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Understanding the Lived Experiences of Hispanic Immigrants with Diabetes Toward Disease Self-Management

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Abstract

The Hispanic population has a higher incidence of diabetes and poorer health outcomes compared to other populations in the United States. Although previous research has reported that cultural and ethnic beliefs play a role in poorer diabetes self-management by Hispanic individuals, limited studies have been focused on the barriers to self-management from the perspectives of Hispanic immigrants. The purpose of this qualitative study was to gain an understanding, through oral history narrative, of the experiences of Hispanic immigrants living with diabetes. In this study, the influence of cultural and ethnic beliefs on diabetes self-management in Hispanic immigrants in the Bronx in New York was explored. Semistructured interviews were conducted with 7 Hispanic immigrants who narrated their lived experiences regarding how they self-manage their conditions. The theory of reasoned action/theory of planned behavior guided this research. Data from in-depth interviews were coded and analyzed for themes. Six themes emerged from these interviews: knowledge of diabetes, diabetes self-management, strong cultural beliefs, social support, lifestyle changes, and strong cultural influence on diabetes management. The results from this study can lead to social change by providing information to health care providers and policy makers who need to deliver culturally sensitive education to both diabetic individuals and their families, which can help in the self-management of the disease.

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Dedication

I dedicate this dissertation to my mummy, Tessie Trinidad, my best mentor, my strength, and my role model for her encouragement, unconditional love, support and enduring patience that sustain me through this process. In loving memory of my dad, the inspiration for this research, I wholeheartedly dedicate this dissertation. Daddy, you always said that I could do anything in this world if I put my mind into it. There is not a moment that I do not miss you!

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To my mother, you are an incredible person, thank you mum for standing by me and for all the sacrifices. I could have not done this without you. I thank you for your endless support and encouragement and for always believing in me.

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Chapter 1: Introduction to the Study

Introduction

Diabetes is a group of metabolic diseases in which insufficient production of insulin or the body's abnormal response to insulin results in high blood sugar (Juvenile Diabetes Research Foundation, 2014). Diabetes has three main classifications: gestational diabetes, type 1 diabetes (T1D), type 2 diabetes (T2D). Diabetes is the seventh leading cause of death in the United States, and approximately 29.1 million Americans are diagnosed with diabetes each year, which has serious health consequences if not managed properly (Centers for Disease Control [CDC], 2014). Diabetes affects many parts of the body and is associated with serious long-term complications such as lower limb amputations, blindness, heart disease, strokes, and kidney failure (CDC, 2014). These complications can develop gradually and may eventually become life threatening (Mayo Clinic, 2014). Glucose management can mitigate these complications, particularly cardiovascular disease; therefore, it is critical that blood sugar levels are monitored regularly (CDC, 2014; Medical News Today, 2014).

In the United States, diabetes has disproportionately affected ethnic minority groups, predominantly the Hispanic population (National Alliance for Hispanic Health [NAHH], 2010). The Harvard School of Public Health (2014) has cited diabetes as a threat to both immigrant (16%) and non-immigrant Hispanics (22%), who are 1.5 times more likely to die from diabetes than non-Hispanic Whites. Diabetes affects all populations, but Hispanics are particularly burdened by the negative health outcomes that are associated to this chronic disease. For more than 20 years, diabetes has affected

Hispanics at higher levels such as 16.9 % in comparison to 10.2 % among non-Hispanic Whites (American Diabetes Association [ADA], 2014; NAHH, 2010). Previous studies have also reported that diabetes increases with age among Hispanic people more than any racial/ethnic group (NAHH, 2010). According to the ADA (2014), the rates of diabetes among Hispanics increases with age, affecting more than 50% for Hispanic women by the time they reach 70 and 44.3% for men aged 70-74. Diabetes has continued to be the major cause of morbidity and mortality in the Hispanic communities (NAHH, 2010). The NAHH (2010) reports that Hispanic children born in the year 2000 are twice as likely to develop diabetes in their lifetime than children of other minority groups.

Many factors can influence the development of and self-care for diabetes among Hispanics. McCloskey and Flennigan (2010) suggested that among the many factors that influence self-management for diabetes care among Hispanics are the ethnic beliefs in the Hispanic culture. Past literature focused on Hispanic diabetes has indicated that cultural and ethnic beliefs influence daily diabetes self-management (Nobles, 2014). These cultural factors include traditional Hispanic diet and family, social support, religion and ethnic beliefs that can positively and negatively influence diabetes management and treatment. Understanding cultural and ethnic practices among Hispanic diabetes patients and how they can conflict with daily regimen of care would improve current diabetes self-management programs among this segment of the population. The Hispanic population is projected to be the dominant demographic in the year 2050; thus, understanding their health and mortality patterns is important (Kposowa, 2013).

