlling their weight by modifying their diet and increasing their exercise. They also cited having a positive attitude, listening to their bodies, and following the guidelines for care. In addition, women tried to remember their past experiences with diabetes and use those to currently manage their condition:

I watch what I eat and take my medicine, you know, and keep count of it once a day and, you know, I do the finger stick once a day, and even it runs low, in the morning when I do my fasting blood, I still take my medicine, because that's my assurance of the day of what I eat that day...I watch very carefully what I eat. (P1)

It's routine now. I know I have to, I like to eat when I want to eat. Diabetes forces me to eat. I can't take medication on an empty stomach. And they want me to be able to eat, like, small meals rather than eating a lot [in a few meals]. (P2)

And sometimes I do when I can't hardly do and I push myself because I try not to let it get me down. I want to get it down, but I don't want to let it get me down. You live with it. You go through some changes and you try to do the best that you can, and you live through it. You go through it. (P6)

The main thing? Watch your weight. If you keep your weight down, then your sugar won't be no problem. (P4)

These strategies illustrate how women learned to monitor their glucose and diet, eliminate bad habits, and recognize their limitations. Almost all the women had been intimately acquainted with the loss of loved ones due to diabetes or had someone in their family who suffered from diabetes. The impression the women had of past experiences with people in their lives who had diabetes ultimately impacted their world view of diabetes, which seemed to affect not only how they dealt with their diabetes, but how each subsequently managed her condition.

## **Discussion**

This section discusses the study findings in the context of the model for understanding the crisis of a physical illness, the conceptual framework that framed the present study. The findings illustrated that the women experienced an initial crisis and subsequent acceptance or resistance to their chronic illness that the women ventured through. The diabetes illness experience was considered a crisis to the women during their lives. The women's transition through disequilibrium due to the crisis to find

resolution, allows equilibrium to be reestablished (Moos, 1982). Hence, the crisis experience evokes a turning point that may be either a healthy adaptation of personal growth and maturation or a maladaptive response of psychological deterioration or decline that impacts an individual's long-term ability to meet future crises (Moos, 1982).

For the current study, as found in previous research by Puavilai (1996), diabetes was viewed as a chronic physical condition that caused crises in low income and low literate African-American women's lives, particularly since, in large part, the changing nature of their diabetes ultimately often resulted in disequilibrium or disorganization in the lives of the women. In a similar light, a previous study showed that women, described as good self managers by their providers, described their early time of learning self-management as chaotic and very difficult (Ellison & Rayman, 1998). This crisis period was evident in this sample of women, because many of the women reacted in a maladaptive way to deal with their diabetes through denial or avoidance of their condition. Hence this framework was appropriate for the majority of women in this study.

The embedded correlational design allowed for exploration of the conceptual framework. This allowed for different sets of research questions to be answered using the information gleaned from the participants in both the qualitative and quantitative data sets. Therefore, different applications to various parts of the conceptual framework (the model of understanding the crisis of a physical illness) were examined. The conceptual framework was modified and had three overarching categories: precursors, skills and experience, and outcomes.

The precursors are the first category in the model. Precursors are the Background and Personal Characteristics Illness-related factors, and the Physical and Social

Environmental factors. The second category, Skills and Experience, includes cognitive appraisal, coping, and adaptive tasks. The outcome was the third category and for this study included diabetes knowledge and self-care activities. From precursors, women with diabetes obtain particular skills and experiences that equip them to live with their chronic condition and have certain outcomes, suggesting a continuous linear flow from precursors to skills and experiences to outcomes, as suggested by Moos (1982). The following section discusses the research findings within the context of the proposed theoretical framework of the study and the research literature. Each category of the framework is used as a heading to discuss the study findings. For each category, implications and suggestions for future research are presented. Limitations, methodological issues and a summary follow.

### **Background and Personal, Illness-Related, Physical and Social Environmental Factors, and Skills and Experience**

#### **Background and Personal Factors**

This study selected factors established by Moos (1982) that were pertinent to the research. These included age, gender, and socioeconomic status (measured by income level) Moo's sociodemographic factor (measured by income level and level of education achieved) was associated with the knowledge of T2DM scores. As the Silverman, Smola, and Musa (2000) study suggested, health is a multidimensional construct and, as such, may be more connected to an individual's total life experiences than would be a designation of not healthy. Religious beliefs, previous illnesses, and coping experiences highlighted from the qualitative findings, help illustrate the multidimensional construct of health, specifically diabetes, as it related to African-American women with T2DM in this study.

Non-significant correlations were found between SKILLD scores and (1) the two income variables: personal income ( $\rho = 0.24$ ) and total household income ( $\rho = 0.21$ ); (2) length of time with diabetes ( $\rho = -0.11$ ); and (3) glycemic control with diabetes ( $r = 0.17$ ). In past studies, higher reported knowledge scores had significant associations with higher incomes, longer duration of diabetes, and better glycemic control (Rothman, 2005). Furthermore, previous research (Nath, 2007) indicated that duration of disease may be a strong predictor of metabolic control. Hence, it was anticipated that African-American women living with T2DM for a shorter period of time would be less knowledgeable about their diabetes. The research findings indicated no such association, so this finding is not consistent with the literature and does not align with the anticipated result that significant correlations would be found. Small sample size and other factors connected to this particular population could be the reason for these findings. Further information and explanations from the qualitative study may help to explain this inconsistency in the findings when compared with the previous studies.

Unlike the quantitative results that showed no association between, for example, duration of time with diabetes and knowledge scores, the qualitative findings suggest the need to consider length of time with diabetes. In the study, participants had had diabetes for anywhere from 1 to 32 years, so it is evident, to some degree, that when reflecting on past experiences regarding when they were initially diagnosed, the women in the study admitted their past inadequate self-care behaviors. They indicated that they did not adapt initially and that, had they acted differently from the very beginning, they would be in a healthier condition today. For example, some indicated that they would

not have had to have a leg amputated or go through laser surgery because of their failing eyesight.

As these women over time became more cognizant of their misconceptions about diabetes, they indicated that, had they not reacted to their diagnosis of diabetes initially by avoidance and denial, they would not have been ineffective in their self-care practices and had such serious consequences. One quote that best illustrates the realization that the women had later in life is:

What you are really working on [regarding diabetes], is you're fighting to live, and you can't start that fight anytime you get ready because diabetes has already started, so when it started then you have to start and you have to go all the way. (P1)

Many of the women came to this realization, however, after a lifetime of consequences due to lack of self-care. It is imperative, therefore, that as health educators we advocate to reach more of these women at the key juncture in their life, when they are first diagnosed. It is important for collaborative efforts between public health, psychology, and health education practitioners to better target the misconceptions and inadequate understanding of diabetes for African-American women, particularly when they are first diagnosed, typically in a clinical setting.

A second observation, from the question on duration of time with diabetes was that the women reported that, because they had had diabetes for a long period of time, they forgot the information previously taught to them in diabetes classes they had had earlier. Further, participants indicated that they had not had a refresher course due to current financial constraints or other competing priorities in their life, such as caring for their grandchildren. Hence, women need access to more diabetes education resources

throughout their lives with diabetes to act as constant reminders about their ongoing diabetes self-care efforts.

Additionally, the importance of duration of time with diabetes was evident in those women who displayed an unwillingness to engage in self-care behaviors when they were first diagnosed with diabetes, because their initial response was denial. Some participants, for example, refused to take their medication due to misconceptions and used folk medicine such as aloe vera as an alternative. Other women expressed their frustration with treatment, when they were first diagnosed, since they felt they were not getting the care they needed from their provider because they felt stereotyped as a “typical diabetic” or they did not feel that their concerns were being addressed by their practitioner. Ultimately, the women’s reactions when they were first diagnosed impacted their subsequent self-care behaviors.

Funnell and Anderson (2003) suggested the need for more information and in-home guidance for diabetics, especially because of the serious and chronic nature of diabetes, the complexity of its management, and the multiple daily self-care decisions that diabetes requires (Funnell & Anderson, 2003). Their study, similar to the current study suggests the urgent nature of helping the newly diagnosed adjust to their new life in general. In this regard, being adherent to a predetermined care program is generally not enough to manage diabetes over the course of a person’s life (Funnell & Anderson, 2003). It is therefore imperative as a public health initiative to start filling the system gaps that would help African-American women diabetics, within their communities to get this consistent, flexible care throughout their lifetime.

Another background and personal factor that the women made reference to was the role of their spiritual beliefs as a supportive agent for changing their lifestyles to employ better self-care practices. Many of the women were recruited from churches with a predominantly high African-American congregation. All the women expressed having a strong faith in God and the important role that God played in their lives to help them not only acknowledge their diabetes, but also to engage in appropriate self-care activities. For example, one participant summed it up best: “You’re right, number one is having faith in God. Because I could have been lost. . . . God give me the wisdom to know what kind of disease I am in and understanding what I need to do to take care of myself” (P6).

Community access for interventions has to increasingly consider the church when promoting self-care efforts, because this study, like previous research, (Rahim Williams, 2004) further justifies the important role a belief in God plays as a strong facilitator of self-care behaviors. Hence, interventions for self-care behaviors within the community may need to find better ways to incorporate a spiritual component in their process of self-care with this target population. By tapping into all the avenues in the community, including the churches, women may have more opportunities to attend education classes for support channels for diabetes despite their competing priorities.

Traditionally, the success of patients in managing their diabetes has been judged by their ability to adhere to a prescribed therapeutic regimen. Unfortunately, this approach does not match the reality of diabetes care because many of the women indicated competing priorities and job demands. Diabetes self-care needs to also be flexible and consistent. Despite attempts to encourage, cajole, and persuade patients to

perform self-care tasks, practitioner frustrations mount when patients are unwilling or unable to follow advice to achieve desired outcomes (Funnell & Anderson, 2003).

In addition, pertaining to the coping experiences, another observation from the qualitative study was that timing of an illness in the life cycle of the woman with diabetes was considered to be of interest in this study. The qualitative findings also found that participants diagnosed with the disease later in life seemed to move to acceptance far quicker than those who were diagnosed early in life. Also, participants drew from past experiences to cope with the illness that threatened their life goals and established roles, as Moos and Tsu (1977) and Moos (1982) suggested. What was notable was that individuals who mentioned that they utilized past experiences in the qualitative study did not always do so positively. For example, some accepted the role they played for their family members who had diabetes, but resented, felt frustrated by or avoided their new role as the one having diabetes. However, for the most part, the women used the experiences positively to impact current self-care behaviors. With the increasing number of younger women diagnosed with diabetes, it is imperative to reach these women to help them adjust to life with their diabetes from the very beginning.

The conceptual framework was modified to include measuring only length of time with diabetes or duration of disease and glycemic control. However, the original tenets of the framework presented by Moos & Tsu (1977) and Moos (1982) also promoted the idea that different organs and functions may have a psychological significance not pertaining to the biological factors related to survival. For example, loss of an eye from diabetes may have more psychological significance than a severe diabetic hyperglycemic crisis that, if left untreated, may directly threaten life. The qualitative

findings also, to a great extent, corroborated Moos' original illness factor in that, for many of the women, loss of their kidney function and having to go on dialysis was such a negative factor it became a motivating catalyst for their self-care activities. However, the significance of the different body parts as suggested by Moos (1982) was not explored in this study and could be an area for future research to explore.

### **Physical and Social Environmental Factors**

These factors, specifically the aesthetic surroundings, the amount of personal space available, and the degree of sensory stimulation that may influence a person's cognitive functioning, mood, and general morale (Moos & Tsu, 1977; Moos, 1982), was beyond the scope of this research. This truncated section was addressed because the qualitative findings in large part dealt with the role of the family in dealing with diagnosis and managing diabetes. In his framework, Moos (1982) suggested the importance of the role of the relationships of patients and their families, features of the work setting, social supports in the wider community, and sociocultural norms and expectations. Findings were reported whereby the role of family was illustrated by the qualitative findings in large part.

As in previous research that used a similar conceptual framework (Pauvaili, 1996), family support was a key sociocultural consideration. For instance, for the women in the study, the role of family or other support had a positive or negative impact on whether they exercised (Carter-Edwards, Skelly, Cagle, and Appel, 2004). In a 2004 study that evaluated the relationship of perceived social support to diabetes self-management, Carter-Edwards and colleagues, found that participants described family and friend support networks as not understanding their needs and providing negative or non-health

promoting advice. This was corroborated in the current study findings when women reported that:

I can still do some things, my mama has got to the point where, I go to her house, she won't let me do anything, you know what I mean, "We don't want your diabetes to kick up." Well you know, that's because they don't quite understand how it works, they want you to be less active, when you should be more active and they don't understand that. (P1)

It was also evident from the findings that not having family or other support impacts their inactivity regarding exercise for their diabetes self-care. This is best illustrated in the following quote, which indicates that not having support accounted for her lack of engaging in diabetes self-care activities despite her knowledge that exercise was important for her diabetes self-management:

Probably get it would be nice if I had a partner that I could go walking with. You know that's exercise, I got a daughter and granddaughter that stay home with me, they don't do nothing with me . . . . I don't have no friends here, I don't have no one to walk with me, it would be nice if I got someone to walk with me, because I can't push myself, I ain't got that energy to get up and do it on my own and that's the only way I can do it besides medicine, and just learn how to exercise. I don't go to an exercise class because it costs money. (P8)

From the findings, most of the women had been intimately acquainted with the loss of loved ones due to diabetes or had had someone in their family who suffered with diabetes, which led to the strong culture of caring for others for these diabetic women. Previous studies, such as Skelly and colleagues (2005), described the development and validation of a new multiple care-giving (MC) measure and examined how familial care-giving related to family composition and psychosocial factors among older African-American women with T2DM. Both MC role and MC barrier scores were positively associated with putting the family's needs first, difficulty saying "No" to family, and the number of adults living in the household. MC-barriers were associated negatively with

quality of life, and positively with stress, barriers to diabetes self-care, and negative perceptions of diabetes competence. In a multivariate model, age and difficulty saying “No” to family seeking help were significant independent predictors of MC-barriers. Both the current study and previous studies therefore suggest that a better understanding of African-American women with diabetes in the context of family and care-giving roles may be important to identifying culturally meaningful strategies to improve self-care behaviors (Samuel-Hodge, Skelly, Headen, and Carter-Edwards, 2005).

