

LIVING WITH TYPE 2 DIABETES

By

CHERIE HODGE

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To my husband Bill whose support and encouragement were unwavering

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## LIVING WITH TYPE 2 DIABETES

By

Cherie Hodge

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Type 2 Diabetes Mellitus (T2DM) is a costly and devastating chronic disease having global impact. Increasing incidence and prevalence of type 2 diabetes threaten to make it the most costly health condition in history. Rural counties in North Florida have a higher prevalence of type 2 diabetes and statistically more diabetes associated complications and the reasons for this are not well understood. This qualitative thematic survey utilized Kleinman's explanatory model to determine perceived diabetes causation, impact of perceived causation on self-management strategies, obstacles to diabetes self-management and possible racial/gender differences in beliefs and practices related to type 2 diabetes in 21 adult diabetic North Florida residents. .

Participants identified complex multifactorial causes of type 2 diabetes, including internal, external, and behavioral causes. Internal and external causes were events or conditions over which the participant had no control and could not be modified. Behavioral causes were things over which the participant had control and the ability to modify. The causes identified in this study were those identified in previous studies.

Management strategies included diet change, weight loss, increasing physical activity, and adherence to pharmacologic therapy. Obstacles included diet change, costs and other aspects of medication management, and dissatisfaction with and uncertainty about current or appropriate management. Facilitators included assuming responsibility for self-management, faith/prayer, education about diabetes management, family support and recognition of potential complications of uncontrolled disease.

The disconnect between provider (physiologic) and patient (multi-factorial) explanations for illness causation previously reported by Kleinman was validated in this study. The importance of “getting the diagnosis into your head” before participants were ready to assume self-management strategies was a finding unique to this study and appears to indicate the importance of reaching a turning point and internalizing the diagnosis.

## CHAPTER 1 INTRODUCTION

### **Background**

Type 2 Diabetes Mellitus (T2DM) is a disease characterized by higher than normal levels of blood glucose, peripheral insulin resistance, and obesity (Votey, 2008). The long-term result of hyperglycemia is damage to body tissues. Areas of the body specifically affected are the kidneys, the heart and vasculature, eyes, autonomic and peripheral nervous systems. The damage to these tissues produces significant morbidity and mortality to persons with T2DM and results in health care expenditures exceeding 100 billion dollars annually (ADA, 2003; DeFronzo, 2001). Control of hyperglycemia to near normal levels has been shown to decrease the rate of all complications associated with T2DM (DCCT, 1993), and is the foundation of diabetes care in the United States (ADA, 2004). Although the pathophysiology of T2DM is not universally agreed upon, it is highly associated with altered insulin response and secretion, yet clearly not associated with autoimmunity as is Type 1 Diabetes (ADA, 2004; Engelgau, Geiss, Saadine, Boyle, Benjamin, Gregg et al., 2004).

According to the 2007 National Diabetes Fact Sheet, a comprehensive statistical assessment of diabetes compiled jointly by the Centers for Disease Control (CDC), the National Institutes of Health (NIH) and the American Diabetes Association (ADA), the overall prevalence of T2DM for adults and children in the United States is 23.6 million persons or 7.8% of the population. Individuals under the age of 20 account for slightly less than 200,000 cases of T2DM, while those over 20 years of age account for 23.5 million cases. There are 1.6 million new cases diagnosed annually. Men over the age of 20 comprise 12 million cases or 11.2 % of their population while women of the same

age comprise 11.5 million cases or 10.5% of their population (CDC, 2010). Although some variability exists in estimates of undiagnosed cases and predictions of future prevalence rates, the predicted numbers continue to escalate (ADA, 2004; CDC, 2007; Engelgau et al., 2004; Harris, Flegal, Cowie, Eberhardt, Goldstein, Little et al., 1998).

Analysis of data trends from the National Health and Nutrition Examination Survey I through III (NHANES) has been utilized widely to monitor diabetes prevalence and estimate changes in incidence and prevalence rates (Engelgau et al., 2004; Harris et al., 1998; Koro, Bourgeois, Bowlin, & Fedder, 2004; Norris, Engelgau, & Narayan, 2001). The analyses performed in each study indicated an increase in the prevalence and incidence of the disease, lower age at onset, and worsening levels of control for those previously diagnosed with T2DM.

According to Cowie (1993), the prevalence rates in minority populations are substantially higher than in Caucasian populations with rates ranging from 20% in blacks to as high as 50% in some Native American populations. The CDC estimated the age-adjusted minority prevalence in 1999-2004 to be 15.5% for non-Hispanic Blacks and 13.3% for Mexican-Americans (CDC, 2007). These numbers do not include those diagnosed with impaired fasting glucose (IFG) or impaired glucose tolerance (IGT), either of which without lifestyle modification interventions may progress to T2DM. It is estimated that by the year 2025 developing countries will experience a 70% increase in disease prevalence while developed countries are estimated to experience a 42% increase (ADA, 2008).

Direct and indirect costs of this disease in the United States in 2002 were estimated at \$132 billion (Koro et al., 2004), an increase from the 1997 estimate of \$98

billion (Norris et al., 2001). In 2002, the annual per-capita health-care costs for persons with type 2 diabetes were \$13,243 compared to \$2,560 for those without (Votey, 2008).

Theories regarding the disparities in prevalence of T2DM in various races or ethnic populations have included differences in location, culture, genetics, and socio-economic status. Socio-economic status and culture are often used as proxies for education, income, access to care, genetics, and environment (California Medi-Cal Study, 2004; Harris, 2001; Karter, Ferrara, Liu, Moffet, Ackerson, & Selby, 2002; O'Brien, Flanders, DeCoufle, Boyle, DeStefano, & Teutsch, 1989; Sudano & Baker, 2005). Socio-economic status, especially lower SES, has been associated with increased prevalence of T2DM (Cooper, 2002; Dallongeville, Cottel, Ferrieres, Arveiler, Bingham, Rudavets et al., 2005; Evans, Newton, Rutas, MacDonald, & Morris, 2000; Nelson et al., 2002; Signorello et al., 2007; Sudano & Baker, 2006;) and general poor health outcomes (Feinglass, Lin, & Thompson, 2007; Kaplan, Pamuk, Lynch, Cohen, & Balfour, 1996). Mortality rates from all causes are significantly associated with lowest income areas and households, and minority populations are overrepresented in these lower income areas (Kaplan et al., 1996). Ethnic/racial disparities in health outcomes persist even when minority populations have equal access to health care through mutual membership in insurance plans (Karter et al., 2002).

The presence of microvascular complications of T2DM were found more often in Hispanics (36%) and blacks (29%) than in whites (22%) in the Veterans Affairs Diabetes Trial (Emmanuelle, Sacks, Klein, Reda, Anderson, Duckworth et al., 2005). This is supported by results of a meta-analysis of existing literature on diabetes complications (Aruyan & Itamar, 2008).

Despite the enormous body of literature related to T2DM, there has been a tendency to concentrate research into two main areas: either identifying a genetic cause for the disease or the study of interventions and adherence to those interventions in order to control the disease and its progression to a variety of well-known complications. Despite extensive research on treatment of T2DM, the number of those affected by this disease increases annually. Why is there no improvement in incidence and management with the massive research and treatment efforts currently in place?

### **Purpose**

The purpose of this study is to explore how people diagnosed with T2DM residing in the North Florida area live with the disease on a daily basis; how each person understands or interprets the disease; how confident each person is that he/she can manage the illness; what strategies/techniques each uses to manage the illness; the effect the diagnosis and disease process has on their lives; and whether race and gender play any role in their reaction to the disease. The use of qualitative inquiry is recommended in areas where description of a problem is needed, usually where little information about a problem exists or in cases where the existing information appears to be erroneous (Germain, 2001; Patton, 1999, 2002). According to Sandelowski and Barosso (2003), "Qualitative research findings contain information about the subtleties and complexities of human responses to disease and its treatment that is essential to the construction of effective, developmentally and culturally sensitive interventions" (p. 782). In the case of T2DM, there is an abundance of information about the disease process and its treatments. A search of Pub Med on the topic T2DM lists over 8,000 articles, yet to the best of the Principal Investigator's (PI) knowledge, current research does not capture the experience of managing this often fatal illness. A qualitative

thematic survey of patients' daily experiences with this disease has the potential to capture the subtle adjustments made in order to deal with the illness and its difficulties by examining the effects of the illness and its management on the patients and their families (Sandelowski & Barroso, 2003). The principle treatment strategy for adults with T2DM involves lifestyle modifications, which may conflict with the patients' beliefs and practices. If practitioners are able to communicate the illness and treatments to meet the perceptions and expectations of the patient, it is possible that more successful outcomes could be generated in the future for people with T2DM.

### **Research Questions**

This study will seek to answer the following questions:

1. What are the perceptions of cause for diabetes?
2. What is the impact of perceived causation on self-management strategies?
3. What are the obstacles to self-management?
4. Are there differences in the way that members of different races or genders in North Florida describe their beliefs and practices related to diabetes?

### **Type 2 Diabetes in Florida**

According to the State of Florida Department of Health, the all-age prevalence rate for diabetes in Florida is 7.6%, and it is among the top ten causes of death, with over 9,000 deaths annually from complications (DOH, 2008). In 2003, there were 47 deaths per 100,000 in the non-white population compared with 19 deaths per 100,000 in the white population (DOH, 2008). Almost nine percent (8.6%) of Florida's population over the age of 20 has been diagnosed with T2DM, which places Florida

higher than the national level of 7.3%. There were an estimated 300,000 to 400,000 undiagnosed cases in the state as of 2002 (DOH, 2008).

The Big Bend area of Florida (Figure 1-1) is comprised of Wakulla County forming the southern edge to Jefferson, Taylor, and Dixie counties on the eastern edge with Leon, Franklin, Gadsden, Liberty, and Madison counties commonly included (Wikipedia, 2008). Residents of these counties often obtain health care in Tallahassee (Leon County), which is the principal city in the region. Table 1-1 below summarizes the diabetes statistics for this area. The statewide prevalence is higher than the national rate, with many of the individual counties having prevalence greater than that of the state or nation.

With the exception of Leon County, with Tallahassee and Florida State University, this area of North Florida has a greater diabetes burden than the remainder of the state, as indicated by state-wide statistics (DOH, 2008). The reason for Liberty County's low amputation rate compared to the death rate from diabetes is not known. Dixie, Gadsden, Jefferson, Liberty, and Taylor counties have higher age-adjusted death rates than the surrounding counties, with Dixie and Liberty counties having the highest death rates. This may be related to occupation, diet, or decreased access to care, although previous work in this area has indicated that access to care is uncharacteristically high, attributable to the high number of State of Florida employees within the population having primary health care through an HMO (Hodge, 2000). This brings into focus the need to study how people respond to this disease process in the Big Bend in order to determine the factors related to the higher rates of complications in this area.

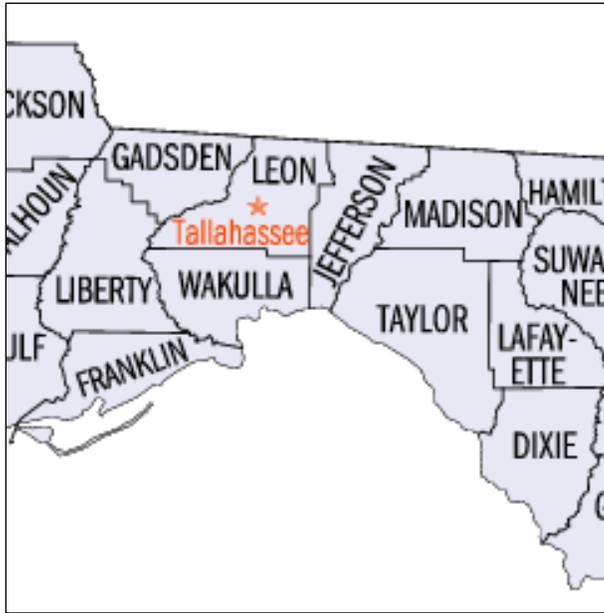


Figure 1-1 US Census Bureau

### Theoretical Framework

The theoretical framework for this study is Kleinman's Explanatory Model (Kleinman, 1980,1988). An introduction to Kleinman's model and interpretive philosophical perspective will be followed by an exploration of literature supporting cultural perspectives on responses to illness

Kleinman's work on explanatory models evolved from his work in medical anthropology in China. Kleinman noted a disconnect between the experience of patients, families, and health care providers in how diseases were perceived, especially if there were differences in cultural background between patient and provider. Health care providers typically are concerned with the specific disease process and its physiologic effects, and how to treat the disease. The patient's perspective is related to the illness and how it affects his/her life. This disconnect often leads to patient

dissatisfaction with the care provided to him/her during the illness (Kleinman, 1980, 1988).

Explanatory models are the way people involved in sickness/illness view the illness and its treatment. Practitioner, family member, and especially the sick person (patient) all have their way of understanding the episode of illness including causes and possible ways to remedy the situation. Often the explanatory models of practitioners differs from those of the patient, as do the explanatory models of family members (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Kleinman, 1980).

Explanatory models are the history of the illness from the patient's perspective. To discover the best way to treat a disease, it is necessary to determine how the patient perceives the illness and its impact on daily activities. The terms disease and illness represent differing perspectives; disease represents the perspective of biomedicine, while illness represents the experience of having the disease (Kleinman, 1988). Explanatory models are shaped by the cultural context in which the sufferer is situated (Kleinman, 1988); therefore it is crucial to consider the cultural influences interacting with the patient and the disease in order to determine the effect of the disease on the individual.

According to Kleinman (1980), "There are five major components explanatory models attempt to explain: (1) etiology; (2) time and mode of onset of symptoms; (3) pathophysiology; (4) course of sickness (including degree of severity and type of sick role); and (5) treatment" (p. 105). The practitioner's explanatory models usually address all of the five components with more emphasis on pathophysiology; while the patient's and family's EM address the areas of greatest concern to them at the time. Often the

practitioner does not share his/her explanatory model with the patient, and the explanatory models practitioners share with researchers have been shown to differ from those shared with patients perhaps because of perceived comprehension inequality (Cohen et al., 1994; Kleinman, 1980).

The explanatory model undergoes changes based on shifting illness status and response to treatment, and it is likely that the model will change associated with subsequent illness episodes (Hunt, Valenzuela, & Pugh, 1998; Kleinman, 1980; Lawton, Peel, Parry, & Douglas, 2008). It is rare that researchers look at explanatory models over a span of time, however; the information obtained in a longitudinal examination of EMs may be helpful in discovering more effective ways of dealing with illnesses, especially chronic illnesses.

Discrepancies or differences between the explanatory models of the practitioner and those of the patient or family often create difficulties in clinical communication (Cohen et al., 1994; Kleinman, 1980). Differences in perspective often create a large communication gap between practitioner, patient, and the patient's family. Providers are typically focused on the cellular pathology and treatment of the disease, while the patient is typically very much more focused on the illness and its manifestations. While the patient's general beliefs about sickness are present and based on general understanding and their experiences with the world as they know it, their model shaped by each unique illness experience, so subsequent illness episodes are likely to produce alterations in explanatory models (Kleinman, 1980).

Kleinman, Eisenberg, and Good (1978) proposed a set of questions to be used in order to determine the patient's explanatory model:

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. What do you think your sickness does to you?
4. How severe is your sickness? Will it have a short or long course?
5. What kind of treatment do you think you should receive?
6. What are the most important results you hope to receive from this treatment?
7. What are the chief problems your sickness has caused for you?
8. What do you fear most about your sickness?

This proposed set of questions is the basis for the interview guide to be used in this study. The interview guide is attached in Appendix B.

## **Culture**

An exploration of the term culture provides many varying definitions of the word depending on the context of usage. Smeltzer & Bare (2004) define culture as “learned patterns of behavior, beliefs, and values that can be attributed to a particular group of people” (p. 7). This indicates that a group of people with a shared experience or disease process could constitute a cultural group. According to Benton and Craib (2001), “Culture is based on community and is not a fixed concept. Culture is a process based on the current experiences and activity of the members. Culture and its meaning arise through the meanings the actors place on it” (p. 87).

According to Young (1993), the rise in the prevalence of T2DM in recent history is associated with socio-cultural and environmental factors. Among the most significant socio-cultural factors identified as influential in the prevalence of T2DM is the constant supply of high-calorie, processed, high-fat foods. Doshi (1995) has identified food not

only as a biochemical necessity, but also a result of one's culture and identity. A review of the existing data on treatment of T2DM reveals that a focus on control of food amounts and the nutritional value of foods are major components of therapy regardless of the professional affiliation of health care providers (Egede & Bonadonna, 2003; Ferzacca, 2004; Franz, Monk, Barry, McClain, Weaver, & Cooper, 1995).

At this time it is not clear whether the high prevalence of diabetes is a learned behavior issue, a cultural phenomenon, or if it is related to access to healthcare, education, and income, or to other issues. Likely there are several factors interacting to bring about the situation under investigation. Since culture plays a major role in the construction of explanatory models, be it through similar experiences, race or geographic origin, or other unifying characteristic, this appears to be a logical focal point of study.

### **Significance for Nursing**

Research that provides improved patient care and knowledge for nursing and other health professions has ethical implications for nursing. The Code of Ethics for Nursing outlines the duties owed by nurses to patients and the profession of nursing (ANA, 2001). Among the ethical standards set forth is the commitment to the patient, family, and community to optimize their health. By studying how this widespread disease affects the patient and family, it is possible to improve nursing's sensitivity to the patient perspective and improve communications with patients about this disease and its management.

With the ever increasing prevalence of T2DM, it is likely that during the course of his/her career a nurse will care for a patient with this disease. It is quite possible that a nurse will care for multiple patients with T2DM on a daily basis. The duty owed by

nurses to their patients is to treat each patient with dignity and recognize their inherent worth by considering lifestyles, and value systems. How better to adhere to our ethical standards than through discovering how patients perceive this illness, and through this improved understanding eventually improve patient outcomes.

Improving individual and professional practice, as well as improving health care delivery systems can be accomplished by discovering ways diabetes affects the lives of the recipients of care, whether these recipients are an individual, a family, or a community. The impact of diabetes is currently world-wide and is anticipated to become even more pervasive if no method to curb its impact is found. Nursing is well suited to finding better ways to manage this disease because of the close relationship of nurses to recipients of care and our commitment to our ethical guidelines.

Utilizing qualitative research methods to study the problem of diabetes will shed light on the patient's perspectives and experiences in living with the illness. This qualitative thematic survey of T2DM, with a focus on the illness experience, will yield information that captures the nuances of adjusting life and lifestyle to accommodate this complex illness. By studying how diabetes affects the lives of those diagnosed with the disease, we may be able to uncover information that will lead to better outcomes and improved quality of life for the vast numbers of people affected by this disease.

The literature review will show that although there has been an abundance of research on the subject, the majority of research related to T2DM focuses on interventions developed in those controlled environments that have been shown to control the blood glucose levels in those environments. Most research has ignored the experiences of people being asked to implement lifestyle changes deemed necessary to

bring about the recommended clinical goals. This suggests that there is an imperative to find some real-world ways to manage the unchecked progression of T2DM.

Table 1-1 State and County Diabetes Statistics from Florida Department of Health 2008

	% Diagnosed	Death Rate/ 100,000	Hospitalizations / 100,000	Amputations/ 100,000	% Obese
State Wide	8.6	21.2	1919	24.3	22.3
Dixie	9.0	41.3	2195.4	28.3	25.4
Franklin	8.6	24.6	1532.8	25.5	25.9
Gadsden	14.1	45.1	2284.4	59.1	33.0
Jefferson	12.4	33.6	1743.7	29.7	33.9
Leon	4.7	20.7	1448.5	22.7	20.5
Liberty	19.1	68.1	2575.1	16.5	38.9
Madison	9.2	40.4	2016.4	18.8	33.6
Taylor	8.9	37.4	2410.0	35.5	31.6
Wakulla	7.0	26.3	2348.3	39.4	28.1

## CHAPTER 2 LITERATURE REVIEW

In an exploration of the literature related to type 2 diabetes mellitus it becomes apparent that there is an abundance of research on this subject. The sheer volume of information available is almost overwhelming. A Pub Med search of the term “type 2 diabetes mellitus” yields over 8,000 references. Searches of other databases such as *JSTOR*, for “diabetes”, yield more than 12,000 references. A comprehensive review of all the material in print related to T2DM, its treatments, and interventions are beyond the scope of this study. A great deal of the literature is related to pharmacological interventions and detection of biologic markers for determining who is at risk for developing T2DM. While treatment and detection studies are a vital part of research, they do not necessarily directly relate to the experience of people living with the disease. What will follow is a focused examination of key information and gaps in the literature that are pertinent to the research questions of this study.

### **Background Material**

Cited as a leading cause of death in the United States, T2DM was present in 9.3% of the U.S. population, or approximately 19.3 million people in 2002, according to information retrieved from the National Health and Nutrition Examination Survey (NHANES) III data set (Cowie, Rust, Byrd-Holt, Eberhardt, Flegal, Engelgau et al., 2006; Harris, Flegal, Cowie, Eberhardt, Goldstein, Little et al., 1999). The prevalence of T2DM is very closely associated with obesity Alexander, Landsman, Teutsch, & Haffner, 2003; Hanson, Imperatore, Bennett, & Knowler, 2002; Evans et al., 2000; Goodpaster, Kelley, Wing, Meier, & Thaete, 1999; Jakicic & Sallis, 2001; Mayer-Davis, D’Antonio, Martin, Wandersman, Parra-Medina, & Schulz, 2001; Resnick, Valsania, Halter, Lin et

al., 1998; Lipton, Liao, Cao, Cooper, & McGee, 1993; Wing, Epstein, Norwalk, Koeske, & Hagg, 1985; Wing et al., 2007). The prevalence of obesity in the United States has reached a level at which more than 50% of adults over the age of 20 years can be classified as either overweight or obese (Whittemore, Bak, Melkus, & Grey, 2003). Data from the NHANES III survey showed that 36% of those with T2DM were overweight, while another 46% were obese (Nelson, Reiber & Boyko, 2002). Metabolic Syndrome, a constellation of symptoms including obesity, hypertension, hyperlipidemia, defective glucose metabolism, and increased insulin resistance, is viewed as a precursor to and is associated with an elevated risk of developing T2DM, coronary heart disease (CHD), and other cardiovascular events, as well as increased morbidity and mortality (Alexander, Landsman, Teutsch, & Haffner, 2003; Barzilay, Spiekerman, Kuller, Burke, Bittner, Gottdiener et al., 2001; Hanson, et al., 2002). An association between a woman's income level and Metabolic Syndrome risk, a precursor to T2DM, was found; the lower the income, the greater the risk of having Metabolic Syndrome (Dallongeville et al., 2005). Other analyses noted a positive association between low socioeconomic status and risk of obesity and T2DM, but did not specifically address Metabolic Syndrome (Drewnowski & Specter, 2004; Ford, Li, Little, & Mokdad, 2008; Harris, 2001;Whittemore et al., 2003).

In the Diabetes Control and Complications Trial (DCCT, 1993), multiple daily injections of insulin (MDI) and frequent self-monitoring of blood glucose (SMBG) to achieve near normal blood glucose levels minimized the development of microvascular and macrovascular complications, including retinopathy, neuropathy, and nephropathy, in subjects with Type 1 diabetes. This landmark study was a milestone for the treatment

of diabetes and confirmed what physicians had believed for years, but could this data be extrapolated to include those persons with T2DM? A small study by Ohkubo et al., (as cited in ADA, 2002) showed that multiple daily injections of insulin and frequent self-monitored blood glucose levels in a group of Japanese male subjects lead to an improvement in glycemic control with an HbA<sub>1c</sub> of 7.1% compared to the control group where the HbA<sub>1c</sub> was 9.4%. The United Kingdom Prospective Diabetes Study (UKPDS) established the link between blood glucose level control and prevention of complications associated with T2DM. This study offered support for the long-held belief that maintaining blood glucose at near normal or normal levels would prevent or forestall retinopathy, neuropathy, nephropathy, and cardiovascular changes associated with morbidity and mortality in the T2DM population (UKPDS Group, 1998). This study is the foundation of current treatment modalities now considered standard medical practice in the treatment of T2DM.

### **Lifestyle Modification**

Consumption of a diet high in saturated fat, red meat, processed meats, fried foods, dairy products, refined grains, and sweets was related to increased prevalence of T2DM, as well as other negative health outcomes like cardiovascular disease (Van Dam, Rimm, Willett, Stampfer, & Hu, 2002; Williams, Knowler, Smith, Hanson, Roumain, Saremi et al., 2001). Dietary control, also referred to as Medical Nutrition Therapy (MNT), is considered a standard of treatment, and is usually recommended as the first-line strategy for T2DM management (Costacou & Mayer-Davis, 2003; Goodpaster et al., 1999; Franz et al., 1995; Jakicic, Wing, & Winters-Hart, 2002; Wing et al., 1985). Subjects have reported the greatest degree of difficulty in diabetes management was sustaining dietary change over an extended period of time, and a

feeling of deprivation associated with avoidance of favorite foods (Ferzacca, 2004; Gazmararian, Ziemer, & Barnes, 2009; Sullivan & Joseph, 1988). It has been reported that adults with T2DM seldom engage in adequate exercise or proper consumption of the five recommended daily servings of fruits and vegetables (Nelson et al., 2002).

Numerous studies from a variety of disciplines have examined the efficacy of diet change and improved glycemic control in patients with T2DM. In almost every case, change in dietary habits with emphasis on low-fat diet composition and reduction in caloric intake was found to reduce blood glucose levels, cholesterol levels, blood pressure, and body weight. Lifestyle changes, however, are difficult to implement and long-term behavioral changes are even more difficult to maintain, which is likely a significant hindrance to achieving optimal levels of glucose control (Jakicic et al., 2002; Pronk & Wing, 1994; Veigener, Perri, Nezu, Renjilian, McKelvey, & Schein, 1990). This lack of adherence to dietary change may be further exacerbated by use of a medical model for diabetes education which discounts patient experience and disregards patient choice (George & Thomas, 2010; Schoenberg, Amey & Coward, 1998)

Eating is a major part of the human experience and is influenced by many variables, including physical, social, and cultural. According to Counihan (1992), “rules about food consumption are an important means through which human beings construct reality” (p. 55). Food is a means by which power differentials are expressed in our society, while the ability to resist hunger and deny oneself access to foods deemed desirable but fattening are values associated with the “Euro-American cultural ideal” (Counihan, 1992, p. 56). Women especially derive power and satisfaction from acknowledged cooking skills as well as providing desirable foods for their families. In

some areas, especially the American South, food preparation prowess may be the most significant source of self-esteem and self-worth available to women (Hughes, 1997).

Restriction of dietary fat intake, especially saturated fat intake, on cardiovascular health is another aspect of MNT that has been the subject of numerous studies (Glasgow & Toobert et al., 2003; Look AHEAD Research Group, 2007; Wing et al., 2001; Wing et al., 2007). In all cases, these trials found improved glucose metabolism, cholesterol values, and blood pressure through lifestyle changes designed to produce weight loss, including increased physical activity and caloric and fat intake reduction. These changes, however, appear to be sustainable for short-term follow-up only. Weight re-gain has been found to negate the benefits subjects obtained through lifestyle modifications and increased their risk of macrovascular and microvascular complications associated with T2DM (Koro et al., 2004; Norris et al., 2001; Williams et al., 1991; Wing et al., 1985; Wing et al., 2004). The view that the American or Western diet is the root of many social and medical ills for the entire population, and not just minorities or ethnic groups, is the topic of *Fast Food Nation* (Schlosser, 2002). Scientific studies support this view (van Dam et al., 2002; Williams et al., 2001). Schlosser's book also cites the number of women entering the workforce since the mid-1970's as a contributing factor in the rise of the Western diet and its association with negative health. Nearly 30% of American women were employed outside the home in 1975, compared to about 60% in the year 2000 (Schlosser, 2002). The increase in working women appears to have produced a greater dependence on prepared food and has resulted in an increased consumption of high-fat, high carbohydrate foods (a.k.a. Western diet) by a majority of the population (Schlosser, 2002). This effect is especially

pronounced in populations with limited financial resources, such as minority and low income populations (Block et al., 2004) as will be discussed in a later section.