Gestational Diabetes and Hispanics

Gestational diabetes affects some women during pregnancy and is associated with significant complications (Fujimoto, Samoa, & Wotring, 2013). It affects between 7%-18% of pregnancies in the United States (Center for Vulnerable Populations, 2013). Additionally, Hispanic women are 50% more likely than non-Hispanic women to have gestational diabetes, which can have dangerous health consequences during and after pregnancy for both the mother and baby, including the higher risk of developing T2D (ADA, 2015). Hispanic women also have a greater predisposition toward gestational diabetes, with a 52.5% chance of developing the disease in their lifetime (Baby Center, 2012).

Type 1 Diabetes and Hispanics

T1D is an autoimmune disease in which the body's own immune system destroys the insulin producing beta cells of the pancreas (Juvenile Diabetes Research Foundation, 2014). With proper treatment, people with T1D can live longer, healthier lives. Treatment includes lifelong insulin therapy, guided diet, and physical activity (Juvenile Diabetes Research Foundation, 2014). T1D affects both children and adults. T1D is more prevalent among Hispanic-American youth 10-19 years old than youths from other ethnic groups (Lawrence et al., 2009). Current study suggests lifetime risk for developing T1D is higher for both Hispanic men and women in comparison to other ethnic groups (Hispanic Health Info, 2015).

Type 2 Diabetes and Hispanics

T2D or hyperglycemia is a condition in which glucose levels in the body are higher than normal (ADA, 2014). T2D is the most common form, affecting 9.2% of the population of the United States (ADA, 2014). Treatment of T2D starts with guided diet, regular physical activity, and frequent monitoring of glucose levels. The Hispanic population is at higher risk than non-Hispanic Whites of developing this type. More than 50% of Hispanic women and 44.3% of Hispanic men will develop T2D by the time they reach 70 and 70-74 years of age, respectively (Schneiderman & Knight, 2014).

Diabetes has reached epidemic proportions in the United States, posing a major public health challenge to Hispanic individuals, especially those with low wealth (Page-Reeves et al., 2013). There is a need to explore culturally congruent diabetes self-management in the Hispanic population (Welier & Crist, 2009). Both public health officials and health care professionals state that self-management is vital to prevent further health complications associated to diabetes; however, adherence to diabetes is difficult for Hispanic people (Fortman, Gallo, Walker & Tsimikas, 2011; Page-Reeves et al., 2013). Understanding factors that are associated with poor diabetes self-management may lead to the development of improved diabetes treatment techniques tailored to the Hispanic population. The goal of this study was to listen to the experiences of Hispanic immigrants living with diabetes and determine how cultural and ethnic beliefs influence their approaches to disease management. Positive social implications of effective efforts to address the problem may include the improvement of current management and treatment methods, which could assist in the decrease of other health risk complications

associated to diabetes in Hispanic communities. The hope is that the insights gained from this study will improve the relationships between Hispanic diabetes patients and their health care providers for improved health outcomes.

Background

The incidence of diabetes in the United States has increased sharply among age groups, genders, and racial/ethnic groups (CDC, 2012). Diabetes affects the lives of 26 million children and adults in the United States (ADA, 2013). The ADA (2013) noted that at least 1.9 million Americans are diagnosed with diabetes and 71,382 individuals die from diabetes each year.

The Hispanic population, the fastest growing ethnic/racial group in the United States, bears a disproportionate burden of diabetes (Calzada & Mora, 2011; Rustveld et al., 2009). Hispanics share 12.8% of diabetes cases in the country- almost twice as many as non-Hispanic Whites (ADA, 2014). The Hispanic community has a 50% more prevalence of diabetes than the rest of the population (Coronado, Thompson, Tejeda, Godina, & Chen, 2007). Previous studies estimate that 20% of all adult Hispanics will have diabetes by 2031 (Rosal et al., 2011). Thus, health care providers are faced with significant challenges in educating the Hispanic community about potential health risks and management of diabetes (Nobles, 2014).

To understand how diabetes has reached such prevalent levels among Hispanics, it is important to understand how various factors influence the group's risk for diabetes. Current studies indicate that genetics, diet, lack of activity, and acculturation play an important role in the increased incidence of diabetes among the Hispanic population

(Perez-Escamilla, 2009). Previous studies on Hispanic diabetes indicated that genetics play an important role in increased risk for diabetes in Hispanic population; other research also indicated that culture has been associated to poor self-management in this segment of the population (ADA, 2013; Caban & Walker, 2006). Further, culture and ethnic beliefs influence the standard diabetes self-management practices and perception among Hispanics resulting in poorer health outcomes in this community (Caban & Walker, 2006).