This sociocultural factor of the role of family emerged and increased or decreased family involvement and impacted self-care activities was evident in the qualitative findings. However, future research needs to focus primarily on other dimensions for this sociocultural family component, not only within the context of the conceptual framework, but to also find ways to improve the measurement of sociocultural variables that affect self-care practices in minority populations.

Social factors, education and public access, for example, still play a significant role in health outcomes with sociocultural and behavioral lifestyle issues being highly correlated with disparities (Ashley, 1999). For these women with diabetes, there was a strong culture of caring for others. This culture of caring for others has major implications for health educators. As grandparents, these women will in turn care for the third generation, and if they pass on a legacy of bad eating habits and other lifestyle traits that are risk factors for diabetes, then the cyclical trend of obesity and incidence and prevalence of diabetes will continue to disproportionately affect these women and their descendants.

The literature on diabetes and behavioral change emphasizes the importance of understanding an individual's cultural beliefs, attitudes, and perceptions, because these factors are also important determinants of the ways in which people with diabetes behave with respect to their self-care (Maillet, D'Eramo, Melkus & Spollett, 1996; Skelly, et al., 2000). An individual's religious beliefs, attitudes, and perceptions played a key role in how they dealt with and managed their diabetes. These attitudes, beliefs, and perceptions that either stagnated care or fostered care. It is therefore imperative that prevention of worsening conditions and promotion of ongoing care are a constant focus for improving the system. Further, since limited research addresses the unique needs of sicker patients from their perspectives (Mason et al, 2002), this study is particularly important because it examines the experiences of a very specific vulnerable segment of people with poor health status.

In addition, other important sociocultural norms pertaining to the stigma of excessive weight, were also evident. Most women indicated that one difficulty they faced was that they felt others were prejudiced against them, particularly at work, and that they had to deal with this during their life experience with diabetes, as was indicated in the following quote:

I've seen how I've treated other people when they were diabetic. I think that it has been to my benefit not to tell them. I worked on this job on a temporary basis at first and I do believe that they would have hesitated in hiring me if they had known that I was a chronic diabetic, you know there other women in the office who are diabetic, so the word is talked about a lot so, it's thrown around a lot. . . . I think that made them wonder, or hesitate a little bit more, despite the fact that I probably was doing a good job and my first evaluation was outstanding. So despite that, I think it would have prejudiced them against me a little bit to know that I was a diabetic, so . . . I think that it was a good idea to withhold that, ah on other jobs that I have had. (P2)

The need to control weight to manage their diabetes was an issue that all the women raised. However, weight was also considered by the women in a sociocultural context. For instance, at one participant's health provider's office, she called the black nurse to reinforce her belief that she could not lose too much weight because she felt that her community would feel that she was on crack or had AIDS. This particular incident was expressed by one individual, but the general sentiment among the participants was the role of friends and family in helping or hindering them with their weight issues; some felt childhood lessons followed through to adulthood. The lesson here is that health educators have to increasingly advocate for improved coverage of targeted classes and social support groups guided by individuals who can identify and correct misconceptions and improve self-care practices based on the context they have to consider.

In addition to the sociocultural, the book by Liburd (2010) *Diabetes and Health disparities*, as an alternative, suggests that to understand and respond to the escalating burden of T2DM among minority populations in the US, a socio-ecological approach needs to be adapted. This approach argues that to move beyond clinical interventions in high risk populations, you must identify the key role of the socioeconomic condition that shape population health, examine the cumulative risks for illness across the lifespan, and understand to a greater extent the social and psychological conditions interacting with biological mechanisms to cause disease (Berkman & Lochner, 2002; Liburd, 2010). This is an important consideration for the current theoretical framework, the model for understanding the crisis of a physical illness that aims to capture many of the dimensions of the socio-ecological approach. Further, employing a mixed methods

study helped to assess various strengths of the model in its consideration of the socio-ecological approach.

Therefore, future research needs to examine the model for the crisis of a physical illness when considering not only the sociocultural aspects of diabetes care and intervention, but also the process of learning to manage diabetes self-care. More needs to be done, therefore, regarding examining how and to what extent the socioecologic domains are all accounted for within the context of a crisis of a physical illness framework, particularly because the framework proposes a continuum of crisis/disruption and possibly refine the context for further exploration of sociocultural variables to better explore the process of learning to self manage diabetes. Only a limited number of studies focusing on the patient's view reveal the process nature of learning to self-care their diabetes (Rayman & Ellison, 2004; Ellison & Rayman, 1998; Hernandez, 1995; Price, 1993).

Further, though the human environment component was not measured using the quantitative knowledge scale, it was addressed because the qualitative findings in large part dealt with the role of the family in dealing with diagnosis and managing diabetes. Particularly because limited evidence indicates that improvements in the social environment are directly associated with decreases in the incidence of T2DM (Liburd, 2010 p. 5), the human environment section provided pilot data to consider in future studies regarding the social environmental factors impacting diabetes self-management.

### **Skills and Experience**

Skills and experience is the second component of the model and includes appraisal and activation, major adaptive tasks, and major types of coping skills. This section was primarily addressed qualitatively. Moos (1982) indicated that collectively the

factors influence one another and affect the self-management skills and experience of a person.

For this study, the skills and experience category was best served by categorizing them as influential factors based on the findings from the qualitative data that illustrate how the women dealt with their diagnosis of diabetes and their self-care behaviors. A key suggestion would be to modify the framework as it pertains to influential factors. This would capture a more interactive process flow of the dynamics of lives of the women with diabetes. In general, the African-American women's experience with diabetes fell into two broad categories, dealing with the diagnosis of T2DM and management of T2DM, with a number of consistent and unique factors influencing both categories. Dealing with the diagnosis was captured by sections such as reactions and influential factors. Reactions to diabetes took the forms of denial, avoidance, or acceptance. These factors clustered around the women's perceived long-term consequences, past experiences, level of awareness or understanding or misunderstanding of their condition, seminal events, and support. Management of T2DM was also organized by the women's descriptions or experiences regarding difficulties or barriers to self-care. The facilitators were generally adaptive tasks and learning coping skills for health care.

**Cognitive appraisal.** This is defined as the way in which the potential stressor is perceived, and may or may not be a mediating factor. Activation or arousal occurs when the environment is appraised as necessitating a response that fosters efforts to adapt and cope that are directed at the perceived adaptive tasks (Moos,1982). The nature of these tasks is affected by the meaning of illness, by personal factors, and by the

selection of relevant coping skills that are influenced by environmental factors. The result of adaptation and coping may affect the outcome of the crisis (Moos, 1982). Only the perceived meaning of the cognitive appraisal process was explored in this study.

The women's perceived meaning of diabetes was that they defined diabetes as a type of illness or as something related to blood sugar, or they defined it based on consequences, as was seen from the qualitative findings. For this study, the individual's perceived meaning of diabetes was a key factor giving great insight into how they experienced diabetes that is how they dealt with their diagnosis and managed their condition.

Past research indicates personal evaluation of health is a complex process not fully understood (Idler, 1999; Silverman, Smola, & Musa, 2000), and the cognitive process of assessing one's health changes as factors in one's illness change (Silverman, Smola, & Musa, 2000). This may shed light on factors that contributed to the women's many and disparate recommendations to others regarding self-care, but found it difficult to manage their own diabetes. They admitted that diabetes was a complex process that required more resources, more support channels, or better treatment.

**Adaptive tasks.** The findings indicate that this section, which falls under skills and experience, could be considered in conjunction with some of the precursor factors. For example, the length of time with diabetes can have adaptive skills (general and illness adaptive tasks) affiliated. The illness tasks include coping with symptoms, their environment and treatment procedures, and their relationship maintenance with healthcare staff.

General tasks include being able to preserve (a) reasonable emotional balance, (b) satisfactory self image and sense of competence and mastery, (c) relationships with family and friends, and (d) preparation for an uncertain future (Moos, 1982). Individuals mentioned some of these domains, but future research needs to explore each to obtain a better sense of the role these play in the illness experience and in helping successful adaption of self-care behaviors.

**Coping skills.** According to the model, coping skills include mental and behavioral components that are viewed as positive and teachable. Coping skills include seven adaptive tasks typically used: (1) denying or minimizing the seriousness of the crisis; (2) seeking information about the illness, treatment procedures, and probable outcomes; (3) learning specific illness-related procedures such as giving self insulin injections or running a home dialysis machine; (4) maintaining a regular routine and setting concrete limited goals; (5) managing self-presentation and ability to request needed reassurance and support; (6) preparing self mentally and rehearse potential alternative outcomes; and (7) finding a general purpose or pattern of meaning in the course of events. Moos (1982) indicated that these can and may be used individually, consecutively, or in various combinations, and this became evident as the study data was collected and analyzed. For example, looking at a participant's life experiences with diabetes, we saw the process of acceptance that occurred after denial. Subsequent reliance on family for encouragement, for example, was evident in the findings.

The women's experience and perceptions self organized into two distinct categories and were affected by a number of consistent and unique factors influencing both categories. When they were first diagnosed, the majority of the participants,

perceived diabetes to mean a type of illness “causing death,” and the majority of women reacted with denial and avoidance. Those who initially denied or avoided their condition disregarded their condition until diabetes caused some serious consequences in their lives in the form of a seminal event; their misconceptions about diabetes led to inadequate understanding of the necessity of treatment.

The women’s experiences had a common denominator: their journey to acceptance and the highs and lows associated with trying to walk the intricate path of diabetes self-care. At the dates of the interviews, all participants accepted their condition and were in the process of caring for their diabetes. In sum, few participants initially accepted their diagnosis and were proactive in their self-care. Over time, surmounting various barriers to self-care through education and experience, their initial fears were assuaged and their beliefs modified, particularly with regard to diabetes meaning “death.” Hence, many of the women recognized that if properly self managed, they could live a long life with diabetes and were currently proactive in their self-care.

Most of the women found a general purpose to their diabetes in that they did their self-care activities and tried to help others so that they could be around for their grandchildren. Combined, these two components, precursors (background and personal factors, illness related factors, physical and social environmental factors) and skills and experiences (cognitive appraisal, adaptive tasks, coping skills) determined the outcome of the crisis, how individuals cared for their diabetes, and their knowledge level (Moos & Tsu, 1977).

That the participants found a general purpose or pattern of meaning in the course of events was evident. The women’s hope of living, not only for themselves but for their

loved ones, encouraged them to endure the journey of living with diabetes. Those who denied it, suffered long-term consequences associated with not caring for their diabetes, then later recognized their folly and belatedly engaged in self-care behaviors. This path is best captured in the following quote:

Well now, what helps me to really try and encourage me to try and do better is, I have three kids that need me, I need to be healthier for myself, and then I have 3 kids that I adopted and that need me to be there for them, and I can't be there for them if I don't take care of myself, and I have a sick husband that also depends on me, so I got to take care of me in order to take care of any of them so I got to take care of me in order to take care of any of them, and I don't want to end up having to go through dialysis and all this other stuff that could happen to you with when your diabetes is not being taken care of. (P11)

In addition, this woman resolved to not allow diabetes to affect her psyche and she was going to deal with it:

you just take it and just go and do what you got to do to maintain yourself, you can do it and don't let it get you down, because if you get in that depressed mood, and it can really take you down fast if you don't really do what you have to do . . . so I wouldn't let it get me depressed . . . because if the cancer didn't get me depressed I definitely wasn't going to let diabetes.

There were various facilitators that fostered better self-care behaviors. The various components presented by Moos in 1982 were comprehensive and a study focused solely on these factors could be augmented by considering the hope the women had for living as another component to add to the coping and adapting process. Allowing the bottom up data approach in this analysis was important as this allowed for new factors to emerge, as opposed to imposing the established categories by Moos on the data. In addition, it may be important to consider domains from other studies. For example Hill-Briggs (2003) proposed a problem-solving model of chronic disease self-management that had four essential components of problem-solving skill from the proposed model of problem solving of chronic disease self-management: problem-solving skills, orientation,

disease specific knowledge, and transfer of past experience. In addition, the study findings revealed the importance of the final domain, the transfer of past experience, which impacted the women in positive and negative ways. This would therefore be an important construct to considering adding for this section, but future research is needed to explore each of these suggestions further to better map out the possibilities how they interact and impact each other within the context of the model for understanding the crisis of a physical illness framework.

### **Outcomes: Diabetes Knowledge and Self-Care Activities**

The outcomes for the conceptual framework, diabetes knowledge and self-care, are discussed next. In addition to the continuous flow from precursors to skills and experiences to outcomes as suggested by Moos (1982) these findings also warrant tracking not only a continuous flow forward, but also a loop backward throughout the framework. For example, as found in previous studies as Pauvali (1996), women perceived different information at different times and repeatedly interpreted that information. Because of this, repeated interpretation, may emerge as a background factor based on a woman's reassessment, acceptance, and use of information, outcome variables such as knowledge, For example, with diabetes knowledge as the outcome variable, it was observed that it could also be included as a precursor variable based on the qualitative findings that suggested that they had limited knowledge to begin with out with that later improved and impacted how they processed their diabetes and adapted. Later we see how the improved knowledge they currently had could again be placed in the precursor section as a background factor from which to start the flow through the framework again, suggesting a continuous loop from one to the other then back to the original factor.

The knowledge individuals initially had about diabetes was very different from the knowledge they gained after skills and experience were obtained. In essence, based on the findings, it was evident that there was no linear progression. Various factors that were thought to play a role later on in the process flow seem to emerge earlier. Hence it was not static, particularly when accounting for the dynamic lives of women with diabetes which illuminate which the components do not always flow in one specific order or rate.