Use of dietary modification to control hyperglycemia is often ineffective. With worsening glycemic control, the use of pharmaceutical agents, such as oral hypoglycemics or insulin may be added to the treatment regimen; effectiveness of therapies wanes over time (Ford et al., 2008; Koro et al., 2004; UKPDS Research Group, 1998). Additionally, there has been an overall increase in glycemic level over the past 10 years despite increasing use of pharmacotherapy (Koro et al., 2004). Neither dietary changes nor medication therapy, alone or combined, has been found to be effective in controlling T2DM and achieving treatment goals, especially in older persons (Fan, 2005; George & Thomas, 2010; Koro et al., 2004).

There is a large body of evidence that reduced caloric and fat intake improves physiologic markers for T2DM and cardiovascular disease. The bulk of the literature involves clinical trials performed under controlled conditions with intense support and reinforcement. The data from repeated NHANES examinations, however, indicates that these studies do not translate into “real world” improvements in morbidity and mortality.

### **Multiple Intervention Studies**

Multiple intervention behavioral modification strategies represent much of the research related to T2DM. Self-efficacy, the belief that one is capable of instituting desired change, was found to be significantly related to behavioral change (Norris et al., 2001; Norris, Lau, Smith, Schmid & Engelgau, 2002). Norris et al., (2001) found little improvement in glucose control following education interventions. A 1% reduction in HbA1c required an average of 23.6 hours of health care provider contact. The number of contact hours necessary to effect this change is in excess of the typical billable hours

for diabetes self-management training allowed by most third party payers (Blue Cross Blue Shield of Florida, 2013)

Several studies have examined the effect of reinforcement and support through a variety of technologies. Telephone follow-up was used to increase adherence to diabetes treatment recommendations (Kim & Oh, 2002; Piette, Weinberger, Kraemer, & McPhee, 2001; Young, Taylor, Friede, Hollis, Mason, & Lee, 2005). Intensive contact and follow-up resulted in a greater decrease in HbA<sub>1c</sub> in the intervention group when compared to the control group, but was still higher than the ADA recommended level of < 7% (Piette et al., 2001). Kim and Oh (2002) studying telephone follow-ups with self-management logs recorded by subjects with HbA<sub>1c</sub> > 8%, found a statistically significant 1-2% decrease in HbA<sub>1c</sub> in the intervention group versus 0.6% in the control group, but remained above the recommended 7% level. Similar results were seen in the PACCTS trial (Young et al., 2005), where the intervention group received telephone call follow-up based on HbA<sub>1c</sub> levels. A reduction of 0.31% HbA<sub>1c</sub> overall, with a 0.49% decrease in subjects with HbA<sub>1c</sub> levels > 7% was found.

Glasgow and Toobert (1999) used computer delivery of dietary teaching and assessment of intake patterns supplemented by telephone follow-ups to reinforce and support desired lifestyle modifications. In the intervention group, a 0.1 to 0.2% reduction in HbA<sub>1c</sub> was found, but was not statistically significant when compared to the control group.

The Diabetes Priority Program, a CD-ROM-assisted interactive computer program, was designed to individually tailor interventions and give immediate feedback on each patient's condition (Glasgow et al., 2005). The control group was managed with

a pre-determined set of guidelines to determine proper treatment of the control patients. The intervention group had more frequent lab tests and more patient-centered interventions than did the control group. There were improvements in physiologic measures and quality of life measures, but these were not statistically significant compared to the control group (Glasgow et al., 2005). This study was the result of a collaboration with a medical mal-practice insurance company whose aims were doubtless to reduce liability exposure of their clients through the use of standardized treatment methods.

Delivering information in a group format extends exposure of patients to the provider, and eliminates errors created through multiple presentations of identical or non-identical material over time (Rickheim, Weaver, Flader & Kendall 2002). A randomized clinical trial that compared results of diabetes education delivery in group format to individual education delivery found improvement in HbA<sub>1c</sub> levels in both groups, with statistically significant greater decreases in the group delivery subjects (Rickheim et al., 2002). A two year study of benefits from group versus individual visits with support education revealed stable HbA<sub>1c</sub> levels in the group delivery subjects versus higher levels in the individual participants ( $p < 0.002$ ) (Trento, Passera, Borgo, Tomalino, Bajardi, Pomerio, Allione et al., 2001). A subsequent study of T2DM subjects also compared group intervention versus individual delivery of diabetes care with emphasis on learning, quality of life, and problem solving indicators in addition to metabolic control measures (Trento, Pawwera, Borgo, Tomalino, Bajardi, Allione et al., 2004). As in the previous study, the group intervention participants had better HbA<sub>1c</sub> levels, greater knowledge and problem-solving skills, and reported better quality of life

than the individual care participants. A qualitative study of group based self-management education indicated that individuals with T2DM identified three factors that determined whether lifestyle changes would be made: 1) obtaining new knowledge, 2) taking responsibility, and 3) receiving confirmation of an already health lifestyle. Factors that motivated individuals to maintain lifestyle changes were: 1) support from others, 2) experiencing an effect, 3) fear of complications and 4) formation of new habits (Rise, Pellerud, Rygg & Steinsbekk, 2013). It is apparent that group delivery of diabetes management information is effective in improving a variety of physiologic and psychologic markers.

### **Race/Ethnicity**

Minorities are disproportionately represented in the T2DM population. Because of extremely high prevalence rates in Native American populations, there has been extensive research related to this group. Hispanic populations, especially in the American Southwest, have also received substantial scrutiny and intervention because of those high prevalence rates. While less well represented in research studies, Blacks have approximately twice the prevalence rates of non-Hispanic whites yet are usually considered only as part of a larger population studies. Data from several studies show Blacks with T2DM have higher blood glucose levels, higher HbA<sub>1c</sub> levels, and more complications, including amputations and nephropathy, compared to whites (Brancati, Kao, Folsom, Watson & Szklo, 2000; Cowie et al., 1993; Eberhardt, Lackland, Wheeler, German, & Teutsch, 1994; Emanuele et al., 2005; Fan, Koro, Fedder, & Bowlin, 2006; Harris et al., 1999; Resnick et al., 1998; Schlundt, Mushi, Larson, & Marrs, 2001; Signorello et al., 2007; Weatherspoon, Kumanyika, Ludlow, & Schatz, 1994). Black females were consistently found to be at greater risk of developing T2DM, have higher

BMI, more diabetic complications, and greater levels of depression than Black males (Bonham & Brock, 1985; Brancati et al., 2000; Oakley, Song, & DuBose-McQuirter, 2005; Resnick et al., 1998; Samuel-Hodge, Headon, Skelly, Ingram, Keyserling, & Jackson, 2005). The increased incidence of T2DM found in minority populations is not well understood, but is suspected to be a function of genetic susceptibility in addition to a function of socio-economic factors, although this has not been conclusively supported in the literature (Brancati et al., 2000; Cowie et al., 1993; Eberhardt et al., 1994; Emanuele et al., 2005; Harris et al., 1999; Lipton et al., 1993; Resnick et al., 1998; Signorello et al., 2007). Theories postulating decreased access to care associated with lower socio-economic status as causative factors related to the increased prevalence of T2DM and poorer outcomes for minority/ethnic populations abound (Cooper, 2002; Dallongeville et al., 2005; Evans et al., 2000; Feinglass et al., 2007; Kaplan et al., 1996; Nelson et al., 2002; Signorello et al., 2007; Sudano & Baker, 2006). A scant number of researchers have concluded that minority access to care and their socio-economic status, while differing from White counterparts, were not a substantial factor in these indicators of poor glucose control (Harris, 2001; Heisler, Smith, Hayward, Oakley et al., 2005; Krein, & Kerr, 2003; Schlundt et al., 2001). Socio-economic status, especially lower socioeconomic status, was associated with increased prevalence of T2DM (Cooper, 2002; Dallongeville et al., 2005; Evans et al., 2000; Nelson et al., 2002; Signorello et al., 2007; Sudano & Baker, 2006) and general poor health outcomes (Feinglass et al., 2007; Kaplan et al., 1996). Socio-economic status is usually measured by income, education, occupation, social class, living conditions, or some combination of these variables (Dallongeville et al., 2005; Evans et al., 2000;

Kaplan et al., 1996; Karter et al., 2002; Sudano & Baker, 2005). Mortality rates from all causes were significantly associated with lowest income areas and households, and minority populations typically live in these areas of lower income, as do poor whites (Kaplan et al., 1996). Ethnic disparities in health outcomes persist even when minority populations have presumably equal access to health care through insurance plans (Karter et al., 2002) which supports Gravelle's assertion (2009) that rather than biology, the health disparities seen in minority populations not the cause of genetic variation, rather they result from sociocultural phenomena that manifest as biological consequences.

Low income level in middle-aged Americans is associated with increases in the 10-year death rates in a non-disease-specific manner (Feinglass et al., 2007). Since 1972, low income level and the increase in income inequality in the United States have contributed to poorer self-rated health (Zheng, 2009).

As previously noted, Black females are one of the highest risk groups for T2DM and its complications. Studies have been undertaken to explore why this occurs and what interventions may improve outcomes. Multiple care-giving responsibilities, fear of complications, and concerns about fatality were found to have a negative impact on self-management in this population, while spirituality had a positive impact (Egede & Bonadonna, 2003; Reid, Hatch, & Parrish, 2003; Samuel-Hodge et al., 2000). Decreasing risk of complications through weight loss is desirable in any population, but especially for Black women because of increased risk of negative outcomes and greater numbers of reported barriers to physical activity (Harris et al., 1999; Resnick et al., 1998; Signorello et al., 2007; Weatherspoon et al., 1994). While a majority of subjects

believed exercise was necessary to control diabetes, lack of time, equipment, and social support were the most frequently cited barriers to participation in physical activity. Individualization of interventions along with church based-support and culturally based dietary change were found to be the most effective for Southern Blacks (Anderson-Loftin, Sullivan, Summers-Bunn, & Tavakoli, 2002; Dutton, Johnson, Whitehead, Bodenlos, & Brantley, 2005; Keyserling, Samuel-Hodge, Ammerman, Ainsworth, Henriquez-Roldan, Elsay et al., 2002; Samuel-Hodge et al., 2000). Diabetes research related to Blacks, especially in the southeastern United States, is an area that has received little attention and presents opportunities for future research in order to change current trends.

### **Rural Populations**

Examination of existing literature about diabetes in rural populations reveals very little previous research. A few studies of weight loss and maintenance, indicators of care, and patient satisfaction represent the bulk of research on this population. Differences in health beliefs about elevated blood glucose levels were found to vary in rural, Black populations (Schorling and Saunders, 2000). The term “sugar” is often used by urban and rural blacks to describe elevated blood glucose levels and T2DM, but they may not understand the importance of treatment or the health implications of this diagnosis when it is referred to in this manner (Schorling & Saunders, 2000). These health beliefs require further investigation.

Weight loss, a key management strategy of T2DM, whether through dietary restriction or increased physical activity or both, was examined in rural and urban populations alike. Level of fitness and degree of adipose tissue were found to be strongly correlated and gender specific, with women having greater degrees of

overweight/obesity than men (Mayer-Davis et al., 2001; Mayer-Davis et al., 2004; Wing et al., 2004; Wing et al., 2007). Intensive lifestyle modifications produced greater weight reduction than the usual care provided at these rural health care clinics (Mayer-Davis et al., 2001; Mayer-Davis et al., 2004). Geographic location may have an influence on these findings, since physical environmental characteristics have a strong association with physical activity levels of rural T2DM subjects (Deshpande, Baker, Lovegreen, & Brownson, 2005). An intensive intervention had a positive impact on increased physical activity and caloric restriction in a rural population (Mayer-Davis et al., 2001; Mayer-Davis et al., 2004). Delivering intensive therapies to rural communities represents a challenge to healthcare providers, especially in light of budgetary restrictions for health care.

Several studies used a similar multifaceted six- month intervention for family practice providers to improve patient care processes and adherence to diabetes care guidelines (Johnson, Eurich, Toth, Lawanczuk, Lee, & Majumdar, 2005; Maddigan, Majumdar, Guirguis, Lewanczuk, Lee, Toth et al., 2004; Majumdar, Guirguis, Toth, Lewanczuk, Lee, & Johnson, 2003; Rosenblatt, Maf-Baldwin, Chan, Fordyce, Hirsh, Palmer et al., 2001). Subjects living in rural areas near large urban areas received more specialty provider care as well as greater amounts of recommended testing (Rosenblatt et al., 2001). Rural physicians in Canada received monthly visits for six months from a specialty care team. Improved provider adherence to standards of care for diabetes resulted in patients receiving more recommended tests and referrals to specialty providers. Findings included improvement in patient satisfaction with care and improved

perceptions of quality of life. The subjects of these studies all had primary care providers because of Canada's nationalized health care.

In a study of care processes for rural uninsured patients with T2DM, researchers found that the quality of care received, as indicated by process measures such as HbA<sub>1c</sub> values, foot examinations, and referral for eye examinations, was greater than other populations (although the comparison population is not specified) (Porterfield & Kinsinger, 2002).

Living conditions undoubtedly influence health care processes and outcomes. People living in rural areas are further removed from care delivery than people living in urban areas, so are less likely to receive routine care, especially if that care is best delivered in a specialty practice. Living conditions may also influence perceptions of health status and risk. People living in rural areas may feel in jeopardy due to the absence of ready health care access and the distances that must be traveled in order to obtain health care. This area of study is one open to further examination.

### **Kleinman's Explanatory Model**

Explanatory models are the way people involved in an illness think about that illness and its treatment. Explanatory models are based on the knowledge that people have about an illness and their general knowledge of the world around them, which is influenced by an individual's culture (Kleinman, 1980). Kleinman incorporated five domains into his theory of explanatory models: (1) etiology; (2) time and mode of onset of symptoms; (3) pathophysiology; (4) course of sickness (including degree of severity and type of sick role; and (5) treatment (Kleinman, 1980, p 105).

The study of Explanatory Models in nursing research is advocated in order to provide more culturally sensitive patient care and to increase desirable patient care

outcomes through improved adherence to therapy (McSweeney, Allan & Mayo, 1997). Conflict between practitioner and patient EM have been shown to decrease adherence to treatment regimens, so it is logical that understanding the patient's EM would increase nurses' sensitivity to cultural differences among patients, produce mutually agreed upon treatment, and improve adherence to therapy (Kleinman, 1980; May & Rew, 2010; McSweeney et al., 1997).

There are several examples of nursing research studies that have utilized explanatory models as their framework (Gregg & Curry, 1994; Martinelli, 1999; May & Rew, 2010; Stuifbergen, Seraphine, & Roberts, 2000; Stuifbergen, Seraphine, Harrison, & Adachi, 2005). Several of these studies have examined EM in ethnic and minority populations (Cabassa, Hansen, Palinkas, & Ell, 2008; Gregg & Curry, 1994; May & Rew, 2010). The present study follows studies utilizing explanatory models and deals specifically with those studies that have examined explanatory models in relation to T2DM. In each case, explanatory model information obtained from patients was utilized to enhance understanding of patient perspective and improve communication and health care outcomes for groups of patients in a culturally sensitive way.

Kleinman (1980) stated previously that there is often conflict between the explanatory models of the patient, family, community, and health care provider. Cohen and colleagues (1994) examined the EM differences between provider and patient. The explanatory models of practitioners often differ from those of the patients, and typically encompassed all five components, although this was not articulated to the patient as often as it was to the researchers. Providers viewed diabetes as a pathophysiologic

problem, while patients viewed it as a problem with social implications (Cohen et al., 1994).

Explanatory models have been used most widely to examine the response of Hispanic populations to T2DM. A mixed method study was utilized to examine the relationship between cultural knowledge and diabetes control in Guadalajara, Mexico (Daniulaityte, 2004). Emotional distress has been found to be the most consistent explanation for T2DM development in Mexican and Mexican-American populations, and *Susto* (scare or fright) was most often mentioned as this type of causal factor (Daniulaityte, 2004; Garcia, Rocha, Lopez, Baer, Dressler, & Weller, 2007; Hatcher & Whittemore, 2007). These findings are supported by a previous study of T2DM causation in Hispanic individuals (Poss & Jezewski, 2002). Similarly, non-diabetic Latinos included strong emotions in their explanatory model of T2DM causation (Arcury, Skelly, Gesler, & Dougherty, 2004). Poor glycemic control was associated with an explanatory model incorporating *Susto*, while good control was associated with a negative response to the diagnosis of T2DM (Garcia et al., 2007).

Hunt, Valenzuela and Pugh (1998) found biomedical explanations were augmented by personal behavior, such as smoking, drinking and overeating in a majority of their subjects. In Hunt's study, subjects who included their own personal behaviors in their EM of diabetes causation were more likely to engage in recommended self-care behaviors than those who believed external factors were causative of T2DM. These findings are consistent with the results of other studies on different ethnic groups (Lawton, Peel, Parry, & Douglas, 2008; Savoca, Miller, & Quandt, 2004; Schoenberg, Amey, & Coward, 1998).

Explanatory models have also been utilized to study responses to T2DM in blacks, although to a lesser degree than Hispanics. Savoca studied the EMs of subjects clustered into two categories: excellent glycemic control and poor glycemic control (Savoca et al., 2003). From the case-based conceptually clustered matrix involving life history and explanatory model two, categories of self-management philosophies emerged from the excellent glycemic control group and three philosophies from the poor glycemic control group. The two philosophical types that emerged from the excellent control group were (1) committed, those who spent no time grieving and worked diligently on self-management and (2) tentative, those who viewed their diagnosis with sadness, resentment, or disregard, and utilized dietary modification as primary treatment. From the poor control group the following three philosophies emerged: (1) hopeful, those who had delayed acceptance of the diagnosis and all of whom had family members with the disease; these subjects stressed self-management as important; (2) hassled, those who experienced anger as the initial reaction to diagnosis and most of whom blamed heredity for disease diagnosis; most felt that proper management of diabetes would reduce their quality of life; and (3) overwhelmed, those who reacted with fear, denial, stress, and depression, most of whom rated diabetes as a low priority, few exercised, and most reported depression and binge eating (Savoca et al., 2003).

Adherence to dietary recommendations coupled with EMs was the focus of a study comprised of white and black women (Schoenberg et al., 1998). The sample population of this study was approximately 50% black and 50% white (black n = 26, white n = 25). The 1994 American Diabetes Association dietary recommendations were used as the basis for evaluation of subjects' dietary practices and the researchers

considered adherent those subjects following at least four of the five recommendations. Subjects following three or fewer of the five dietary recommendations were considered non-adherent. Eighty percent of the subjects whose EMs reflected an internal causation of diabetes were adherent to dietary recommendations, while only 50% of those whose EMs reflected causation external to themselves were adherent to recommended dietary modifications. Surprisingly, the researchers found no relationship between ethnicity and perceived etiology or treatment approach.

Understanding the explanatory models of patients can yield insight into self-management strategies and factors promoting or inhibiting adherence to treatment recommendations. Explanatory models have typically been utilized to study ethnic minorities, but not often utilized for comparison between ethnic groups. By studying differences between groups, further insight into factors guiding self-management strategies could be realized.

## **Culture**

The concept of culture encompasses many different aspects of human socialization and its definition changes depending on the context of usage. One of the major problems with examining the effects of culture on a given problem is how to define culture: because the variable meaning of the term. For the purposes of this paper culture is defined as:

The shared patterns of behaviors and interactions, cognitive constructs, and affective understanding that are learned through a process of socialization. These shared patterns identify the members of a culture group while also distinguishing those of another group (CARLA, 2013)

Culture is dynamic, changing over time and shaped by the experience of the individual members of a group or the entire group (Caprio, Daniels, Drewnowski, Kufman,

Palinkas, Rosenbloom et al., 2008). Culture, therefore, is influenced by and influences the members of a specific group of people.

The literature on cultural influences and T2DM is sparse, and the term culture appears most often as a proxy for ethnicity or race, while few of the differences attributed to one race are truly distinct genetic features of that race. Rather they may be widely shared among many racial groups (Gravlee, 2009). The largest body of information on cultural influences in T2DM relates to Mexican-Americans living in the southwestern United States, especially Texas. Oomen, Owen, and Skaggs (1999) conducted a literature review to discern the deficiencies in self-management interventions for Hispanic women with diabetes. Their examination revealed that the constructs of self-efficacy, internal locus of control, and perceived health value were likely inappropriate considerations for Hispanic females whose main considerations are self-sacrifice and the well-being of the family (Oomen et al., 1999).

Caban and Walker (2006) reviewed three studies related to cultural influences and Hispanics with T2DM. *Susto*, a condition of extreme fright, was considered a factor in the development of diabetes by many members of different Hispanic sub-groups, but most commonly in the Mexican-American sub-group living in the southwestern United States. The influence of *susto* as the causation of diabetes became weaker when subjects were acculturated into the mainstream culture and exposed to Western medicine. The use of alternative therapies or *curanderos* (faith healers) was identified in only a small number of subjects and not usually utilized in relation to diabetes management. In most cases religion and God were generally viewed as part of the subject's support system, and not causative of the disease, which is in conflict with the

results of a previous study (Oomen et al., 1999). Fatalism about diabetes and its complications was noted most frequently in subjects living in rural areas. The lack of knowledge about the unique and shared health beliefs of the many sub-groups of the Hispanic community make generalization about cultural influences difficult (Caban & Walker, 2006).

In two studies focus groups were conducted to develop culturally appropriate diabetes self-management programs for Hispanics (Vincent, Clark, Zimmer, & Sanchez, 2006; Weiler, & Crist, 2009). Family support was deemed vital to maintaining prescribed lifestyle changes. Information about modifying traditional foods to incorporate needed dietary changes, as well as access to understandable information about diabetes were also identified as important concerns (Vincent et al., 2006). High-tech information access, such as computers and web-sites, was not a priority for the study participants.

Skaff, Mullan, Fisher, and Chesla (2003) developed a model of control beliefs, disease management behaviors, and health indicators. The researchers used two measures of control beliefs, “one diabetes specific (diabetes self-efficacy) and one global (mastery)” to determine effects on health care outcomes for a group of patients with T2DM. In the Latino population, global mastery (a sense of the ability of the self to control the environment) was more indicative of management capability, while in the European-American population self-efficacy (the person’s belief about their own ability to control outcomes) was more indicative of management capability (Skaff et al., 2003). The lack of a clear definition about the sample population of this study is problematic. Further study in this area is needed, but it appears to indicate a focus on global mastery may produce better diabetes management interventions for Hispanics.

Culturally appropriate and realistic interventions have been developed for Hispanic populations (Ingram, Torres, Redondo, Bradford, Wang, & O'Toole, 2007; Martyn-Nemeth, Vitale, & Cowger, 2010). The use of dance as an exercise intervention was well received by the study subjects, with 75% attendance at each session and all participants achieving the physical activity goals by the end of the program (Martyn-Nemeth et al., 2010). *Promotoras* are community health workers who typically have also been diagnosed with T2DM and serve as a supplement to the support system of the subjects. A pilot study of *promotora*-guided intervention to improve self-management behaviors in a rural community on the US-Mexico border was deemed successful (Ingram et al., 2007). The program was originally designed to receive referrals from a community health center, but subjects began self-referring to the classes, so the intervention grew beyond its original intent. The net result of the program was lowering of HbA<sub>1c</sub> by 1% in high-risk subjects (Ingram et al., 2007). These studies support the use of culturally appropriate interventions to increase self-management of T2DM.

There is a small body of literature exploring the connection between culture and the prevalence of T2DM in African Americans. An exploration of barriers to self-management in a mostly African American group revealed that the emotional stress of the illness, accompanied by frustration, social isolation, interpersonal conflicts, depression, and fear were recurrent themes (Gazmararian, Zeimer, & Barnes, 2009). Many participants did not understand the significance of HbA<sub>1c</sub> or the possible consequences of having elevated blood glucose levels that are often asymptomatic. Participants identified services vital to them, including refresher courses, support group discussions, and nutrition and medication education. Numerous barriers were identified

that if addressed successfully could improve self-management for this group (Gazmararian et al., 2009).

Poor recruitment and retention of subjects for studies was found to be a barrier to implementing interventions for African-American and rural populations (Burns, Soward, Skelly, Leeman, & Carlson, 2008). The study by Burns and colleagues (2008) involved delivery of “culturally sensitive symptom-focused teaching and counseling” to older black women. Because recruitment and retention had previously been problematic with this subject population, strategies such as providing a toll-free phone number, offering culturally appropriate materials, delivering home interventions, and providing incentives for participation were utilized and led to a 91% retention rate for this study. By increasing participation in research studies in the future, the knowledge base about the effects of culture on diabetes in specific groups will increase.

Another group studied the effects of a culturally specific intervention aimed at older rural black women to help subjects improve symptom recognition and improve self-management strategies in this population (Leeman, Skelly, Burns, Carlson, & Soward, 2008). The researchers focused on symptoms of hyperglycemia and hypoglycemia, numbness and tingling in the feet, and foot pain. The premise of this intervention was that people with T2DM live with chronic and acute symptoms, and their correct interpretation of the symptoms will lead to an appropriate intervention and improved health outcomes. Storytelling was utilized to teach each patient about the symptom of most concern to her. Participants in the study had high levels of satisfaction with the intervention, as well as lessened symptom distress and improved quality of life (Leeman et al., 2008).

Shared decision-making, a process in which physicians and patients collaborate on treatment options and plans that accommodate patient preference, is positively associated with improved health care (Benbassat, Pipel, & Tidhar, 1998). Analysis of the results from five focus groups identified racial disparities in shared decision-making. The researchers identified physician bias, discrimination, and cultural discord as factors that might influence the physician not to share test results with black patients perceived as domineering. Black patients identified mistrust of white physicians who were perceived to have negative attitudes toward the patient, and internalized racism as factors that impede patient interaction in decision making (Peek, Odoms-Young, Quinn, Gorawara-Bhat, Wilson, & Chin, 2010). Further research is needed to find ways to overcome these identified barriers to shared decision-making on treatment of diabetes.

### **Summary**

There is a large body of literature related to T2DM and specifically to interventions aimed at controlling T2DM. In many of these studies caloric restriction and weight management were key strategies in controlling the disease process. The interventions developed by using the biomedical model for management of T2DM are well known and work well in the controlled environment of a research setting. The data related to day-to-day control, however, points to worsening control of the disease in large populations disproportionately composed of various minorities in the United States.

There are a disproportionately large number of minority and non-white groups in the population of those diagnosed with T2DM. Gravlee (2009) proposed that the differences seen in these groups may be influenced more by racism, which becomes engrained in behavior, resulting in the biologic differences seen within racial/ethnic

groups rather than genetic differences which have not been verified to date. Some studies have indicated that the modern diet is to blame, although this has been identified as contributory, rather than causative, in most cases. Popular literature has shown that all segments of American society are subject to the negative effects of a fast paced lifestyle that increases consumption of processed and nutritionally inadequate foods. More descriptive studies are needed to determine why this disease continues to increase in prevalence, particularly among minority and populations.

Several counties within the Big Bend area of North Florida have a higher percentage of the population diagnosed with T2DM and have higher numbers of hospitalizations and complications than the state-wide average (Table 1.1). The differences in the course of disease in the outlying counties of the Big Bend suggest some differences in how these people perceive and deal with this disease. Further investigation is necessary in order to determine why these differences exist.

## CHAPTER 3 METHODS

### **Background**

The purpose of this study was to describe the impact of type 2 diabetes mellitus (T2DM) on the lives of persons living in rural areas of North Florida, specifically how these persons understand the disease, the strategies they use to manage the disease, obstacles to disease self-management and whether race or gender plays any role in their response to the disease. Examining similarities and differences between and among various groups may help to explain differences in self-management of the disease. Despite a large body of literature related to best practices to control T2DM, in the United States there continues to be an annual increase in the prevalence of diabetes, a decrease in glucose control, and an increase in complications associated with the disease. This indicates a need for descriptive studies of the illness experience of those affected, focusing on determining the underlying reasons for worsening patient outcomes.