Hispanic Culture and Ethnic Beliefs

Caban and Walker (2006) noted that some Hispanics with diabetes integrate Western and alternative medicine, but they do not usually discuss this with their health care providers. The use of folk healers or *curanderos* alternative providers is popular among Hispanics, especially common among first generation Hispanic immigrants (Gallaraga, 2007). The *curanderos* or folk healers play an important role in ancient Mexico and are held to the same standard as modern-day health care practitioners; however, limited research is available indicating the use of *curanderos* in diabetes care (Caban & Walker, 2006; Tafur, Crowe, & Torres, 2009). The significance of understanding the role of *curanderos* in diabetes management is critical to the relationship between a Hispanic individual with diabetes and conventional physicians. The key to a physician–patient relationship of sharing information is based on the observed quality of care and the patient's contentment with the medical care (Ortiz, Rodriguez, & Markides, 2009). The use of alternative health care providers by Hispanic

patients with diabetes may result from the dissatisfaction with the quality of care they receive from their physician (Ortiz et al., 2009).

Another sociocultural influence affecting diabetes management among Hispanics is the familist cultural tradition (Weiler & Crist, 2009). These are central to Hispanic culture and can have positive and negative impacts on diabetes management. The Hispanic culture is predominantly a patriarchal society; adults with an ailment are more likely to take advice from a respected member of the community like a religious leader than from their health care provider (Desai, Ramar, & Kolo, 2010). Thus, a younger Hispanic might be reluctant to interfere with health care decisions of an elder patient unless asked to help by the elder person.

One of the many obstacles in attaining goals in diabetes management among Hispanics with diabetes is diet (Caballero, 2011). Some aspects of the Hispanic culture can make it challenging to maintain a healthy, guided diet (Caballero, 2011). Traditional Hispanic food can be high in fat and calories. Hispanic culture also involves high social pressure to overeat during family celebrations. There is a cultural value called *simpatia*, a deferent compliance with others' wishes, meaning that declining food when offered is considered impolite and socially unacceptable (Caballero, 2011).

Another belief that might affect the health care behavior of Hispanics is *fatalismo*, which is the understanding of Hispanic diabetes patients that their diabetes condition might be out of their control and they must leave it to "higher being" (Caballero, 2011; Desai, Ramar, & Kolo, 2010). This belief can influence their decision to seek treatment

for their condition, which can result in the further development of health complications like heart disease if they choose to not seek treatment.

Susto is another cultural belief influencing health behavior among Hispanics. *Susto* is the belief that illnesses are caused by a scare or emotionally traumatic event that results in lost soul, anxiety, appetite loss, and social withdrawal (Caban & Walker, 2006). It is believed that *susto* occurred prior to the diagnosis of diabetes. The treatment for *susto* involves sweeping the body with herbs and other substances. It is also believed in the Hispanic culture that extreme emotional states can cause the onset of diabetes like *coraje* [anger], *tristeza* [sadness], and *gusto* [joy] (Caban & Walker, 2006). Furthermore, many Hispanics with diabetes see no point in seeking medical attention for their condition, as it is their belief that diabetes is out of their control (Weisenberger, 2012). Weisenberger (2012) also noted that in some instances, Hispanics may link the trauma from a stressful incident such as car accident to the onset of their disease.

Genetic Factor

The Hispanic population has increased susceptibility to T2D due to both genetic and environmental predispositions (Caballero, 2007). The ADA (2014) has suggested that T2D has a stronger link to family history and lineage than T1D. T2D has consistently been found to be of higher prevalence among the Hispanic population than among non-Hispanic Whites (Caballero, 2007). People who trace their ancestry to Native Americans, including Mexican- and Latin-Americans, are more susceptible to developing diabetes (Perkins, 2013).

A theory from 1962 proposed the "thrifty gene" hypothesis as the underlying factor contributing to higher rates of T2D among minority groups, including the Hispanic population (Caballero, 2007). According to this theory, humans have evolved to be efficient in storage and utilization of food through natural selection (Magness, 2010). Further, because people from indigenous groups experienced multiple instances of famine, they developed a way to store fat more efficiently to preserve energy during periods when food is not in abundance (Caballero, 2007). However, this genetic adaptation has become harmful to modern Hispanic people because food supplies are now abundant, leading to a high incidence of obesity.

Socioeconomic Factor

Research suggests that socioeconomic status is one modifiable risk factor associated with higher rates of diabetes among Hispanic people (Link & McKinlay, 2009). Lower socioeconomic status is measured by income, education, and occupational status, and these social issues can be significant within Hispanic communities (Jang, 2009). There are a disproportionate number of Hispanic people in poverty; about 22% of Hispanics live below the poverty line compared with 10% of non-Hispanic Whites (Vega, Rodriguez, & Gruskin, 2009). People of lower socioeconomic status are more likely to become obese because of limited access to nutritious food combined with the lack of time for physical activity (Wallach & Rey, 2009). Furthermore, having a lower socioeconomic status affects access to adequate health care because of factors like lack of transportation to and from health care facilities that provide preventive care and management as well as isolation from mainstream American culture (Ramar & Desai, 2010). In addition, current

literature indicates that about 60% of undocumented Hispanic immigrants lack health insurance coverage compared to Hispanic citizens or permanent residents (Ramar & Desai, 2010). The subject of socioeconomic factors will be discussed further in the literature review chapter.