### **Diabetes Knowledge**

Previous studies stratified the SKILLD knowledge scores into two categories >50% for high knowledge and  $\leq$ 50% for low knowledge about diabetes (Rothman et al., 2005). The study found that 55.8 % of the participants had high knowledge, while 44.2% had low knowledge. It had been anticipated that participants would have low knowledge about their diabetes as was true in previous studies (Rothman et al, 2005). The women's demographics found that 61.5% of the women had had some form of diabetes education class or had been taught by their doctor about diabetes. This may account for why the women in this study had higher than the average knowledge levels.

The reality of the findings, however, is that stratifying an individual's knowledge score according to certain cut-off points does not represent the entire picture, since 44.2% had low knowledge in this study. Further, previous studies indicated that both limited literacy and limited health literacy are prevalent among most patients with diabetes, and are associated with poorer knowledge about the illness and its complications, worse glycemic control, and higher rates of retinopathy (Powell et al, 2007). Though the stratification was set at the midpoint, in Rothman and colleagues study, where anything above the midpoint was deemed to be high knowledge, higher

standards for knowledge levels need to be achieved for African-American women, especially because it is well established, particularly in the health education literature, that knowledge does not translate to behavioral change. It is therefore also important to note that despite the fact that, for this study, the majority of participants fell in the high knowledge category, (Rothman et al., 2005) the qualitative findings in part indicated how knowledge helped some but also hurt others. Knowledge hurt the women because of past experiences with loss that tainted their view of someone with diabetes, so it rendered them inactive regarding self-care. In a different light, knowledge helped some individuals because past misconceptions were altered by new knowledge and they came to the realization that they could live a long and productive life if they effectively managed their diabetes. However, positive findings indicate that comprehensive diabetes management programs, with educational strategies appropriate to low-literate patients, were of greater benefit to patients with low literacy than those with higher literacy (Rothman, et al., 2004).

The quantitative study indicated that participants had high knowledge of diabetes and the qualitative study revealed possible factors that accounted for this. First, many of the women had had diabetes for a long period of time or had relatives or friends who had diabetes. Further, the results show the majority of women in this study had diabetes education classes. Hence, past experiences coupled with more diabetes self-care education could also have accounted for this finding. For example, the women specifically indicated that their knowledge was gleaned through various life experiences with diabetes, and at the time of their interviews many of the women had had diabetes for an average 9 years with a range of 1 to 32 years.

Despite the high knowledge that women reported they had, they indicated that it was not until certain factors regarding past experiences or seminal events occurred that they used this knowledge for themselves as a motivator for better self-care of their condition. Influential factors may have included such seminal events as loss of a family member or friend to diabetes, overcoming certain fears, or experiencing debilitating physical conditions due to long-term consequences of poor self-care such as complications associated with not monitoring diabetes or just denying their condition because of the stigma or difficulty of accepting their condition.

Individual women's perceived meaning of diabetes was a key factor in how they integrated it into the context of their lives. Most women initially perceived diabetes to mean "causing death," and many of those women subsequently reacted to this perception with denial and avoidance. For those who initially denied or avoided their condition, they distanced themselves from their diabetes and disregarded their condition until the diabetes caused some serious consequences in their lives in the form of a seminal event. The women's experiences had a common denominator; their eventual journey to acceptance and the highs and lows associated with trying to walk the intricate path of diabetes self-care.

Ellison & Rayman (1998) showed that women, identified as good self managers by their providers, described their early time of learning self-management as chaotic and very difficult. In a similar light, Rayman and Ellison (2004) qualitatively described the early experiences and day-by-day reality of learning to self-manage T2DM among women in an intensive control program; they identified some of the reasons for their difficulties and that understanding and early timing of successful self-management as

necessary to the design and timing of positive intervention management. This study confirms this finding and also recognizes that priority needs to be given to this learning and accepting, early in the disease process for African-American women with T2DM. Further, interspersed with their lack of knowledge and the difficult adjustment after initial diagnosis, the concept of fatalism needs to be considered as a possible factor that may have been affecting these women when they were first diagnosed. Minimizing their condition because they were not aware of the potential severity of diabetes was not a factor for the women in this study, since all had had experience with someone who was either severely affected by diabetes or died as a consequence of the disease. More credence could therefore be given to the women having fatalistic attitudes. Fatalism is characterized by perceptions of hopelessness, worthlessness, meaninglessness, powerlessness, and social despair (Egede & Bonadonna, 2003). Although not well characterized as a barrier to effective self-management for African-Americans, fatalism appears to contribute to ineffective diabetes self-care and poor outcomes for this population (Egede & Bonadonna, 2003). Thus it is not a stretch to suggest the need for future research to explore whether the impact of the initial phase for women who were diagnosed with diabetes may be caused by perceiving diabetes to be a result of fatalistic perceptions that consequently limits diabetes self-management care practices. The study's findings indicate that although many women started out with a possible fatalistic approach, most ultimately decided to better care for their diabetes. It is important to also consider the role of depression (Jack, 2010), as a reaction to a diagnosis of diabetes.

Evans (2003) noted that according to some social epidemiologists education has been proposed to equip individuals with the means to become people who gain control of their health by developing healthy lifestyle that help to mediate the association between health and education. Further, previous research has identified the associations between educational attainment and health behaviors that are particularly important in diabetes (Karter, Stevens, Brown, Duru, Gregg, Gary, et al., 2007). Karter and colleagues (2007) focused on educational disparities in diabetes-related health behaviors. They found that patients with less education had significantly lower predicted probabilities of adapting health-seeking behaviors, being a non-smoker, and engaging in regular exercise.

Further, various unhealthy behaviors and psychological states have been associated with poor childhood conditions inadequate education, blue-collar employment, and financial barriers (Murray, Salomon, Mathers and Lopez, 2002). Health education is a prerequisite for effective self-management of diabetes, but previous research corroborates that knowledge does not necessarily predict outcomes. Therefore, in populations that have large knowledge deficits, even a small increase in knowledge may contribute to improved self-care (Nath, 2007). The study's findings which refuted the null hypothesis because there was a positive significant correlation ( $\rho = 0.24$ ) between SKILLD scores and the year of education. Hence, participants with more years of education were more likely to have better knowledge about diabetes. Increased years of education equipped individuals with key information that made resources not only accessible, but how to obtain that information more accessible. Consequently, in the qualitative findings, individuals with increased education levels

noted that they sought information, constantly read literature about diabetes, went to ongoing diabetes classes. These individuals also expressed diabetes self-management as an intricate task that involved a number of variables, while those who were less educated were not as enthusiastic or motivated to seek for future knowledge about diabetes, or they did not feel that diabetes care was a struggle; they were more concerned with doing what they needed to do to which primarily was taking their medication and altering their diet and having to follow rules and all that entailed.

The findings also suggest, with regard to clinical practice, more attention be paid in the form of resources geared toward women at the initial stages of their disease. This may mean increased numbers of health educators and counselors to do initial assessments, which should include lifestyle, as well as knowledge, to help better serve the individual. In 2007 the American Association of Diabetes Educators stated that diabetes education had seven self-care behaviors that are essential for improved health status and quality of life. They are healthy eating, being active, glucose monitoring, taking medications, problem solving, healthy coping, and reducing risks. However, factors that contribute to the gap between actual delivery and use of these skills need to be further explored, identified, and improved. For health educators, this may also mean ensuring that these assessments are in sync with pertinent theory, such as the Transtheoretical Stages of Change model (Prochaska, Redding, & Evers, 2002, p.100), to make sure that these assessments help tap into the dimensions necessary to solicit relevant information. Future research could also look into various assessments to ensure that they capture the relevant information needed from these women so that health educators, clinicians can better serve them.

This study explored some of this target population's experiences with their diabetes, and their self-care practices. The participants listed some treatment concerns, but gaps were also evident to the researcher regarding why more is not being done to implement the transfer of healthcare system education to practical use by the patients. More attention needs to be focused on the period right after diagnosis. Diagnosis sensitivity training, where clinicians develop support systems within their practices to better deal with the misconceptions, fears, depression, and fatalistic views that individuals recently diagnosed with diabetes may have. Though hospitals may be equipped with social workers, health educators, ministers, and counselors, you need a multidisciplinary team to help an individual recently diagnosed deal with her diabetes.

In addition, it was evident that not all women take advantage of the diabetes education classes or information told to them or given to them by their doctors. Further, some women fall through the system once they are diagnosed; this was demonstrated by the 44.2% that had low knowledge about their diabetes. The findings suggest, therefore, that in addition to classes, perhaps the system needs assessments to gauge their readiness to accept their diagnosis, and their readiness to learn. There are a number of potential intervention points for health educators. Thus there is value for clinical practices to consider using this study as a pilot for understanding the importance of intervening from the very beginning and following up, waiting until the participant goes through some crisis or seminal event to bring her to that point. It is clear that education classes and doctors' advice were considered by the study participants, but this was not sufficient to sustain long lasting change.

Diabetes self-care activities help prevent severe long-term consequences and may ultimately improve quality of life. It is evident from the findings in this study that, far more often than not, women with diabetes wait until they are affected physically in part before they seek treatment as can be seen from the following quote:

I have retina disease in my eyes, that is the down that is a downfall, of the diabetes because I wasn't taking care of the diabetes the way I was suppose to. So that's nobody's faults but mine. As long as I do what I suppose to do for the diabetes, then I wouldn't have these faults, like you know a heart attack, a little mild stroke. Right now I never had high blood pressure, but now I have high blood pressure . . . if I'd a start from when they first diagnosed me with the diabetes, of taking the pills, exercising, eating right, doing what I want, doing what I suppose to do . . . I wouldn't a had these things. (P4)

### **Diabetes Knowledge and Self-care Activities**

The findings of this study, specifically showed that SDSCA-specific diet were positively correlated ( $r = 0.28$ ) and were significant. This means that if an individual had higher knowledge scores, they were more likely to also have better specific diets that included fruits and vegetables and avoidance of high fat foods and full-fat dairy products. SKILLD scores and SDSCA-foot care were also positively correlated ( $\rho = 0.40$ ) and were significant. The results showed that participants who tended to engage in self-care activities for foot care during the last seven days by checking their feet and inspecting the inside of their shoes had more knowledge about diabetes than their counterparts. The findings from this study refuted the null hypothesis that participants would have no associations between level of knowledge about diabetes and their self-care activities for foot care and specific diet.

Donahoe and colleagues (2000), when evaluating a model of diabetes, integrated foot care in a randomized control trial, and also found that patients in the intervention group who had foot exams, and received foot care education found these useful. The

qualitative results from that study also indicated that women not only had good knowledge about their foot care but were likely to engage in foot care, as many participants indicated taking better care of their feet.

Other findings from the Gale and colleagues (2008) qualitative study, which explored beliefs about diabetic foot complications and everyday foot self-care practices among people with T2DM, found that most participants were unsure of what a foot ulcer was and unaware of the difficulties associated with ulcer healing. Prevention of accidental damage to the skin was not considered a priority, as few participants knew that this is a common cause of foot ulceration. In the current study, however, though foot ulceration was not the specific term used the participants were both quantitatively and qualitatively aware of the importance of preventing accidental damage to the skin regarding foot care, in large part to prevent foot amputation. The points regarding foot care are illustrated in the following:

I told you about my best friend, who dead and gone now. She never watched her sugar. She knows she had it and she knows it was serious, but sometimes I wonder if she ever realized how serious it could be, you know cause the way you treat yourself . . . like I saw her walk around with no shoes on and bumping and stumping your feet up against furniture and going on. You know you just can't do that. You have to be more careful. You have to be very careful . . . but you just don't go around taking chances like that and if you do happen to hurt yourself, your hand or your feet, you need to watch that very closely. (P4)

Many participants in this study also recognized that lower-limb amputation is more common in people with diabetes. Unlike Gale and colleagues' (2008) study, whose participants predominantly perceived that the cause was due to poor blood supply to the feet and unrelated to foot ulceration, only one person in the current study specifically mentioned this possibility, but this was beyond the scope of the present study. However, what was important to recognize from this finding is that individuals did not necessarily

need to know the specific cause to be alarmed, knowing the consequences of losing a limb.

Past experience also acted not only as a teacher for the women, but as a motivator to engage in better foot care, and this could explain the possible significant results identified in this study. It is plausible to consider that maybe knowledge gained from past learning experiences with diabetes and other illnesses may account for the positive relationships between foot care and knowledge of diabetes scores. Clark and colleagues (1991) found that, although self-management tasks are specific to an illness, for example, measuring blood glucose for diabetes, there are also core self-management tasks that are common to all illness categories that include physical activity, smoking cessation, maintaining a healthy diet, recognizing and responding to symptoms, and using medications, to list a few.

Valuable insight was gained from the qualitative findings regarding how individuals may extend such self-care tasks as monitoring symptoms in general to foot care, specifically based on past experiences. The qualitative study also illustrated that women with other co-morbidities, such as cancer, felt that, since they made it through cancer, they would not allow diabetes to impact them. They viewed cancer to be more threatening, so if they could do self-care activities to help themselves with their diabetes care they were encouraged to do so.

However, past experiences and prior learning did not necessarily help the women engage in self-care behaviors. Furthermore, although the women with diabetes had good knowledge about diabetes in general, they were unable to engage in preventive behaviors for a variety of reasons. For example, the women expressed physical

constraints, such as not having the energy or having knee issues or foot pain or chronic pain that incapacitated them from doing the necessary exercises that were identified from the qualitative findings. This is illustrated in the following:

I wish I could have energy to get up and walk, walking is good for you. I did it before, before I got real heavy, and I use to enjoy walking, and just be outside playing with the kids, the grandchildren. But all that gone. (P8)

I can't walk like I could a few months ago, matter a fact, because I don't have my knee. I It hurts me to sit down, it hurts me to stand up, it hurts me when I'm lying down, so you see I am in pain 24/7. (P4)

However, knowledge does not predict behavior. Some questions on the knowledge scale for diabetes pertained to exercise. Specifically, the question asked how many times per week and for how long someone with diabetes should exercise. In this study, SKILLD scores and SDSCA-exercise were negatively correlated ( $r = -0.07$ ), and it was not significant. The possible discrepancy between having knowledge and using that knowledge in part was explained by the qualitative findings. It would therefore be important for future research to consider not only correlating, but doing regression analyses, to see to what extent women's knowledge may be associated or predict behaviors in similar domains, specifically using women's knowledge response scores individually on the SKILLD survey to the corresponding activities measure on the SDSCA-activities survey.