### **Methodology**

Approval of the University of Florida Institutional Review Board (IRB 01) was granted in June 2012 and renewed in May of 2013. The study was conducted in two rural counties in North Florida. The Primary Investigator (PI) interviewed a total of 21 subjects between the ages of 41 and 79 years old, diagnosed with T2DM who were recruited through referrals from health care providers at the two clinics agreeing to host the research. The patients were pre-screened by the health care providers and interviews were conducted on the day of the physician appointment immediately prior to or following the subject's physician appointment.

Utilizing the Informed Consent contained in Appendix C, the PI described to potential participants all components of the study, including inclusion/exclusion criteria. Questions about the study were answered and participants were informed that they were free to withdraw from the study at any time without further obligation or adverse relationship. The Informed Consent (Appendix C) was read to the prospective participants and printed copies of the consent were provided to the participants. No signed consent forms were obtained by the PI since this would constitute the only identifiable link to the study participants. No protected health information was collected during the study and no record of participants was maintained by the PI in order to insure the privacy of the participants. Any protected health information inadvertently disclosed by the participants was removed during the transcription process.

### **Data Collection**

Information on the demographics of the study participants was collected utilizing demographic information sheet attached as Appendix A. The interviews in this study were completed using a semi-structured interview guide as a framework for the interviews (see interview guide Appendix B). The use of semi-structured interview guides allowed for focus on the subject under investigation with expansion of topics brought out during the interview process, which would not be possible with an inflexible interview guide or questionnaire (Kvale, 2007). In addition to the main questions listed in the interview guide that directed the interview toward the topic being investigated, the interviewer also utilized probative questions to clarify answers given by subjects. The interviewer also used follow-up questions to pursue the implications of answers brought out in the main questions and the probative questions (Rubin & Rubin as cited in Warren, 2001). Semi-structured interviews were conducted over the space of one

month at two clinics in two rural counties in North Florida in a vacant office located within those facilities. It was expected that each interview would diverge from the questions contained in the interview guide based on individual responses to each question. It was impossible to predict how much, or in what way questions would diverge from the interview guide in advance of conducting each interview due to the uniqueness of each participant's experience.

Each recorded interview was identified only by the age, gender, and race of the participant with no identifying data linking the participant to the interview. Interviews were recorded on a digital recorder and transcribed only by the investigator on the day of the interview or on the following day. Since audio recordings are considered identifiable data, the recordings were required to be secured at all times. While transporting the recorder between the research sites and the PI's home the recorder was stored in a locked HIPAA compliant bag, the only key to which was in the PI's possession at all times. While in the PI's home and not in use for transcription, the recorder was stored in a locked safe within the PI's home. Originally the recorded interviews were to be uploaded onto the remote access desktop at the College of Nursing, later it was determined that the recordings should not be uploaded onto the secure computer as this audio recording constituted an identifiable link to the participants so the recordings were deleted from the device once it was determined that transcribed interviews were accurate. Any protected health information that was inadvertently revealed during the interview was not transcribed. The transcribed interviews were stored on a secure, remote desk-top computer at the University of Florida per IRB protocol. At the conclusion of the study the digital recorder was turned in

to the College of Nursing Information Technology personnel for destruction per IRB and college policy. The transcribed interviews were read and re-read to insure accuracy of the transcriptions. The transcribed interviews were formatted in a table configuration as outlined in the analysis section that follows. Field notes about interviews and unusual events occurring during the interview process were made and kept on a digital data device stored in the PI's home in a locked file cabinet. This device was also destroyed at the conclusion of the study.

### **Setting**

As previously stated, recruitment of participants for this study, was conducted at two health care clinics in two rural counties in North Florida. Participants were between the ages of 41 and 79 years old diagnosed with T2DM, and consented to be interviewed.

### **Sample**

According the 2010 Census (2012), the population of the first of these two counties was 57.6% white, 38.8% black, and 4.7% Hispanic, and for the second county was 35.9% white, 56 % black, and 9.5% Hispanic. In a perfect situation it would be expected that the participant population would reflect the demographics of the county in which the participants were interviewed. While comparison among different racial groups was of interest, no one who consented to be interviewed was refused participation in the study with the exception of those meeting the exclusion criteria listed below.

A convenience sample of 21 adult subjects currently diagnosed with T2DM currently living in two rural counties in North Florida were interviewed with emphasis on how this illness affected the daily life of each person, and the ways they have adjusted

their lifestyles to accommodate the illness. The study population consisted of one Hispanic, twelve black, and eight white participants. The racial composition of the study population was 4.8% Hispanic, 38.1% Caucasian, and 57.1% Black, which more closely reflects the demographic characteristics of one county than the other.

The goal of sampling is to have a sufficient number of interviews to reach saturation which is the point at which new ideas or themes no longer emerge from the data (Morse, 1995). Recommendations for sample size adequate for achieving saturation in the qualitative interviewing are 6 to 8 interviews for a homogenous sample and 12 to 20 when it is necessary to achieve maximum variation (Guest, Bunce, & Johnson, 2006). The sample size of 21 was adequate to insure adequacy of variation.

### **Exclusion Criteria**

Exclusion criteria included those unable to speak English and those with neurological deficits resulting in verbal communication impairment (inability to speak). Additionally, those under the age of 18 or over the age of 80 years of age were excluded. No participant having engaged in informed consent activities later decided to withdraw. Had that happened those participants would have been excluded from the study.

### **Human Subjects**

One week prior to each interview session the investigator telephoned the physician office to verify that potential participants had agreed to be interviewed and ascertain the appointment time(s) for those individuals. Persons agreeing to participate in the study were given informed consent in an unoccupied office within the facility. The PI read the Informed Consent to all potential participants and a copy of the Informed Consent was furnished to all participants. Everyone who was read the Informed

Consent agreed to be interviewed. To insure confidentiality of responses, interviews were conducted in private with only the PI and the participant present. The interviews were transcribed verbatim by the investigator no later than the day after the interview. The transcripts were read and re-read while listening to the audio recording to verify accuracy of the transcription. Once the transcript was verified, the recording was erased per protocol from the Institutional Review Board of the University of Florida. The audio recorder was kept in a locked carrying case, the only key to which was in the possession of the PI, while in transit and was stored in a locked file cabinet in the PI's home, which is equipped with a security system. Upon completion of interviews, the digital recorder utilized to record participant interviews was scheduled for destruction according to the University of Florida's privacy policy.

### **Data Analysis**

All observations, field notes, and interviews were transcribed using Microsoft Word, and the transcribed interviews were converted into a table format as described by LaPelle (2004). Examples of these tables can be found in Chapter 4 under the discussion of each research question. Data analysis in qualitative research is an ongoing process occurring during and after each interview and observation session. Because of the short time frame during which these interviews were collected, the majority of data analysis occurred after all interviews were completed. According to Kvale (2007), no standard method of analysis for qualitative interviews exists, but analysis of qualitative interview data begins with the participant description obtained during the interview and may include discovery of new meanings and relationships previously unrealized by the participant. The interviewer condenses and interprets the data during the interview, probing for clarification and verification from the subject. The

interviewer then transcribes and analyzes the interview alone or with the help of other researchers to discover and develop the meanings within the interview (Kvlae, 2007).

An abundance of rich information was elicited from the subjects during the interview process. Responses to each question in the semi-structured interview were examined on a line-by-line basis and coded with a descriptor, then responses to each question were compared for each question across interviews. Responses to all questions across subjects were compared for similarities and differences. Using constant comparison, a technique that compares each finding with existing findings as they are developed during data analysis, each response was compared to the others so that all codes could be clearly identified and distinguished from each other (Charmaz, 2003). Following descriptive coding of responses analysis of the descriptive codes took place. Many codes were developed, discarded, and revised during the constant comparison of interview data. Some codes were combined and revised during this analysis process.

The tasks of text analysis are: (1) identifying themes and sub-themes, (2) determining which themes are important in order to have a manageable number and (3) building code books with hierarchies of themes (Ryan & Bernard, 2003). Themes are defined by Ryan and Bernard (2003) as abstract constructs that link phrases or expressions found in the text of the interview. Responses to each question were continuously compared and grouped into themes (Ryan, 2003). A codebook was then developed in a table format matching that of the transcribed interviews to facilitate sorting to be done later (LaPelle, 2004). Codes were sorted into associated themes or categories to determine patterns of the developing themes (Kvale, 2007; Ryan &

Bernard, 2003). Verification of coding, thematic patterns, and thematic importance was originally planned to occur through review by the Data Analysis Group in the College of Nursing at the University of Florida in order to ensure validity and reliability. The sessions with the Data Analysis Group, however, did not fulfill this function of the research design. The coded interviews, along with answers to specific research questions were presented to the Data Analysis Group on three separate occasions, with recommendations received by the PI on each occasion.

Member checks, or presenting the data to the study participants for verification, is a strategy outlined by Guba and Lincoln (1981) to enhance validity and reliability. Since interviews were anonymous and no record of participant names was maintained per IRB protocol, it was not possible to re-interview participants in order to conduct member checks. Subsequent participants were asked about information obtained during interviews with previous participants. This information provided insight into this population about their experiences with T2DM.

### **Validity and Reliability**

Patton (2002) has defined validity as a term normally limited to quantitative inquiry since it is associated with instrument design and measurement of the intended concept(s). For many years, some qualitative researchers have disregarded these two concepts, stating that they pertained only to quantitative research, but others have argued that without consideration of validity and reliability, qualitative research is rendered worthless (Agar, 1996; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Ryan & Bernard, 2003.).

Validity is based on the judgment of the investigator, and these judgments must be clearly explained by the investigator so that anyone reading this research has a

clear understanding of how the data were interpreted and is then able to replicate and possibly refute these findings. Validity and reliability are also obtained through agreement among investigators and researchers about the analysis (Ryan & Bernard, 2003).

### **Personal Issues**

The PI approached this study with years of experience as a nurse practitioner treating T2DM patients using a medical model, and thus had preconceived notions that this population may be chronically non-adherent to prescribed therapy and lifestyle modifications. The PI was also cognizant of the difficulty typically associated with lifestyle/behavioral modification in any patient population. This bias was assumed from the standpoint of the clinician, not from that of the patient dealing with a chronic illness requiring considerable lifestyle modifications. The treatment regimens can be extremely complex and costly in both time and money. With the hectic pace of modern life, it is likely that subjects perceive little benefit in adding more routine to their already busy lives. The investigator was required to bracket preconceived notions in order to ensure that investigator biases did not influence the results of the study. Bracketing involves identifying and setting aside assumptions or preconceived notions about the subject of inquiry (Gubrium & Holstein, 2003). By disclosing these assumptions in written format and continually addressing them during data analysis the researcher has attempted to prevent these assumptions from influencing the data found in this study. Feedback from dissertation committee members, as well as the Data Analysis Group, helped to limit biased conclusions.

## **Risk**

Although there is little harm that could result from exposure of a subject's identity within the community where he or she lives, some subjects might have been reluctant to reveal behaviors to interviewers, thus they might not have been candid if their responses were identifiable. With the confidentiality of responses assured, there should be no more risk to the participants of this study than that of a routine health care visit.

## **Benefit**

While it is anticipated there is likely no immediate direct benefit to participants related to this study, there may be benefits in the future to the population of patients diagnosed with T2DM. Beneficial information about the experiences of participants may be uncovered that could help guide future interventions and treatments making T2DM less difficult to manage.

## CHAPTER 4 RESULTS

The purpose of this study was to explore how people diagnosed with T2DM residing in the North Florida area live with the disease on a daily basis; how each person understands or interprets the disease; how confident each person is that he/she can manage the illness; what strategies/techniques each uses to manage the illness; what effect the diagnosis and disease process has on their lives; and whether race or gender plays any role in their reaction to the disease. Kleinman's Explanatory Models theory provided the theoretical framework for this study. The research questions formulated to answer the above questions are: (1) What are the perceptions of cause for diabetes? (2) What is the impact of perceptions on self-management strategies? (3) What are the obstacles to self-management? (4) Are there differences in the way that members of different races or genders in North Florida describe their beliefs and practices related to diabetes? Each research question will be discussed in numerical order with a summary of the information at the end of the discussion of the research question.

### **Participant Demographics**

A total of 21 subjects between the ages of 41 and 79 years old, diagnosed with type 2 diabetes were interviewed for this study. The study population consisted of seven black females, five black males, four white females, four white males, and one Hispanic male. The composition of the study sample, as previously stated, closely reflects the population demographics of the counties where these interviews were conducted.

## Research Question 1

### Findings

The first research question is what are the participants' perceptions of causation for type 2 diabetes mellitus (T2DM)? The participants in this study felt the need to give context laden answers that included information about their situation, experiences and the experiences of others known to them with T2DM, rather than simple and direct answers to the question. These answers reflect the complexity of their perceptions and provided valuable insight into their experiences of living with T2DM. Kleinman's Explanatory Model theory states that the context of the illness is informed by physiologic, psychologic and sociocultural factors that interact on the illness sufferer (and family) to create the EM of the illness for the individual (Kleinman, Eisenberg & Good, 1978).

Many participants talked about their reactions to their diagnosis when asked about causation, "I denied it. I said I aint got no diabetes. You know, it wasn't nothing to knock you out, but then the symptoms kept showing up." Others reported experiencing fear:

Scared me (laughs). It scared me, I, you know.... And it (laughs); I didn't like the sound of it I'll tell you that, I sure didn't.... But, uh it's just a bad, bad thing to say I've got diabetes (laughs). I think it takes a lot out of you over time. But, uh I didn't really like the sound of it when they told me.

This participant's laughter seems to signify that she may have been uncomfortable with this subject even though later she stated that diabetes was, "just something else you have to put up with". Some participants initially stated they did not know what caused their T2DM, but later reported a wide array of causative factors. For

example one woman was apparently diagnosed with Gestational Diabetes (GDM) but her explanation was:

When I first went, I was young, and there was this lady doctor her name was (name) and she told me when I was here having children that there was sugar in my blood then. That been ever since back in the '70s. And so it rocked on and rocked on it never did, you know, appear. That's when I was little, then when I gained weight. Weight has a lot to do with it. I went to another doctor and he said "did you know you were a diabetic?" I said no I didn't know that. He said well you've been one all the time but you've gained weight and it has come to the surface.

This participant appears to believe she had elevated blood sugar since she first became pregnant in the 1970's, even though she does not appear to equate elevated blood sugar at that time with any form of diabetes but believes gaining weight caused T2DM to appear later. She later implicated weight gain and inappropriate diet as causative explanations for T2DM.

### **Causation.**

Explanations of causation for T2DM seemed to fall into three distinct, sometimes overlapping categories: external, internal and behavioral. In most cases, there was not a single causative factor or event. External causes were events or reactions occurring outside the individual over which the participant had no control; these included two serious medical events, two adverse medication events, stress, and work/living conditions. Internal causes are those things occurring within the participant and which the participant did not have the ability to modify such as heredity, aging and pancreatic failure. Behavioral causes include diet, weight gain, inactivity, and tobacco and alcohol usage over which the participant potentially has control. These categories and the related themes are discussed below.

Only five participants reported an external cause of their T2DM. Again, external causes are those occurring outside the participant over which the participant has no control. Two participants stated that they were diagnosed with T2DM during serious medical events and believed these events were the direct cause of their diabetes; in one case surgery (appendectomy) and in the other a brown recluse spider bite. In both cases these participants were hospitalized and bed bound for many days. The participant who reported having an appendectomy as the cause for T2DM was also hospitalized for many days, “And I had to go under that anesthetic and it was 6 days I had to lay in that bed in that hospital”. The participant who reported a spider bite as causative of T2DM was also hospitalized for 6 days, almost lost the affected hand, and was diagnosed with hypertension at the same time. He reported that he had not seen a HCP in fifteen to twenty years prior to the spider bite. Unusual events had been identified in a previous study as causative of T2DM and in that study external causation theories were associated with poor adherence to self-management recommendations (Hunt et al., 1998). Two participants identified medication side effects as causative, one specifically identified the use of corticosteroids as causative, “I think, (pause) when I was in the hospital and them shooting them steroids in me got my sugar all out of whack. Uh, I think; that’s the first time I ever really knew”. The other participant who reported medication side effects as the cause of her diabetes could not state specifically which medication she thought caused the disease, although she stated the medication was prescribed for sinus problems. The prolonged immobility (and associated illness stress) of the first two participants could have provoked persistently elevated blood glucose, and corticosteroids are known to elevate blood glucose levels (Epocrates,

2013). It is also possible that these participants had T2DM prior to these events and had not previously been diagnosed because most were not routinely accessing health care prior to their hospitalizations.

One participant reported several external causes for T2DM including the stress of caring for her elderly mother, along with long work hours and sleep deprivation as the cause of her diabetes,

They say stress plays a part in it. I took care of my mom most of my life. She had dementia. That and working. I'd get up at 3:00 and work from anywhere from 1 to maybe 5 or 6 pm some days. Like I said, I didn't sleep that much (pause) (I sleep) Maybe 5 or 6 (hours). Some nights I wake up every hour... Last night I slept pretty good, actually. Cause I was tired from the night before (Laughs). I had 12 hours at work (laughs).

This participant had previously identified genetics/heredity and dietary excess as the causes of her T2DM. Stress has been identified previously as a causative explanation for T2DM (Hatcher & Whittemore, 2007; Hunt et al., 1998).

The five participants who identified external causes of T2DM also identified other causes such as behavioral and internal causes. This blending of causation explanations is consistent with Kleinman's theory which states that explanatory models of illness are influenced by multiple factors and are specific to the individual experiencing the illness (1980).

Internal causes of T2DM identified by participants included heredity, aging/retirement, and pancreatic failure. Family history of T2DM was reported by all subjects in this study, "I don't know. I mean, I'm not sure. It's in the genes? Or it appears to be, some of it... but (I) know it runs in my family". Yet most participants did not identify this as a direct cause of their T2DM or in some cases that it was related to developing the disease. Some were astounded that they developed T2DM despite their

family history, “When they first told me I had sugar, diabetes I couldn’t believe it but I know my momma and daddy they had diabetes, but I wouldn’t have never thought I’d have had it”. This participant could not verbalize why she did not think she would have developed T2DM. Heredity and aging are documented risk factors associated with the development of T2DM. Pancreatic dysfunction is a documented result of developing T2DM (ADA, 2004; Cowie et al., 2006; Inzucchi et al., 2012;). The lack of recognition by most participants that family history of T2DM is a risk factor for developing the disease would appear to indicate a need for education based prevention programs in this area.

Several participants reported that at the time of their diagnosis their health care provider (HCP) told them they had T2DM all their lives. One participant who was diagnosed ten years prior to this interview at the age of 58 stated, “I’m like what do you mean a diabetic? And I was told yes you are, and I’m like for how long have I been a diabetic. And I was told well basically all of your life. And I could not wrap my head around that”. Another participant reported doubt about the information given to him at diagnosis,

I went to the hospital and a doctor I had never seen before stopped at the door and had my name and asked me if I was diabetic and I said “no”. And he says “yes you are”. I said “how would you know, I’ve never seen you before?” He said “because of your age and your race”.

The dismissive nature of the HCP’s comment may be an attempt to provide information about the hereditary nature of the disease, but did not fulfill the need for tangible information these patients were seeking. By disregarding the patients’ request for information the HCP created confusion about the validity of the diagnosis. These cases are examples of patient practitioner disconnect in explanatory model of causation (Cohen et al., 1994; Kleinman, 1980).

A few participants viewed developing T2DM as inevitable because of their family history, “No. I don’t know. I just knew it was going to happen. It’s genetic you know. My momma, my grand-daddy, I think my aunt was diabetic. It’s just a lot of people in my family with it”. Heredity is one of the most significant risk factors for T2DM; most participants in this study did not identify family history or heredity as causative of their T2DM.

Aging, a non-modifiable factor in causation was reported by several participants, “I guess it’s these golden years. (Laughing) I guess that had something to do with it. There’s so many wonderful things that happen to you during these years”. This last statement by this participant was facetious and seems to indicate some difficulty adapting to aging. Some participants related aging to weight gain, “Because the older you get you have to do more stuff to burn calories all and everything. Because you can gain fat in your tissues then. You can get fatter quicker when you get older than when you’re younger”. Aging was not the sole factor implicated in development of T2DM by these participants; rather there were multiple factors that were impacted by the aging process. Usually decreased physical activity and reduced need for food were implicated concurrently by those reporting aging as a cause for T2DM. A few participants felt aging facilitated weight gain and fat accumulation.

Aging and retirement are difficult to separate when discussing illness causation related to aging because retirement is an inevitable part of the aging process if the person is employed, “I wasn’t exercising as much as I had because I was getting older. I quit, I wasn’t, I quit being as active as I had been, you know.... (I was) Fairly physical yes. I was extremely active at work. Now that I’m retired I am much less physically

active”. In certain circumstances we have the ability to choose when to retire, but for many there is a mandatory retirement age, so whether this is modifiable by the participant may be particular to the individual and the nature of their occupation. As previously noted, aging, especially being over the age of 45, has been identified as a risk factor for T2DM (Inzucchi et al., 2012; Cowie et al., 2006; ADA, 2004). The participants who identified aging and/or retirement as causative or contributory in development of T2DM also identified other factors that occurred as a result of the aging process or retirement; often physical activity was reduced, and nutritional requirements were decreased. There is overlap in causation explanations, often behavioral causes are blended with either external or internal causes.

Only one participant reported pancreatic failure as the cause of T2DM, but later included behavior (diet) as causative, “I guess my pancreas just wore out... My husband always told me, cause I’d put 2 teaspoons of sugar in a cup of coffee, and I’d have 1 or 2 cups of coffee every morning... you’re gonna be a diabetic. I’d come home at night and I’d have a snickers, which is full of chocolate and nuts, and a cup of coffee which is two more teaspoons of sugar before I’d go to bed. I did that for 4 years”. Her initial response suggested that her diabetes had an internal non-modifiable cause, but with further reflection a behavioral cause for her T2DM was evident, again showing a blended explanation of causation.

Twelve participants identified behavioral causes for developing T2DM. Behavioral causes are those that would be considered modifiable by the participant and include such things as diet (type and/or quantity of food), weight gain, physical inactivity, tobacco use and alcohol consumption. The type and/or quantity of food consumed was

most frequently identified as causative or at least as having a promoting role in the development of T2DM, “and stuff I was eating before the sugar like mashed potatoes with butter, plenty of butter and stuff like that, it’s full of sugar. And that increased my (pause) risk of having diabetes”. This participant clearly understood that starches are carbohydrates and contribute to blood glucose levels. Interestingly, several participants identified “sweets” consumption as causative of T2DM and elevated blood glucose levels, differentiating sweets from carbohydrate consumption which would also include starches, “especially if you like sweets like I do. But uh, yeah you’re going to have to watch that”. This suggests that participants who do not recognize that starches and sugars have the same effect on glycemic control may not be appropriately modifying their diet and could have difficulty in self-managing their T2DM.

Weight gain, which is typically a result of dietary excess, was also identified by participants as a significant cause or an influential factor in developing T2DM,

...then when I gained weight. Weight has a lot to do with it. I went to another doctor and he said, “did you know you were a diabetic?” I said, “No I didn’t know that”. He said, “Well you’ve been one all the time but you’ve gained weight and it has come to the surface”.

Weight gain has been shown to promote the development of T2DM while weight loss has been shown improve glycemic control and to be one of the most difficult lifestyle modifications to maintain (Auryan & Itamar, 2008; Bonham & Brock, 1985; Cowie, Harris, Silverman, Johnson, & Rust, 1993; Goodpaster, Kelley, Wing, Meier, & Thaete, 1999; Jakicic, Wing, & Winters-Hart, 2002).

Physical inactivity was reported by many participants as contributory in development of T2DM, “I’m not too much on exercise. I worked as an accountant for 30 years, behind closed doors at a desk. So not a whole lot of exercise”. Lack of physical

activity has been shown in numerous studies to have a deleterious effect on health in general, especially because a sedentary lifestyle facilitates weight gain which is one of the risk factors for developing T2DM (Jakicic, Wing, & Winters-Hart, 2002; Mayer-Davis, D'Antonio, Martin, Wandersman, Parra-Medina, & Schulz, 2001; Mayer-Davis, D'Antonio, Smith, Kirkner, Martin, Parra-Medina, et al., 2004; Pronk & Wing, 1994; Wing, Epstein, Norwalk, Koeske, & Hagg, 1985). As described earlier, some participants considered physical inactivity to be part of the aging process, "I wasn't exercising as much as I had because I was getting older". While none of the participants in this study had amputations which would have contributed to immobility, a few participants were not able to exercise because of physical limitations such as back, joint or extremity pain, "Uh huh. 'Cause see I can't exercise like I want to, like I used to because my knees and legs are so bad". Increasing physical activity is an instrumental aspect of T2DM self-management because it is associated with maintaining ideal body weight and decreased blood glucose levels (ADA, 2004; Look AHEAD Research Group, 2007; Mayer-Davis, D'Antonio, Martin, Wandersman, Parra-Medina, & Schulz, R. 2001; Votey 2008; Wing, Epstein, Norwalk, Koeske, & Hagg, 1985). Physical inactivity is considered a modifiable risk factor for T2DM; in those cases where physical inactivity is viewed as a process of aging or when patients have functional impairments that limit physical activity, specialized interventions to provide modifiable exercise programs may be warranted.

Four male participants linked alcohol consumption with diet and other factors as causative. For example this participant, when asked about causation had stated that his diet was causative, but later included, "After I left high school I started smoking and

drinking. The gaining the weight and drinking liquor too (laughs). I used to drink real heavy, not, not when I was working". This participant wanted me to understand that he was not consuming alcohol during work hours, indicating discomfort with the admission of alcohol usage. Consuming more than 20 grams of alcohol per day has been shown to be a risk factor for developing T2DM (Beulens, Stolk, Van der Schouw, Grobbee, Hendricks & Bots, 2005; Carlsson, Hammar, Grill & Kaprio, 2003). Only one participant identified tobacco use as causing T2DM, "Uh. (pause) I'd been chewing tobacco and dipping snuff since I was about six years old. There was an old white guy used to come by and put it on the porch. He give it to me then. Now he's selling it to me. He got me (laughs)". When asked directly if the participant thought using tobacco had caused his T2DM he stated, "I believe so". Smoking tobacco has been shown to be a risk-factor for developing T2DM (Wannamethee, Shaper & Perry, 2001), but no literature was found related to chewing tobacco and its relationship to T2DM. Several participants identified tobacco cessation as a self-management strategy they employed but only one participant identified tobacco use as causative.

## **Summary**

Participants in this study gave blended, context laden answers to questions about causation of their T2DM. Their answers often involved stories of experiences involving other people they have known who were diagnosed with T2DM as well as the circumstances surrounding their own diagnosis. This is consistent with Kleinman's model and several studies (Cohen et al., 1994; George & Thomas, 2010; Hatcher & Whittemore, 2007; Hunt, Valenzuela & Pugh, 1998; Schoenberg, Amey & Coward 1998). Three categories of cause for T2DM were identified; external, internal, and behavioral. External causes were events or conditions over which the participant had no

control and included serious medical events, adverse medication reactions, stress, sleep deprivation and long work hours. Internal causes were conditions or factors that were not modifiable by the participant, including heredity, aging, retirement, and in one case pancreatic failure. All participants identified a family history of T2DM whether or not they identified this as a direct cause of their T2DM. Behavioral causes, which are modifiable, included dietary excess and inappropriate food preparation and consumption, physical inactivity, tobacco use, alcohol consumption, and weight gain. In most cases, the explanations of causation given by the participants overlapped categories of causes and typically included causes from at least two categories previously identified.

Patients who believe that T2DM “just happened” to them, meaning it was something over which they had or have no control, have been shown to have lower levels of commitment to self-management (Savoca, Miller & Quandt, 2004; Hunt et al., 1998). Increasing patients’ understanding of the causes of T2DM, including the link between behavior and risk of developing T2DM, could increase commitment to self-management. Most participants identified a multifactorial, highly contextual and personalized explanation of causation for T2DM which did not include the pathophysiology that figures prominently in HCP explanatory models. This multifactorial, highly personalized explanation of causation is consistent with Kleinman’s Explanatory Model and with other studies of T2DM (George & Thomas, 2010; Hatcher & Hunt et al., 1998; Schoenberg, et al., 1998; Weller et al., 2012; Whittemore, 2007). The disconnect between patient and HCP explanatory models of causation for T2DM may impede the patient’s commitment to self-management strategies, especially in cases

where the patient views the information given to them at diagnosis as incorrect or unbelievable. Further studies are needed to determine whether eliminating the disconnect between HCP and patient explanatory models could increase commitment to self-management strategies.