Hispanic Diet as a Risk Factor

The traditional Hispanic diet is influenced by the Hispanic person's country of origin and the dietary practices in their adopted communities. Hispanic immigrants usually stay with the core of their authentic Hispanic cuisine, which consists of healthful fresh fruits, beans, and herbs. The longer these Hispanic immigrants live in the United States, the more their diet and eating behaviors change (Rodriguez, 2013). Research notes that as Hispanic immigrants become more assimilated into the culture of United States, they usually adapt to the "American diet," which is high in fat and sugar and low in fiber (Calzada & Mora, 2011). This type of diet, combined with lack of exercise, can lead to obesity, thereby increasing the risk of developing diabetes (Calzada & Mora, 2011).

Physical Activity as it Relates to Hispanic Health

Physical inactivity appears to be more prevalent among Hispanics compared to non-Hispanic Whites (Ickes & Sharma, 2012). However, one of the key factors in reducing diabetes risk is physical activity; moderate weight loss and regular exercise is encouraged as part of diabetes management (Ickes & Sharma, 2012). Being sedentary and insufficiently active contributes to the higher prevalence of obesity, which is a risk factor for diabetes and cardiovascular diseases (Nyberg, Ramirez, & Gallion, 2011). According to research estimates, about 38% Hispanic aged 2-19 are overweight or obese due to lack

of physical activity (Nyberg et al., 2011). Reports from current literature indicate that among Hispanic women, 74% do not participate in physical activity, and their activity levels decrease with age (Ickes & Sharma. 2012). With increasing assimilation into mainstream American culture, work-related time constraints, and environmental access, physical inactivity among Hispanics becomes increasingly common (Ickes & Sharma. 2012; Nyberg et al., 2011).

Diabetes Prevention in Hispanic Populations

Lifestyle changes are required to reduce the prevalence of diabetes among the Hispanic population (Duggan et al., 2014). Cultural and ethnic beliefs are among the biggest barriers to adhering to prescribed glycemic control recommendations. As will be evident in the literature review of Chapter 2, little has been done to assess the impact of cultural beliefs on diabetes management among Hispanic diabetes patients.

Problem Statement

Diabetes is a major public health problem in the United States and a chronic disease that can lead to complications and premature death if not adequately controlled (Lopez, 2006; Swan, 2010). Hispanics have worse glycemic control when compared to other ethnic/racial groups, which puts them at higher risks for long-term complications such as cardiovascular disease, amputations, end-stage renal disease, and visual impairment (Rustvelt et al., 2009). As the Hispanic population continues to increase, the diabetes rates may reach epidemic proportions (Lopez, 2006). Dealing with diabetes disease management is a concern for health care providers and health care leaders.

Self-management is an effective tool in reducing risks for further health complications (Swan, 2010). However, research indicates poor self-management is common among Hispanic patients with diabetes (Fortman, Gallo, Walker & Tsimikas, 2011). A growing body of literature suggests that this has been a contributing factor to the development of many health risks within the population (Campos, 2007; Kalyango, Owino, & Nambuya, 2008). Previous researchers have also posited that some of the underlying barriers to adherence among Hispanic people with diabetes include cultural and ethnic beliefs (Calzada & Mora, 2011). According to Swan (2010), misconceptions and misunderstanding about diabetes management is common. Among these misconceptions include ethnic beliefs like *susto*, which refers to cause and effect of the illness that has a strong influence on the response of Hispanic diabetes patients to diabetes management and treatment (Lopez, 2006; Wallace & Benyshek, 2006). Many Hispanic individuals with diabetes identify a past experience that may have contributed to their diabetes conditions when hearing about their diagnosis (Wallace & Benyshek, 2006). They think their condition "may have precipitated from an event causing diabetes rather than an illness in itself" (Jezewski & Poss, as cited by Wallace & Benyshek, 2006). Due to these ethnic beliefs, Hispanics may experience and think about diabetes differently from other subgroups, including the health care providers who treat them (Coronado et al., 2004).

Although there have been studies on diabetes management conducted in the Hispanic communities, there is limited research centered on the influence of ethnic beliefs in diabetes self-care (Nobles, 2014; Weiler & Crist, 2009). However, researchers

have cited that these cultural and ethnic beliefs play a major role in the higher incidences of diabetes among Hispanics (Cusi & Campos, 2011). These cultural and ethnic beliefs have also been found as contributing factors in poorer diabetes self-management (Caballero, 2006; Tyson, Smith, & Daza, 2012).