In the qualitative findings, once they were first diagnosed with diabetes, these women, reported low diabetes knowledge. Though only current knowledge levels were measured in this study, Rothman, Malone, Brayant, Horlen, DeWalt, and Pignone, (2004) showed that comprehensive diabetes disease management programs, with educational strategies appropriate for low literate patients, were of greater benefit to patients with low literacy than those with higher literacy.

Family support coupled with education may also help in changing lifestyle and act as a key motivating factor for women with diabetes. Deakin and colleagues (2006) hypothesized in their study that the intervention used (X-PERT Program) would lead to increased diabetes self-management and sustained improvements in clinical, lifestyle, and psychosocial outcomes. The study did not refute the hypothesis, and participation in the X-PERT Program led to improved glycemic control; increased intake of fruits and vegetables; increased knowledge about diabetes; readiness to change and setting and achieving goals; and improved self-management skills through increased physical activity and foot care at 14 months. Similar to the findings in the present study, increased knowledge about diabetes was associated with increased intake of a specific diet (eating fruits and vegetables and avoiding high-fat foods or full-fat dairy products). Increased knowledge itself is not a predictor of behavior (Nath, 2007), rather health educators are charged with the task of understanding health behavior to transform knowledge about behavior into effective strategies for health enhancement (Glantz, Rimer, & Lewis, 2002). However, having a greater understanding of the type of foods to be avoided or reduced are key health messages that point diabetics in the right direction for care. The qualitative findings also indicated that women learning what foods not to eat, in combination with family support for eliminating that food, helped motivate them to engage in better self-care behaviors.

I: So that's motivating you to do to eat better too, your daughter losing all that weight.

P: Now she [her daughter] beginning to read the cans and stuff and seeing what's in them, and the things she be drinking she be telling me about certain things you know (laugh) . . . so I said you know I guess I want her to go with me and start buying some of the stuff what she buying . . . she have to write all of this down, she got to give it to me . . . like last week she lost 7 inches of fat . . . and I want she going to run off some of the copies

of the recipes, like what the doctor, they had gave her all kinds of recipes.  
(P13)

Further, a study by Osborn and Egede (2010) applied the Information–Motivation–Behavioral Skills (IMB) model to diabetes self-care using the diabetes knowledge scale and the summary of diabetes self-care activities measure. With regard to the outcomes for these scales, diabetes self-care information and motivation were associated with behavior, and behavior was linked to lower A1C levels. In essence, having more information (greater diabetes knowledge), having more personal motivation (less diabetes fatalism), and having more social motivation (more social support) was associated with better diabetes self-care behavior; and behavior was the sole predictor of glycemic control.

For the present study, it was hypothesized that there would be no association between knowledge and glycemic control, and this was confirmed from the study's findings. However, although past studies measured knowledge differently from the present study, the results found that increased diabetes knowledge was positively associated with performing better diabetes self-care regarding glycemic control, a discrepancy not obvious from the qualitative findings. One explanation could be that, since individuals with less knowledge had less access to testing supplies, as was evident from the qualitative findings, when they were tested, it may have been when they were at the doctors, for example. Knowing they were going to the doctor, they could possibly have started eating better and doing things to look good at the doctor's office so that they would not be treated as a "typical diabetic"—overweight and unconcerned—as some participants expressed from the qualitative findings. The small sample size may have also accounted for this discrepancy.

In this study, 7 of the 52 participants smoked and 45 did not. The independent *t*-test indicated no statistically significant difference in SKILLD scores between the two groups. Previous studies by Haire-Joshu and colleagues (1999) summarized the literature on diabetes and smoking related to epidemiological risks, efficacy, and cost-effectiveness of different cessation approaches, and found that there was minimal information on the effectiveness of cessation interventions specific to people with diabetes. Nevertheless, they indicated that there is no reason to assume that cessation intervention would be more or less effective in this population. Although the findings from the current study showed no association between knowledge about diabetes and self-care regarding smoking or nonsmoking, the qualitative findings revealed that diabetic smokers still have very similar triggers and struggles about quitting smoking, despite the fact that they know it is not good when combined with diabetes. The role of another sociocultural support with regard to smoking in a negative light is also highlighted in the following quote:

I got to stop, I know I got to stop and I try not to buy, but then a friend came up there you ain't got no cigarettes, you know you don't buy 'em then you won't smoke um but then she come round you then she goin give me a couple, that's why they sticking out the pack like this . . . . It's a bad habit and I really got to stop, I sure do, but then I be here by myself and, what it is I be here by myself and I get bored, and that's another thing that don't make me eat, smoking the cigarettes, don't make me eat, I smoking a cigarette I done forgot about everything else, as long as I got some water or ice in my hand, I mean, I'm smoking a cigarette, not that's a bad habit, now that's what gets me right now. (P9)

Though only 13.5% of the participants in the present study smoked, those participants had a desire to quit smoking. Haire-Joshu and colleagues (1999) also indicated that there is a clear need to increase the frequency of smoking cessation advice and counseling for patients with diabetes, given the strong and consistent data

on smoking prevalence; combined risks of smoking and diabetes for morbidity, mortality, and several complications; and the proven efficacy and cost-effectiveness of cessation strategies.

### **Health Education and Diabetes Self-care**

Diabetes self-management education (DSME) plays a specific role in diabetes care because it is an ongoing process of facilitating the knowledge, skills and ability necessary for diabetes self-care, which incorporates the needs, goals, and life experiences of the diabetic for the ultimate outcomes of 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., 2007). From a health education standpoint, applying the crisis framework and using a mixed method study allowed the researcher to identify, in part, the mechanisms relevant to health educators that support actions and lifestyles that are of positive benefit to an African-American woman's life with diabetes. The study also helped gain valuable information that addressed many areas of health education that can be used as a guide launching pad for future health promotion programs.

Prolonged planning and routine monitoring, prevention, coordination of care, education, and self-management are constantly needed for those with chronic illnesses, but far too often, prevention and health promotion are shortchanged, despite the fact that many diseases such as heart disease, cancer, high blood pressure and diabetes are among the most prevalent and costly, yet are the most preventable of all health problems (CDC, 2005). The findings of the study indicated that 56% of the sample recruited has a high level of knowledge. This is a step in the right direction and gives health educators hope; however, future research is needed to identify how to better use

assessment then educational strategies that improve a patient's ability to identify effective diabetes care action plans, as well as conduct self-management behaviors starting with their diagnosis and for subsequent periods for long-term care.

A key question is how to mobilize and involve patients in their own care and guide them in learning about their diabetes. Gazmararian and colleagues (2003) indicated that there are many opportunities to improve patients' knowledge about their chronic diseases. In addition, Skelly and colleagues (2000) indicated that preliminary work must be done to identify concepts that are important to the particular group under study. This call has been answered in other studies that focused not only on African-Americans, but also Mexican-Americans and Puerto Ricans, to develop culturally appropriate messages. Studies such as the present one are needed to continue this research endeavor because the diabetes epidemic continues to rise disproportionately in minority populations (CDC, 2003). Health educators need to be advocates for assembling a more multidisciplinary team, including psychologists and using assessments to help us identify immediate concerns and issues and to help patients tackle the problem.

The study findings also highlighted the importance of identifying and further exploring when and what defines an individual's adaptation of effective self-care and when after initial diagnosis did it happen. Individuals have different adaptive processes, so health educators need to better identify individual's adaptive or non adaptive behavior to better target intervention strategies for an individuals in clinical settings. For example women of lower socioeconomic status had jobs that were more physically demanding and retired at a later age. Competing life priorities therefore may have resulted in them being unable to manage their diabetes. Health educators may also

consider the diffusion of innovations theory as a possible strategy for diabetics to accept their condition (Oldenburg & Parcel, 2002).

In addition, for the society at large, not employing their knowledge about self-care and self-care activities presents some serious long-term implications particularly as it relates to cost, because limited initial self-care by diabetics potentially results in high costs if more prevention is not channeled to early stages of diabetes self-care. The findings suggested that this vulnerable group of women had more extensive needs due to limited self-care practices when they were first diagnosed, typically resulting in more extensive needs and higher healthcare utilization (Mason et al., 2002). Findings from this study could help clinicians understand the sociocultural lives of these women and how best to configure and consider treatment in the context of their lives. For example if they lack the means to purchase medication, then they clearly need to be connected to a clinic that is state funded.

In every culture the older generation passes the torch to the next, including African-American women. Their culture of caring for others has major implications for health educators, especially because many of these women end up caring for their grandchildren exclusively or in conjunction with parents. As diabetics, if they pass on a legacy of bad eating habits and other lifestyle traits that are risk factors for diabetes, then the trend toward obesity and the incidence and prevalence of diabetes will continue to disproportionately affect these women. To establish a more positive cyclical pattern therefore means that health educators need to target African-American women regarding their eating habits, their exercise behaviors by advocating for and improving educational and community support channels that increase women's likelihood to

choose to adopt better lifestyle traits to pass on to the next generation and subsequently reduce the physical and economic costs to the individual and ultimately society at large.

### **Cost and Diabetes Self-care**

Within the healthcare system, chronically ill individuals are expensive to treat and become a disproportionate part of medical care costs. Chronic and non-acute care consumes much of the healthcare system's dollars and affects people from all arenas of life with different ages, income levels, and geographic regions (Anderson & Knickman, 2001). Specifically, total health care and related costs, for the treatment of diabetes, runs about \$132 billion annually (NIDDKD, 2005). Practical, policy, and systemic change is possible if more prevention dollars were given to promote awareness of good for such chronic illnesses as diabetes. The reality is that approximately 95% of the \$2 trillion is spent on health care for direct medical services and only 5% is allocated for prevention-based programs (Goetzel 2001; McGinnis et.al. 2002; Satcher 2006; Thorpe 2005). Incentivizing prevention activities like medication use and exercise may be a way to get initially diagnosed women to focus on getting medications for treatment or engaging in healthy behaviors (Sutherland, Christianson, & Leatherman, 2008). Because some argue that the healthcare system is designed to deliver acute symptom-driven crisis management care, it is less effectively configured to financially contribute to diabetes self-care through health promotion; particularly regarding the development of community-based collaborative daily self-management initiatives. Therefore, policy-makers may need to consider refocusing on more long-term fixes instead of Band Aid crisis management for the escalating costs attributable to chronic illnesses.

This is particularly true for chronic illnesses that can be self-managed and have positive results. A health promotion- and prevention-focused system would offer a more

efficient use of scarce medical dollars in the long run. Health educators and health services researchers have a role to play in helping policy-makers' transition from recognizing to actually funding prevention and health promotion projects that would potentially prolong life and impact generations.

This means that to effectively address diabetes self-care in the context in which we live, it is imperative that health educators become more creative. Health educators are effective tools to improve the health status of Americans because they are uniquely positioned to act as patient advocates and create social marketing projects that help improve our social capital. For example, in a clinical or hospital setting where individuals learn that they have major diseases, such as diabetes, health educators and psychologists can also advocate to recruit a multidisciplinary team approach to do more effective assessments to help better target individuals and their self-care needs before they fall through the cracks of the system and only surface when they are stricken with severe health consequences, which ultimately further drive up health costs that, had there been intervention and compliance, could have been minimized.

Particularly salient are the challenges faced by the chronically ill Medicaid enrollees who bear the brunt of disparities for health care. Medicaid recipients by their very nature and eligibility requirements are disproportionately disadvantaged and suffer more complex health conditions (Lillie-Blanton and Lyons, 1998). Medicaid recipients were not specifically identified by the demographic survey, but the semi-structured interviews revealed that some of the women in this study belonged to this group, making clear by their histories and comments that increased disease management (including self-management) techniques for this population are needed. By increasing

a diabetes disease management focus on participants, cost savings are a potential benefit. Future research should examine diabetes self-care programs in a primary care setting to evaluate if it resulted in fewer ambulatory care-sensitive discharges in this population. Medicaid funds, spent on ambulatory care-sensitive care conditions such as diabetes, could save money to be applied to other patients or expand enrollment if individuals are properly managed in a primary care environment, which would mean they would not have fewer hospitalizations for that condition.

Rahim-Williams (2004), whose research looked at African-American women and self-management, suggested that accessible community-based self-management programs covered by insurance should be funded and offered by private health care providers and public health programs, including community-based organizations, service clubs, faith-based institutions, and health care programs with access to the target community. This study also embraces this view in an effort to better serve the target population studied.

In 2002, the American Diabetes Association outlined clinical practice recommendations. Further, Funnell and colleagues 2009, noted that a goal of self-management training and education is to ensure the collaborative processes through which people with or at risk for diabetes gain the knowledge and skills needed to modify behavior and successfully self-manage their diabetes and all related conditions, helps individuals with diabetes achieve optimal health status, a better quality of life, and reduce the need for costly health care. Health educators and health services researchers, adopting this goal, can ultimately impact policymakers' decisions to continuously consider the old adage, "an ounce of prevention is worth a pound of cure."

The findings also indicate that focusing on prevention is something the women in this study need to understand when they are first diagnosed with diabetes so that they can slow the progression of their diabetes and increase their quality of life.

### **Methodological Issues**

From the study process, various methodological concerns arose regarding the data collection. Some participants were not available to do follow-up interviews. For example, some participants who were on the extremes regarding higher or lower knowledge levels consented only to the first part of the study and not the second, or were not accessible by phone because they did not have one or it was disconnected. Participants were more concerned about having someone to speak to about their diabetes and the concerns they had than they were interested in measuring their knowledge.

Revisions of the IRB documents had to be done at various times to make every effort to expand the recruitment criteria. On various occasions, the most comfortable place for the participant meant that their grandchildren or other factors competed for their attention during the interview. Another competing issue was that participants occasionally were interested in talking to someone generally regarding where to find resources or getting resources, and so they were also focused on this during the data collection or obtaining resources for care.