## **Research Question 2**

### **Findings**

The second research question is what is the impact of perceptions of causality for T2DM on self-management strategies? Participants' explanations of causation were discussed in detail in Question 1. Although this seemed like a very good research question at the outset of the project, it became apparent during data analysis that there were not clear differences in self-management strategies based on perceptions of causation. Perception of causation and other factors, however, did impact commitment to self-care especially where participants questioned the accuracy of the diagnosis or causation explanation presented to them at initial diagnosis. Every participant in this study had multifactorial explanations of causation for their T2DM. Three categories of causation factors were discovered; external, internal and behavioral. Participant explanations of causation typically included causative factors from at least two, and sometimes all three, of the categories of causation. The management strategies reported by participants are discussed below.

### **Management strategies.**

In all cases participants were utilizing a combination of self-management strategies rather than single strategies. A variety of management strategies including diet modification, medication, increasing physical activity, weight loss, alcohol and tobacco cessation, following HCP recommendations, testing, faith and prayer, and in a

very few cases alternative therapies were reported by the participants. Additionally participants compared themselves to other persons with T2DM as a justification or barometer for their own ability to self-manage. For example, if the participant had a friend whose blood glucose levels were higher than his/hers, the participant then inferred that he/she was successfully self-managing his/her T2DM. Festinger's Social Comparison Theory (1954) postulates that people learn and gauge their competence through a comparative process with persons known to them or observed by them.

The most commonly identified management strategy by participants in this study was diet change. Diet change or modification meant different things to different participants. Reported dietary changes identified by participants included: change in food preparation, portion control and changes in the types of food consumed. One individual described how she and her husband had changed their food preparation methods to conform to dietary recommendations:

I've been a little bit more aware of what I've been eating. And uh, we don't do much fried stuff at all. We've got to where we cook on the grill a lot, and uh boil stuff, broil, bake. Uh, we're pretty well staying out of the fried stuff.

Two participants identified portion control as a management strategy because they had previously eaten large portions of foods typically restricted in T2DM patients,

Portion control (laughs). Eating, you know. I still love bread (pause) and some sweets. But I've found after not eating some of this stuff a little bit will go a long way.

Diet change, with respect to the type of food consumed represented the greatest area of difficulty for most participants, "I used to eat a lot of pork meat. We used to go buy a hog and kill it and make chicharones and carnitas and now I don't do that". A majority of participants further expressed difficulty with diet recommendations specifically because of problems altering their sweets consumption, "I love chocolate,

but I eat just a little chocolate. I eat just a little chocolate”. Participants sometimes gave conflicting information about their sweets consumption, “Not being able to eat all my chocolates that I want. (Pause)...I give up all my desserts. And just stay away from sugar (pause) and chocolates, but I don’t (laughs). I have to have my York mints, two small York mints every night. Occasional nutritional lapses were noted by several participants, “And you can have a little bit of sweets, you know, just in moderation, but most of the time I do pretty good on that” While a few participants reported mostly avoiding sweets, the majority of participants reported that they had not moderated consumption of sweets and other simple carbohydrates. Continuing to consume simple carbohydrates can cause elevations in blood glucose if this consumption is not being considered when planning management. If consumption of simple carbohydrates is the norm for the patient, and if the HCP knew this was the case, adjustment of medication could prevent elevations in blood sugar levels. Occasional departures from recommended dietary modifications may serve as a reward and give participants motivation to maintain dietary change most of the time. Whether the participants strictly adhered to recommended dietary strategies, or modified their diet to include items that may conflict with conventional management guidelines, most perceived that they were managing their diet appropriately. However, it appeared that many participants lacked a clear understanding of the differences in how simple and complex carbohydrates were metabolized and the effect of these carbohydrates on their blood glucose.

The participants in this study identified use of medications as a self-management strategy they employed. Some participants spoke of their medication use in generalities while some spoke specifically about which medications they were using, “I used to take

pills and now I'm on two shots. Two different kinds. I'm on insulin and I'm on Victoza".

Many of the participants in this study were prescribed Victoza, a relatively new medication for the treatment of T2DM, and most believed that this medication was helping them to better control the disease especially because they felt that it helped to reduce weight. Many participants were using medication for management of more than one disease process, reporting particularly pharmacologic interventions for hypertension and hyperlipidemia.

And now I take all this here medication (points to the bag she has sitting on the floor by her chair). And so like I said, I took (pause) I take, let me see, yeah I take four medications for high pressure.

Every participant was being prescribed pharmacologic therapy to manage their disease and were generally satisfied with their regimens. There were no participants in this study who were controlling their T2DM with only lifestyle modifications.

Increasing physical activity was also identified as a common management strategy by numerous participants. Most participants increased physical activity by walking increasing distances on a daily basis,

I feel like walking or exercising now, and all that... Let me see, it's over a mile I walk every day, sometimes in the evening. You know, when I feel like it I walk two times a day, sometimes I walk more than 2 times.

Others increase their physical activity by exercising in a gym, "Uh, they actually put in a gym at work. I was going everyday but I got lazy. Now I go in there maybe 2 or 3 times a week." Other participants reported not feeling the need to formally exercise because of a physically active occupation, "I'm pretty physical in my work, so increasing my exercise like they talked about; I don't think that's going to help much". Some participants are unable to exercise because of physical limitations, "Uh huh. 'Cause see I can't exercise like I want to, like I used to because my knees and legs are so bad".

Other participants reported that their physical activity efforts had waned because of uncertainty about the proper course of action, “you’re unsure if you need to participate in certain activities and things, you know. Especially if you take the medication. Sometimes I’m not as active as I should be”. Whether or not participants formally exercise, or are unable to exercise because of health problems, all acknowledged the importance of increasing physical activity when managing T2DM. Increasing physical activity and controlling diet are well established self-management strategies and have also been shown in previous studies to present difficulty for patients either in implementing the intervention or maintain the change once implemented (Dutton, Johnson, Whitehead, Bodenlos & Brantley, 2005; Garcia, Rocha, Lopez, Baer, Dressler & Weller, 2007; Gazmarian, Ziemer & Barnes, 2009; Savoca, Miller & Quandt, 2003). Most of the participants in this study reported increasing their physical activity; some were more committed to increasing physical activity than others. Those two participants with physical limitations were the only participants who did not report actively engaging in some type of physical activity.

Weight loss was reported by some participants as an important management strategy. This may have been achieved through increasing physical activity and/or diet change, “No, I don’t think mine’s bad, at least I hope it’s not ‘cause I’ve lost some weight and I’m, I eat right and I exercise and I’m feeling fine”. Weight loss may also be the result of a specific medication that a significant number of participants in this study have been prescribed to control their diabetes, “So far I’ve been managing it pretty good with medication and I hope with the weight I’m losing now I can get off the medication... I’ve lost 87 pounds since I’ve, since I’ve been on Victoza. I’ve been on that for one year and

I've lost that much weight". All participants recognized the need to control their weight in order to effectively manage their diabetes. Many participants identified weight reduction as an intervention that would help them to be medication free. The five participants who were prescribed Victoza reported the greatest amount of weight loss, which they attributed directly to that medication. Only one participant felt that she had achieved adequate weight loss and did not desire any further reduction. Weight loss, or maintaining ideal body weight is a widely recognized and difficult self-management strategy for T2DM patients (ADA, 2012, Mayer-Davis, D'Antonio, Martin, Wandersman, Parra-Medina, & Schulz, 2001; Nelson, Reiber, & Boyko, 2002; Pronk & Wing, 1994; Votey et al., 2008; Whittemore, Bak, Melkus, & Grey, 2003; Wing, Hamman, Bray, Delahanty, Edelstein, Hill et al., 2004).

Some male participants identified that they had previously consumed alcohol and now abstained as a management strategy, "And Dr. (name) said I guess you could drink a drink or two now, if you drink in moderation that will help to keep the arteries cleaned out. I said no I can't do that doctor. If I drink, by god, I'm going to drink until I get me a belly full of it. He said no you better not fool with it then". Only one participant had identified smoking or tobacco use as a factor in developing T2DM but several participants identified that they had stopped using tobacco, one just several days prior to being interviewed. Altering intake, whether it is food in general, simple sugars, alcohol or tobacco, is perceived by the participants as a vital but difficult self-management strategy which is consistent with findings in other studies (Ferzacca, 2004; Gazmararian, Ziemer, & Barnes, 2009; Sullivan & Joseph, 1988).

Following HCP recommendations was a strategy used by the majority of participants to control diabetes, “I don’t feel like it’s a (pause) crippling disease, you know, ‘cause it’s really not. If you just, I think if you’ll just do what your doctors tell you to do, or half way do what they tell you to do”. Following the recommendations of the HCP did not signify that the participants had relinquished responsibility for management of their diabetes; rather they appeared to recognize the expertise of the HCP and trusted that advice, “all I do is just to try and do the right thing.... Take the medicine like they tell you and go ahead”. Most of the participants in this study were confident in the care they were receiving from their HCP.

Testing the effects that different foods and activities had on the blood sugar level was identified by relatively few participants to verify whether their self-management strategies were beneficial:

Like I said I test myself to see what’s what. I eat the wrong kind of food, and take it (blood sugar), then I know, you know, and don’t exercise you know. That’s why I know what happens if I quit..... And do the proper challenge. With the diabetes.

Monitoring the effect of intake on blood sugar is a recommended self-management strategy and reinforces the results of diet and exercise on blood sugar level (ADA, 2012; UKPDS, 1998; Votey et al., 2008). Only 4 participants actually identified testing blood sugar as one of their self-management strategies. This may have simply been an omission in the statements of those who did not report this self-management strategy, but it may also be related to the low income level of people living in this geographic area and the clinic population, since test strips used in the blood glucometers typically cost at least \$1.00 each ([www.drugstore.com](http://www.drugstore.com), 2013).

Faith and prayer were cited by a few participants as a beneficial management strategy, “Cause even though I’m on the pills and the shot, but I’m already claiming that I’m healing about it by the grace of the lord”. Some participants felt that faith and prayer could cure diabetes,

Mom was actually in her 50’s like me. Now she did try to do something. She was actually prayed for, and it went away.... So she was really cured and didn’t have to take medication or anything.

A positive relationship between engagement in other self-care activities of T2DM and faith/prayer/spirituality has been found in previous studies, especially in Hispanic and African-American populations (Garrow & Egede, 2006; Hatcher & Whitemore, 2007; McKenzie & Skelly, 2010; Pagan & Tanguma, 2007; Watkins, Quinn, Ruggiero, Quinn & Choi, 2013). The sample population for this study contained only one Hispanic subject, but more than 50% Black. The Hispanic subject did not report faith and prayer as a self-management strategy but many black subjects, especially females reported reliance on faith and prayer as a management strategy for their T2DM. Additionally the quote above is from a white female subject who reported her mother had been cured of T2DM by prayer and she believed prayer could cure her as well. Although only identified by a few participants in this study spirituality has been shown to be an important aspect of T2DM self-management.

Only a few Participants reported the use of alternative therapies or home remedies to manage their diabetes. The most commonly used alternative therapy was cinnamon, “I’ll tell you something that I found. I have found that if I take a half a teaspoon, I don’t know a half of a little spoon, I don’t know whether that’s a teaspoon or tablespoon or what, of cinnamon in the morning. That is one of the best things I can do”. This gentleman reported that the cinnamon would decrease his blood sugar one or two

days after ingesting the cinnamon. Only one participant reported taking multiple alternative therapies,

I take about a teaspoon of vinegar for my high blood pressure every morning. I take about two good swallows of aloe juice every morning for my stomach. Oh, I take garlic too. Garlic for my high blood pressure and for a lot more stuff. I also drink blueberry juice, diet blueberry juice, cranberry juice, cherry juice, pomegranate and all kinds of juice, for the antioxidants. Ginger ale, 'cause that ginger helps my stomach, helps me digest my food at night. Um hum.

This participant had numerous health complaints for which she was taking alternative therapies, although high intake of sweetened or natural juices can contribute to high blood glucose. The majority of participants denied the use of any home remedy or alternative therapy to manage their diabetes. Previous studies have found the use of alternative therapies or home remedies to be more common in some ethnic or racial populations, but that was not the case with this study population (Baker, Gutierrez-Williams, White, Kluger & Coleman, 2008; Blevins, Leyva, Brown, Wright, Schofield & Ashton, 2007; White & Johnston, 2007).

### **Perceptions affecting commitment to self-management.**

Management of T2DM requires that those who effectively self-manage their disease come to terms with their diagnosis and accept responsibility for self-management. The shift to effective self-management occurred at different times, and was dependent on the participant's particular acceptance of the diagnosis. The participant's acceptance of the diagnosis did not appear to be based on their explanation of causation; rather there were other factors that influenced when the participant would commit to self-management. The factors influencing commitment to self-management included initial reactions to their diagnosis, development of symptoms, a mental shift which caused the participant to take personal responsibility, perceptions

that a change was necessary to improve health and prevent unacceptable outcomes, how the participant compared his/her own control to that of other people they knew with T2DM, the belief that T2DM was curable or not, and whether the participant found the HCP's explanation of causation credible. All of these perceptions are discussed below.

Some participants accepted their diagnosis and immediately began self-management initially with diet and exercise but progressed to medication management within a couple of years,

Like they had told me a good while that I had it but it must have been under control. They didn't put me on no pills or nothing right then, but a little later on I guess it got a little worse.

This participant denied making any diet and exercise changes or engaging in any other interventions prior to being prescribed medication, but experienced no delay in beginning prescribed self-management strategies once instructed. Immediately after diagnosis, many participants began to manage their disease by utilizing medication and other self-management strategies that were introduced by their HCP, "but thank god I've got help to control my diabetes and stuff. That and my blood pressure by exercising, keeping everything under control and you know and my medication".

Some participants experienced a delay in shifting into self-management, and in some cases the delay spanned several months to years. One participant described being in denial about having T2DM when he was initially diagnosed and refused to take medication or make lifestyle changes for several years,

I denied it. I said I ain't got no diabetes. It kept showing up, and according to a doctor in Tallahassee he said "you're a diabetic" and he put me on that medication where I stick myself two (times per day), take my sugar and whatever it was I'd dial it up (insulin pen) and stick myself that, you know, with that medication.

This man accepted the diagnosis, came to terms with having diabetes, and began to self-manage several years after initial diagnosis. In the course of our conversation this participant stated that in addition to taking his medication as prescribed, which was a tremendous forward progression in his self-management, he had also made diet changes, stopped drinking and smoking, and lost weight. When asked about what had caused this shift to self-management he described several complications he had experienced because he had ignored T2DM,

uh swollen legs and things, shortness of breath, it shortens your breath too...I've been having poor eyesight and they say that causes some of it. And my sex drive is not what it used to be because of it. Uh, I've been offered different things for my sex drive but I've got a bad heart, so I let that alone.

Unfortunately this gentleman had to experience severe complications of T2DM before he could accept the diagnosis and begin self-managing the disease.

Some participants described a shift into self-management specifically involving a change in mental outlook or attitude about the disease process or diagnosis which was identified by them as a necessary precursor to engaging in satisfactory self-management,

And it looks like I'm doing better. And now it's done got in my head... I think that helps you more in being a diabetic. If you are a diabetic, your mind. If you don't get that set in your mind you aint going to get there. It's got to be in there (pointing to his head).

Prior to "getting it into your head" those who identified this phenomenon had not fully committed to self-management. The concept of "getting it into your head" appeared to be crucial to some participants in shifting them into acceptance of the diagnosis and subsequently self-management. This occurred in different ways, and in some cases participants could not articulate what created this change in outlook. Getting it into your

head may be a consequence of reaching a turning point but this was not articulated by the individuals who identified “getting it into your head”. Determining which patients have not been able to “get it into your head” would help to determine those who need further intervention to increase commitment to self-management. Discovering what helps patients “get it into your head” is a potential area for further investigation.

Some participants reported that they reached turning point in the course of their disease as a result of the HCP describing in very strong terms the impact their lack of self-management was having on their bodies. Others could not actually describe how they had arrived at this point. Participants who had dealt with denial of the diagnosis, refusing to fully commit to self-management, likewise reached a turning point,

Because I’m in an eight to nine A<sub>1c</sub> category, and that’s not good. It needs to be below a 7, or below a 6 and I’ve got a lot of work to do. Exercise and get on a regimen for my meds that will help reduce that.

Some participants reported that their turning point was related to fear of the consequences of non-management,

It is a turning point. What they told me about my lack of control really got my attention. My blood sugar here this morning is 357. I feel lousy, (pause) and (nurse practitioner) and (nurse) really read me the riot act today. So this visit today has gotten my attention and I am going to take action and get this thing into compliance”.

Upon reaching the turning point in their disease process these participants shifted from resistance of their diagnosis to a different, presumably better, level of self-management of their disease. Some of these participants had only recently experienced their turning point, in two cases this had occurred on the day of the interview. It remains to be seen whether these patients truly internalize this need for improved self-management and continue to act on this new perception.

While discussing their experiences living with T2DM, some participants compared their diabetes with that of other people known to them:

Well, I don't think it's that bad. It could be a lot worse, from talking to other people about it. There's a lot of people who claim their sugar runs a lot higher than mine. (Long pause) Some people talk about their sugars being up in the two hundreds or three hundreds. Mine has not been that high.

Another participant reported, "Because a lot of people gets theirs up to 4 or 5 hundred, mine never gets that high". Social Comparison Theory states that humans are driven to evaluate their abilities and these evaluations influence future behavior (Festinger, 1954). By comparing the results of their self-management to that of other known diabetics, whether family or friends, these participants believe they are able to gauge their ability to manage their diabetes. Of course, appraisal of one's ability can be inaccurate or erroneous, but comparing one's diabetes self-management to that of others gives participants a barometer with which to measure of their own competence. Most of the participants who used comparison to evaluate their self-management were able to accurately gauge their ability to self-manage T2DM based on their self-report of control level.

As discussed in the findings of Question 1, all participants reported a family history of T2DM and a majority of participants reported that the family members had poor outcomes with their disease management, "My mother had her leg taken off. One of 'em, I forget which one it was". Certainly negative experiences of loved ones can have a powerful influence on a person's perception of, reaction to and management of T2DM, "My momma took all that stuff (multiple medications) and she got worse. Some people you can prod 'em. They'll sit right there and take their medicine but still won't move". This participant had learned from watching the course of T2DM in family

members that it was important to be physically active as part of diabetes management. While some participants reported that developing T2DM was beyond their control due to its hereditary nature, the experiences of close contacts or family members who failed to self-manage diabetes has been shown to inform peoples' perceptions of T2DM and increase commitment to self-management in persons exposed to these experiences (Savoca, Miller & Quandt, 2003). In one case, the participant reported that having cared for parents with T2DM prepared her to self-manage her own disease after diagnosis, "But by experimenting, by them having it you know I learned how to, you know I learned how to give the shots and stuff and give 'em they pills and stuff". This participant's experience with her family members provided her with a knowledge base about managing T2DM long before she herself was diagnosed with the disease.

When asked whether participants believed T2DM could be cured or if it was a temporary disease process, the majority of participants felt that it was possible to cure or reverse the disease process,

I heard a guy talk and it happened to him. He said he was diabetic all and everything, he started doing proper exercising; he says he is diabetes free. So, I, there, I know there are people who, you know, it can happen.

Some participants, however, felt that once diagnosed with T2DM the disease would be with them until they died, "Well, it think it will last until I leave this world. It's something I think I'll always have 'cause there's no cure for diabetes". One participant knew that her brother was able to control his T2DM without medication but was uncertain whether this would apply to her because it had not been discussed by her HCP,

Because like I said, my brother when he got really heavy he ended up on medication, but then when he lost the weight he didn't have to take the medication anymore, so I don't know if that's going to happen with me or not. I don't understand how it works when you are older. If that's

something that will happen. So I don't know. I really don't know what the prognosis is for me with that. I don't know.

There is likely some disparity between the way health care providers would define cure and the way these participants define cure. While HCPs define cure as being free of a disease or malady, most participants in this study seem to define cure as being able to control their diabetes without taking medication, "Well, I do not know. And I hope if I keep losing this weight I can get it where I won't have to take medication. But I don't know how long that's going to be". Many participants identified the most important thing they hoped to get from diabetes treatment as being free from taking medication. Research has shown a fatalistic outlook about the eventual outcomes exists in certain populations when dealing with T2DM (Egede & Bonadonna, 2003). If participants believe that T2DM is incurable and that complications of the disease are inevitable, they may be less likely to engage in adequate self-management and resign themselves to what they perceive as their fate. None of the participants in this study identified a fatalistic outlook despite some perceiving the disease to be incurable.

Several participants identified explanations of causation provided by their HCP at the time of diagnosis which were found to be implausible by the participant. These participants reported prolonged resistance to the diagnosis because of these explanations and had long delays in commitment to self-managing their disease. One participant reported being told he had diabetes because of age and race,

I went to the hospital and a doctor I had never seen before stopped at the door and had my name and asked me if I was diabetic and I said no. And he says yes you are. I said how would you know, I've never seen you before? He said because of your age and your race.

Another participant reported that at the time of diagnosis the HCP told her she had T2DM all her life. This participant who was diagnosed several years prior to this interview at the age of 60 stated,

I'm like what do you mean a diabetic? And I was told yes you are, and I'm like for how long have I been a diabetic. And I was told well basically all of your life. And I could not wrap my head around that.

These statements by the HCPs are likely abbreviated attempts to state the hereditary nature of T2DM and disclose their own explanatory model of causation, but did not fulfill the need for tangible information the patient was seeking. By disregarding the patients' request for information the HCP created distrust and doubt in the validity of the diagnosis and resulted in a delay in the patient accepting the diagnosis and shifting into self-management. The participant who was told she had T2DM all her life experienced eight years of resistance to her diagnosis and treatment, during which time her T2DM was uncontrolled and she was exposed to potential damage from hyperglycemia. This participant had accepted the diagnosis and became committed to self-management of T2DM only immediately prior to being interviewed.

### **Summary**

No clear differences in management strategies emerged that were based on explanation of causation for T2DM were identified. Each participant had multifactorial explanations of causation which were unique to their personal experiences. The majority of participants used multiple strategies to manage their diabetes. Engagement in self-management strategies was influenced by their emotional response to the diagnosis, "getting it into your head", reaching a turning point because of explicit HCP interaction, perceived validity of the diagnosis, and experiences of others. Before they could engage in adequate self-management strategies, participants indicated that they

had to accept their diagnoses. Several stated that they had to get it into their head (or mind) in order to begin to focus on self-management. Many believed T2DM could be cured, came to accept being diagnosed with T2DM, and moved into some improved level of self-management. Some participants experienced a long delay between diagnosis, acceptance, and the shift to self-management and this is discussed in depth below.

Self-management strategies reported by the participants included diet modification, medication, increasing physical activity, weight loss, alcohol and tobacco cessation, following HCP recommendations, testing, faith and prayer, and alternative therapies. With the exception of faith/prayer and alternative therapies, most of the management strategies employed by the participants are consistent with and supported by the literature on diabetes management (ADA, 2004; Inzucchi et al., 2012; Votey, 2008;). Faith has been documented in the literature as influential in certain populations, especially African Americans and Hispanics (Garrow & Egede, 2006; Hatcher & Whittemore, 2007; Pagan & Tanguma, 2007). The use of alternative therapies, reported by only a few participants, have been minimally studied and of those studied only cinnamon was found to be effective in helping to prevent hyperglycemia (Baker, Gutierrez-Williams, White, Kluger & Coleman, 2008; Blevins, Leyva, Brown, Wright, Schofield & Ashton, 2007; White & Johnston, 2007). The minimal use of alternative therapies in this study population appears to indicate the majority of participants are relying on HCP direction for management of disease more than community input, which differs from the findings of a previous study (Reid, 1992). Experiential information from family members or close contacts, however, appears to influence commitment to self-

management strategies. Results from previous studies support this finding (George & Thomas, 2010; Rise, Pellerud, Rygg & Steinsbekk, 2013; Savoca et al., 2003).

Exploring experiential influences provides an opportunity for HCPs to understand the perceptions of their patients and to address and correct misconceptions in order to improve self-management.

Denial of the diagnosis led to delays in shifting into self-management of T2DM for unpredictable lengths of time, usually at least one year, sometimes much longer.

Causes for denial could not always be determined, but was sometimes a result of the manner in which they were informed of the diagnosis. A turning point was described by several people, after which they moved into acceptance and shifted into another level of self-management of T2DM. This shift to improved self-management is necessary if the disease is to be adequately managed and complications prevented although not all diagnosed with T2DM will shift to self-management (Egede, & Bonadonna, 2003; Garcia, Rocha, Lopez, Baer, Dressler & Weller, 2007; Norris, Lau, Smith, Schmid, & Engelgau, 2002; Weiler & Crist, 2009;).

Delays in implementing self-management of T2DM can produce prolonged hyperglycemia which predisposes the participant/patient to complications (UKPDS, 1998). Identifying patients who are experiencing resistance to their diagnosis presents an opportunity to intervene and move the patient toward self-management. Determining which patients are experiencing resistance to being diagnosed with T2DM has potential for further investigation as does the manner in which diagnosis and causation are communicated to patients by their HCP.

Perceptions of causation as well as the anticipated course of T2DM have been shown to be influential on patients' intention and commitment to self-management (Cabassa, Hansen, Palinkas, & Ell, 2008; Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Hunt, Valenzuela, & Pugh, 1998; Lawton, Peel, Parry, & Douglas, 2008). Perceptions of causation were not found to influence which self-management strategies were used for the participants in this study, nor were there any participants in this study who identified a fatalistic anticipated outcome for their disease which conflicts with the findings of a previous study (Egede, & Bonadonna, 2003).

### **Research Question 3**

#### **Findings**

Research question three is what are the obstacles to self-management? Facilitators of self-management of T2DM were also identified. Obstacles to self-management reported by the participants in this study were related to diet change, several aspects of medication management, having multiple disease processes, living alone, limited transportation, sexual dysfunction, and HCP interactions. Facilitators to self-management reported by the participants included taking responsibility for self-management, prayer and faith in God, education about diabetes management, worry and family/social support. Obstacles to self-management are discussed in detail first, followed by facilitators.

#### **Obstacles**

Obstacles to self-management identified by participants in this study are numerous. The most often reported barrier to self-management was dissatisfaction or difficulty with diet recommendations. As previously noted, diet modification is one of the primary steps in controlling T2DM, especially because diet change can reduce obesity

which is a key risk factor in development of T2DM (Inzucchi, Bergenstal, Buse, Diamant, Ferrannini, Nauck, et al., 2012). For a few participants, there was general difficulty adhering to the diet recommendations,

And I went and; it's hard to eat what they tell you. I've done the best I can. But it's not, not what they tell you. Especially because we are used to a different kind of food.

The participant quoted above is Hispanic and identified having to give up many culturally engrained foods as part of his T2DM self-management including pork, beans and tortillas. Participants' dissatisfaction or difficulty with diet recommendations were chiefly related to simple carbohydrate deprivation,

Uh oh, you're going to have to give up sweets. I'm a pretty good sweet eater. And you're going to have to watch, you know, your diet, uh and things with sugar in them.

Some participants continued to consume simple carbohydrates in a routine manner despite knowledge of diet restrictions to control hyperglycemia,

Oh I am, only because it's a treat, but I'm doing it for my heart is the, um, the dark chocolate. I'm allowing myself; I get the Hershey's dark chocolate bar, the big one a piece about that size (indicates size with her hands about 2 inches by 2 inches) and I'll eat about that much of a dark chocolate bar every night as a treat. It's just my treat to myself, um, and it doesn't seem to, it doesn't really appear to affect my blood sugar that much.