One of the cultural beliefs affecting the Hispanic population regarding diabetes self-management is familism. Familism is the prioritization of family over other individuals in the community (Gallaraga, 2007). Familism is an important factor in the health care decision making of the Hispanic patient, as traditional Hispanic individuals are more likely to seek advice from family members for their health care decisions (Gallaraga, 2007). To date, there have been studies focused on the influence of *susto* and *familismo* in the Hispanic populations in the United States; however, this previous literature has been focused on specific Hispanic populations. For example, previous studies on the influence of *susto* on diabetes management have been consistent among Mexican people with diabetes in the United States (Weller, Baer, Garcia, & Rocha, 2012). These provide evidence on the influence of *susto* on diabetes management for Mexicans and Mexican-Americans in the United States; however, the evidence may not apply to other Hispanic immigrants residing in different parts of the country. It is important to recognize that each Hispanic group may hold a distinct belief and may not be familiar with other Hispanic groups' ethnic beliefs practices. Exploring these factors is essential to the development of diabetes management and effective prevention for future complications for Hispanic immigrants with diabetes. Understanding the perspective of Hispanic people with diabetes may help illuminate ways to assist in control of this

disease. Through this qualitative narrative research, I explored the lived experiences of Hispanic immigrants with diabetes and the role of cultural and ethnic beliefs in diabetes management adherence among this population.

Purpose of the Study

The purpose of this study was to gain an understanding, through oral history narrative, of the experiences of Hispanic immigrants living with diabetes. This understanding is important for both managing and formulating policy for diabetes. There has been insufficient attention on the role of cultural and ethnic beliefs in diabetes management among the Hispanic population, the largest minority group in the United States (Calzada & Mora, 2011, Nobles, 2014). The life experiences and perspective of the Hispanic population regarding diabetes management are important to meeting the challenges of culturally sensitive, competent, and effective health care.

Research Questions

The main research question for this study is: What are the perspectives of Hispanic with diabetes towards disease self-management?

The subquestions are:

1. What are the self-reported ethnic or cultural beliefs toward health care needs for Hispanics with diabetes?
2. What is the lived experience on a daily basis for immigrant Hispanics with diabetes?
3. What are the cultural and ethnic beliefs that may influence how Hispanic immigrants manage their own diabetes condition?

Theoretical Framework

The present study was guided by the theory of reasoned action/theory of planned behavior (TRA/TPB). TRA and TPB are centered on cognitive factors like beliefs and values that may influence the health care behavior of individuals (Glanz, Rimer, & Viswanath, 2008, p. 68). Cultural and cognitive factors can affect the management of diabetes (Formosa, McInnes, & Mandy, 2012). TRA and TPB are focused on the constructs of attitude, subjective norm, and perceived control to explain different behavioral intentions and to predict influences on the individual's health care behavior (Glanz et al., 2008, p. 68).

According to TRA, intention is directly influenced by three constructs: subjective norm, perceived behavioral control, and attitude toward the intent to perform the behavior (Glanz et al., 2008, pp. 78-79). Intention consists of a combination of attitudes toward performing a certain behavior and subjective norms; therefore, a particular behavior is more likely to occur if the individual has a strong intention or the knowledge and skill to carry it out (Glanz et al., 2008, pp. 78-79). Individuals with a strong emotional negative response to the behavior are not likely to comply, whereas those with a strong emotional positive attitude towards it are more likely to change their behavior (Glanz et al., 2008). Subjective or perceived norm describes the social pressure that an individual feels to perform a behavior. If others view the behavior as positive, the individual will be motivated to meet their expectations; therefore, the likelihood that the behavior will occur increases (Bareolos, 2007; Glanz et al., 2008, pp. 78-81). TRA provided this study with the most appropriate framework due to its understanding of culture on normative beliefs.

This theoretical framework helped to explain which preventive health care behaviors the participants considered manageable or difficult to practice.

Nature of the Study

This study included a qualitative method of inquiry to determine Hispanic immigrants' perception of how to manage diabetes. A qualitative approach allowed for an in-depth exploration of participants' perception and understanding of managing their diabetes condition (see Al Qazaz, Hassali, Shafie, Sulaiman, & Sundram, 2011). Qualitative methodology provides additional pertinent information and broader comprehension to the data that were collected quantitatively. It provides complex textual descriptions on how the participants experience phenomena (Family Health International, n.d.). The oral history narrative approach was used to gather personal recollections of events—along with the causes and effects of the events—from the individuals themselves (see Creswell, 2013, p. 73). Oral history allows the researcher to tap into the rich life experiences of the participants and obtain valuable knowledge by gaining insight about pivotal moments of their lives (Hesse-Biber & Leavy, 2011, pp. 131-135).

Definition of Terms

Blood sugar or glucose: The main sugar that the body produces from food that is eaten. The glucose is carried through the body, providing the body with energy (MedlinePlus, 2014).

Curanderos: Trained spiritual faith healers who use prayers, herbal medicine, healing rituals, spiritualism, massage, and psychic methods to treat illnesses (American Cancer Society, 2014).

Diabetes: A chronic medical condition that affects the body's inability to sufficiently produce insulin (ADA, 22014).

Familist: Relates to a social framework that is focused on family relationships rather than on the needs of the individual (Weiler & Crist, 2009).

Fatalismo: The belief that life events are inevitable and that there is little people can do to affect their future (Dimension of Culture, 2011).