### **Limitations**

The study had several limitations that should be noted when interpreting the results. Various considerations should be made based on recruitment. The sample was small and recruited from the North Central Florida region. Although the 52 participants were adequate for this study, the results cannot be generalized to all African-American

women with diabetes. Consequently the study insights and recommendations pertain to this specific culture of women with diabetes and may not apply to the different geographic regions. Because the study primarily identified associations, they should be interpreted with caution and should not seek to predict behavior. Lack of anticipated sample size and power or chance may account for absent relationships between variables that in previous studies showed the presence of a relationship. Further potentially confounding variables could have impacted the relationships identified in this study.

The anticipated sample size was not achieved due in part to recruitment difficulties. These difficulties in participant recruitment, including no financial incentives, impacted the ability to recruit participants. Besides the posting of requests for volunteers, one recruitment strategy, snowball sampling, was used and this may have resulted in potential bias in participant responses, particularly when they were recruited by family members or friends. Furthermore, the sample population did not lend itself to effective follow up because the attrition rate was relatively high. For example, it was the hope of the researcher to take the qualitative sample from the original sample of African-American women, based on their scores from the SKILLD survey. Due to participant drop out, lack of a follow up contact number, and lack of interest in participating in a follow-up interview, and the researcher deferred to interest and availability. For qualitative research, no set standard exists for the total number of participants needed. To overcome this limitation, estimates were made based on prior research (Guest, 2006; Patton, 2002) for the point at which saturation is likely to occur.

In addition, the findings from the survey will be informative for a particular subset of the community (who provide only one perspective) and the small sample size may allow recommendations to be made for only that limited subset. Since all the interviews for both data sets were self-reports this could have influenced the findings and so inferences should be made with caution. For example, the design did not include access to medical records for blood glucose levels to determine the specific HbA1C levels for individuals, it was based on self-reporting. Also, many of the study participants had had diabetes education and may not be representative of all individuals in the target population with diabetes.

### **Summary**

The purpose of this study was to assess diabetes knowledge and self-care practices and explore experiences regarding diabetes among African-American women. Fifty-two participants met the study criteria. The statistical power showed a favorable result (0.92) based on a two-tailed hypothesis and type I error at 0.05. The mean age for the sample was 55, ages ranging from 40 to 64. The majority (86.5%) of the participants were from Alachua County. Participants had had diabetes for an average of 9 years, the longest for 32 years. The mean for those who disclosed their blood sugar reading was approximately 136, with a minimum reading of 70 and a maximum of 263. Participants completed as much as 15 years and as little as 7 years of school, with the mean number of years completed being approximately 11.97. Approximately 42.3% of the participants had personal incomes of \$10,000 or less, while for total household income, 30.8% of the participants had an income of \$10,000 or less. Over half of the sample (61.5%) participated in some form of diabetes education classes, while 38.5% had no formal classes.

For this concurrent embedded design, the analyzed data provided information to answer the general question of what additional information was obtained during the correlation study from the qualitative data. Unlike the triangulation embedded design which merges data from different data sets to answer a similar research question, this aim of the concurrent embedded design was to answer different research questions and bring the data together in a discussion as a part of the analysis, and the supportive qualitative data set either reinforces or refutes the results of the primary quantitative data set (Creswell & Clark, 2007).

Similar to previous studies, the qualitative component helped to explore patients' values, motivations, and goals, which has been shown to be more effective in addressing barriers to improving self-care activities (Heisler et al., 2005). For this study, the qualitative component augmented the quantitative data in an effort to better understand key areas that the population of interest needed to address regarding their diabetes self-care. The quantitative findings measured knowledge and self-care activities cross-sectionally, while the qualitative study spanned the years of the women's lives with diabetes and subsequently provided substantial information not obtained from the survey data. Regarding the findings of the quantitative study, interpreting them has to be done with caution as the qualitative findings shed light on possibilities that accounted or refuted the quantitative finding.

It was hypothesized in the correlational study that the women in the study would have no higher than an average level of knowledge about diabetes; that their knowledge scores would have no association to with (a) income, (b) years of education, (c) length of time with T2DM, or (d) glycemic control; and that there were no associations between

the respondent's level of knowledge of diabetes and their self-care activities. Generally, in the descriptive study, these African-American women's experiences were examined as they related to managing their diabetes and their perceptions about diabetes and its meaning. In general, the findings from this study present mixed results. A few hypotheses were partially supported with statistically significant findings and aligned with previously reported research results. The major findings were summarized briefly with a subsequent discussion of the implications.

Using Rothman and colleagues, 2005 study's stratification rationale, the sample fell in the high knowledge category, since 55.8% of the participants scored above 50. It was anticipated that respondents would have no higher than an average knowledge of diabetes, but in this study respondents had a higher than the average level of knowledge about diabetes.

The findings confirm the null hypothesis that there were no associations between SKILLD scores and the following: personal and household incomes; length of time with diabetes; and glycemic control of diabetes. Further, there were no statistically significant differences in SKILLD scores and glycemic control between the two groups. In addition, there were no associations between the respondent's level of knowledge of diabetes and their self-care activities as they related to participants' (a) general diet (following a healthful eating plan within the last 7 days and month); (b) exercise (negative  $r$ ); (c) blood sugar testing (positive  $\rho$ ); and (d) smoking status. These inconsistent findings were explained and supported by the qualitative data.

However, other findings refuted the null hypothesis because there was a positive significant correlation ( $\rho = 0.24$ ) between SKILLD scores and the years of education.

Hence, participants with more years of education were more likely to have better knowledge about diabetes. Further, the null hypothesis was also rejected for other activities, because there was an association found between knowledge scores and both specific diet and foot care. Specific diet was having eaten within the last seven days amounts greater than or equal to five servings of fruits or vegetables or high-fat foods such as red meat or full-fat dairy products. SKILLD scores and SDSCA-specific diet were positively correlated ( $r = 0.28$ ) and statistically significant.

There were wide-ranging diabetes experiences expressed by the African-American women in this study. Research questions 4 and 5 were answered interchangeably under the following three section divisions: A Portrait of the African-American Diabetic Woman, Dealing with T2DM, and Managing T2DM, which represented the general themes of the African-American women's experiences. Their experiences and perceptions fell into two distinct categories and were affected by a number of consistent and unique identified factors influencing both categories.

Five major themes were identified that influenced how the women dealt with their diagnosis. These clustered around (1) perceived long-term consequences; (2) past experiences; (3) seminal events; (4) level of awareness or understanding or misunderstanding; and (5) support. Once participants acknowledged the importance of self-care, they were typically proactive in the management of their care. There were, however, times when they did not manage or were inactive regarding their care. "Proactive" and "inactive" appropriately captured the highs and lows on a daily basis of the diabetes self-care journey for these women. Despite their desire to care for their diabetes, this journey was not always easy and difficulties that arose impacted their self-

care behaviors, including such treatment concerns as medication issues, and concerns about their providers and lifestyle changes, which included self-management, personal barriers, and inadequate resources.

There were also influential factors that helped many of these women manage their diabetes. These were referred to as facilitators, which were categorized as adaptive strategies (coping skills). These included improved awareness or thinking, various supports, role of past experiences, spiritual or religious beliefs, and adapting new strategies for care.

In essence, measuring these women's knowledge cross-sectionally and obtaining the results, although it may show higher knowledge levels, did not capture the reality for the women when they initially found out they had diabetes and the process it took for them, even after the classes and doctors' advice, to get to the present regarding knowledge of and action for self-care. The qualitative findings also indicated that almost all these women initially had low knowledge when they received their diagnosis years prior. Years of experience and increased knowledge about diabetes allowed them to get to the positions they were at now regarding having more knowledge about diabetes self-care (as was indicated from the findings) and the actual care that they currently employed day to day.

The discussion section addressed the study findings in the context of the model for understanding the crisis of a physical illness. The sections of the discussion were framed according to each of the categories in the theoretical framework and for each; implications and suggestions for future research were presented followed by methodological issues and limitations. The model for understanding the crisis of a

physical illness was useful for this study because it appropriately explained the relationship between some of the variables used in this study as they are associated with outcomes in the literature, and that were anticipated for this study as well. Suggestions for modification were highlighted and areas not addressed in this study were also noted regarding the need for future research to address and examine these areas.

The study design facilitated the different applications to various parts of the conceptual framework (the model of understanding the crisis of a physical illness) to be examined. Further, collecting the qualitative data provided support for the primary data and delved into various perceptions, skills, and experiences that impacted the framework and identified various areas of the model that need to be examined further. Hence, the qualitative study provided possible explanations to account for quantitative findings that refuted the null in the current study or were inconsistent with previous research. For example, the importance of length of time with T2DM, not having any association in the quantitative study, proved invaluable to the qualitative findings. The study findings also provided rich pilot information for the areas that need to be further explored. The continuous flow from precursors to skills and experiences to outcomes as suggested by Moos (1982) was not observed in these findings; rather this study noted a loop back pattern, and various factors that are thought to play a role later down the process flow seemed to emerge earlier in these instances. Hence, it was not static, particularly when accounting for the dynamic lives of these women with diabetes which illuminate the fact that components do not always flow in one specific order.

Despite their initial reactions of denial or avoidance to diabetes care, many of the women realized the folly of their inactivity after a lifetime of consequences due to lack of self-care. For example, initially some participants refused to take medication due to misconceptions and used folk medicine, such as aloe vera, as an alternative. Other women strongly expressed their frustrations with treatment, since they felt they were not getting the care they needed from their provider because they felt stereotyped as “typical diabetic” or they did not feel that their concerns were being addressed by their practitioner. Religious beliefs and previous illnesses and experiences highlighted from the qualitative findings help illustrate the multidimensional construct of health, specifically as it related in this study, to African-American women with T2DM. Inadequate resources (such as financial constraints), competing priorities (such as caring for their grandchildren), and lack of flexibility in treatment were also listed as possible impediments to sustained self-care practices were also cited. Hence, these women need more access to diabetes education resources to act as constant reminders of their ongoing diabetes self-care efforts.

It is clear that the education classes and provider advice worked once individuals were ready to accept their condition. However, more consistent efforts to sustain long-term knowledge and self-care activities were also discussed, especially in light of the results that showed that many women had forgotten the information previously taught to them in diabetes classes. The role of health educators to advocate to become more creative, particularly as patient advocates, and to better reach these women at the key juncture in their life when they were first diagnosed were also noted. As a public health initiative, filling the system gaps that would help African-American women, within their

community, to get this consistent flexible care throughout their lifespan with diabetes is an imperative.

Various limitations of the study pertained specifically to recruitment, including the methods used (snowball sampling), lack of financial incentives for the target population, inability to repeat sample due to attrition issues, and small sample size. In addition, various methodological issues arose particularly due to recruitment. Some participants who may have been considered important for a follow-up interview were not available to do so. Participants were also more concerned about having someone to speak to about their diabetes and the concerns they had than they were interested in measuring their knowledge. There was a need to revisit IRB to expand the study criteria. The location for interviews was not always ideal due to competing factors. Further, interviewees at times were particularly interested in talking about diabetes and obtaining resources for care.

Ultimately, the women are the glue that determined how securely they were committed to their self-care practices, so in an effort to improve their individual lives and reduce the societal burden, more prevention efforts need to tap into as many aspects of these women's lives to help ensure that they have reminders to do self-care, interspersed throughout the community, that actually encourage and foster sustained change regarding their diabetes self-care practices. The following chapter summarizes the entire document, and presents various conclusions, implications, and recommendations.

Table 4-1. Demographic characteristics of participants

		How old are you?	How long have you known that you have T2DM?	What was your blood sugar the last time they took blood from your arm?	How many years of school did you complete?
N	Valid	52	52	44	52
	Missing	0	0	8	0
Mean		55.0192	9.3846	135.8864	11.9712
Median		56.0000	5.0000	128.5000	12.0000
Mode		59.00	5.00	130.00	12.00
Minimum		40.00	1.00	70.00	7.00
Maximum		64.00	32.00	263.00	15.00

Table 4-2. Personal yearly income

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	\$10,000 or less	22	42.3	42.3	42.3
	>\$10,000 but <=\$20,000	13	25.0	25.0	67.3
	>\$20,000 but <=\$30,000	13	25.0	25.0	92.3
	>\$30,000	4	7.7	7.7	100.0
Total		52	100.0	100.0	

Table 4-3. Total household yearly income

		Frequency	%	Valid %	Cumulative %
Valid	\$0.00	1	1.9	1.9	1.9
	\$10,000 or less	16	30.8	30.8	32.7
	>\$10,000 but < = \$20,000	13	25.0	25.0	57.7
	>\$20,000 but < = \$30,000	15	28.8	28.8	86.5
	>\$30,000	7	13.5	13.5	100.0
	Total	52	100.0	100.0	

Table 4-4. Participants' county

		Frequency	%	Valid %	Cumulative %
Valid	Alachua	45	86.5	86.5	86.5
	Levy	6	11.5	11.5	98.1
	Putnam	1	1.9	1.9	100.0
	Total	52	100.0	100.0	

Table 4-5. Sources of information for diabetes treatment

		Frequency	%	Valid %	Cumulative %
Valid	Classes	28	53.8	53.8	53.8
	Doctor	4	7.7	7.7	61.5
	None	20	38.5	38.5	100.0
	Total	52	100.0	100.0	

Table 4-6. Descriptive statistics for total SKILLD score

	N	Min.	Max.	Mean	Median	Mode	SD	Range
Total SKILLD score	52	0.00	100.00	57.31	60	70	17.50	80

Table 4-7. Frequency for total SKILLD scores

		Frequency	%	Valid %	Cumulative %
Valid	20.00	3	5.8	5.8	5.8
	30.00	3	5.8	5.8	11.5
	40.00	5	9.6	9.6	21.2
	50.00	12	23.1	23.1	44.2
	60.00	9	17.3	17.3	61.5
	70.00	13	25.0	25.0	86.5
	80.00	6	11.5	11.5	98.1
	100.00	1	1.9	1.9	100.0
Total		52	100.0	100.0	

Table 4-8. K-S Z for income, years of school, length of time with diabetes, blood sugar reading, total SKILLD score

		What is your income each year?	What is your total household income?	How many years of school completed?	How long have you known that you have T2DM?	What was your blood sugar the last time they took blood from your arm?	Total SKILLD score
N		52	52	52	52	44	52
Normal Parameters <sup>a,b</sup>	Mean	1.98	2.21	11.97	9.38	135.88	57.31
	SD	0.99	1.09	1.66	8.23	40.98	17.50
Most Extreme Differences	Absolute	0.260	0.194	0.295	0.222	0.184	0.150
	Positive	0.260	0.194	0.243	0.222	0.184	0.104
	Negative	-0.173	-0.188	-0.295	-0.154	-0.097	-0.150
K-S Z		1.87	1.4	2.130	1.601	1.220	1.09
Asymp. Sig. (2-tailed)		0.00	0.04	0.00	0.01	0.10	0.190

<sup>a</sup>Test distribution is normal.