Other participants continued to consume simple carbohydrates in a more sporadic fashion, "Not being able to eat my sweets. (Laughs) Dessert. But we all cheat once in a while". The participant quoted above who consumes dark chocolate routinely also identified herself as an Ice Cream addict and could not stop consuming Ice Cream,

I was an ice cream-holic. Yeah, I ate ice cream, and that probably started (laughing) that I will blame, when I was a kid they were trying to get me to gain weight and I couldn't gain weight so the doctor said "she needs to, drink a milk-shake every day". So, this is when I was in high-school, I got

to buy a milk shake every day in the cafeteria and ever since then I have always loved ice cream.

This participant continued to consume chocolate on a routine basis as well as indulging her self-described ice cream addiction. Diet change has been shown to be one of the most difficult lifestyle changes people with T2DM will need to make in order to adequately control their blood glucose levels (Mayer-Davis, D'Antonio, Smith, Kirkner, Martin, Parra-Medina, et al., 2004; Nelson, Reiber, & Boyko, 2002; Votey, 2008; Wing, Epstein, Norwalk, Koeske, & Hagg, 1985). Finding dietary alternatives the participants will be satisfied with, and that meet cultural expectations of patients, is a difficult and daunting task for HCPs, especially when cultural differences exist between HCPs and patients. Knowing, however, that patients are indulging in high carbohydrate intake would allow HCP's to adequately treat this intake to prevent resulting hyperglycemia and potential complications.

Uncertainty about proper management strategies was reported by two participants as an obstacle to self-management. Both of these participants were uncertain specifically regarding appropriate diet modification, "I don't quite understand why sometimes I can eat (pause) white stuff, doesn't bother me, sometimes I can eat it and it (blood sugar) shoots straight up. So that's the kind of thing that I don't really understand". This participant experienced unpredictable results when consuming carbohydrates. Although some confusion as to the appropriate course of action in managing chronic illnesses is probably common, it remains an issue that needs to be addressed by HCPs in order to facilitate the best outcomes for the participants. Dietary education typically occurs at the time of diagnosis, and rarely thereafter since third party payers are reluctant to reimburse HCPs for these efforts (BCBS of Florida, 2014).

Reinforcement of dietary information periodically throughout life after diagnosis could alleviate uncertainty about proper diet modification and likely produce better patient outcomes.

Medications presented several different obstacles to self-management for these participants. Some participants were simply reluctant to take medications, particularly if the medications they were prescribed required self-injection,

And they went to givin' me insulin; they started first in the pills. You know the pills in it and after the years that there he uh doctor say you had to move up to a needle. I took that pretty hard I didn't like that there needle, but you had to give yourself a shot.

Difficulty with self-injection was identified by those participants using insulin to manage their T2DM, but not by those who were prescribed Victoza. Insulin self-injection has been identified as a barrier in previous studies and insulin itself has a negative connotation in some populations (Cabassa et al., 2008; George & Thomas, 2010; Watkins et al., 2013; Minze, Dalal & Irons, 2011). Overcoming the stigma associated with self-injection of insulin will likely require skillful patient education on the part of HCPs.

Some participants felt that managing multiple medications was an obstacle in and of itself,

You might get tired of taking all those pills and stuff, you know. It's a lot of stuff you'll be putting into your body, you know... It's like me I take probably about, I take two pills in the morning, and 2, 4, 5, I take six (pills) within every 24 hours. You know. I know some people that take 8 or 10.

For some participants the potential for adverse drug effects associated with multiple medications was viewed as an obstacle,

Now I tell you I've seen my mother-in-law die, my father-in law die, and I seen my momma die. My daddy dies, and there's lots more and I walk in

there. Now, this is a fact; they had a whole bag full of medicine. I know all that medicine can't be doing them good.

This gentleman was currently well controlled, by his report, on only two medications. His prejudice against multiple medications because of the experience of his close family members may have a negative impact on his health in the future. Managing even a simple medication regimen was identified as an obstacle to management because of interference with routine activities, "But (pause) making sure that I take them (medications) on time. Remembering to take them. Especially if I'm not, if I am at church or visiting someone". Being away from home at medication administration time presents specific considerations and planning to adequately manage the disease.

Several participants, especially those who were prescribed Victoza, reported that one of the biggest obstacles to management was the cost of their medications,

and getting the medicine. It's expensive, the medicine, even with insurance. Doctor (name) talked to the company and I get help with the Victoza and the insulin, but the Victoza is still high even with all that. If it wasn't so expensive it would be better".

Many of the aspects of managing medication regimen present obstacles for these participants with regard to self-management even when their medication regimen is simplified and patient assistance from the pharmaceutical companies is secured.

Two participants stated that they were unhappy with their current management regimen and viewed it as an obstacle. When asked if this participant felt she was receiving the appropriate treatment for T2DM this participant replied, "No I don't. I really don't, because there's certain things I can see; you know other people be telling what their doctors do and they're all right". This participant felt that the HCP she was currently seeing for T2DM was trying her best to control T2DM but she was aware other treatment options were available. She felt she was not being treated as others were in

other practices because she had Medicare rather than another form of insurance. In only one case did the participant view the HCP providing care for T2DM as an obstacle, “Because of, uh I wouldn’t be wanting a different doctor if I wasn’t...I want them to refer me to the endocrinologists at (regional academic hospital), uh, because (pause) I’m getting worse and I know this is serious”. This participant had previously identified the only way he could control his hyperglycemia was through fasting, but also identified that he had not truly modified his diet in any other way. It should be noted that the majority of the participants in this study were very satisfied with their current management strategies and with their HCP.

Frustration that management strategies were not providing the desired level of blood glucose control was reported by three participants,

And another thing, when I get to taking all this medication that they’re giving me for it and it (blood sugar) still gets high; I guess that’s the hardest thing. Uh huh. I get frustrated when I’m doing what they tell me and my sugar is still high.

Frustration is likely a common reaction when dealing with a chronic illness, especially when the management strategies used do not meet expectations of the patient.

Verification and reinforcement of appropriate self-management strategies periodically throughout the course of treatment could help patients stay on track and prevent frustration over inadequate blood glucose control.

Many participants identified having multiple disease processes they were managing in addition to T2DM as a barrier to self-management. Hypertension and hyperlipidemia and arthritis were most frequently identified as coexisting with T2DM by these participants. Hypertension and hyperlipidemia are strongly associated with the development of T2DM (; Alexander, Landsman, Teutsch, & Haffner, 2003; Barzilay,

Spiekerman, Kuller, Burke, Bittner, Gottdiener et al., 2001; Grundy, Brewer, Cleeman, Smith, & Lenfant, 2004; Hanson et al., 2002). Arthritis was also identified by a large number of participants as an additional condition they were managing along with their T2DM. The most significant risk factor for osteoarthritis, the most common type of arthritis, is increasing age (Arthritis Foundation, 2014). It is not surprising that these diseases were identified by the participants as coexisting with their T2DM, but the co-occurrence of multiple disease processes further complicates issues with medication administration and management identified in the previous section.

Only two participants identified living alone as a barrier to self-management. Living alone presented difficulties in getting needed food and medications as well as having someone to check on these individuals in the event of low blood sugars or illness. One participant reported that she needed someone to check on her periodically because of weakness, “That’s kind of bad for me because I live alone and I; sometimes I think I’m going to fall”. The other participant that identified living alone as a barrier was unable to cook for himself and was forced to rely on others to bring food to him, or to purchase prepared meals at restaurants or convenience stores and these were not perceived as meeting the dietary requirements of T2DM. It is possible that other subjects lived alone but did not identify this as a barrier to self-management.

Limited transportation access was reported by only one participant as an obstacle to care. This unique report was surprising since this is a rural area with little public transportation and previous studies have reported that transportation limitation was a deterrent to care in rural areas. The only public transportation option in this particular participant’s situation is Big Bend Transport and this requires advance notice

of appointments and potentially long waiting times for pick-up following appointments. The participants in this study were all able to find transportation to the clinics and thus were able to access health care. Those people for whom transportation is the most limited were not interviewed because they were unable to access health care at these clinics due to their lack of transportation. These unheard residents may present a very different list of obstacles to self-management if they were to be interviewed.

Sexual dysfunction was identified by males as a barrier to self-management. One participant reported,

Just, you know, uh lots of guys have a appetite you know to take their old lady out and have a good time; me, my diabetes cause me to have a low sex drive which means women don't excite me like they used to before I was a diabetic.

This participant stated that he did not utilize pharmaceutical interventions for sexual dysfunction because of the cost of these medications and his limited income. Another participant who identified sexual dysfunction as a barrier additionally had what he identified as significant heart disease, so he would not utilize pharmaceutical treatment to improve sexual dysfunction because of potential cardiovascular events that could result from these treatments. Sexual dysfunction in men, or erectile dysfunction, has a higher rate of prevalence in men with T2DM than those without and this is typically due to poor control of T2DM and atherosclerotic changes associated with poor glycemic control and duration of T2DM. (DeBerardis, Franciosi, Belfiglio, Nardo, Greenfield, Kaplan, et al., 2002; Kalter-Leibovici, Wainstein, Ziv, Harman-Bohem, Murad, & Raz, 2005). It is unlikely that sexual dysfunction truly impeded self-management strategies but it is very likely that it impacted their self-perception which would have a negative impact on the participant's overall outlook. Sexual dysfunction has been shown to be

associated with depression, lower scores on mental function testing, and lower satisfaction with sex life and life in general, yet most HCPs fail to assess this aspect of their patients' health (DeBerardis, Franciosi, Belfiglio, Nardo, Greenfield, Kaplan, et al., 2002). This is a potential area of intervention to improve patient's quality of life.

As discussed in the results for question 2, following HCP recommendations was a strategy used by the majority of participants to control their diabetes. There were two participants who stated their interactions with the HCP were not satisfactory and they did not follow recommendations because of these interactions, for them this was a significant obstacle in self-management,

Yeah. I think I'm in pretty good shape. I can run with a teenager if I have to. And I can outwork most mules if I have to. I don't think it's that bad, no. Not as far as I see it. But they get all these test results on your blood and they say it's something else... I think (pause). I think they put on a little bit more on it than what they should.

When asked to clarify this statement, the participant stated that he thought HCP's amplified the findings of blood work to make the patient's level of control seem worse than it really was. Both participants were engaged in self-management strategies. One participant was motivated to improve her self-management and was engaging in strategies to bring about a positive change in her blood glucose control while the other was continuing with his current strategies because he believed them to be sufficient.

### **Facilitators**

Facilitators of self-management identified by the participants in this study included taking responsibility for self-management, prayer and/or faith in God, education about diabetes management, worry and family support as facilitators in self-management. Each of these facilitators is discussed in detail below.

Taking responsibility for disease management was reported by several participants as an important facilitator in self-management, “And I’m going to have to do it within myself, you know. I’m (pause) I’m going to have to do the most work, ‘cause nobody can do it but me”. Some of the participants who reported taking responsibility for management as an important facilitator had only recently reached a turning point in which they accepted their diagnosis, while others had been self-managing the disease for many years. Likely there is a continuum of responsibility for self-management with no responsibility at one end and taking responsibility for one’s own self-management at the opposite end of the continuum. This sense of responsibility for self-management appears similar to or related to “getting it into your mind” that was identified as a management strategy in question two, but was identified separately from that concept during specific questioning about facilitators.

A few participants reported that their faith in God and/or prayer, in addition to being a management strategy, was also a facilitator in their self-management efforts, “The good Lord. I do a lot of praying. Reading the bible. Um hum (pause). Um hum. My faith keeps me in good shape”. The use of faith and prayer as a facilitator appears different than utilizing it as a management strategy,

Mom was actually in her 50’s like me. Now she did try to do something. She was actually prayed for, and it went away.... So she was really cured and didn’t have to take medication or anything.

The use of prayer as a management strategy appears to relinquish control and responsibility for self-management to God, while those identifying faith and prayer as a facilitator gain strength and fortitude to engage in necessary self-management strategies. The use of prayer in the diabetic population has only been minimally studied but has been shown to be a commonly reported alternative self-management technique

(Garrow & Egede, 2006; Pagan & Tanguma, 2007). While faith and prayer could be a facilitator for self-management, as previously stated, patients could also relinquish control of self-management and place control in the hands of God, potentially disregarding medical advice and discarding self-management strategies. Most participants in this study appeared to be using faith and prayer as a facilitator.

Several participants identified education about diabetes and its management as a facilitator. This education was often formal and presented in the HCP office or the Diabetes Center. It could also be informal and obtained from close friends, church members, or family as identified by one lady's statement, "Talking to other people that have diabetes and learning from them. There are many people at church that have diabetes".

A few participants identified worry about high blood sugars and the potential resulting complications was a motivational force to improve self-management,

(teary eyed) I've got a son that's, uh (pause) forty years old, but he's mentally handicapped. And it's just me and him. And I know I (pause) need to stay as healthy as I can for as long as I can for him. He's (pause) dependent on me for most of his care, you know. (Pause) He's not able to work or anything, (pause) so he needs me to be there for him (pause) and to be in good enough health to take care of him.

This participant was worried that if he did not begin to control his hyperglycemia and subsequently developed complications of uncontrolled T2DM his dependent adult son would have to be institutionalized, and that possibility is completely unacceptable to this participant. The participants who identified worry were all worried about the ramifications of poor control and wanted to avoid complications of uncontrolled T2DM. Finding ways to motivate patients and increase their commitment to self-care and avoid complications uncontrolled hyperglycemia is an important intervention in T2DM.

Identification and recognition of risks associated with poor glycemic control may inspire patients to attain an optimal or better level of health. Detailing the benefits of improving glycemic would appear to be a way to increase commitment to self-management.

Several participants reported that support from family members or close social contacts facilitated their efforts at self-management, “My family, I guess. I’m still here with my children and my grandchildren. They call and check on me. They bring me food”. In some cases support involved helping the participant to increase physical activity, “Yes, my family (pause) my son and daughter who live with me. And my friends will also walk with me and encourage me to remain active”. Family or social support has been shown to help increase adherence to self-management strategies (Bertera, 2003; Chelsea, Fisher, Mullan, Skaff, Gardiner, Chun, et al., 2004; Mayberry & Osborn, 2012; Samuel-Hodge, Headen, Skelly, Ingram, Keyserling, Jackson, et al., 2000; Wen, Shepherd & Parchman, 2004;). Determining the support system of a patient could help HCPs determine which patients will need more intensive interventions and monitoring because of lack of support.

## **Summary**

Participants in this study identified both obstacles and facilitators to self-management of their T2DM. Obstacles reported by participants included diet change, several issues related to medication management, having multiple disease processes, living alone, limited transportation, sexual dysfunction and worry. Restriction of simple carbohydrate consumption was the most commonly identified issue related to dietary modification, although there were general difficulties with diet modification as well. Managing multiple medications and the cost of these medications were the most commonly identified obstacle related to medications.

Only two participants stated uncertainty about correct or appropriate management, and this was related to variable effects of dietary intake. Numerous participants gave conflicting and contradictory information about their current dietary practices most of which is in conflict with dietary recommendations for persons diagnosed with T2DM. Continuing dietary education could help participants by refreshing knowledge of appropriate dietary management. It is likely all patients could benefit from formal dietary education throughout the course of management.

Managing multiple medications can be a difficult task for any patient; people diagnosed with T2DM frequently have multiple disease processes they must manage as was the case with most participants in this study. Often control of hyperglycemia requires multiple pharmacologic therapies used concurrently with lifestyle modification. Managing a complex, multiple medication regimen can be problematic for patients, especially if they are reluctant to take medications in the first place as were some of the participants of this study (Fan, 2005; Ford et al., 2008; Koro et al., 2004; UKPDS Research Group, 1998). The use of multiple medications can also present difficulties with scheduling medication administration. The use of combination medications, two or more medications combined in one pill can simplify scheduling medication administration and possibly improve adherence to therapy.

Cost of medications is frequently a problem, especially when patients are taking multiple medications, or newly marketed medications as were many participants of this study. The majority of these participants are retired and living on a fixed income, which further exacerbates issues with medication cost. This participant group presents a somewhat unique situation in that almost half of the participants have been prescribed

Victoza, a relatively new medication with a cost of over \$500 for a one month supply ([www.drugstore.com](http://www.drugstore.com)). Pharmaceutical assistance programs are available from most pharmaceutical manufacturers to help defray the cost of medications for those with low income levels and/or no insurance coverage. The providers in the practice sites where this study was conducted frequently utilize pharmaceutical assistance programs for their patients, but cost of medication still presents a financial hardship for these participants since the medication costs \$85 even with pharmaceutical assistance. Twenty to twenty three percent of the population in these counties lives below the poverty level and the median household incomes for these two counties is approximately \$30,000 ([City-data.com](http://City-data.com)). The participants currently taking Victoza are extremely satisfied with their management because Victoza therapy appears to be helping them manage not only their blood sugars but their weight as well. It is unlikely they would want to change therapy despite the cost; however the recent information emerging in television commercials about the potential adverse effects of Victoza may change the participant perspective about that medication (Alves, Batel-Marques & Macedo, 2012).

Taking responsibility for self-management, faith/prayer, family support and worry were all identified as facilitators to self-management by the participants in this study. Responsibility for self-management appears to have developed once the participant accepted or came to terms with the diagnosis, and is related to a perceived benefit of self-management by the participant. Finding interventions to move participants toward acceptance and a sense of responsibility for their own outcomes could improve blood glucose control and prevent complications of T2DM. Worry was identified as a facilitator in that it increased awareness of a lower level of control than was necessary to prevent

unwanted complications of uncontrolled or poorly controlled T2DM. This awareness of potential harm appears to signal recognition of a need to change self-management strategies in order to achieve the desired outcomes of disease management.

Faith/prayer, identified by some as a facilitator of self-management, is also one of the most commonly reported alternative therapies by patients with T2DM. Reliance on faith or prayer in lieu of prescribed self-management strategies could have a negative impact on outcomes. Persons who relinquish responsibility for their self-management to God rather than engaging in self-management strategies themselves could suffer complications from lack of control. If faith and prayer are a source of strength or empowerment utilized with prescribed self-management strategies this could improve patient outcomes.

#### **Research Question 4**

Research question 4 asks whether any differences exist in the way that members of different races or genders in North Florida describe their beliefs and practices related to diabetes. The themes and codes identified for each race and gender group are displayed in table format for ease of reading. Similarities and differences between genders and races were found in causation, perceptions, strategies, barriers and facilitators. There were more similarities noted than differences. The overall comparison of causation, perceptions, strategies, barriers and facilitators will be presented in table format as previously stated. Differences in each category are discussed in detail preceding each table.

## Findings

### Causation

Similarities in causation are addressed in Figure A-1 in Appendix A. Differences in causation are discussed in depth here. Males in general did not implicate diet in their explanation of causation. One black male did identify diet as a cause of his T2DM, yet most males identified diet change as a strategy they employed in the management of diabetes. All White males identified aging as a cause of T2DM while no Black males identified this as a cause. One Black female and two White males identified retirement as causative. These same individuals identified aging as causative; it may be difficult to separate aging and retirement since retirement is typically a consequence of aging. Sleep deprivation was identified as causative by one White female and one White male. Long work hours, which may contribute to sleep deprivation, was identified by one White female; the same one who identified sleep deprivation as causative.

Four participants of twenty-one identified external causes of T2DM. More males than females identified an external cause of their diabetes. Two Black males (surgery; spider bite), one White male (corticosteroid use), and one Black female (medication side effect) identified the events in parentheses as causative of their T2DM. Only male participants identified alcohol consumption as a cause of T2DM. Only one Black male identified tobacco use as causative.

Gestational Diabetes (GDM) history was identified by one individual, although she did not identify this as a cause of her T2DM, nor did she specifically identify this hyperglycemia during pregnancy as GDM. GDM is a well-known risk factor for development of T2DM post-pregnancy (Lee, Hiscock, Wein, Walker & Permezel, 2007).

## **Perceptions**

Similarities in perception are presented in Figure A-2 in Appendix A. Differences in perceptions are discussed in depth here. Only female participants identified depression as a result of being diagnosed with T2DM. Black females (2) identified T2DM as interfering with normal life. Females expressed frustration about managing their blood sugars, while males described being overwhelmed by the work of managing diabetes. Males identified that they had already lived longer than their family members with T2DM, while no females made this distinction. One Black female identified receiving what she perceived as differential care based on having Medicare rather than private health insurance.

## **Management strategies**

Similarities in identified self-management strategies are presented in Figure A 3 in Appendix A. An in depth discussion of differences is presented here. Only Black males identified insulin therapy as a strategy to manage their diabetes. Others may have been utilizing insulin therapy but did not discuss that during the interview process. Portion control was identified by only one participant (White female) as a management strategy although many participants had identified weight gain and diet as causing T2DM. Weight loss was not identified as a self-management strategy for White males, most of whom were not overweight. Males identified responsibility for their own diabetes management as strategy they employed. One Black female who had just experienced a turning point in acceptance of her diagnosis and recognition of the dangers of hyperglycemia also expressed that she must now take responsibility for self-management of diabetes. Faith in God and/or prayer was identified as a management strategy by females, Black females more than White females. The use of home

remedies or alternative therapies was identified by only four participants, one Black female, one Black male and two White males. Alternative therapies identified by participants included cinnamon and apple cider vinegar most frequently. In most cases the people using these therapies could not specifically state the beneficial nature of these therapies, although some believed cinnamon would lower blood glucose levels. The Black female who utilized multiple alternative therapies was doing so to manage multiple disease processes.

Two participants, a Black female and a White male, discussed the mental aspects of T2DM and the importance of keeping a positive attitude, but Black males specifically discussed “getting it into your head” or mind. These mental aspects of self-management appear to be related to acceptance of the diagnosis, which was identified by all groups, but was mentioned separately by the same subjects who also discussed acceptance of the diagnosis.

### **Barriers and facilitators**

Similarities in identified barriers to self-management are presented Figure A 4 in Appendix A. An in depth discussion of differences in barriers is presented here Black males did not identify difficulty with diet change as a barrier to self-management. Male participants identified sexual dysfunction as a barrier to self-management of T2DM. Only two participants identified living alone as a barrier (one Black female and the Hispanic male). Limited transportation was identified as a barrier by only one participant, a Black female, which was surprising given the lack of public transportation in these two counties. Worry was identified as a barrier to self-management only by male participants, two Black males and one White male. One Black male identified

ineffective exchange of information and negative comments from his HCP as barriers to self-management. In addition to this he doubted the information given to him by the HCP; specifically he did not believe that his level of control was as bad as the HCP presented to him. Difficulty managing the medication regimen was identified as a barrier by only two participants, one Black male, and one White female.

Similarities in identified facilitators of self-management are presented in Figure A-5 in Appendix A. An in depth discussion of differences in facilitators is presented here. Black females (2) and Black males (1) identified being motivated to improve control as a facilitator to self-management. Negative comments from the HCP were identified as a facilitator to self-management by a black female participant, while a black male participant had identified negative comments from the HCP as a barrier to self-management. Faith in God and/or prayer was identified as a facilitator to self-management only by females. Worry, which had been identified as a barrier to self-management in other groups was identified as a facilitator of self-management by some Black females and one White male because this worry made them aware of potential complications of uncontrolled T2DM and motivated them to improve their level of control through implementation of better self-management strategies.

## **Summary**

There were many similarities in explanation of causation, perceptions, strategies, barriers and facilitators among all racial groups and both genders. The similarities within and among these groups was far greater than the few differences that were found. The differences, as well as the similarities provide insight into some aspects of living with T2DM. The size of this sample, however, does not allow for generalization to other populations or geographic areas.

The omission of diet as a cause for T2DM by most of the male participants (only one Black male identified diet as causative) even though they identified diet change as a strategy to manage their diabetes is of interest. If patients do not recognize the role diet, especially the role of dietary excess which leads to weight gain, plays in the development of T2DM then they might not understand the role diet change plays in self-management. This could present opportunities for intervention, education and improvement in control.

The perception that diabetes may be curable was by identified by numerous participants in every race and gender group. If patients believe that they can alter the course of their disease by adhering to diet and treatment recommendations commitment to self-management could be maximized. Curability, however, likely means something different to patients than it does to health care providers (HCP). Patients appear to believe management of T2DM without medication represents being cured of the disease, while most HCPs recognize the disease as incurable and a life-long process which may be controlled through lifestyle modifications and pharmacologic therapy. It appears that, for these participants, management of T2DM without medication is a highly desirable state of affairs. If HCP's could emphasize the importance of lifestyle modification and the role these strategies play in weight reduction and glucose management, along with the possibility the disease could be managed without the use of medication, the commitment to lifestyle modifications could be enhanced.

The identification of the self-management strategy "getting it into your head" which was identified only by the Black males, appears to be a crucial concept that allows these participants to transition toward optimal self-management of the disease.

This concept appears to be different from acceptance of the diagnosis which was identified by all races and genders, but was not investigated further at the time of interviews because this was not recognized until after interviews were completed. Maintaining a positive mental attitude, identified by Black females and White males, may also be a related concept but was investigated as a separate concept after identification. These concepts and their relationships to one another and to self-management are an area for further investigation. Finding interventions to help patients “get it into their heads” or minds, as well as to accept the diagnosis and maintain a positive attitude could lead to improved control of diabetes. T2DM is a complex disease process requiring multiple management strategies. Encouragement and praise from HCPs about a patient’s self-management could improve the patient’s perception about the ability to self-manage this complex disease process and produce a more positive outlook about self-management.

Barriers to self-management included several factors outside the control of HCP’s. Sexual dysfunction and managing the medication regimen are barriers identified by participants that HCP’s could influence. Only male participants identified sexual dysfunction as a barrier to self-management. It is unlikely that sexual dysfunction actually impedes self-management but it causes concern for the participants, so it should be addressed by HCP’s (DeBearardis, et al., 2002; Kalter-Liebovici et al., 2005; Schipilliti et al., 2011). This may be a subject HCP’s are reluctant to address, but they must become adept at discussing and treating this issue in order to increase the ability of patients to concentrate of self-management of diabetes.

Facilitators of self-management identified by participants included being motivated to improve control, negative comments from the HCP and faith in God and/or prayer. Motivation to improve control is difficult to measure, but capitalization on motivation at the appropriate moment could lead to better outcomes in self-management. HCP's must be attuned to subtle changes in the patient that could indicate that they are motivated to improve control of their diabetes. Negative comments by the HCP were identified as both facilitator and barrier to self-management. HCPs must be cautious in the use of these type comments because they could have unintended effects on the patient. It is difficult to determine what makes the difference in these perceptions but this appears to be vital in moving some patients toward a stronger commitment to self-management. Worry about hyperglycemia and its accompanying complications can motivate patients to engage and commit to self-management strategies. Lack of motivation to self-manage T2DM has previously been identified as a barrier to management by HCPs (Simmons, Lillis, Swan & Harry, 2007). Developing interventions that will increase motivation of patients to self-manage T2DM and move them toward responsibility for their own management is an area that requires further investigation.

Family and social support has been shown to be influential in self-management strategies for T2DM (Mayberry & Osborn, 2012; Wen, Shepherd & Parchman, 2004). HCP's should investigate the social support systems of their patients and if these are lacking refer these patients to support groups in an effort to improve self-management. Developing community support groups is a possible avenue to increase social support for T2DM patients.

## CHAPTER 5 DISCUSSION AND CONCLUSIONS

The purpose of this study was to explore how people diagnosed with T2DM residing in two small rural areas in North Florida live with the disease on a daily basis; how each person understands or interprets the disease; how confident each person is that he/she can manage the illness; what strategies/techniques each uses to manage the illness; what effect the diagnosis and disease process has on their lives; and whether race and gender play any role in their reaction to the disease. The theoretical framework for this study was Kleinman's Explanatory Model Theory which focuses on the illness experience of the individual suffering from the disease. Questions proposed by Kleinman to elicit the Explanatory Models of the participant's illness were used to develop the interview guide and the research questions. The research questions for this study, as previously stated were: (1) What are the perceptions of cause for diabetes? (2) What is the impact of perceptions on self-management strategies? (3) What are the obstacles to self-management? (4) Are there differences in the way that members of different racial groups or genders in North Florida describe their beliefs and practices related to diabetes? Detailed analysis of each research question was discussed in Chapter 4. This chapter includes a discussion of the major findings of the study, followed by limitations of the study and directions for future research and recommendations for HCPs.