Hispanic: The term generally used to refer to a person originating from Latin America or Spanish descent living in the United States (freedictionary.com).

Simpatia: Accord, agreement and harmony in relationships, marriage, and society (Caballero, 2011).

Susto: A traditional belief in the Hispanic culture that illnesses are caused by a scar or emotional traumatic event that results in loss soul, inducing anxiety, appetite loss, and social withdrawal (Caban & Walker, 2006).

Assumptions

In this study, I assumed that Hispanic immigrants attributed the development of diabetes to some of their cultural beliefs. I further assumed that these Hispanic immigrants' cultural practices hindered their ability to manage their condition. The participants in this current study self-identified as Hispanic immigrants in cultural orientation and language, and I further assumed that due to their immigration status, their familiarity with North American medicine was low. I also assumed that participants would be willing to discuss their daily experiences with diabetes and their answers were honest.

Limitations

This study was based on a limited sample of qualitative interviews with immigrant Hispanic people with T2D diabetes in New York. Therefore, the findings of this study may not be generalized to the diabetic Hispanic population of the United States and requires further investigation through future studies. Another limitation concerning the population of study is the criteria; the participants must speak English fluently and should have been living in the United States in the past 15 years.

The research design is another possible limitation. The research quality was dependent on my skills as an interviewer. My presence during the data gathering, which is unavoidable in qualitative study, might have influenced participants' answers. To deter the participants from providing dishonest answers, I emphasized on the importance of providing honest answers that will help health care providers to understand their daily experiences living with diabetes. Issues of anonymity and confidentiality can be an issue when the findings are being presented. The participants were assured confidentiality. Another possible limitation of this study is the longitudinal effects. My measurements of the stability of and changes within the sample was constrained. The last limitation is that I am not of Hispanic descent, which may have influenced how participants conveyed information.

Delimitations

Delimitations explain the scope of the study. Because the current study was focused on a specific group of Hispanic immigrants, the result of the study may not apply to other Hispanic immigrant groups in the United States. A longitudinal study is

recommended for Hispanic immigrant groups from different cities in the United States for the result to be generalized. With regard to my fluency of the Spanish language, a native Spanish speaker was necessary to assist with interpretation of data that was in Spanish. My lack of fluency in the Spanish language was acknowledged clearly at the beginning of this study.

Significance

This study is important for health care professionals who treat Hispanic diabetes patients, as the study may facilitate development of appropriate diabetes management techniques tailored to this group. In addition, adequate understanding of the cultural and ethnic beliefs of Hispanic patients can improve the communication of the patients with their health care providers, increasing the quality of the care provided and enabling the patients to better manage their condition.

With the findings in this study, health care providers and policy makers, as well as other related medical organizations, will have useful information that they can use for developing culturally sensitive approaches to treating Hispanic diabetes patients. This study may result in positive social change by improving the quality of diabetes care programs tailored to the needs of the Hispanic immigrant population.

Summary and Transition

Diabetes has been a consistent health issue among Hispanic people, affecting 12% of this segment of the population (ADA, 2010; NAHH, 2010). In this chapter, I summarized how diabetes has gained prevalence among Hispanic people. I also summarized how various factors influence risks for the steady growth of diabetes among

Hispanic people exceeding other groups of the population in the United States. Learning the influence of cultural and ethnic beliefs on how Hispanic patients manage diabetes can assist in the development of diabetes management programs that specifically target the Hispanic population.

Chapter 2: Literature Review

Introduction

The purpose of this study was to gain an understanding, through oral history narrative, of the experiences of Hispanic immigrants living with diabetes. Gaining an understanding of the challenges of Hispanic immigrants with diabetes is important to understand the influence of culture and ethnic beliefs in diabetes management adherence among this segment of the population. Although researchers have known that Hispanic people are at higher risk for diabetes than non-Hispanic Whites, previous literature has offered little insight into the daily experiences of Hispanic immigrants with diabetes (Schneiderman & Knight, 2014). Future research efforts related to this subject must consider the complex influence of cultural and ethnic beliefs on disease management to understand the higher prevalence of diabetes among Hispanic people. Public health practitioners, educators, and health care providers can use the findings of this study to develop more effective approaches to providing a culturally and linguistically appropriate diabetes management care with the potential of achieving much improved diabetes outcomes among Hispanic people.

In this chapter, I review the literature covering diabetes program for the Hispanic and non-Hispanic communities. This literature review includes studies on cultural and ethnic beliefs, depression and stress, physical activity, literacy, and patient–physician relationships. The research on Hispanic immigrants with diabetes toward disease self-management provided by clinicians has both qualitative and quantitative history. This literature included education programs for Hispanic subgroups, community intervention

approaches, structured and unstructured interviews, surveys, and medical-record reviews. The following literature review encompasses a variety of approaches to gaining understanding of culture and ethnic beliefs as barriers and factors to diabetes prevention and control among Hispanics and their perception of diabetes self-management and treatment.