<sup>b</sup>Calculated from data.

Table 4-9. Correlations between SKILLD score and incomes (personal and total household)

			TOTAL SKILLD SCORE	What is your income each year?	What is your total household income?
Spearman's rho	TOTAL SKILLD SCORE	Correlation	1.000		
		Coefficient			
		Sig. (2-tailed)	.		
		N	52		
	What is your income year?	Correlation	.24	1.000	
		Coefficient			
		Sig. (2-tailed)	.093	.	
		N	52	52	
	What is your total household income?	Correlation	.21	.844**	1.000
Coefficient					
Sig. (2-tailed)		.14	.000	.	
	N	52	52	52	

\*\* . Correlation is significant at the 0.01 level (2-tailed).

Table 4-10. Correlation for total SKILLD score and years of education completed

			TOTAL SKILLD SCORE	How many years of school did you complete?
Spearman's rho	TOTAL SKILLD SCORE	Correlation	1.000	.24
		Coefficient		
		Sig. (2-tailed)	.	.088
		N	52	52

\*\* Correlation is significant at the 0.01 level (2-tailed).

Table 4-11. Correlation for total SKILLD score and length of time with diabetes

		How long have you (been diagnosed) or known that you have T2DM?
Spearman's rho TOTAL SKILLD SCORE	Correlation Coefficient	-.11
	Sig. (2-tailed)	.44
	N	52

Table 4-12. Correlations for total SKILLD score and blood sugar reading

		What was your blood sugar the last time they took blood from your arm?
Total SKILLD score	Pearson correlation	0.166
	Sig. (2-tailed)	0.282
	N	44

Table 4-13. Descriptive Statistics for participants' total SKILLD score and glycemic control

		Outcome of glycemic control	N	Mean	SD	Std. Error Mean
Total SKILLD score	Good		16	55.00	18.98	4.74
	Not good		28	60.00	17.43	3.29

Table 4-14. Independent sample test for glycemic control

		Levene's test for equality of variances		<i>t</i> -test for equality of means					95% confidence interval of the difference	
		F	Sig.	<i>t</i>	df	Sig. (2- tailed)	Mean diff.	Std. error diff.	Lower	Upper
Total SKILLD score	Equal variances assumed	0398	0.532	-0.89	42	0.380	-5.00	5.64	-16.38	6.38
	Equal variances not assumed			-0.87	29.18	0.39	-5.0	5.8	-16.8	6.8

Table 4-15. K-S Z Scores for SDSCA-general diet, specific diet, exercise, blood sugar testing and foot care

		On how many of the past 7 days and month did you follow a healthful eating plan?	On how many of the last 7 days did you eat >5 servings of fruits or vegetables or high fat foods, such as red meat or full-fat dairy products?	On how many of the last 7 days did you participate in at least 30 minutes of physical activity? And did you participate in a specific exercise session other than what you do around the house or as part of your work?	On how many of the last seven days did you test your blood sugar? And the amount of times suggested by your provider	On how many days of the last seven days did you check your feet? And did you inspect the inside of your shoes?
N		52	52	52	52	52
Normal parameters <sup>a,b</sup>	Mean	3.83	5.00	2.56	4.15	4.12
	SD	2.43	1.71	2.21	2.73	2.58
Most extreme differences	Absolute	0.12	0.17	0.15	0.24	0.20
	Positive	0.096	0.12	0.15	0.15	0.13
	Negative	-0.12	-0.17	-0.12	-0.024	-0.19
K-S Z		0.83	1.25	1.09	1.70	1.41
Asymp. Sig. (2-tailed)		0.49	0.09	0.19	0.01	0.04

<sup>a</sup>Test distribution is normal.

<sup>b</sup>Calculated from data.

Table 4-16. Correlations for Total SKILLD score and SDSCA-general diet

		On how many of the past 7 days and month did you follow a healthful eating plan?
Total SKILLD score	Pearson correlation	0.003
	Sig. (2-tailed)	0.985
	N	52

Table 4-17. Correlations for total SKILLD score and specific diet

		On how many of the last 7 days did you eat >5 servings of fruits or vegetables or high fat foods such as red meat or full-fat dairy products?
Total SKILLD score	Pearson correlation	0.282*
	Sig. (2-tailed)	0.043
	N	52

\*Correlation is significant at the 0.05 level (2-tailed).

Table 4-18. Correlations for total SKILLD scores and SDSCA-exercise

		Mean for questions: On how many of the last 7 days did you participate in at least 30 minutes of physical activity? And did you participate in a specific exercise session other than what you do around the house or as part of your work?
Total SKILLD score	Pearson correlation	-0.069
	Sig. (2-tailed)	0.625
	N	52

Table 4-19. Correlations for total SKILLD score and SDSCA-blood sugar testing

		Mean score for questions: On how many of the last seven days did you test your blood sugar? And the number of times suggested by your provider?
Spearman's rho Total SKILLD score	Correlation coefficient	.092
	Sig. (2-tailed)	.518
	N	52

Table 4-20. Correlations for total SKILLD score and SDSCA-foot care

		Mean score for questions: On how many days of the last seven did you check your feet? And did you inspect the inside of your shoes?	
Spearman's rho	Total SKILLD score	Correlation coefficient	0.396**
		Sig. (2-tailed)	0.004
		N	52

\*\*Correlation is significant at the 0.01 level (2-tailed).

Table 4-21. Descriptive statistics for cigarette smokers

	Have you smoked—even one puff—during the past 7 days?	N	Mean	SD	Std. error mean
Total SKILLD score	Yes—smoker	7	55.71	16.18347	6.11678
	No—non-smoker	45	57.56	17.85746	2.66203

Table 4-22. Independent samples test total SKILLD score and smokers and non-smokers

		Levene's test for equality of variances		t-test for equality of means						
		F	Sig.	t	Df	Sig. (2-tailed)	Mean difference	Std. error difference	95% confidence interval of the difference	
									Lower	Upper
Total SKILLD score	Equal variances assumed	0.038	0.85	-0.26	50	0.799	-1.84	7.18	-16.26	12.58
	Equal variances not assumed			-0.28	8.45	0.789	-1.84	6.67	-17.08	13.40

## CHAPTER 5 SUMMARY, CONCLUSIONS, RECOMMENDATIONS

### **Summary**

In the US, chronic diseases account for approximately 75 percent of the more than \$2+ trillion health care expenditure (CDC, 2009). Diabetes Mellitus, specifically, is one of the chronic conditions that is a leading cause of disability and death (National Institute of Diabetes and Digestive and Kidney Diseases, 2005). In 2005, approximately 180 million people worldwide had diabetes and 1.1 million died from this condition (WHO, 2006). In the US, 23.6 million people, or 7.8 percent of the American population, has diabetes, of which 17.9 million people know they have diabetes, and 5.7 million people go undiagnosed (National Institute of Diabetes and Digestive and Kidney Diseases, 2008). In addition, almost half of diabetes deaths occur in people under 70 years. It is evident that the disease burden of diabetes is great. This chapter presents the summary, recommendations, and conclusions of the study.

The chance of having T2DM are increased with (1) having a family history of diabetes, (2) being a member of an ethnic group, such as African-American or Native American, (3) being overweight or obese, (4) having had diabetes while pregnant (gestational diabetes), (5) having high blood pressure, (6) having abnormal cholesterol (lipid) levels, and (7) having limited physical activity (FDH, 2005). Furthermore, of the 15.7 million people with diabetes in 2002, more than 8.1 million of them were women (CDC, 2002). As the population ages and obesity becomes more prevalent, the need for diabetes education and self-care is urgent (Lewis, 2007). As in the rest of the US, the prevalence of diabetes among adults in Florida has also continued to increase,

particularly among obese individuals. Of them, the incidence of diabetes is 44.6%, more than twice the rate of those who are not obese (FDH, 2005).

In order to achieve goals in diabetes care for specific minority groups particularly susceptible to this disease, a greater understanding is needed of the experiences of those affected by diabetes and their level of knowledge of managing their condition. A major call to action is that researchers, practitioners, and individuals need to collectively identify their roles in ensuring that individuals with diabetes receive appropriate and adequate patient education, particularly for self-management skills to adequately control the condition, as well as prevent adverse health outcomes. However, a critical missing link to developing interventions at multiple points in the lives of African-American women with diabetes is meeting frequently with them when they are in the initial process of dealing with and managing their diagnosis.

This study used two methods, quantitative correlational and qualitative descriptive design, to explore self-care knowledge and experiences regarding diabetes care among African-American women with T2DM. The specific aims of the study were (1) to assess knowledge about diabetic African-American women's self-care; (2) to explore the associations between African-American women's level of knowledge of diabetes self-care and (a) income level, (b) years of education, (c) length of time with diabetes, (d) level of glycemic control, and (e) their self-care activities; and (3) to explore the experiences of African-American women in managing their diabetes, as well as their understanding of diabetes.

The five research questions proposed in this study are as follows:

## Quantitative

- 1) What knowledge level do African-American women with diabetes have about their diabetes?
- 2) Was African-American women's knowledge level about their diabetes self-care associated with income, year of education, length of time with diabetes, and glycemic control?

**Null Hypothesis H01.** Respondent's knowledge scores had no associations to a) income, b) years of education, c) length of time with diabetes, and d) glycemic control.

- 3) What were the associations between African-American women's levels of knowledge for diabetes self-care and their self-care activities?

**Null Hypothesis H02.** There were no associations between respondent levels of knowledge for diabetes self-care and their self-care activities.

## Qualitative

- 4) What were African-American women's experiences managing their diabetes? What adaptive tasks and coping skills did they use?
- 5) How did African-American women perceive their diabetes? What did diabetes mean to them?

Informed consent was secured prior to interviewing the women. Four instruments were used in this study, including a survey to collect biographic and demographic information; the Spoken Knowledge in Low Literacy Diabetes Scale (SKILLD) to measure diabetes knowledge of self-care; the Summary of Diabetes Self-Care Activities (SDSCA) instrument to determine current self-care activities or behaviors; and the interview guide used to explore life experiences, knowledge, and understanding of diabetes and how women with diabetes manage their chronic illness. The data were collected from June 2009 to June 2010.

Fifty-two participants met the study criteria. The statistical power showed favorable results. The mean age for the sample was 55, with a range of 40-64. The majorities of participants were from Alachua County (86.5%) and had had diabetes for an average of 9 years, the longest being 32 years. The mean for those who disclosed their blood sugar reading was approximately 136. The mean number of years of school completed was 11.97. Approximately 42.3 percent of the participants had an income of \$10,000 or less and 67.3 percent reported making \$20,000 or less. When asked about total household income, 32.7 percent of the participants had incomes of \$10,000 or less and 57.7 percent reported making \$20,000 or less nearly two-thirds (61.5%) had participated in some form of diabetes education classes, while 38.5 % had had no formal classes.

The results revealed mixed findings. Some proposed hypotheses were partially supported by statistically significant findings and corroborated previously reported findings. Other findings were different from previously reported findings in the literature. It was anticipated that respondents would have no higher than an average knowledge of diabetes, but respondents in this study had higher than the average levels of knowledge about diabetes.

Despite positive and negative correlations identified, they did not reach statistical significance. The findings revealed that there were no significant associations between SKILLD and personal and household incomes, length of time with diabetes, and successful glycemic control. In addition, regarding their glycemic control, there were no statistically significant differences in SKILLD score between the two groups (those who managed their glucose well and those who did not).

The results also revealed that there was a significant positive correlation ( $\rho = 0.24$ ) between SKILLD and years of education. It appears that participants with more years of education were more likely to have better knowledge about diabetes. However, there were no significant associations between the respondent's level of knowledge of diabetes self-care and their self-care activities as those related to participants' (a) general diet (following a healthful eating plan within the last 7 days and month); (b) exercise (negative  $r$ ); (c) blood sugar testing (positive  $\rho$ ); and (d) smoking status. Associations were also found between knowledge scores and (a) specific diet and (b) foot care. Specific diet referred to having eaten, within the last 7 days, servings equal to or greater than five servings of fruits or vegetables or high fat foods such as fried food, red meat or pork, or full-fat dairy products. SKILLD and SDSCA-specific diet were positively correlated ( $r = 0.28$ ) with statistical significance. The results showed that participants who tended to engage in eating more fruits and vegetables and less high fat foods within the week prior to questioning had more knowledge about diabetes than their counterparts. In addition, SKILLD and SDSCA-foot care were also positively correlated ( $\rho = 0.40$ ) and was significant.

These women had wide-ranging diabetes experiences. They also perceived the cause of their diabetes as being due to genetics/hereditary, being overweight, having bad habits concerning eating and exercising and having two or more physical co-morbidities such as high blood pressure, high cholesterol, and stress, as well as issues with treatment. Not practicing preventative measures and poverty were also indicated by them as possible causes of diabetes.