### **Major Findings**

#### **Question 1**

Research question one explored participant's explanation of causation for T2DM. As previously stated, explanations of causation included internal causes, external

causes and behavioral causes. External causes included two serious medical events, two medication adverse events, stress, and work/living conditions. Internal causes included heredity, aging/retirement and pancreatic failure. Behavioral causes include diet, weight gain, inactivity, tobacco and alcohol usage; all of these being factors over which the participant potentially has control. With the exception of the two serious medical events identified as causative, the majority of causation explanations were commonly identified and accepted causes of T2DM (Hatcher & Whitmore, 2007; Schorling & Saunders, 2000; Van Dam et al., 2002; Williams et al., 2001). Kleinman's theory of Explanatory Models (EM) states there are multiple factors that inform the participant's EM about causation of their chronic illness. The majority of participants in this study did not identify independent, discrete causes for T2DM; their explanations of causation were complex and multifactorial. The complexity of explanatory models for these participants is consistent with previous research involving persons with T2DM using Kleinman's theory (Arcury, Skelly, Gesler, & Dougherty, 2004; Cabassa, Hansen, Palinkas, & Eil, 2008; Kleinman, 1980; May, & Rew, 2010).

Only one participant identified elevated blood glucose levels during pregnancy. According to her report she was not given any information about these elevated blood glucose levels, nor was she treated for hyperglycemia at that time. This participant appears to have been diagnosed with Gestational Diabetes Mellitus (GDM) even though she did not specifically identify that as her diagnosis. She did not appear to be aware that Gestational Diabetes is a predictor of T2DM development within 15 years after diagnosis of GDM (Lee, Hiscock, Wein, Walker & Permezel, 2007).

Kleinman (1980) has stated that health care professionals (HCP) have explanatory models (EM) of disease processes that differ from those of their patients and contain more pathophysiology information than the EMs of patients. In most instances, however; HCPs do not often share their EMs with their patients (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Kleinman, 1980). The explanatory models of the participants in this study were consistent with those of previous studies with respect to the multifactorial, highly contextual nature of their explanations (Arcury, Skelly, Gesler, & Dougherty, 2004; Cabassa, Hansen, Palinkas, & Eil, 2008; May, & Rew, 2010). Although the explanatory models of the HCPs at the two clinics where this study was conducted were not explored, it is expected that the HCPs would have EMs that differed from those of the participants since HCP EMs typically include the pathophysiology of the disease process and the effects on the body and patient EMs contain more information about social alterations and implications (Cohen et al., 1998; George & Thomas, 2010; Weller et al., 2012). A disconnect between the explanatory models of HCPs and those of the patient may contribute to lack of commitment to particular self-management strategies recommended by HCPs. The result of this disconnect was evident in the study participants who identified implausible explanations of causation by their HCP at the time of diagnosis. Resolving the disconnect through inquiry about patient explanatory models by HCPs, and by sharing appropriate HCP explanatory models with patients could lead to increased understanding and commitment to self-management strategies. There is more research into the explanatory models of Hispanic populations, especially Mexican-Americans, than in any other group. Exploring explanatory models of African-Americans and Whites especially

compared to those of HCPs could help to develop interventions to eliminate this discrepancy and move patients toward stronger commitment to self-management.

Most participants implicated multiple factors in their explanation of causation including dietary practices, decreased physical activity, weight gain, aging, retirement and heredity. All participants in this study identified a family history of T2DM whether or not they identified this as a cause of their own diabetes. The hereditary aspect of T2DM is perhaps the most significant risk factor for developing T2DM (ADA, 2004; Branchati et al., 2000; Caprio et al., 2008; Cowie et al., 2006). Most participants implicated their dietary practices as causative or at least influential in developing T2DM, even if this was not their initial answer about the causation. Participants, who identify inappropriate diet as a cause for their T2DM, have previously been shown to be more likely to adhere to diet modification as a strategy for self-management (Garcia, Rocha, Lopez, Baer, Dressler, and Weller, 2007; Schoenberg, Amey, & Coward, 1998). This has implications for identifying patients who may need further education about risk factors and dietary management and those who are likely to be successful with less intensive education.

## **Question 2**

Research question two explored the relationship of management strategies identified by the participants to the causality explanations identified by the participants. No clear associations between management strategies and causality emerged during data analysis. The majority of participants had multifactorial explanations of causation, believed T2DM could be cured, came to accept being diagnosed with T2DM, and moved into accepting responsibility for self-management. All of the participants were utilizing multiple strategies to control T2DM, and with few exceptions were utilizing very similar self-management strategies. With the exception of faith/prayer and a few

alternative therapies, most of the management strategies employed by the participants are consistent with and supported by the literature on diabetes management (ADA, 2004; Votey 2008). Faith, the most commonly identified alternative therapy in US, has been documented in the literature as providing social support, coping skills for dealing with chronic illnesses, and adherence to diet modification in certain populations, especially African Americans and Hispanics (Garrow & Egede, 2006; Hatcher & Whittemore, 2007; Pagan & Tanguma, 2007; Watkins, Quinn, Ruggiero, Quinn & Choi, 2013). The use of alternative supplements, reported by only four participants in this study, have been minimally studied and only cinnamon has been found to be possibly effective in helping to prevent hyperglycemia (Baker, Gutierrez-Williams, White, Kluger & Coleman, 2008; Blevins, Leyva, Brown, Wright, Schofield & Ashton, 2007; White & Johnston, 2007). The use of complementary and alternative therapies is associated with a decrease use of preventive services, increased number of emergency department visits, and seeking health care advice from persons other than HCPs (Brown, Upchurch, Garcia, Barton & Hanis, 1998; Garrow & Egede, 2006; Jose, Bahalia, Sharma, Hota, Sivaprasad & Pandhi, 2007; Pagan & Tanguma, 2007). Alternative therapies were used by few participants in this study indicating that the majority of participants are relying using HCP directed strategies rather than on community or socially acquired treatments which differs from the findings of previous studies (Brown, Upchurch, Garcia, Barton & Hanis, 1998; Reid, 1992).

Participants' experiential information involving family members or close contacts, however, appears to strongly influence commitment to self-management (George & Thomas, 2010; Rise, Pellerud, Rygg & Steinsbekk, 2013; Savoca et al., 2003). Several

participants who self-reported good control and acceptance of responsibility for self-management also identified having family members who had experienced poor outcomes with T2DM, most of whom were deceased at the time of interview. These participants identified that their self-management practices differed from those of their deceased family members with a goal of having more favorable outcomes for their T2DM. The management strategies identified by participants that differed from those of family members included increasing physical activity and stricter adherence to dietary modification as well as adherence to prescribed pharmacotherapy. Exploring patient perceptions based on experiential influences provides an opportunity for HCPs to understand the perceptions of their patients and to provide individualized personally relevant treatment.

Participants who rejected the explanation of their diagnosis by their HCP experienced resistance to the diagnosis and long delays in acceptance and engagement in self-management strategies. There was not a specific length of time for a participant/patient to move from rejection of diagnosis, disbelief or denial to self-management. But this acceptance/acknowledgement of the diagnosis/disease appears to be crucial for the participant to shift toward optimal or improved self-management which appears similar to “getting it into your head”. This verbalization appears to indicate an internalization and recognition of diabetes as a problem which needs to be resolved in order to prevent undesirable consequences. Delays in implementing self-management of T2DM can produce prolonged hyperglycemia which would predispose the participant to complications of the disease (UKPDS, 1998).

Denial of the diagnosis led to delays in shifting into optimal or improved self-management of T2DM for unpredictable lengths of time, at least one year or more for three participants. The turning point, which was unique to the individual experiencing it, was described by several people, after which they moved into acceptance of the diagnosis and shifted into a different (presumably better) level of self-management of T2DM. Self-management which produces near normal glucose levels is necessary if the disease is to be adequately managed and complications prevented (Egede, & Bonadonna, 2003; Garcia, Rocha, Lopez, Baer, Dressler & Weller, 2007; Norris, Lau, Smith, Schmid, & Engelgau, 2002; UKDPS, 1998; Weiler & Crist, 2009). Determining which patients are experiencing resistance to the diagnosis and delay commitment to self-management may help move patients more quickly from resistance and into commitment to self-management appears to be necessary since lack of commitment to self-management has previously been identified as a major deterrent to desirable T2DM outcomes (Savoca, Miller & Quandt, 2003; Simmons, Lillis, Swan & Harr, 2007). Examining the experiences and causal explanations of patients could help in determining denial or resistance to T2DM diagnosis, especially in those cases where there is disparity in HCP explanatory models that the patient perceives as implausible, and could lead to strategies to move patients toward acceptance and improved self-management.

### **Question 3**

Research Question three explored the barriers to and facilitators of T2DM self-management. Dietary restriction or modification is a mainstay of T2DM management along with other lifestyle modifications (ADA, 2004; Votey, 2008). Strictness of the management regimen, including dietary modification, especially with regard to

carbohydrate consumption has been shown to be the most significant obstacle for patients in previous studies (Ferzacca, 2004; Gazmararian, Ziemer & Barnes, 2009; Simmons, Lillis, Swan & Harr, 2007; Sullivan & Joseph, 1988). Dietary modification and adherence to same, especially in regard to carbohydrate restriction, was identified most frequently by participants in this study as an obstacle to self-management of T2DM and has been well documented in literature as problematic (Anderson-Loftin et al., 2002; Ferzacca, 2004; Gazmararian, Ziemer & Barnes, 2009; Leeman et al., 2008; Mayer-Davis et al., 2004; Sullivan & Joseph, 1988; Viegner et al., 1990; Whittemore et al., 2003; Wing, Epstein et al., 1985; Wing, Goldstein et al., 2001). Many participants identified giving up the foods they had consumed in the past as difficult. Developing modifications based on individual and cultural preferences, including items that are preferred or acceptable to southerners and Hispanics may increase adherence to this most difficult self-management strategy (Inzucchi et al., 2012).

Most participants felt they were able to adequately manage their treatment regimen. Only two participants stated uncertainty about correct or appropriate management, and this was related to variable effects of dietary intake specific to these two participants. Most participants identified difficulty with adhering to dietary recommendations as a barrier to self-management. As previously noted, this particular barrier is commonly identified in diabetes research (Anderson-Loftin et al., 2002; Ferzacca, 2004; Gazmararian, Ziemer & Barnes, 2009; Leeman et al., 2008; Mayer-Davis et al., 2004; Sullivan & Joseph, 1988; Viegner et al., 1990; Wing, Epstein et al., 1985; Wing, Goldstein et al., 2001; Whittemore et al., 2003). Continuing dietary

education throughout the course of disease management would likely benefit all patients with T2DM.

Many barriers related to medication management were identified by the participants in this study. The need to take multiple pharmacologic therapies was cited by three (3) participants as a barrier. Acquiring and remembering to take multiple medications can be problematic to participants, especially if they are reluctant to take medications in the first place (Fan, 2005; Ford et al., 2008; Koro et al., 2004; UKPDS Research Group, 1998). The use of multiple medications can also present difficulties with scheduling medication administration. The use of combination medications, two or more medications combined in one pill or tablet can simplify scheduling medication administration and possibly improve adherence to therapy.

Cost of medications is often a problem when patients are taking multiple medications, or newly marketed medications. The majority of these participants were retired and living on a fixed income, which further exacerbates issues with medication cost. This participant group presented a somewhat unique situation in that a large number of participants had been prescribed Victoza, a relatively new medication with a cost of over \$500 for a one month supply ([www.drugstore.com](http://www.drugstore.com)). Pharmaceutical assistance programs were used by many participants to help defray the cost of medications, but co-pays of \$85.00 per month still presented a financial hardship for many of these participants. As previously discussed, the residents of these two counties have lower median income levels and higher numbers of persons living below the poverty level than in other Florida counties ([City-data.com](http://City-data.com), 2013). However, the participants taking Victoza were extremely satisfied with their management because

they felt this helped them manage not only their blood sugars but their weight as well. It is unlikely they would want to change therapy despite the cost.

Surprisingly lack of transportation was cited as a barrier by only one participant. The rural characteristics of the geographic areas in which this study was conducted, along with limited public transportation, led me to believe this would be a significant barrier to these participants. As stated previously, people for whom limited transportation was most problematic were obviously not at the study sites because they had limited means of transportation. These people are therefore not represented in this study. If they could have been interviewed, they likely would have reported this as a significant barrier to care.

#### **Question 4**

Research question four explored the similarities and differences between each gender and racial group. Each of the preceding questions was examined to determine patterns based on the demographic make-up of the group. Detailed Tables of the analysis of these findings, explored by race and gender, were presented in Chapter 4. These differences are discussed below.

#### **Causation**

Male participants did not identify diet as causative of their DM although all groups, including males, identified diet change as a management strategy they employed. All White males identified aging as a cause of T2DM while no Black males identified this as a cause. One Black female and two White males identified retirement as causative. Sleep deprivation was identified as causative by one White female and one White male. Long work hours, which may contribute to sleep deprivation, was identified by only one White female, who also identified sleep deprivation as causative.

Age older than 45 years has been previously identified as a risk factor for developing T2DM but is a non-modifiable risk factor (ADA, 2008; Arcury et al., 2004; CDC, 2007; Branchati et al., 2000; Cowie et al., 1993; Schoenberg et al., 1998). Weight gain and sedentary lifestyle, or at least decreases in physical activity, often accompany older age and retirement which likely contributes to age as a risk factor for T2DM (Bell et al., 2005; Deshpande et al., 2005; Harris et al., 1999). Keeping adults active into middle and late years of life may change the prevalence of age as a risk factor in T2DM. Community outreach activities related to increasing physical activity could be instrumental in this regard.

Blacks and Whites identified weight gain, physical inactivity, and stress as causes of T2DM. The Hispanic male did not identify these as causative, but this was the only Hispanic representative in the study population, therefore this result is not generalizable to the study population or the population at large. Alcohol consumption was identified as causative by male participants only. One Black male participant identified tobacco use as a causative factor in T2DM.

### **Perceptions**

All groups reported a negative response to being diagnosed with T2DM and this included three participants who doubted the validity of the diagnosis (a Black female, a Black male, and the Hispanic male). All groups gave examples of family members or close associates who had experienced poor outcomes with their T2DM. Most participants felt that they had good control of their T2DM and that there was a possibility of cure, although some gave conflicting information about their level of control and the possibility of cure when asked more than once about these perceptions.

Only female participants identified depression as a response to being diagnosed with T2DM. Black females (2) identified T2DM as interfering with normal life. Females expressed frustration about managing their blood sugars, while males described being overwhelmed by the work of managing diabetes. Males identified that they had already lived longer than their family members with T2DM, while no females made this distinction. Having lived longer than family members could give these participants an increase sense of self-efficacy in managing their T2DM and lead to a stronger commitment to self-management. All these males identifying longer life than family had also identified that they perceived an adequate level of control.

### **Self-management Strategies**

No clearly defined or discernable differences in selection of self-management strategies related to causality by race and gender became apparent through data analysis. Most participants identified diet change, increasing physical activity, weight loss, acceptance of the diagnosis, and following HCP advice as management strategies they utilized to manage their T2DM. Most participants denied the use of alternative therapies and /or home remedies with respect to T2DM management. It appears that this group was relying most heavily on information provided to them by their HCP for self-management of T2DM.

Insulin therapy was identified by only Black males as a strategy to manage their diabetes. Others may have been utilizing insulin therapy but did not discuss that during the interview process. Portion control was identified by only one participant (White female) as a management strategy although many participants had identified weight gain and diet as causing T2DM. Weight loss was not identified as a self-management strategy for White males, most of whom were not overweight. Males identified

responsibility for their own diabetes management as strategy they employed. One Black female also identified that she recently (same day) began to take responsibility for her self-management; it is not known whether she was able to follow through with her commitment. Faith in God and/or prayer was identified as a management strategy by females only, Black females more often than White females. The use of home remedies or alternative therapies was identified by only four participants, one Black female, one Black male and two White males. The Black female utilized multiple alternative therapies to treat several illnesses, but not T2DM.

Two participants, a Black female and a White male, discussed the mental aspects of T2DM and the importance of keeping a positive attitude, but Black males specifically discussed “getting it into your head” or mind. These appear to be related to acceptance of the diagnosis, which was identified by all groups, but was mentioned specifically and separately by the three Black male subjects who also discussed acceptance of the diagnosis.

Three participants had experienced long delays in acceptance of their diagnosis and engagement in self-management strategies. In two cases this delay was related to the manner in which they were informed of their diagnosis. In one case this delay lasted longer than 10 years, resulting in unnecessary exposure to hyperglycemia and risk of complications related to that exposure. The strategies of self-management appear to be the same despite when or how the participants come to self-manage, so the issue for these participants is the length of time that expired while they were not self-managing their disease well and were likely exposed to the damaging effects of hyperglycemia.

## **Barriers to Self-management**

Difficulty with dietary recommendations was the most frequently identified barrier to self-management. Multiple medications and management of medication administration was identified as a barrier by Blacks and Whites of both genders. Black males did not identify difficulty with diet change as a barrier to self-management

Only male participants identified sexual dysfunction as a barrier to self-management of T2DM. Two participants identified living alone as a barrier (one Black female and the Hispanic male). Limited transportation was identified as a barrier by one participant, a Black female, which was surprising given the lack of public transportation in these two counties. Dissatisfaction with current treatment or HCP was identified as a barrier by only one participant, a White male. Worry was identified as a barrier to self-management only by male participants, two Black males and one White male. One Black male identified ineffective exchange of information and negative comments from his HCP as barriers to self-management. In addition to this he doubted the information given to him by the HCP; specifically he did not believe that his level of control was as bad as the HCP presented it to be. Taking time to explain the significance of lab results could help patients to recognize differences in levels of control and the need to improve self-management of T2DM. Difficulty managing the medication regimen was identified as a barrier by only two participants, one Black male, and one White female. Working with these individuals to simplify their medication regimen might improve their perceived skill level and improve their commitment to self-management.

## **Facilitators of Self-management**

Most participants were satisfied or happy with their current treatment regimen and HCP and also identified education about T2DM as a facilitator of self-management.

Black females (2) and Black males (1) identified being motivated to improve control as a facilitator to self-management. HCP interactions was identified as a facilitator to self-management by a Black female participant, while a Black male participant had previously identified negative comments from the HCP as a barrier to self-management. Faith in God and/or prayer was identified as a facilitator to self-management by Black females.

### **Limitations**

#### **Generalizability**

The sample for this study consisted of twenty one (21) individuals almost equally divided between males and females. Morse (1995) states the saturation is achieved when no new ideas or themes emerge from the data. No new ideas or themes emerged approximately after the half-way point of interviewing. While this is a sufficient sample to insure saturation and validity according to Guest, Bunce and Johnson (2006), it is insufficient for generalization of these results to the T2DM population or to the general population.

#### **Member Checks**

As part of the study design there were no records kept as to the identity of the participants. This made member checks, a presentation of the findings to the study participants in order to verify that the findings and conclusions of data analysis were indeed what the participants identified during the interview process, not possible. Subsequent interviewees were asked about information found in previous interviews, but not all subsequent interviews could confirm information identified by previous interviewees.

## **Data Limitations**

There were some themes or concepts that emerged rather early and those were investigated during subsequent interviews, but there were some other codes and themes that emerged late in the data analysis process which were not investigated further. The short time frame during which the interviews were conducted limited the exploration of these late developing themes.

The design of this research study specifically excluded examination of medical records of participants in order to ensure the anonymity of the participants. The settings for this study were very small rural medical clinics where most of the participants were well known to each other. It was not uncommon to hear the participants conversing with others in the waiting room about recent events in the community and persons that were mutually known to the participant and others at the clinic. Without assurances of anonymity it is doubtful I would have received the high level of cooperation that I experienced during the interview process. As a result of insuring anonymity of participants, there is no objective data with which to verify self-report of glucose control.

Health care providers were not interviewed during this study. Interviewing the HCPs likely would have yielded information about their EMs and their perceptions of the control level of these participants. This would have identified any disconnect between patient and current provider explanatory models which is suspected to exist based on the literature (Kleinman, 1980).

### **Kleinman's Explanatory Model Theory**

Kleinman's Explanatory Model theory was the theoretical framework selected for this study by the primary investigator. This theory has been utilized in previous studies related to T2DM and was expected to yield great insight into the participant's

experiences of living with T2DM. Kleinman's Explanatory Model theory encompasses multiple influences in the formation of a patient's (sufferer's) explanatory model of illness. This model encompasses 1) etiology; (2) time and mode of onset of symptoms; (3) pathophysiology; (4) course of sickness (including degree of severity and type of sick role; and (5) treatment. This model, however; tends to compartmentalize each of these entities and does not accommodate or take into account a multifactorial, blended, highly contextual explanation of causation which was the norm for the participants in this study. The compartmentalization of the elements which contribute to the explanatory model did not allow development of an explanation of the specific influences on selection of self-management strategies. The lack of clear influences on selection of self-management strategies could also be related to the multiple management strategies required for this complex disorder. T2DM requires lifestyle modification including increasing physical activity or exercise, changing dietary habits, in addition to pharmacologic agents in order to control blood glucose levels. Some studies utilizing Kleinman's theory have also employed other instruments to investigate the frequency with which participants engaged in specific diabetes management strategies (George & Thomas, 2010; Watkins et al., 2013). In addition, information obtained from HCPs, which is doubtless influenced by education and personal beliefs likely influences selection of self-management strategies. Information from HCPs was not directly investigated and was only noted if participants shared that information as part of their explanatory model. Investigating HCP influences on selection of self-management strategies could yield further insight into factors influencing the patient's ability to live with T2DM.

## **Personal Bias**

As a nurse practitioner in the North Florida with specific experience treating T2DM patients using a medical model, I acknowledge having had preconceived notions that the T2DM population may be chronically non-adherent to prescribed therapy and lifestyle modifications. I am aware of the difficulty typically associated with lifestyle/behavioral modification in any patient population. The treatment regimens for T2DM can be extremely complex and costly in both time and money. The investigator was required to bracket preconceived notions in order to ensure that investigator biases did not influence the results of the study. As previously stated bracketing involves identifying and setting aside assumptions or preconceived notions about the subject of inquiry (Curium & Holstein, 2003). By disclosing these a priori assumptions and continually addressing them during data analysis I believe I was able to prevent these assumptions from influencing the data found in this study. Feedback from dissertation committee members, as well as the Data Analysis Group at the University Of Florida College Of Nursing, was used to minimize these biases.

## **Directions for Future Research**

When asked about the cause of their T2DM, most participants gave very context-rich explanations that encompassed more information than simply causation of the disease/illness. This need to give context to explanations is consistent with the multi-factorial nature of T2DM and with Kleinman's Explanatory Model theory. Self-care recommendations for T2DM are multi-faceted, reflecting the complicated etiology of the disease. Recommended interventions for T2DM include diet modification, weight reduction, increased physical activity, and pharmacotherapy in order to control blood glucose levels (ADA, 2004; Votey 2008). The multi-factorial explanation of causation

reported by these participants incorporates their own stories into their explanatory model of illness to create a “personally relevant” explanation of causation which is consistent with previous studies (Brown, Upchurch, Garcia, Barton & Hanis, 1998; Hatcher & Whittemore, 2007; Hunt, Valenzuela & Pugh, 1998). Explanatory models undergo revision throughout the process of the illness and are influenced by introduction of new information to the patient. Previous studies have found that explanatory models of Hispanics are not consistent with HCP explanatory models (Cabassa, Hansen, Palinkas, & Ell, 2008; Hunt, Valenzuela, & Pugh, 1998; Poss, & Jezewski, 2002;), however with only one Hispanic participant in the study nothing can be generalized about what this participant identified. Explanatory models of causation of Blacks and Whites have not been widely studied; however, the one study located showed consistent explanatory models with the participant population of this study, including past dietary excess, aging, obesity or overweight, and pancreatic malfunction (Schoenberg, Amey & Coward, 1998). Further exploration of explanatory models of illness for Blacks and Caucasians could yield further insight into the complexity of self-management and remains a possible area for further investigation. Comparison of patient and HCP explanatory models in these populations could further confirm the existence of a disconnect between HCP and patient perspectives on this chronic disease.

Repeating this study with a redesign incorporating an instrument such as the Subscales of Diabetes Self-Care Activities (SDSCA) could yield a better picture of self-management strategies employed by the participants (Toobert, Hampson & Glasgow, 2000). Using the SDSCA would benefit results by fully addressing use of self-

management strategies and the frequency of use of these strategies. Further, asking participants directly to identify factors that influence which self-management strategies they employ would further elucidate thoughts about self-management strategy use.

The lack of influence of limited transportation in this study population raises the possibility that these results would have been quite different if people for whom limited transportation was an issue were included in the study population. Repeating this study in a community setting, such as a church or senior citizen center, rather than a health care setting might incorporate participants that were unavailable in the clinical settings utilized in this study. This might present a very different picture of how patients are living with T2DM than seen in the study setting for this study.

Many of the participants in this study identified family members or close associates who were deceased after many complications of poor control of T2DM. Perhaps witnessing the poor outcomes of others gave these participants the motivation to commit to self-management of their disease. Patient perceptions based on experiences with family members with T2DM is an area that could be explored in order to determine perceptions about self-management, and the anticipated course of the disease, and then these perceptions especially if erroneous could be addressed to improve self-management strategies.

How information about diagnosis of T2DM is delivered to patients appears to influence whether the information is accepted by the patient, as well as whether the patient will commit to self-management of the disease in a timely manner. Studying the behavior of HCPs engaged in caring for the T2DM population as well as other chronic disease populations could identify techniques that are beneficial or harmful in delivery of

diagnosis and management information. In this way, negative reaction to information presented by HCPs may be prevented.

The most often identified barrier to self-management in this and previous studies was difficulty with dietary recommendations (Auryan, S., & Itamar, R., 2008; Bagnasco, Di Giacomo, DaRin Della Mora, Catania, Turci, Rocco & Sasso, 2013; Bonham, & Brock, 1985; Caban, & Walker, 2006; Ferzacca, 2004; Franz et al., 1995; Garcia et al., 2007; Hatcher & Whittemore, 2007; Hunt, Valenzuela & Pugh, 1998; Jakicic, Wing & Winters-Hart, 2002; Mayer-Davis et al., 2004; Norris, Engelgau & Narayan 2001; Samuel-Hodge et al., 2000; Schoenberg, Amey & Coward, 1998; Sullivan & Joseph, 1988; Wing et al., 2001; Whittemore, Bak, Melkus & Grey, 2003). Despite an abundance of research into dietary modification for T2DM, developing interventions that are tailored to the individual remains an area for potential development. Developing dietary modifications specifically tailored to cultural preferences would likely increase adherence to recommendations but may not be possible (Inzucchi et al., 2012).

Based on statistical information from the Florida Department of Health it was expected that the study population would have a high number of complications associated with T2DM. None of the participants in this study had amputations, blindness, or were currently undergoing hemodialysis. Having access to a stable group of HCPs, rather than seeking health care on a sporadic basis through emergency and acute care facilities or the local health departments may have been influential in the lack of complications seen in the study population. The original design of this study was to recruit participants from the local health departments, but this was not possible after several years of severe federal budget cuts eliminated the provision of primary care at

local health departments. Different results may have been obtained by recruiting participants through the health departments and this is an area for future research. Repeating this study through a community based source such as a church or community center may have produced vastly different results than those seen in this study.

### **Summary**

The incidence of T2DM is increasing, especially in persons over the age of 20, and as our population ages it is expected that the numbers of people over 20 years of age diagnosed with the disease will increase at a proportional rate. (CDC, 2010; National Diabetes Fact Sheet, 2007). Almost nine percent (8.6%) of Florida's population over the age of 20 has been diagnosed with T2DM, which places Florida higher than the national level of 7.3% with both of these counties having incidence rates of T2DM exceeding the state-wide rate. By studying how persons diagnosed with T2DM, living in these two counties, respond to this disease I hoped to determine the factors related to the higher rates of death and complications in these counties. All the participants in this study received health care at two facilities, operated by a single practice group, with a stable group of HCPs. These participants were utilizing self-management strategies that are widely recommended for T2DM were receiving periodic health care supervision, had no significant complications related to uncontrolled or poorly controlled diabetes, and perceived that their diabetes was under control. Perhaps the stable HCP access contributed to the lack of complications witnessed in this study population, which differed from the anticipated results.