Literature Search Strategy

I gathered literature relating to my study from the following databases dating from 2007 to 2015. Database sources include the Educational Resources Information Center (ERIC), Google Scholar, Thoreau, Cumulative Index to Nursing and Allied Health (CINAHL), PubMed, Medline, Science Citation Index Expanded (ISI Web of Science), Health Sciences: SAGE full-text collection, Health and Medical Complete, Science Direct, Database of Abstracts of Reviews of Effects (DARE), ProQuest, Health and Medical Complete, Annual Reviews, Science Direct, and Elsevier Direct. I also reviewed professional journals for articles relating to diabetes, and diabetes management among Hispanics. These journals include the *Journal of the American Dietetic Association, Diabetes, Diabetes Care,* and *Annals of Family Medicine. Journal of Health Care for the Poor and Underserved.*

Medical search terms included *diabetes, diet, diabetes* and *culture* combined with *Hispanics, Latinos, Hispanic Americans, Mexicans, Cubans, and Puerto Ricans, Caribbean Hispanics, Latin Americans,* or *Hispanic immigrants.* To these key terms were added *acculturation and diabetes, ethnic beliefs, attitude towards illness, cultural diversity, barriers to diabetes adherence, cultural competency, depression, health*

services, health beliefs, familist, preventive health care, emotional stress, health literacy, socio economic, environmental factor, impact, curandero, familism, gender role, coraje, and *susto.* Additional terms used in various combinations were *Hispanic lived experiences, qualitative, quantitative, narrative, case study, surveys, randomized control trial,* and *cohort studies.* These terms were used to locate relevant literature in all databases accessed for this study.

The Hispanic Population and Diabetes

The U.S. census reports that the Hispanic population is the fastest growing and the largest minority group in the United States (U.S. Census, 2010). An estimated 40 million Hispanic people live in the United States, with another 3.9 million more living in Puerto Rico (U.S. Census, 2010). The Hispanic community in the United States comprises people from diverse geographic locations, including South and Central America, Mexico, the Caribbean, and Spain. Each subset of the community practices unique customs and traditions that differ from those practiced by the Hispanic people found in mainstream U.S. culture. The variations in the cultures of these different groups means that broad conclusions cannot be drawn about the larger Hispanic population in the United States (Schmid, 2006). Padilla and Villalobos (2007) suggested that understanding the culture of a community—shared beliefs, values, and behavior—assists in the implementation of successful health programs for intervention or prevention. The Hispanic population in the United States has three major subgroups: Mexican-Americans, Puerto Ricans, and Cubans. Diabetes studies focused on each subgroup indicate higher prevalence of diabetes cases in comparison to non-Hispanic Whites in the United States.

Mexican-Americans make up 64% of the Hispanic population in the United States, representing 14.5% of the entire U.S. population (Ohio State University, 2010; Vaello, 2008). Diabetes rates among Mexican-Americans are unusually high at 16.3% compared to 9% among non-Hispanic Whites (Kendzor et al., 2014). Mexican-Americans are also one of the heaviest groups in the U.S. population; three out of four Mexican-American adults are either overweight or obese (Martorell, 2005). Researchers have noted that Mexican children especially those who live along the U.S.–Mexico border have low intake of the traditional Mexican diet of fruits and vegetables (Martorell, 2005). Studies have also suggested that one of the contributing factors of the higher rates of diabetes among Mexican-Americans is lower socioeconomic status and education (Kendzor et al., 2014). The lack of education and lower understanding of disease management has been noted to contribute to higher rates of diabetes among Mexican-American communities, particularly with older individuals (Ramar & Desai, 2010).

The Puerto Rican subgroup of Hispanics in the United States ranks as the poorest among Hispanics. Their lower socioeconomic status has been cited as one of the factors contributing to their poorer health outcomes. The CDC (2014) reports Puerto Rico's diabetes rates rose from 11.7% in 1995 to 12.7% in 2010 (Caribbean Business, 2014). Over 500,000 out of the 3.7 million people in Puerto Rico suffer from diabetes (Caribbean Business, 2014). In the United States, Puerto Ricans make up 10.1% of all diabetes cases among the overall Hispanic population (CDC, 2014). Puerto Ricans, just like Mexican-Americans, are burdened by higher rates of diabetes. Current literature suggests that few culturally appropriate diabetes programs are focused on Puerto Rican-

Americans, which does not address the high rates of diabetes and diabetes-related complications for this population (Osborn et al., 2011).