The majority of the participants, when they were first diagnosed, perceived diabetes to mean a type of illness “causing death,” and the majority of women reacted with denial and avoidance with a few exceptions for those who accepted their condition from the very beginning. The reactions to their diagnosis of diabetes that each woman went through were identified as denial, avoidance, or acceptance. Those who initially denied, avoided, or disregarded their condition found that diabetes caused serious consequences in their lives in the form of a crisis, usually a serious illness that showed their choices to adapt were in ways that either helped or were further hurt by their disease.

The women’s experiences had a common denominator: their journey to acceptance and the highs and lows associated with diabetes self-care. In sum, half the participants initially accepted their diagnoses and were proactive in their self-care. Surmounting various barriers to self-care through education and experience, over time their initial fears were assuaged and their beliefs modified, particularly with regard to diabetes automatically meaning “death.” Hence, many of the women recognized that, if properly self-managed, they could live a long life with diabetes. Five major themes were identified that influenced how the women dealt with their diagnoses. These themes clustered around (1) perceived long-term consequences; (2) past experiences; (3) seminal events; (4) level of awareness or understanding or misunderstanding; and (5) support. Typically, once participants acknowledged the importance of self-care, they were proactive in the management of their care. There were, however, some who did not manage well or ignored it. “Proactive” and “inactive” appropriately captured the highs and lows of the diabetes self-management journey for some of these women on a

daily basis. Difficulties arose that influenced their self-care behaviors due to treatment concerns such as medication issues, concerns about their health care practitioners, and necessary lifestyle changes, as well as self-management, personal barriers, and inadequate resources.

Influential factors that helped these women manage their diabetes are referred to as facilitators, which are adaptive strategies and coping skills. These included improved awareness or thinking, various supports, role of past experiences, spiritual or religious beliefs, and adapting new strategies for care. In essence, measuring women's knowledge cross-sectionally and obtaining the result, although it may show higher knowledge levels, did not capture the reality of the women when they initially found out they had diabetes and the process it took for them, even after the classes and doctors' advice, to get to the point they are now at regarding some knowledge and motivation for self-care. The qualitative findings also indicated that women who had received their diagnoses years before initially had low knowledge but years of experience and increased knowledge about diabetes allowed them to get to the position they were at today, regarding having more knowledge about diabetes self-care (as indicated by the findings) and the actual care that they currently employ.

The discussion section addressed the study findings in the context of the model for understanding the crisis of a physical illness. The sections of the discussion were framed according to each of the categories in the theoretical framework and for each section, implications and suggestions for future research were presented followed by methodological issues and limitations. The model for understanding the crisis of a physical illness was useful to this study because it appropriately explained the

relationship between some of the variables used in this study as they are correlated or not with outcomes in the literature. Suggestions for modification were highlighted and areas not addressed in this study were also noted regarding the need for future research to address and examine these areas.

The study design facilitated the different applications to various parts of the conceptual framework (the model of understanding the crisis of a physical illness) to be examined. Further, collecting the qualitative data provided support for the primary data and delved into various perceptions, skills, and experiences that impact the framework and identified various areas of the model that need to be examined further. Hence, the qualitative study was able to provide possible explanations to account for findings that refuted the null hypothesis in the current study or were inconsistent with previous research. For example, the importance of length of time with diabetes was irrelevant to the quantitative study, but proved invaluable to the qualitative findings. The study findings also provided rich pilot information for the areas that need to be further explored. The continuous flow from precursors to skills and experiences to outcomes as suggested by Moos (1982) was not observed in these findings; rather, it was a loop back, and various factors that were anticipated to play a role later on in the process seemed to emerge earlier. Hence, it is a process that is not static or even necessarily chronological, particularly when accounting for the dynamic lives of women with diabetes, illuminating a process that does not always flow in one specific order or direction.

Many of the women, despite their initial post-diagnosis reactions of denial or avoidance of diabetic self-care, eventually experienced negative consequences.

Valuable insight was gained from the qualitative findings regarding how individuals may extend self-care from monitoring symptoms in general to foot care, specifically based on past negative experiences. However, for some neither past experiences nor prior learning helped them engage in positive self-care behaviors. Though the women had high knowledge about diabetes in general, they were unable to engage in preventive behaviors for a variety of reasons. For example, the women expressed such physical constraints as not having the energy or having other issues, such as knee problems or foot or chronic pain that precluded necessary exercises, which was identified from the qualitative findings. On the positive side, family support coupled with diabetic education may also help to change lifestyle.

The study findings also highlighted that it is important to identify and further explore when and what defines an individual's adaptation of effective self-care. Individuals have different adaptive processes and so health educators have to better identify individuals' adaptive processes to better target interventions in an individualized way in clinical settings.

It is clear that the education classes and health care advice provided by practitioners work once individuals are ready to accept their condition. However, more consistent efforts to sustain long-term knowledge and self-care activities were also discussed, especially in light of the results that showed that many women forgot the information previously taught to them in diabetes classes. The role of health educators to be more creative and to better reach out to these women at this key juncture in their lives when they are first diagnosed were also noted. As a public health initiative, it is

imperative to fill the system gaps, thus helping diabetic African-American women to get consistent, flexible care within their community throughout their lifespan with diabetes.

Various limitations specifically related to recruitment of participants should be noted when interpreting the results. For example, the methods used (snowball), lack of financial incentive for the target population, inability to sample due to attrition issues, and small sample size were issues that could be improved in future study. Though the final 52 participants were adequate for this study, the findings from the survey were informative for a particular subset of the community (who provide only one perspective) and the small sample size may allow recommendations to be made for only a limited subset of the population. Because the study primarily identified associations, they should be interpreted with caution and should not be applied to predicting behavior.

### **Conclusions**

The results from the study justified the following conclusions:

1. More African-American women in this study had a higher degree of knowledge diabetes than expected. Furthermore, they had a higher average rate of knowledge of diabetes as measured by the Spoken Knowledge in Low Literate Diabetes Scale (SKILLD), using Rothman and colleagues 2005 study's stratification rationale. It was also observed that the participants perceived their initial knowledge of diabetes to be low when they were first diagnosed and, though they had gained knowledge since, they still indicated having more to learn regarding diabetes and their self-care.
2. There were no significant correlations identified between African-American women's diabetes knowledge and personal and household incomes; length of time with diabetes; and glycemic control. Further, between the two groups of African-American women, those who controlled their blood sugar effectively, and those who did not, there was no significant difference in their knowledge levels.

3. African-American women's knowledge of diabetes was associated with number of years of education completed. Specifically, there was a positive significant relationship between their knowledge of diabetes and their years of education.
4. There was no significant relationship between African-American women's level of knowledge of diabetes and their self-care activities as they related to (a) their general diet (following a healthful eating plan within the last 7 days and month); (b) their exercise (negative  $r$ ); (c) their blood sugar testing (positive  $\rho$ ); and (d) their smoking status.
5. There was a significant association found between African-American women's knowledge of diabetes and their self-care activities as it related to (a) their specific diet and (b) their foot care. Specific diet referred to as having eaten, within the last seven days, greater than or equal to five servings of fruits or vegetables or high fat foods. Foot care referred to the number of days, within the last seven days, they check their feet or inspected the inside of their shoes. By using preventive health care measures such as foot care, African-American women's diabetes self-care efforts were supported.
6. African-American women had wide-ranging diabetes experiences and perceived the cause of their diabetes as being due to genetics/hereditary, being overweight, having bad habits (excessive and poor eating and too little exercise) or physical co-morbidities, including high blood pressure, high cholesterol, and stress, as well as issues with treatment. Not engaging in preventative health measures, poor choices in life style, and poverty were also indicated to a lesser degree as possible contributing factors. It is important to eliminate possible fatalistic attitudes or help treat the depression that women may experience after learning they have diabetes.
7. African-American women's experience and perceptions organized around the themes of: dealing with a diagnosis of T2DM and management of T2DM. Dealing with the diagnosis was divided into two sections: (1) reactions — denying, avoiding, or accepting/recognizing and (2) influential factors — perceived long

term consequence, past experience, seminal events, level of awareness or understanding or misunderstanding, and support. While management of T2DM fell into the categories of proactive and inactive and was divided into two sections: (1) difficulties — treatment concerns, lifestyle changes, personal barriers, and inadequate resources and (2) facilitators — improved awareness or thinking, various supports, role of past experiences, spiritual or religious beliefs, and adapting new strategies for care.

8. The life experiences of the African-American women demonstrated potential intervention points that could be targeted for each woman at different stages of life. Focusing on prevention is something the women in this study need to understand when they are diagnosed with diabetes so that they can manage a slower progression of their diabetes and increase their quality of life. For instance, when they were first diagnosed, the misconceptions about diabetes led to ineffective self-care because their initial reactions were avoidance and denial. With professional counseling and an increase in knowledge regarding diabetes, their self-care activities can improve. Family support was a key sociocultural consideration, specifically the role family played in promoting or hindering self-care activities. In addition, experiences with loss of family members and friends to diabetes granted many a certain wisdom, gained from experience, and they were eventually better for the experience despite periods of denying their condition or distancing themselves from self-care.

### **Implications and Recommendations for Future Research**

It is important to note that some of the implications below are similar to those reported in other studies (Rahim-Williams, 2004; Pauvali, 1996) because they still have not been appropriately addressed or remedied within the health care system.

1. It is important for collaborative efforts between public health, psychology, and health education practitioners in clinical settings to better target the misconceptions and inadequate understanding of diabetes for African-American women, particularly when they are first diagnosed.

2. In addition to diabetes education classes, support groups with health educators and peer support personnel should be available to help women process the information they obtained from the group and help them discuss a comparison between their prior knowledge and their new knowledge to form an effective knowledge base from which to engage in effective self-care practices that are more aligned with clinical practice settings.
3. Health educators need to help ensure that the current education does not fall prey to: a) a lack of understanding of individuals' cultural milieu of food preparation and eating; b) a focus on a generic diabetes education care package and not individualizing care packages; c) a focus on imparting the severe consequences regarding ignoring diabetes and avoid imparting knowledge regarding recognition of lesser symptoms.
4. Ineffective self-care can result in serious long-term implications, particularly as they relate bodily damage and cost, because initial limited self-care for diabetes results in potentially high costs if better care is not incorporated by the patient in the early stages of diabetes self-care. Therefore, health policy changes that promote prevention and, for those already diagnosed, health promotion efforts supporting those with such chronic illnesses as diabetes cannot continue to be minimized and funding needs to be assigned in greater amounts.
5. Greater knowledge and effective self-care behaviors are needed to, not only help the individual, but it also impact subsequent generations. Individuals with more knowledge are better able to help break the cycle of inactive self-care and to be proactive and impart that knowledge to family and friends to also help them with their diabetes care. If they pass on a legacy of bad eating habits and other lifestyle traits that are risk factors for diabetes, then the cycle that promotes increased rates of obesity and diabetes will continue to disproportionately affect these women.
6. Diabetes self-care needs to be flexible, consistent, and accessible. Patients need access to more diabetes education resources to act as constant reminders for

their ongoing diabetes self-care efforts. It is imperative a public health initiative needs to start filling the system gaps that would help African-American women, within their community, to get this consistent flexible care throughout their life spans.

7. Health educators play invaluable roles as: a) trainers of clinicians and other health care practitioners and (b) advocates for systemic changes.

#### **Health educators as trainers for physicians and other health care**

**practitioners.** a) They need to understand the sociocultural lives of these women and how best to configure and consider treatment in the context of their lives; b) individualize care because a one size fits all approach using diabetes education classes, though important, is not enough; c) focus on care of patient immediately after diagnosis as part of the care process and practitioners need to have “diagnosis sensitivity” training as a part of their “cultural sensitivity” training.

**Health educators need to be advocates for systematic change.** They need to advocate for clinical settings to have a multidisciplinary team to help tackle the problem of diabetes as it relates to self-care practices for minority populations, particularly collaborating with psychologist to use assessments to help identify immediate concerns and issues that contribute to inadequate self-management of diabetes. Further, health educators could do various assessments in clinical settings to help determine a patient’s readiness to accept his or her condition, teach skills to better teach self-care skills and activities, and to identify and advocate for the abolition of barriers to sound care.

**Health educators as advocates for patients.** In addition to more diabetes classes, assessments affiliated with these classes need to be implemented to not only gauge individual readiness to learn, but also readiness to accept the diagnosis to better

target possible intervention points for health educators. Health educators need to be advocates for policy change to help influence policy makers to prevent delaying prevention and health promotion efforts that may result in increased physical and financial cost for the individual and increased costs to society in general.

**Health educators as advocates for systematic changes and increased disease management focus.** A prevention advocate specialist needs to be created within the already established disease management arena where the job is to help newly diagnosed patients engage in effective self-care practices to ward off severe consequences that many women in this study ultimately faced due to their initial resistance to self-care practices. These prevention specialists would be assigned to the newly diagnosed. Their role and responsibility would be to visit the home and help the diabetic adjust to care. Further, they would be there to help reduce fears and clear up misconceptions. Their role would also entail helping the women source medication and equipment and help them to adjust to their self-care practices. In addition to case management functions, they could be rewarded by bonuses the longer their patients have long-term beneficial outcomes due to prevention strategies that the health educator helped the patient learn to do effectively.

**Increased insurance coverage.** Rahim-Williams (2004), who looked at African-American women and diabetic self-management, suggested that accessible community-based self-management programs should be covered by insurance offered by private health care providers and public health programs, including community-based organizations, service clubs, faith-based institutions, and health care programs with

access to the target community. This study also embraces this view in an effort to better serve the target population studied.