T2DM is a growing health concern world-wide and continues to drain resources from the health care budget. The burden of T2DM is expected to continue long into the

future. Finding information about how people adapt to this disease is a necessary step in improving patient outcomes.

### **Health Care Provider Recommendations**

Difficulty with dietary management was identified as the main barrier to self-management by the majority of participants with only a few participants identifying uncertainty about dietary management as a barrier as well. Continued reinforcement of dietary teaching, even referral to a nutritionist, would likely assist patients in dealing with this issue. Developing culturally acceptable dietary modifications could produce better adherence and improved glycemic control.

Difficulty managing the medication regimen and cost of medications were identified as barriers to self-management. The use of combination medications once a stable dose of each medication has been established for the patient would reduce the overall number of individual pills or tablets the patient is required to take and could improve patient satisfaction with treatment and confidence in their ability to manage the medication regimen. Awareness of the cost of medications and use of less expensive medications for patients on a fixed income could improve patient adherence to prescribed medication regimens. These HCPs are presently utilizing pharmaceutical assistance programs extensively, so it would appear that these providers are cognizant of this issue to their patients.

Believing that a cure for T2DM is possible was identified as a perception by a large number of the participants in this study. The word “cure”, as previously stated, likely means different things to the patient than the HCP. It appears that the meaning of being cured to the participants is equivalent to being medication free. If HCPs emphasize the role of lifestyle modifications such as weight loss and increasing physical

activity in achieving ideal body weight and a medication free disease management is achievable at least for the short term, it is possible that patients would commit more fully to self-management of T2DM and produce better patient outcomes.

The identified disconnect between HCP explanatory models of illness encompassing the pathophysiology and anticipated course of T2DM disease progression, and those of patients which typically include multiple factors encountered during their experience and the experiences of others known to them likely contributes to a lack of commitment to self-care strategies (Cohen, Tripp-Reimer, Smith, Sorofman & Lively 1994; George & Thomas, 2010; Lawton, Peel, Parry & Douglas, 2008; Simmons, Lillis, Swan & Harr, 2007). Those patients who do not believe the causal explanations of their HCP, such as the participants of this study who rejected the HCPs causal explanations, likely feel frustration and resist the advice given them about how to manage their disease (Cohen, Tripp-Reimer, Smith, Sorofman & Lively, 1994; George & Thomas, 2010; Hatcher & Whittemore, 2007). Exploring the explanatory models of patients and resolving any discrepancy could lead to collaboration between HCP and patient yielding improved adherence to prescribed self-management strategies and improved patient outcomes.

Health care providers should be very clear in their articulation of T2DM causation. Several of the participants identified HCP explanations about causation that were unclear and considered unlikely. There must be accurate information conveyed to the patient in order to avoid rejection of the diagnosis and subsequent delay moving toward acceptance of the diagnosis of T2DM and taking responsibility for self-management. Exploring the perceptions of patients who have family members or close

contacts that have been diagnosed with T2DM could shed light on patients who may need further interventions to move them toward acceptance of the diagnosis and commitment to self-management. Patient experiences with self-management of T2DM and experiences of people known to the patient likely influence the explanatory model and decisions about self-management strategies (George & Thomas, 2010; Savoca et al., 2003; Rise, Pellerud, Rygg & Steinsbekk, 2013; Schoenberg, Amey, & Coward, 1998). How individuals encounter information about diabetes self-management appears to be influential in their commitment to self-manage their disease.

Management of T2DM requires that those who effectively self-manage their disease come to terms with their diagnosis and accept responsibility for and actively engage in self-management. Acceptance of the diagnosis and responsibility for self-management occurs at different points in the disease process and may be influenced by a wide array of factors as previously discussed. The multiple interventions required to adequately self-manage T2DM require a strong patient commitment if the disease is to be adequately managed over the patient's lifetime. Determining whether the patient is fully committed to self-management appears crucial to optimizing outcomes since lack of commitment to self-management has been identified by health care providers as a barrier to adequate control. It may be difficult to determine whether the patient has accepted the diagnosis and the responsibility for disease self-management because patients may be reluctant to express lack of acceptance and commitment to their HCP even if they recognize that they lack either of these. Utilizing a behavior frequency tool, such as the Diabetes Self-management Questionnaire (DSMQ), may help to indirectly

determine acceptance and commitment by assessing how often patients engage in recommended self-care behaviors.

The need for information about diet and other self-management strategies would appear to be life-long and periodic reinforcement would likely benefit all persons diagnosed with this chronic disease. Funding for continued diabetes education is limited and third party payers do not generally reimburse HCPs for more than 2 hours of diabetes education per year (BCBS of Florida, 2014). The use of community dwelling diabetes counsellors has been studied in Hispanic populations and has been shown to improve glycemic control in persons diagnosed with T2DM who attend these support groups. (Ingram, M., Torres, E., Redondo, F., Bradford, G., Wang, C., & O'Toole, M., 2007). Community support groups could be instrumental in providing T2DM patients with information and support to help inform patients about practical solutions to self-management of this complex disease. This type of intervention might provide information that would be presented in a more culturally sensitive manner and might be better received by persons attending these sessions.

T2DM is a chronic condition with impact on longevity, quality of life, and economic resources. Finding alternate methods to deliver improved care could help to alleviate the burden of this costly disease.

APPENDIX A  
ANALYSIS FIGURES

Black Females (7)	Black Males (5)	White Female (4)	White Males (4)	Hispanic Males (1)
External cause (med side effect)	External causation	Internal Pancreatic Failure	External causation (corticosteroid )	Incidental lab work finding
Behavioral cause (weight gain)	Behavioral cause (weight gain)	Behavioral (weight gain)	Behavioral (weight gain)	
Behavioral cause (Diet/quantity)	Behavioral cause (Diet)	Behavioral (diet)		
Heredity	Heredity	Heredity	Heredity	Heredity
Inactivity	Inactivity	Inactivity	Inactivity	
Stress	Stress	Stress		
	Alcohol consumption		Alcohol Consumption	Alcohol consumption
Retired			Retired	
Getting older		Getting older	Getting older	
		Sleep Deprivation	Sleep Deprivation	
		Long work hours		
GDM				
	Tobacco use			

Figure A-1 Comparison of Causation

Black Females (7)	Black Males (5)	White Females (4)	White Males(4)	Hispanic Male (1)
Neg response to DX	Doubted diagnosis			
Mind over matter		Disease is manageable		
Negative experience of family/others				
	Adjusting to the disease	Adjusting to the disease		
Denial	Denial			
Depression		Depression		
Thankful for resources				Thankful for resources
	Living longer than family members			Living longer than family members
Good control	Good control	Good control	Good Control	
	Under control	Under control	Under control	
Variable control	Variable control	Variable control	Variable control	
Uncontrolled	Uncontrolled	Uncontrolled		
Grief over Dx				
Curable	Curable	Possible cure	Possible cure	
No cure, lifelong				
Frustration	Overwhelmed	Frustration	Overwhelmed	
Interferes w/ normal life				
	Car Analogy			
	Bill Payment analogy			
Differential care R/T insurance				

Figure A-2 Comparison of Perceptions

Black Females (7)	Black Males (5)	White Females (4)	White Males (4)	Hispanic Male (1)
Diet change	Diet Change	Diet change	Diet change	Diet change
Weight loss	Weight loss	Weight loss		Weight loss
Physical activity	Physical activity	Physical activity	Physical activity	
(+) attitude	Getting it in your Mind		(+) attitude mental aspect	
Acceptance of diagnosis	Acceptance of diagnosis	Acceptance of diagnosis	Acceptance of diagnosis	Acceptance of diagnosis
Altered CHO intake		Altered CHO intake	Altered CHO intake	
	Insulin therapy initially			
			Self-Control	
Responsibility	Responsibility		Responsibility	
		Portion control		
Follows HCP advice	Follows HCP advice	Follows HCP advice	Follows HCP advice	Follows HCP advice
Continued CHO intake	Continued CHO intake	Continued CHO intake	Continued CHO intake	
Testing	Testing			
Faith/Prayer		Faith/Prayer		
	Occasional diet lapses	No diet change	No diet change	
	Communicate w/ HCP (1)	Communicate w/ HCP	Communicate w/ HCP	
	Comparison	Comparison	Comparison	
	Alcohol Cessation		Alcohol Cessation	Alcohol cessation Tobacco cessation
No home remedies	No home remedies	No home remedies	No home remedies	No home remedies
(+) Home remedies (19) Numerous	(+) home remedies (10) Apple cider vinegar		(+) home remedies Cinnamon (16, 17)	

Figure A-3 Comparison of Self-Management Strategies

Black Females (7)	Black Males (5)	White Females (4)	White Males (4)	Hispanic Male (1)
Difficulty w/diet advice		Difficulty w/diet advice	Difficulty w/diet advice	Difficulty w/diet advice
Multiple diseases	Multiple diseases	Multiple diseases		
Lives alone				Lives alone
	Sexual Dysfunction		Sexual Dysfunction	
	Questioning HCP	Dependence/ loss of independence	Dependence/ Loss of independence	
Reluctant to take meds	Reluctance to take meds	Reluctance to take meds	Reluctance to take meds	
Cost of Meds	Cost of Meds			
Multiple Meds	Multiple Meds	Multiple Meds		
Uncertain about management		Uncertain about management		
	Ineffective info exchange			
	Negative HCP comments			
	Worry		Worry	
	ADE of Treatment		ADE of Treatment	
	Medication management	Medication management		
Frustration			Unhappy w/ provider	
Limited transportation				

Figure A-4 Comparison of Barriers

	Black Female (7)	Black Male (5)	White Females (4)	White Males (4)	Hispanic Male (1)
Facilitators	Support		Family support	Family support	Family support
	Happy w/ current Tx	Happy with current TX	Happy with current TX	Happy with current TX	Happy with current Tx
	Education	Education	Education		Education
	Fear as motivator			Fear as motivator	
	Motivated to improve control	Motivated to improve control			
	Faith/Prayer				
	(-) HCP comments				

Figure A-5 Comparison of Facilitators

APPENDIX B  
DEMOGRAPHIC INFORMATION

Gender	M	F		
Race	White	Black	Hispanic	
Age				

Figure B-1 Demographic Information

## APPENDIX C INTERVIEW QUESTIONNAIRE

These questions may be asked in any order, and other questions may be prompted by the responses given by the participants.

1. When were you diagnosed with Diabetes?
2. What would you say caused your diabetes?
3. Tell me what it was like to learn that you had Diabetes?
4. Why do you think it started when it did?
5. What do you think your diabetes does to your body?
6. How bad do you think your diabetes is?
7. How long do you think it will last?
8. What do you fear most or what worries you most about your sickness?
9. What kind of treatment do you think you should receive?
10. What are the most important results you hope to receive from the treatment?
11. What are the chief problems your sickness has caused for you? (You, your family, and at work).
12. Do you use any cure or treatment other than what the doctor tells you to use?
13. Do you think the doctor is giving you the right treatment for your diabetes?
14. What are the things that help you live with your diabetes?
15. What is the hardest thing about having diabetes?

## APPENDIX D INFORMED CONSENT

Protocol Title: Living with Type 2 Diabetes

Please read this consent document carefully before you decide to participate in this study.

**Purpose of this research study:**

To explore the experience and explanatory models of people diagnosed with type 2 diabetes.

**What you will be asked to do in the study:**

You will be asked to answer questions during a session scheduled around your usual diabetes care appointment at the health department. The interview will be tape-recorded for transcription by the interviewer after the interview is complete. There will be no way for anyone to identify who was being interviewed.

**Time required:**

Approximately 1 hour.

**Risks and benefits:**

The risks of participating are no different than those of a routine health care visit. There is no anticipated benefit to you by participating in this study.

**Compensation:**

At the completion of the interview you will be given a \$15.00 visa gift card to defray any expenses incurred as part of your participation in this study.

**Confidentiality:**

Letters of consent will be given to anyone interested in participating in the study. No signed consent form will be used since this information would identify study participants. The researcher will make and keep a list of people participating in the study along with their appointment times and a method of contact. This list will be stored in a locked file cabinet in the researcher's home. Once data collection is finished, the list will be destroyed.

**Voluntary participation:**

Your participation in this study is completely voluntary. There is no penalty for not participating in the study.

**Right to withdraw from the study:**

You have the right to withdraw from the study at any time without consequences.

**Who to contact if you have questions about the study:**

Cherie Hodge, Doctoral Student, University of Florida College of Nursing (850) 510-5119

Dr. Susan Schaeffer, PhD, ARNP, FNP-BC, Chair and Clinical Associate Professor, Department of Women's, children's and Family Nursing, University of Florida College of Nursing (352) 273-6366

**Who to contact about your rights as a research participant in the study:**

IRB Office, Box 112250, University of Florida, Gainesville, FL 32611-2250; phone (352)392-0433

## LIST OF REFERENCES

- Agar, M. H. (1996). *The Deliberate Stranger*. San Diego: Academic Press .
- Alexander, C. M., Landsman, P. B., Teutsch, S. M., & Haffner, S. M. (2003). NCEP defined metabolic syndrome, diabetes, and prevalence of coronary heart disease among NHANES III participants age 50 and older. *Diabetes*, *52*(5), 1210-1214.
- Alexander, G. K., Uz, S. W., Hinton, I., & Jones, R. (2008). Culture brokerage strategies in diabetes education. *Public Health Nursing*, *25*(5), 461-470.
- Alves, C., Betel-Marques, F., & Macedo, A. F. (2012, Nov). A meta-analysis of serious adverse events reported with exenatide and liraglutide: Acute pancreatitis and cancer. *Diabetes Research & Clinical Practice*, *98*(2), 271-284.  
doi:10.1016/j.diabres.2012.09.008
- American Diabetes Association. (2002). Implications of the United Kingdom Prospective Diabetes Study. *Diabetes Care*, *25*(S1), S28-S32.
- American Diabetes Association. (2003). Standards of medical care for patients with diabetes mellitus. *26*(1), 33-50.
- American Diabetes Association. (2004). Diagnosis and classification of diabetes mellitus. *Diabetes Care*, *27*(1), S5-S10.
- American Diabetes Association. (2004). Screening for type 2 diabetes. *Diabetes Care*, *27*(1), S11-S14.
- American Diabetes Association. (2004). Standards of medical care for patients with diabetes mellitus. *Diabetes Care*, *27*(1), S15-S35.
- American Diabetes Association. (2008). *Incidence and prevalence*. Retrieved July 1, 2009, from American Diabetes Association:  
[http://professional.diabetes.org/Disease\\_Backgrounder.aspx?TYP=6&MID=236](http://professional.diabetes.org/Disease_Backgrounder.aspx?TYP=6&MID=236)
- American Nurses Association. (2001). *Nursing World*. Retrieved July 3, 2009, from Nursing World:  
[http://www.nursingworld.org/ethics.code.protected\\_nwcoe629.htm](http://www.nursingworld.org/ethics.code.protected_nwcoe629.htm)
- Anderson-Loftin, W., Sullivan, P., Summers, P., Bunn, P., & Tavakoli, A. (2002). Culturally competent dietary education for southern rural African-Americans with diabetes. *The Diabetes Educator*, *28*(2), 245-257.
- Arcury, T., Skelly, A., Gessler, W., & Dougherty, M. (2004). Diabetes meanings among those without diabetes: Explanatory models of immigrant Latinos in rural North Carolina. *Social Science & Medicine*, *59*, 2183-2193.
- Arthritis Foundation. (2014). *Osteoarthritis*. Retrieved Feb 1, 2014, from Arthritis Foundation: <http://www.arthritis.org/conditions-treatments/disease-center/osteoarthritis>

- Auryan, S., & Itamar, R. (2008). Gender-specific care of diabetes mellitus: particular considerations in the management of diabetic women. *Diabetes, Obesity and Metabolism*, 10(12), 1135-1156.
- Bagnasco, A., Di Giacomo, P., Da Rin Della Mora, R., Catania, G., Turci, C., Rocco, G., & Sasso, L. (2013). Factors influencing self-management in patients with type 2 diabetes: A quantitative systematic review protocol. *Journal of Advanced Practice Nursing*, 70(1), 187-200. doi:10.1111/jan.12178
- Baker, W. L., Gutierrez-Williams, G., White, C. M., Kluger, J., & Coleman, C. I. (2008). Effect of cinnamon on glucose control and lipid parameters. *Diabetes Care*, 31(1), 41-43.
- Barzilay, J. L., Spiekerman, C. F., Kuller, L. H., Burke, G. L., Bittner, V., & Gottdiener, J. S....Savage, P. J. (2001). Prevalence of clinical and isolated subclinical cardiovascular disease in older adults with glucose disorders. *Diabetes Care*, 24(7), 1233-1239.
- Bell, R. A., Quandt, S. A., Arcury, T. A., Snively, B. M., Stafford, J. M., & Smith, S. L. (2005). Primary and specialty medical care among ethnically diverse older rural adults with type 2 diabetes: The ELDER diabetes study. *Journal of Rural Health*, 21(3), 198-205.
- Ben-Arye, E., Schiff, E., Karkabi, K., Keshet, Y., & Lev, E. (2011). Exploring association of spiritual perspectives with complementary medicine use among patients with type 2 diabetes in Israel. *Ethnicity & Health*, 16(1), 1-10. doi:10.10080/133557858.2010.510181
- Benbassat, J., Pilpel, D., & Tidhar, M. (1998). Patient's preferences for participation in clinical decision making. *Behavioral Medicine*, 24(2), 81-88.
- Bertera, E. (2003). Psychosocial factors and ethnic disparities in diabetes diagnosis and treatment in older adults. *Health & Social Work*, 28(1), 33-42.
- Beulens, J. W., Stolk, R. P., Van der Schouw, Y. T., Grobbee, D. E., Hendricks, H. F., & Bots, M. L. (2005). Alcohol consumption and risk of type 2 diabetes among older women. *Diabetes Care*, 28(12), 2933-2938.
- Blevins, S. M., Leyva, M. J., Brown, J., Wright, J., Schofield, R. H., & Ashton, C. E. (2007). Effect of cinnamon on glucose and lipid levels in non-insulin dependent type 2 diabetes. *Diabetes Care*, 30(9), 2236-2237.
- Block, J. P., Scribner, R. A., & DeSalvo, K. B. (2004). Fast food, race/ethnicity and income. A geographic analysis. *American Journal of Preventive Medicine*, 27(3), 211-217.
- Blue Cross Blue Shield of Florida. (2013, August 1). *Medical coverage guidelines. Diabetes self-management training and educational supplies*. Retrieved Feb 1, 2014, from Blue Cross Blue Shield of Florida: <http://mcgs.bcbsfl.com/index.cfm?fuseaction=main&doc=Diabetic Self-Management...>

- Bonham, G. S., & Brock, D. B. (1985). The relationship of diabetes with race, sex, and obesity. *The American Journal of Clinical Nutrition*, 41, 776-783.
- Branchati, F. L., Kao, W. H., Folsom, A. R., Watson, R. L., & Szklo, M. (2000). Incident type 2 diabetes in African-American and White adults. The atherosclerosis risk in communities study. *JAMA*, 283(17), 2253-2259.
- Brown, S., Upchurch, S., Garcia, A. A., Barton, S. A., & Hanis, C. A. (1998). Symptom related self-care of Mexican-Americans with type 2 diabetes: Preliminary findings of the Starr County diabetes education study. *The Diabetes Educator*, 24(3), 331-339. doi:10.1177/0145721179802400308
- Burns, D., Soward, A., Skelly, A., Leeman, J., & Carlson, J. (2008). Effective recruitment and retention strategies for older members of rural minorities. *The Diabetes Educator*, 34(6), 1045-1052.
- Caban, A., & Walker, E. A. (2006). A systematic review of research on culturally relevant issues for Hispanics with diabetes. *The Diabetes Educator*, 32(4), 584-595.
- Cabassa, L., Hansen, M., Palinkas, L., & Eil, K. (2008). Azucar y nervios: Explanatory models and treatment experiences of Hispanics with diabetes and depression. *Social Science & Medicine*, 66, 2413-2424.
- California Medi-Cal Type 2 Diabetes Study Group. (2004). Closing the gap: Effect of diabetes case management on glycemic control among low-income ethnic minority populations. The California Medi-Cal type 2 diabetes study. *Diabetes Care*, 27(1), 95-103.
- Caprio, S., Daniels, S. R., Drewnowski, A., Kaufman, F., Palinkas, L., Rosenbloom, A., & Schwimmer, J. B. (2008). Influence of race, ethnicity and culture on childhood obesity: Implications for prevention and treatment. *Diabetes Care*, 31(11), 2211-2221.
- Carlsson, S., Hammar, N., Grill, V., & Kaprio, J. (2003). Alcohol consumption and the incidence of type 2 diabetes. A 20 year follow-up of the Finnish Twin Cohort Study. *Diabetes Care*, 26(10), 2785-2790.
- Center for Advanced Research on Language Acquisition. (2013). What is culture? Minneapolis, MN. Retrieved January 29, 2014, from <http://www.carla.umn.edu/culture/definitions.html>
- Centers for Disease Control and Prevention. (2007). *Diabetes among adults: US, 1999-2004*. Retrieved October 10, 2008, from Health Data for All Ages: <http://209.217.72.34/HDAA/TableView/tableView.aspx>
- Centers for Disease Control and Prevention. (2010). *2007 National Diabetes Fact Sheet*. Retrieved September 5, 2010, from Centers for Disease Control and Prevention: <http://www.cdc.gov/diabetes/pubs/estimates07.htm>

- Charmaz, K. (2003). Grounded theory. Objectivist and constructivist methods. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (2nd ed., pp. 249-291). Thousand Oaks, CA: SAGE Publications.
- Chelsea, C. A., Fisher, L., Mullan, J. t., Skaff, M. M., Gardiner, P., Chun, K., (2004). Family and disease management in African-American patients with type 2 diabetes. *Diabetes Care*, 27(12), 2850-2855.
- Citi-data.com. (2013). *Gadsden County, Florida detailed profile*. Retrieved February 9, 2014, from City-data.com: [http://www.city-data.com/county/Gadsden\\_County-FL.html](http://www.city-data.com/county/Gadsden_County-FL.html)
- Citi-data.com. (2013). *Madison County, Florida detailed profile*. Retrieved February 9, 2014, from City-data.com: [http://www.city-data.com/county/Madison\\_County-FL.html](http://www.city-data.com/county/Madison_County-FL.html)
- Cohen, M. Z., Tripp-Reimer, T., Smith, C., Sorofman, B., & Lively, S. (1994). Explanatory models of diabetes: Patient practitioner variation. *Social Science & Medicine*, 38(1), 59-66.
- Cooper, H. (2002). Investigating socio-economic explanations for gender and ethnic inequalities in health. *Social Science & Medicine*, 54, 693-706.
- Corticosteroids-adverse events*. (2013, 12 10). Retrieved from Epocrates: <http://www.epocrates.com>
- Counihan, C. M. (1992). Food rules in the United States: Individualism, control and hierarchy. *Anthropological Quarterly*, 65(2), 55-66.
- Cowie, C. C., Harris, M. I., Silverman, R. E., Johnson, E. W., & Rust, K. F. (1993). Effect of multiple risk factors on differences between Blacks and Whites in the prevalence of non-insulin-dependent diabetes mellitus in the United States. *American Journal of Epidemiology*, 137(7), 719-732.
- Cowie, C. C., Rust, K. F., Byrd-Holt, D. D., Eberhardt, M. S., Flegal, K. M., Engelgau, M. M., . . . Gregg, E. W. (2006). Prevalence of diabetes and impaired fasting glucose in adults in the US population. National Health and Nutrition Examination Survey 1999-2002. *Diabetes Care*, 29(6), 1263-1268.
- Dallongeville, J., Cottel, D., Ferrrieres, J., Arveiler, D., Bingham, A., Ruidavets, J. B., . . . Amouyel, P. (2005). Household income is associated with the risk of metabolic syndrome in a sex-specific manner. *Diabetes Care*, 28(2), 409-415.
- Daniulaityte, R. (2004). Making sense of diabetes: Cultural models, gender and individual adjustment to type 2 diabetes in a Mexican community. *Social Science & Medicine*, 59, 1899-1912.
- DeBerardis, G., Franciosi, M., Belfiglio, M., Greenfield, S., Kaplan, S. H., Pellegrini, F., . . . Nicolucci, A. (2002). Erectile dysfunction and quality of life in type 2 diabetes patients. *Diabetes Care*, 25(2), 284-291. Retrieved Feb 9, 2014, from <http://care.diabetesjournals.org/>

- DeFronzo, R. A. (2001). *Treatment of type 2 diabetes mellitus: A sound approach based upon it's pathophysiology*. Lawrenceville, NJ: Academy of Medicine of New Jersey.
- Department of Health, State of Florida. (2008). *Diabetes Fact Sheet*. Retrieved May 20, 2009, from Department of Health, State of Florida: <http://www.doh.state.fl.us/family/dcp/factsheet.html>
- Deshpande, A. D., Baker, E. A., Lovegreen, S. L., & Brownson, R. C. (2005). Environmental correlates of physical activity among individuals with diabetes in the rural midwest. *Diabetes Care*, 28(5), 1012-1018.
- Diabetes Control and Complications Trial and Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine*, 329, 977-986.
- Doshi, S. L. (1995). Food and nutrition in culture: The conceptual framework. In S. L. Doshi, *Anthropology of Food and Nutrition*. Jaipur: Rawat Publications.
- Drewnowski, A., & Specter, S. E. (2004). Poverty and obesity. The role of energy density and energy costs. *American Journal of Clinical Nutrition*, 79, 6-16.
- Dutton, G. R., Johnson, J., Whitehead, D., Bodenlos, J. S., & Brantley, P. J. (2005). Barriers to physical activity among predominately low-income African-American patients with type 2 diabetes. *Diabetes Care*, 28(5), 1209-1210.
- Eberhardt, M. S., Lackland, D. T., Wheeler, F. C., German, R. R., & Teutsch, S. M. (1994). Is race related to glycemic control? An assessment of glycosylated hemoglobin in two South Carolina communities. *Journal of Clinical Epidemiology*, 47(10), 1181-1189.
- Egede, L. E., & Bonadonna, R. J. (2003). Diabetes self-management in African-Americans: An exploration of the role of fatalism. *The Diabetes Educator*, 29(1), 105-115.
- Emanuelle, N., Sacks, J., Klein, R., Reda, D., Anderson, R., Duckworth, W., & Abraria, C. (2005). Ethnicity, race, and baseline retinopathy correlates in the Veterans Affairs Diabetes Trial. *Diabetes Care*, 28(8), 1954-1958.
- Engelgau, M. M., Geiss, L. S., Saadine, J. B., Boyle, J. P., Benjamin, S. M., & Gregg, E. W. (2004). The evolving diabetes burden in the United States. *Annals of Internal Medicine*, 140(11), 945-950.
- Evans, J. M., Newton, R. W., Rutas, D. A., MacDonald, T. M., & Morris, A. D. (2000). Socio-economic status, obesity and prevalence of type 1 and type 2 diabetes mellitus. *Diabetes Medicine*, 17, 478-480.
- Fan, T. (2005). Glycemic control unimproved despite changes in treatment strategies (clinical rounds). *OB GYN News*, 40(17), 32.

- Fan, T., Koro, C. E., Fedder, D. O., & Bowlin, S. J. (2006). Ethnic disparities and trends in glycemic control among adults with type 2 diabetes in the U.S. from 1988 to 2002. *Diabetes Care*, *29*(8), 1924-1925.
- Feinglass, J., Lin, S., & Thompson, J. (2007). Low-income middle-aged Americans have higher 10 year death rates even after controlling for their worse health at baseline. *Journal of Gerontology: Social Sciences*, *62B*(4), S209-S217.
- Ferzacca, S. (2004). Lived food and judgements of taste at a time of disease. *Medical Anthropology*, *23*, 41-67.
- Festinger, L. (1954, May). A theory of social comparison processes. *Human Relations*, *7*, 117-140. doi:10.1177/001872675400700202
- Ford, E. S., Li, C., Little, R., & Mokdad, A. H. (2008). Trends in A1c concentrations among US adults with diagnosed diabetes from 1999 to 2004. *Diabetes Care*, *31*(1), 102-104.
- Franz, M. J., Monk, A., Barry, B., McClain, K., Weaver, T., & Cooper, N. (1995). Effectiveness of medical nutrition therapy provided by dietitians in the management of non-insulin dependent diabetes mellitus: A randomized, controlled clinical trial. *Journal of the American Dietetic Association*, *95*(9), 1099-1017.
- Garcia, J. G., Rocha, A. L., Lopez, I., Baer, R., Dressler, W., & Weller, S. (2007). Diabetes is my companion: Lifestyle and self-management among good and poor control Mexican diabetic patients. *Social Science & Medicine*, *64*, 2223-2235.
- Garrow, D., & Egede, L. (2006). Association between complementary and alternative medicine use, preventive care practices, and use of conventional medical services among adults with diabetes. *Diabetes Care*, *29*(1), 15-19.
- Gazmaririan, J., Ziemer, D., & Barnes, C. (2009). Perception of barriers to self-care management among diabetic patients. *The Diabetes Educator*, *35*(5), 778-788.
- George, S., & Thomas, S. (2010). Lived experience of diabetes among older, rural people. *Journal of Advanced Nursing*, *66*(5), 1092-1100. doi:10.1111/j.1365-2648.2010.05278x
- Germain, C. P. (2001). Ethnography. The method. In P. Munhall, *Nursing Research: A Qualitative Perspective* (3rd ed.). Boston, MA: Jones and Bartlett.
- Glasgow, R. E., & Toobert, D. J. (2000). Brief, computer-assisted dietary self-management counseling. Effects on behavior, physiologic outcomes and quality of life. *Medical Care*, *38*(11), 1062-1073.
- Glasgow, R. E., Nutting, P. A., King, D. K., Nelson, C. C., Cutter, G., Gaglio, F., . . . Whitesides, H. (2005). Randomized effectiveness trial of a computer-assisted intervention to improve diabetes care. *Diabetes Care*, *28*(1), 33-39.

- Goodpaster, B. H., Kelley, D. E., Wing, R. R., Meier, A., & Thaete, F. L. (1999). Effects of weight loss on regional fat distribution and insulin sensitivity in obesity. *Diabetes, 48*(4), 839-847.
- Gravlee, C. C. (2009). How race becomes biology: Embodiment of social inequality. *American Journal of Physical Anthropology, 139*, 47-57.
- Gregg, A., & Curry, R. H. (1994). Explanatory models for cancer among African-American women at two Atlanta neighborhood health centers: The implications for a cancer screening program. *Social Science & Medicine, 39*(4), 529-526.
- Grundy, S. M., Brewer, H. B., Cleeman, J. I., Smith, S. C., & Lenfant, C. (2004). Definition of metabolic syndrome. Report of the national heart, lung and blood institute/American heart association conference on scientific issues related to definition. *Circulation, 109*, 433-438. doi:10.1161/01.CIR0000111245.75752.C6
- Guba, E. G., & Lincoln, Y. S. (1981). *Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches*. San Francisco, CA: Jossey-Bass.
- Gubrium, J. F., & Holstein, J. A. (2003). Analyzing interpretive practice. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (2nd ed., pp. 214-248). Thousand Oaks, CA: SAGE Publications.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.
- Hanson, R. L., Imperatore, G., Bennett, P. H., & Knowler, W. C. (2002). Components of metabolic syndrome and incidence of type 2 diabetes. *Diabetes, 51*(10), 3120-3127.
- Harris, M. I. (2001). Racial and ethnic differences in health care access and health outcomes for adults with type 2 diabetes. *Diabetes Care, 24*(3), 454-459.
- Harris, M. I., Eastman, R. C., Cowie, C. C., Flegal, K. M., & Eberhardt, M. S. (1999). Racial and ethnic differences in glycemic control of adults with type 2 diabetes. *Diabetes Care, 22*(3), 403-408.
- Harris, M. I., Flegal, K. M., Cowie, C. C., Eberhardt, M. S., Goldstein, D. E., Little, R. R., . . . Byrd-Holt, D. D. (1998). Prevalence of diabetes and impaired fasting glucose, and impaired glucose tolerance in US adults. The third National Health and Nutrition Examination Survey, 1988-1994. *Diabetes Care, 21*(4), 518-524.
- Hatcher, E. & Whittemore, R. (2007). Hispanic adults' beliefs about type 2 diabetes: Clinical implications. *Journal of the American Academy of Nurse Practitioners, 19*, 536-545.
- Heisler, M., Smith, D. M., Hayward, R. A., Krein, S. L. & Kerr, E. A. (2003). Racial disparities in diabetes care processes, outcomes and treatment intensity. *Medical Care, 41*(11), 1221-1232.

- Hodge, C. (2000). *Health promoting behaviors of middle-aged white collar workers (Unpublished master's thesis)*. Tallahassee, FL.
- Hughes, M. H. (1997). Soul, black women and food. In C. Counihan, & P. Van Esterik, *Food and culture* (pp. 272-280). New York: Routledge.
- Hunt, L. M., Valenzuela, M. A., & Pugh, J. A. (1998). Porgue me toco a mi? Mexican-American diabetes causal stories and their relationship to treatment behaviors. *Social Science & Medicine*, 46(8), 959-969.
- Ingram, M., Torres, E., Redondo, F., Bradford, G., Wang, C., & O'Toole, M. (2007). The impact of promotoras on social support and glycemic control among members of a farmworker community on the US-Mexico border. *The Diabetes Educator*, 33(6), 172S-178S.
- Inzucchi, S. E., Bergenstal, R. M., Buse, J. B., Diamant, M., Ferrannini, E., Nauck, M., . . . Matthews, D. R. (2012). Management of hyperglycemia in type 2 diabetes: A patient centered approach. Position statement of the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). 35(June), 1364-1380. Retrieved April 2, 2013, from <http://www.care.diabetesjournals.org>
- Jakicic, J. M., Wing, R. R., & Winters-Hart, C. (2002). Relationship of physical activity to eating behaviors and weight loss in women. *Medicine & Science in Sports & Exercise*, 34(10), 1653-1659.
- Johnson, J. A., Eurich, D. T., Toth, E. L., Lewanczuk, R., Lee, T. K., & Majumdar, S. R. (2005). Generalizability and persistence of a multifaceted intervention for improving quality of care for rural patients with type 2 diabetes. *Diabetes Care*, 28(4), 783-788.
- Jose, V. M., Sharma, N., Hota, D., Sivaprasad, S., & Pandhi, P. (2007). Study of association between use of complementary and alternative medicine and non compliance with modern medicine in patients presenting to the emergency department. *Journal of Postgraduate Medicine*, 53(2), 96-101.
- Kalter-Leibovici, O., Wainstein, J., Ziv, A., Harman-Bohem, I., Murad, H., & Raz, I. (2005). Clinical, socioeconomic, and lifestyle parameters associated with erectile dysfunction among diabetic men. *Diabetes Care*, 28(7), 1739-1744. Retrieved Feb 9, 2014, from <http://www.care.diabetesjournals.org/>
- Kaplan, G. A., Pamuk, E. R., Lynch, J. W., Cohen, R. D., & Balfour, J. L. (1996). Inequality in income and mortality in the United States: Analysis of mortality and potential pathways. *British Medical Journal*, 312, 999-1003.
- Karter, A., Ferrara, A., Liu, J., Moffet, H., Ackerson, L., & Selby, J. (2002). Ethnic disparities in diabetic complications in an insured population. *JAMA*, 25(9), 2519-2527.

- Keyserling, T. C., Samuel-Hodge, C. D., Ammerman, A. S., Ainsworth, B. E., Henriquez-Roldan, C. F., Elasy, T. A., . . . Bangdiwala, S. (2002). A randomized trial of an intervention to improve self-care behaviors of African-American women with type 2 diabetes. *Diabetes Care*, 25(9), 1576-1582.
- Kim, H., & Oh, J. (2003). Adherence to diabetes control recommendations: Impact of nurse telephone calls. *Issues and Innovations in Nursing Practice*, 44(3), 256-261.
- Kleinman, A. (1980). *Patients and healers in the context of culture. An exploration of the borderland between anthropology, medicine and psychiatry*. Berkeley, CA: University of California Press.
- Kleinman, A. (1988). *The illness narratives. Suffering, healing and the human condition*. Cambridge, MA: Basic Books.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, 251-258.
- Koro, C. E., Bourgeois, N., Bowlin, S. J., & Fedder, D. O. (2004). Glycemic control from 1988 to 2000 among US adults with type 2 diabetes. *Diabetes Care*, 27(1), 17-20.
- Kvale, S. (2007). *Doing interviews*. London: SAGE Publications.
- LaPelle, N. (2004). Simplifying qualitative data analysis using general purpose software. *Field methods*, 16(1), 85-108.
- Lawton, J., Peel, E., Parry, O., & Douglas, M. (2008). Shifting accountability: A longitudinal qualitative study of diabetes causation accounts. *Social Science & Medicine*, 67, 47-56.
- Lederbach, J. P. (1995). *Preparing for peace: Conflict transformation across cultures*. Syracuse, NY: Syracuse University Press.
- Lee, A. J., Hiscock, R. J., Wein, P., Walker, S. P., & Permezel, M. (2007). Gestational diabetes mellitus: Clinical predictors and long-term risk of developing type 2 diabetes. *Diabetes Care*, 30(4), 878-883.
- Leeman, J., Skelley, A. H., Burns, D., Carlson, J., & Soward, A. (2008). Tailoring a diabetes self-care intervention for use with older, rural African-American women. *The Diabetes Educator*, 34(2), 310-317.
- Lipton, R. B., Liao, Y., Cao, G., Cooper, R. S., & McGee, D. (1993). Determinants of incident non-insulin dependent diabetes mellitus among blacks and whites in a national sample. *American Journal of Epidemiology*, 138(10), 826-839.
- Look AHEAD Research Group. (2007). Reduction in weight and cardiovascular disease risk factors in individuals with type 2 diabetes. *Diabetes Care*, 30(6), 1374-1384.

- Majumdar, S. R., Guirguis, L. M., Toth, E. L., Lewanczuk, R., Lee, T. K., & Johnson, J. (2003). Controlled trial of a multifaceted intervention for improving quality of care for rural patients with type 2 diabetes. *Diabetes Care*, 26(11), 3061-3066.
- Martinelli, A. M. (1999). An explanatory model of variables influencing health promotion behaviors in smoking and non-smoking students. *Public Health Nursing*, 16(4), 263-269.
- Martyn-Nemeth, P., Vitale, G., & Cowger, D. (2010). A culturally focused exercise program in Hispanic adults with type 2 diabetes. A pilot study. *The Diabetes Educator*, 36(2), 258-267.
- May, K. M., & Rew, L. (2010). Mexican-American youths' and mothers' explanatory models of diabetes prevention. *Journal for Specialists in Pediatric Nursing*, 15(1), 6-15.
- Mayberry, L. S., & Osborn, C. Y. (2012). Family support, medication adherence and glycemic control among adults with type 2 diabetes. *Diabetes Care*, 35, 1239-1245.
- Mayer-Davis, E. J., D'Antonio, A. M., Smith, S. M., Kirkner, G., Martin, S. L., Parra-Medina, D., & Schultz, R. (2004). Pounds off with empowerment (POWER): A clinical trial of weight management strategies for black and white adults with diabetes who live in medically underserved rural communities. *American Journal of Public Health*, 94(10), 1736-1742.
- Mayer-Davis, E. J., D'Antonio, A. M., Wandersman, A., Parra-Medina, D., & Schulz, R. (2001). Pilot study of strategies for effective weight management in type 2 diabetes: Pounds off with empowerment (POWER). *Family & Community Health*, 24(2), 27-35.
- McKenzie, C., & Skelly, A. H. (2010). Perceptions of coronary heart disease risk in African-American women with type 2 diabetes. A qualitative study. *The Diabetes Educator*, 36(5), 766-773.
- McSweeney, J. C., Allan, J. D., & Mayo, K. (1997). Exploring the use of explanatory models in nursing research and practice. *Journal of Nursing Scholarship*, 29(3), 243-248.
- Minze, M. G., Dalal, K. & Irons, B. K. (2011). Removing barriers to insulin use. *The Journal of Family Practice*, 60(10), 577-580.
- Morse, J. (1995). The significance of saturation. *Qualitative Health Research*, 5, 147-149.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*. Alberta, Canada. Retrieved January 18, 2010, from University of Alberta Canada- International Journal of Qualitative Methods: <http://www.ualberta.ca/~ijqm/>

- National Institutes of Diabetes, Digestive and Kidney Diseases. (2007). *National Diabetes Statistics*. Retrieved June 22, 2009, from National Institutes of Diabetes, Digestive and Kidney Diseases:  
<http://diabetes.niddk.nih.gov/dm/pubs/statistics/index.htm>
- Nelson, K. M., Reiber, G., & Boyko, E. J. (2002). Diet and exercise among adults with type 2 diabetes. Findings from the third National Health and Nutrition Examination Survey (NHANES III). *Diabetes Care*, 25(10), 1722-1728.
- Norris, S. L., Engelgau, M. M., & Narayan, K. M. (2001). Effectiveness of self-management training in type 2 diabetes. *Diabetes Care*, 24(3), 561-587.
- Norris, S. L., Lau, J., Smith, S. J., Schmid, C. H., & Engelgau, M. M. (2002). Self-management education for adults with type 2 diabetes. *Diabetes Care*, 25(7), 1159-1170.
- Oakley, L. D., Song, M. K., & DuBose-McQuirter, M. (2005). Positive and negative depression coping in low-income African-American Women. *Research in Nursing & Health*, 28, 106-116.
- O'Brien, T. R., Flanders, W. D., DeCoulfe, P., Boyle, C. A., DeStefano, F., & Teutsch, S. (1989). Are racial differences in the prevalence of diabetes in adults explained by differences in obesity? *JAMA*, 262(11), 1485-1488.
- Oomen, J., Owen, L., & Suggs, L. S. (1999). Culture counts: Why current treatment models fail Hispanic women with type 2 diabetes. *The Diabetes Educator*, 25(2), 220-225.
- Pagan, J. A., & Tanguma, J. (2007). Health care affordability and complementary and alternative medicine utilization by adults with diabetes. *Diabetes Care*, 30(8), 2030-2031.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: SAGE Publications.
- Peek, M. E., Odoms-Young, A., Quinn, M. T., Gorawara-Bhat, R., Wilson, S., & Chin, M. (2010). Race and shared decision-making: Perspectives of African-Americans with diabetes. *Social Science & Medicine*, 7, 1-9.
- Piette, J. D., Weinberger, M., Kraemer, F. B., & McPhee, S. J. (2001). Impact of automated calls with nurse follow-up on diabetes treatment outcomes in a Department of Veterans Affairs health care system. *Diabetes Care*, 24(2).
- Porterfield, D. S., & Kinsinger, L. (2002). Quality of care for uninsured patients with diabetes in a rural area. *Diabetes Care*, 25(2), 319-323.
- Poss, J., & Jezewski, M. A. (2002). The role and meaning of susto in Mexican-Americans' explanatory model of type 2 diabetes. *Medical Anthropology Quarterly*, 16(3), 360-377.
- Pronk, N. P., & Wing, R. R. (1994). Physical activity and long-term maintenance of weight loss. *Obesity Research*, 2, 587-599.

- Reid, B. (1992). Its like you're down on a bed of affliction: Aging and diabetes among black Americans. *Social Science & Medicine*, 34(12), 1317-1323.
- Reid, L., Hatch, J., & Parrish, T. (2003). The role of historically black university and the black church in community-based health initiatives: The project direct experience. *Journal of Public Health Management Practice*, 9(Supplement), S70-S73.
- Resnick, H. E., Valsania, P., Halter, J. B., & Lin, X. (1998). Differential effects of BMI on diabetes risk among black and white Americans. *Diabetes Care*, 21(11), 1828-1835.
- Rickheim, P. L., Weaver, T. W., Flader, J. L., & Kendall, D. M. (2002). Assessment of group versus individual diabetes education. *Diabetes Care*, 25(2), 269-274.
- Rise, M. B., Pellerud, A., Rygg, L., & Steinsbekk, A. (2013). Making and maintaining lifestyle changes after participating in group based type 2 diabetes self-management education: A qualitative study. *Plos One*, 8(5), e64009. doi:10.1371/journal.pone.0064009
- Rosenblatt, R. A., Maf-Baldwin, L., Chan, L., Fordyce, M. A., Hirsh, I. B., & Palmer, J. P. (2001). Improving the quality of outpatient care for older patients with diabetes. Lessons from a comparison of rural and urban communities. *Journal of Family Practice*, 50(8), 676-680.
- Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, 15(1), 85-109.
- Samuel-Hodge, C. D., Headen, S. W., Skelly, A. H., Ingram, A. F., Keyserling, T. C., Jackson, E. J., . . . Elasy, T. A. (2000). Influences on day-to-day management of type 2 diabetes among African-American women. *Diabetes Care*, 23(7), 928-934.
- Sandelowski, M., & Barroso, J. (2003). Classifying the findings of qualitative studies. *Qualitative Health Research*, 13(7), 905-923.
- Savoca, M., Miller, C., & Quandt, S. (2004). Profiles of people with type 2 diabetes mellitus: The extremes of glycemic control. *Social Science & Medicine*, 58, 2655-2666.
- Schipilliti, M., Caretta, N., Palego, P., Selice, R., Ferlin, A., & Foresta, C. (2011, August). Metabolic syndrome and erectile dysfunction. The ultrasound evaluation of cavernosal atherosclerosis. *Diabetes Care*, 34, 1875-1877. Retrieved 2014, from <http://care.diabetesjournals.org/>
- Schmitt, A., Gahr, A., Hermanns, N., Kulzer, B., Huber, J. & Haak, T. (2013). The diabetes self-management questionnaire (DSMQ): development and evaluation of an instrument to assess diabetes self-care activities associated with glycaemic control. *Health and Quality of Life Outcomes*. Retrieved from: <http://www.hqlo.com/content/11/1/138>
- Schlosser, E. (2002). *Fast food nation. The dark side of the American meal*. New York: Houghton Mifflin Company.

- Schlundt, D. G., Mushi, C., Larson, C. O., & Marrs, M. (2001). Use of innovative technologies in the evaluation of Nashville's REACH 2010 community action plan: Reducing cardiovascular disease and diabetes in the African-American community. *Journal of Ambulatory Care Management, 24*(3), 51-60.
- Schoenberg, N. E., Stoller, E. P., Kart, C. S., Perzynski, A., & Chapleski, E. (2004). Complementary and alternative medicine use among a multi-ethnic sample of older adults with diabetes. *The Journal of Alternative and Complementary Medicine, 10*(6), 1061-1066.
- Schoenberg, N., Amey, C., & Coward, R. (1998). Stories of meaning: Lay perspectives on the origin and management of non-insulin dependent diabetes mellitus among older women in the United States. *Social Science & Medicine, 47*(12), 2113-2125.
- Schorling, J. B., & Saunders, J. T. (2000). Is "sugar" the same as diabetes? A community based study among rural African-Americans. *Diabetes Care, 23*(3), 330-334.
- Signorello, L. B., Schlundt, D. G., Cohen, S. S., Steinwandel, M. D., Buchnowski, M. S., & McLaughlin, J. K. (2007). Comparing diabetes prevalence between African-Americans and whites of similar socio-economic status. *American Journal of Public Health, 97*(12), 2260-2267.
- Simmons, D., Lillis, S., Swan, J., & Harr, J. (2007). Discordance in perceptions of barriers to diabetes care between patients and primary and secondary care. *Diabetes Care, 30*(3), 490-495.
- Skaff, M. M., Mullan, J. T., Fisher, L., & Chesla, C. (2003). A contextual model of control beliefs, behavior, and health: Latino and European-Americans with type 2 diabetes. *Psychology and Health, 18*(3), 295-312.
- Smeltzer, S. C., & Bare, B. (2004). Health care delivery and nursing practice. In M. J. Bayer (Ed.), *Brunner & Suddarth's textbook of medical surgical nursing* (10th ed., pp. 5-18). Philadelphia: Lippincott, Williams & Wilkins.
- Stuifbergen, A. K., Seraphine, A., & Roberts, G. (2000). An explanatory model of health promotion and quality of life in chronic disabling conditions. *Nursing Research, 49*(3), 122-129.
- Sudano, J. J., & Baker, D. W. (2005). Explaining US racial/ethnic disparities in health declines and mortality in late middle age. The roles of socio-economic status, health behaviors, and health insurance. *Social Science & Medicine, 62*(4), 909-922.
- Sullivan, E. D., & Joseph, D. H. (1988). Struggling with behavior change: A special case for clients with diabetes. *The Diabetes Educator, 24*(1), 72-77.
- Toobert, D., Hampson, S. E., & Glasgow, R. E. (2000). The summary of diabetes self-care activities measure. *Diabetes Care, 23*(7), 943-950.

- Trento, M., Passera, P., Borgo, E., Tomalino, M., Bajardi, M., Cavallo, F., & Porto, M. (2004). A 5 year randomized controlled study of learning, problem solving ability, and quality of life modifications in people with type 2 diabetes managed by group care. *Diabetes Care*, 24(6), 670-675.
- United Kingdom Prospective Diabetes Study Group. (1998). Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes. *Lancet*, 352, 837-853.
- United States Census Bureau. (2007). *Florida county population estimates*. Retrieved July 18, 2007, from US Census Bureau: [http://factfinder.census.gov/servlet/GCTTable?\\_bm=y&geo\\_id=04000US12&box\\_head...](http://factfinder.census.gov/servlet/GCTTable?_bm=y&geo_id=04000US12&box_head...)
- United States Census Bureau. (2010). *Florida county selection map*. Retrieved September 29, 2010, from U S Census Bureau: [http://quickfacts.census.gov/qfd/maps/florida\\_map.html](http://quickfacts.census.gov/qfd/maps/florida_map.html)
- United States Census Bureau. (2012). *Gadsden county quick facts from the U. S. Census Bureau*. Retrieved February 4, 2012, from United States Census Bureau: <http://quickfacts.census.gov/qfd/states/12/12039.html>
- United States Census Bureau. (2012). *Madison county quick facts from the U. S. Census Bureau*. Retrieved February 4, 2012, from United States Census Bureau: <http://quickfacts.census.gov/qfd/states/12/12079.html>
- Van Dam, R. M., Rimm, E. B., Willett, W. C., Stampfer, M. J., & Hu, F. B. (2002). Dietary patterns and risk for type 2 diabetes mellitus in U.S. men. *Annals of Internal Medicine*, 136, 201-209.
- Viegner, B. J., Perri, M. G., Nezu, A. M., Renjilian, D. A., McKelvey, W. F., & Schein, R. L. (1990). Effects of intermittent, low-fat, low-calorie diet in the behavioral treatment of obesity. *Behavioral Health*, 21, 499-509.
- Vincent, D., Clark, L., Marquez-Zimmer, L., & Sanchez, J. (2006). Using focus groups to develop a culturally competent diabetes self-management program for Mexican-Americans. *The Diabetes Educator*, 32(1), 89-97.
- Votey, S. R. (2008). *Diabetes mellitus type 2- A review*. Retrieved July 12, 2010, from Emedicine.com: <http://www.emedicine.com/emerg/TOPIC134.htm>
- Wannamethee, S. G., Sharper, A. G., & Perry, I. J. (2001). Smoking as a modifiable risk factor for type 2 diabetes in middle-aged men. *Diabetes Care*, 24(9), 1590-1595.
- Warren, C. A. (n.d.). Qualitative interviewing. In J. F. Gubrium, & J. Holstein (Eds.), *Handbook of interview research: Context & method*. Thousand Oaks, CA: SAGE Publications.
- Watkins, Y. J., Quinn, L. T., Ruggiero, L., Quinn, M. T., & Choi, Y. (2013). Spiritual and religious beliefs and practices and social support's relationship to diabetes self-care activities in African-Americans. *The Diabetes Educator*, 39(2), 231-239.

- Weatherspoon, L. J., Kumanyika, S. K., Ludlow, R., & Schatz, D. (1994). Glycemic control in a sample of black and white clinic patients with NIDDM. *Diabetes Care*, 17(10), 1148-1153.
- Weiler, D., & Crist, J. (2009). Diabetes self-management in a Latino social environment. *The Diabetes Educator*, 35(2), 285-292.
- Wen, L. K., Shepherd, M. D., & Parchman, M. L. (2004). Family support, diet and exercise among older Mexican-Americans with type 2 diabetes. *The Diabetes Educator*, 30(6), 980-993.
- White, A., & Johnston, C. (2007). Vinegar ingestion at bedtime moderates waking glucose concentrations in adults with self-controlled type 2 diabetes. *Diabetes Care*, 30(11), 2814-2815.
- Whittemore, R., Bak, P. S., Melkus, G. D., & Grey, M. (2003). Promoting lifestyle change in the prevention and management of type 2 diabetes. *Journal of the American Academy of Nurse Practitioners*, 15(8), 341-349.
- Wikipedia. (2008). *Big bend (Florida)*. Retrieved March 1, 2008, from Wikipedia: [http://en.wikipedia.org/wiki/Big\\_Bend\\_\(Florida\)](http://en.wikipedia.org/wiki/Big_Bend_(Florida))
- Williams, D. E., Knowler, W. C., Smith, C. J., Hanson, R. L., Roumain, J., Saremi, A., . . . Nelson, R. G. (2001). The effects of Indian or Anglo dietary preferences on the incidence of diabetes in Pima Indians. *Diabetes Care*, 24(5), 811-816.
- Wing, R. R., Epstein, L. H., Norwalk, M. P., Koeske, R., & Hagg, S. (1985). Behavior change, weight loss and physiological improvements in type 2 diabetes patients. *Journal of Consulting and Clinical Psychology*, 53(11), 111-122.
- Wing, R. R., Goldstein, M. G., Acton, K. J., Birch, L. L., Jakicic, J. M., Sallis, J. F., . . . Surwit, R. S. (2001). Lifestyle changes related to obesity, eating behavior, and physical activity. *Diabetes Care*, 24(1), 117-123.
- Wing, R. R., Hamman, R. F., Bray, G. A., Delahanty, L., Edelstein, S. L., & Hill, J. O. (2004). Achieving weight and activity goals among diabetes prevention program lifestyle participants. *Obesity Research*, 12(9), 1426-1434.
- Wing, R. R., Jakicic, J., Neiberg, R., Lang, W., Blair, S. N., & Cooper, L. (2007). Fitness, fatness, and cardiovascular risk factors in type 2 diabetes: Look AHEAD study. *Medicine & Science in Sports & Exercise*, 39(12), 2107-2116.
- Young, R. J., Taylor, J., Friede, T., Hollis, S., Mason, J. M., Lee, P., . . . Gibson, J. M. (2005). Pro-active call enter treatment support (PACCTS) to improve glucose control in type 2 diabetes. *Diabetes Care*, 28(2), 278-282.
- Young, T. K. (n.d.). Diabetes among Canadian Indians and Inuit: An epidemiological overview. In J. R. Joe, & R. S. Young (Eds.), *Diabetes as a disease of civilization. The impact of culture change on indigenous peoples*. Berlin: Mouton de Gruyter.
- Zheng, H. (2009). Rising U. S. income inequality, gender and individual self-related health, 1972-2004. *Social Science & Medicine*, 69(9), 1333-1342.

## BIOGRAPHICAL SKETCH

Cherie Hodge received her Bachelor of Science in Nursing and her Master of Science in Nursing from Florida State University. She worked as a Family Nurse Practitioner for several years in Family and Endocrine practices providing direct patient care to many patients with diabetes. She is currently an Associate Professor of Nursing at Tallahassee Community College.