### **Recommendations for Future Research**

1. Health educators need to play an increased role in clinical settings to help assess recently diagnosed individual's concerns, beliefs, and readiness to accept their condition and to learn about diabetes. For example, using the Diabetes Health Belief Model scale (DHBM, a scale based on an 11-question questionnaire on health beliefs that operationalizes the health belief model for individuals with diabetes (Powell et al., 2007), needs to be a tool that is used in the clinical setting more often when individuals are initially diagnosed with diabetes. Also, there is a need to explore ways to better assess patients' readiness to not only learn about their condition, but where they are in accepting and internalizing their diagnosis so that the well established and structured education classes do not go underutilized.
2. Health educators need to continue to be a key resource for diabetics and increasingly ensure that literature for diabetics is written in an accessible but comprehensive manner. In addition to suggested meal plans for diabetics according to race, maybe meal plans specific to African-Americans and their tastes and traditions in particular would be helpful. However, more studies need to be done to make the literature more specific to a particular group within a culture.
3. Provide opportunities to generalize the findings in this study by doing further studies that focus on: a) the assessment of both clinicians' care of African-American women with diabetes and their views of African-American women with diabetes and how that impacts future treatment encounters; b) the need to understand how people make their choices; and c) the need to identify the role the transtheoretical model stages of change (Prochaska, Redding, and Evers, 2002) may play in dealing with diabetes and the possible intervention points that need to be addressed in clinical settings.

4. Identify individuals' adaptive models, self-efficacy regarding how they view diabetes, and their locus of control to better target interventions in clinical settings
5. Future studies should explore the extent to which each of the coping skills and adaptive tasks within the context of the model for understanding the crisis of a physical illness were major contributors to self-care. Thus far, the findings indicate that some are contributing factors, but future studies should try to tap into each of the adaptive tasks as defined by the model as key areas for intervention for these women to improve their self-care behaviors.
6. It is important to consider diabetes as a continuum of crisis/disruption and ultimately target interventions to better address diabetes self-care in the following two areas: dealing with the diagnosis and self-management of diabetes to help African-American women better adjust to and live with it. Future research needs to examine the model, the crisis of a physical illness when considering the sociocultural and socioecological aspects of diabetes care and intervention to manage diabetes self-care. Considering the model for the crisis of a physical illness for future research is also warranted as a possible framework to expand on the possible process of learning to self-manage diabetes care. More needs to be done to examine how and to what extent the socioecologic (Liburd, 2010) domains are all accounted for within the context of the crisis of a physical illness framework. Further, the significance to a person of the effect on different body parts, as suggested by moos (1982), was not explored in this study, but could be an area for future research to explore as it relates to suggesting, motivating, and implementing better health care practices, particularly to help control diabetes.

APPENDIX A  
DEMOGRAPHIC INTERVIEW GUIDE

1. Do you have Type 2 Diabetes (As diagnosed by a doctor)?
2. What county are you a resident of in Florida?
3. How old are you? Or What year were you born?
4. How long have you (been diagnosed) or known that you have type 2 diabetes?
5. What is your blood sugar reading the last time they took blood from your arm?  
\_\_\_\_\_
6. What is your income each year?
  1. Less than 10, 000 per year
  2. Greater than 10,000- less than 20,000 per year
  3. Greater than 20,000- less than 30,000 per year
  4. Greater than 30,000 per year
7. What is your total household income?
8. How many years of school did you complete? What was the last grade of school that you completed?
9. What types of diabetes treatment have you participated in?
10. What race best describes you? American Indian or Alaskan Native, Asian or Pacific Islander, Black-other, Black-African American, Hispanic.

Exclusion criteria

11. Have you ever been diagnosed with a mental illness (anything that will not allow you to answer questions to the best of your knowledge for this survey)?
12. Are you Pregnant?

APPENDIX B  
SPOKEN KNOWLEDGE IN LOW LITERACY DIABETES SCALE

**1. What are the signs and symptoms of high blood sugar?**

How do you feel when your blood sugar is high or when you were diagnosed?

Needs at least (2): *Extreme thirst, frequent urination, drinking or eating, blurred vision, and/or drowsiness/fatigue*

**2. What are the signs and symptoms of low blood sugar?**

How do you feel when your blood sugar is too low?

Needs at least (2): *Hunger, nervous/jitteriness, mood swings/irritability, confusion, sweaty, or fast heart rate*

**3. How do you treat low blood sugar?**

What should you do if your sugar is too low? How can you bring your blood sugar up if it's too low?

Accept very general answer: *Juice, milk, hard candy, 15 grams of carbohydrates AND check blood sugar*

**4. How often should a person with diabetes check their feet?**

Once a day, once a week, or once a month?

Accept: *Daily*

**5. Why are foot exams important in someone with diabetes?**

Why is it important to look at your feet? What are you looking for?

Accept very general answer: *Prevention of morbidity due to neuropathic/immunologic consequences of diabetes*

**6. How often should you see an eye doctor and why is it important?**

How often? Why?

Accept: *Seen at least yearly AND screen/manage retinopathy, glaucoma, blindness, etc*

**7. What is a normal fasting blood glucose or blood sugar?**

When you get up first thing in the morning and check your blood sugar before you eat or take medicine, what should it be? What two numbers?

Accepted range: *70 (or 80) to 120*

**8. What is a normal Hb A1C (hemoglobin A1C) or “average blood sugar test”?**

When they draw blood from your arm and get an average blood sugar reading what should it be?

Accept either: *Normal*  $\leq 6\%$  or *Target*  $\leq 7\%$

**9. How many times per week should someone with diabetes exercise and for how long?**

How many times a week? How long or how much per day?

Accept within: *3-5 times per week for a total of 30-45 min each (must include frequency and duration)*

**10. What are some long-term complications of uncontrolled diabetes?**

Do you know anyone that has diabetes and had “bad things” happen to them? What are some of those “bad things”?

Needs at least (2): *Blindness/impaired vision, kidney damage/dialysis, amputation, neuropathy/ impotence/ gastroparesis, or cardiovascular disease.*

APPENDIX C  
SUMMARY OF DIABETES SELF-CARE ACTIVITIES MEASURE

*Instructions: The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.*

**Diet**

1. How many of the last seven days have you followed a healthful eating plan?

0  1  2  3  4  5  6  7

2. On average, over the past month, how many Days per week have you followed your eating plan?

0  1  2  3  4  5  6  7

3. On how many of the last seven days did you eat five or more servings of fruits and vegetables?

0  1  2  3  4  5  6  7

4. On how many of the last seven days did you eat high fat foods such as red meat or full-fat dairy products?

0  1  2  3  4  5  6  7

**Exercise**

5. On how many of the last seven days did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0  1  2  3  4  5  6  7

6. On how many of the last seven days did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?

0  1  2  3  4  5  6  7

**Blood Sugar Testing**

7. On how many of the last seven days did you test your blood sugar?

0  1  2  3  4  5  6  7

8. On how many of the last seven days did you test your blood sugar the number of times recommended by your health care provider?

**Foot Care**

9. On how many days of the last seven days did you check your feet?

0  1  2  3  4  5  6  7

10. On how many days of the last seven days did you inspect the inside of your shoes?

0  1  2  3  4  5  6  7

**Smoking**

11. Have you smoked a cigarette-even one puff-during the past seven days?

0. No

1. Yes. *If yes*, how many cigarettes did you smoke on an average day? Number of cigarettes\_\_\_\_\_

APPENDIX D  
QUALITATIVE INTERVIEW GUIDE

1. When you are describing your condition to others, how do you describe it or what do you call it?

*Probe: What does diabetes mean to you?*

2. What do you think caused your diabetes?

3. Tell what it's like to have diabetes?

*Probe: Describe the experience when you learn that you had diabetes*

4. How has it (diabetes) affected your life?

*Probe: How does your body feel now that you have diabetes?*

5. How do you take care of your illness?

*Probe: Describe how did you learnt about how to take care of your diabetes?*

6. What do you do to take of your illness?

*Probe: What helps you to take care of your diabetes?*

*Probe: What makes it difficult or gets in the way for you do what you need to do to take care of your diabetes?*

*Probe: What adaptive tasks and coping skills do you use to take care of your illness?*

7. What would you tell others who just learned they have diabetes about the illness?

*Probe: What would be important to know about them in order for you to talk to them about their illness?*

APPENDIX E  
LETTER TO PARTICIPANTS

<b>Date:</b> _____	<b>Time:</b> _____
<b>Facilitator:</b> _____	<b>Audio</b>
<b>Consent:</b> _____	
<b>Interview #:</b> _____	<b>Informed</b>
<b>Consent:</b> _____	

**Understanding Self Care Practices for African American Women with Type 2 Diabetes**

Good Morning/Afternoon/Evening [Interviewee Name]. My name is Gail Young and I am a Graduate student at the University of Florida. The purpose of this survey is to identify for African American women, such as yourselves knowledge about diabetes self care and to explore your experiences with managing your diabetes as well as your understanding of diabetes.

Your participation in this survey/interview is entirely voluntary and you will not be penalized in any way for refusing to respond to the survey. If you agree to participate in the survey/interview/focus group please be encouraged to answer all of the questions. If you prefer not to answer any question you find objectionable you may skip it and move on to the next, without any penalty.

**All information received from you will be confidential as explained to you or read by you in the informed consent.** Please be as accurate and honest as possible in answering the questions.

Gail Young will read and explain the form to you, and then you will be encouraged repeat to me your understanding of it or review the form yourself. Once you fully understand the form and if you are interested in participating in the study, then you will be asked to sign the form, before you begin the study.

The questions that will be asked of you by Gail Young, should take approximately 20-30 minutes to complete. If you are chosen to do the Individual interview/focus group then at an agreed upon time and date, and the interview will last between 45-60 minutes. Before you begin this individual interview or focus group, you will be also asked to sign an audio consent form. This is a minimal risk study. No compensation is offered.

THANK YOU for taking the time to participate in this study. For more information about the Study please contact Gail Young, (Department of Health Education and Behavior, P.O. Box 118210, Gainesville, FL 32611; gaildale@ufl.edu) or William Chen,

Department of Health Education and Behavior, P.O. Box 118210, Gainesville, FL 32611; wchen@hnp.ufl.edu), 352-392-0583 ext 1284. The information you provide will be extremely useful to the communities.

For questions about your rights as a research participant, please contact the Institutional Review Board Office at 352-846-1494 or PO Box 100173, Gainesville, FL 32610.

APPENDIX F  
LETTER TO POTENTIAL SITES FOR RECRUITMENT

**DATE**

Name  
ADDRESS  
Gainesville, FL

Dear X (NAME /TO WHOM IT MAY CONCERN),

I would like to schedule a meeting with you in the near future to discuss your site as a possible place for recruiting participants for my dissertation research. I will be delighted to have the opportunity to meet with you and look forward to sharing my research with you and your team. My name is Gail Young and I am a doctoral candidate in the department of Health Education and Behavior at the University of Florida. The focus of my research is to assess core knowledge about African American women diabetes self care; explore the level of self care activities that these women engage in as well as identify their experiences managing diabetes and their understanding of diabetes. Low income, low literate African American women with Type 2 diabetes will be the targeted participants for my study. The project title is: Understanding Self Care Practices for African American Women with Type 2 Diabetes.

I write to inquire if you believe your population would be willing to participate in this study. Specifically we would like the opportunity to put up flyers and recruit individuals from your facility. If a private room is available, it may be better to conduct my study at your facility if you invite us to do so. If a room is not available, then if agreed, a secluded area on the compound will be requested and agreed upon. If this is not possible, another location such as a public library room will be used and an interview scheduled with the participant.

If you have any questions prior to our meeting please contact me at 305-785-5317 or 352-358-4122. Otherwise, I will contact you to schedule our meeting. I wish you continued success with your facility and I look forward to meeting with you in the near future.

Best Wishes,  
Gail C. D. Young, Doctoral Candidate  
Department of Health Education and Behavior,  
Campus Address: PO Box 117330,  
Gainesville, FL 32611,  
352-358-4122 or 352-392-0583 ext 1409  
[gcdyoung@gmail.com](mailto:gcdyoung@gmail.com), or [gaildale@ufl.edu](mailto:gaildale@ufl.edu)

APPENDIX G  
FLYER USED TO RECRUIT PARTICIPANTS

**WE NEED YOUR HELP**

**WE NEED YOUR HELP**

**JOIN A STUDY THAT WANTS TO HEAR ABOUT YOU**  
**AND HOW YOU CARE FOR YOUR DIABETES**

If you are:

1. An African American Woman
2. Between 40-64 years old with Type 2 diabetes
3. If you have at most a 2 year college degree but less than a 4 year college degree

**PLEASE PARTICIPATE IN AN INTERVIEW AND/OR  
FOCUS GROUP**

**To learn more about the study please contact:**

**Gail Young, MA, PhDc**

**UF, College of Health and Human Performance**

**352-358-4122 or 305-785-5317**

**COME JOIN THIS STUDY**

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## BIOGRAPHICAL SKETCH

Gail was born and raised in Jamaica, West Indies. In 1995, she came to the United States where she completed a dual degree, Bachelor of Science in psychology and Bachelor of Arts in Spanish, from Howard University in Washington, DC, with honors and received various academic and athletic scholarships. As an undergraduate, she received the Arthur Ashe Jr. Award for outstanding academic and athletic achievement for 1997-1999. In summer 1997, Gail received the Lucey E. Moten International Relations Fellowship to study abroad in Spain at the University of Salamanca. After graduating, she moved to New York, completing a master's in psychology at Columbia University Teachers College.

She moved to the D.C. area to work as a substance abuse counselor at Alcohol and Drug Services, Fairfax County, Virginia. She later worked as a research assistant at the University of Miami in Coral Gables, and as a Social Services Counselor for the State of Florida Department of Corrections in Miami. In 2004, she attended the University of Florida Department of Health Education and Behavior. There she worked as a teaching assistant and a research assistant for the Medicaid Reform Evaluation project, as well as the Project Coordinator/Research Assistant at the Rehabilitations Outcomes Research Center of Excellence. She graduated with her Doctor of Philosophy in Health Behavior in 2010. Her research interests include women's health, diabetes education, minority women's issues, Medicaid and the underserved population, and public health policy regarding women's issues. Gail has been the wife of Mark Terafi Young since 2005 and has a beautiful daughter, Saree Young. Her family includes her wonderful parents and in-laws, her three loving brothers and sisters-in-law, and many aunts, uncles, cousins, and loving and supportive friends and church family.