Cuban-Americans represent 4% of the Hispanic population in the United States (Huffman, Vaccaro, Zarini, & Nath, 2009). Past literature indicates that Cuban-Americans have been given little attention in terms of their health status (Huffman et al., 2009). Past research also revealed that deaths from diabetes are more than twice as common among Cuban-Americans as non-Hispanic Whites. Cuban-Americans have the highest death rates associated to diabetes at 44% compared to Puerto Ricans at 39% and Mexican-Americans at 37% (Huffman et al., 2009). Previous literatures covering the health status of Cubans also suggests that culture play a great role in diabetes management. Cuevas (2013) indicated that due to stigma and social expectations, the family and support do not always provide a positive influence. A Hispanic cultural belief like *fatalismo* is found more among Cubans who are older, with less education and who fall within a lower socioeconomic bracket (Cuevas, 2013). Similar to other Hispanic subgroups, food also plays an important role in diabetes management among Cubans with diabetes (Cuevas, 2013).

Hispanic Acculturation to Mainstream U.S. Culture

For Hispanic immigrants, the acculturation to U.S. mainstream culture goes beyond language use and preference (Perez-Escamilla & Putnik, 2007); it is more complicated and may not be constant across dimensions. For instance, Hispanic immigrants have distinct culture and practices that differentiate them from those Hispanic individuals born in the United States. Despite lower socioeconomic status and lack of

education, the new immigrants are found to be generally healthy (Trooskin et al., 2010). However, Hispanic immigrants tend to lose the protective influence of their native culture on their general health as their length of stay in the United States progresses (Trooskin et al., 2010).

When individuals begin to assimilate more into the mainstream culture of the United States, they can begin to change their health behavior and start to adapt to their new surroundings (Trooskin et al., 2010). Their diet changes, and as a result, obesity has become a significant health issue. Heavy acculturation among the immigrant Hispanics with mainstream U.S. culture has been associated with the higher incidences of diabetes cases in these communities (Escare, Morales, & Rumbaut, 2006). A cross-sectional analysis of Hispanics across the United States between 2007 and 2010 revealed that the risk of diabetes was higher among those acculturated Hispanics than those who have not been acculturated to the U.S. mainstream culture (O'Brien, Alos, Davey, Bueno, & Whitaker, 2014).

Although acculturation of Hispanic to the mainstream U.S. culture has been beneficial in terms of access to health care and improved socioeconomic status, the less acculturated Hispanics with diabetes tend to have a healthier diet than their more acculturated counterparts (Mainous, Diaz, & Geesey, 2008). Acculturated Hispanics who have adopted the "American" diet are less likely to consume food with higher fiber and more inclined to have a diet higher in saturated fat. However, some acculturated Hispanic communities recognize the importance of healthy dietary habits and increased physical activities in maintaining healthy lifestyle changes (Ghaddar, Brown, Pagan, & Diaz,

2010). Past research on Hispanic acculturation has also demonstrated that Hispanic immigrants have difficulty maintaining their traditional practice as they adapt to mainstream U.S. culture, which has been linked to the likelihood of developing diabetes (Mainous et al., 2008).

Although acculturation has been observed to have influence on the health behavior of Hispanic immigrants, it is also important to include some distinct health barriers that are associated to the higher rates of diabetes cases among Hispanic communities. Access to health care, language, culture, and economic barriers all play a role in the higher rates of diabetes mortality and morbidity, diabetes complications, and access to provision of appropriate diabetes management for Hispanic populations (NAHH, 2010; Nobles, 2014). Many Hispanic immigrants work in low paying jobs that preclude them from obtaining health insurance. Factors like inadequate health insurance and access to preventive care are important to consider, but taking cultural influence on health behavior and decision making into account is also important for improved health outcomes among Hispanic immigrants with diabetes (Ghaddar et al., 2010; NAHH, 2010).

Hispanic Cultural Values

The Hispanic immigrant population in the United States come from diverse backgrounds. Although they have the Spanish language in common, their history, traditions, ethnic beliefs, and values vary from each subgroup (Caballero & Tenzer, 2007). The Hispanic population is the fastest growing minority group in the United States, making up 12% of the entire U.S population (U.S. Census, 2010). Hispanic people

have strong feelings of belonging to their group and work hard to be a part of their community ("Understanding Hispanic Culture," 2014). Hispanic people also tend to be less confrontational and find ways to avoid arguments. Additionally, Hispanic individuals place a higher importance on loyalty to their community and put high value on family. The traditional Hispanic family is a close-knit group and family is the most important social unit and the family needs usually overrules the individual's needs ("Understanding Hispanic Culture," 2014). This network in the Hispanic culture is a source of support when addressing a variety of challenges or crises that may arise. According to researchers, these cultural factors along with certain environmental influence are important to consider when discussing the development of diabetes management programs designed for Hispanic people (Cusi & Ocampo, 2011; Nobles, 2014).

Familism and Diabetes

Familism in the Hispanic culture is a set of normative beliefs that focused on the importance of the family unit and emphasizes the obligations and support that members owe to both immediate and extended families (Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, as cited by German, Gonzales, & Dumka, 2009). Although familism is not inherent to the Hispanic community, the high priority accorded to family is considered to be a core cultural value in Hispanic traditions, which is passed on from generation to generation through the teaching of parents and social interactions that parents have with their children (German et al., 2009). Familism is a belief in the Hispanic culture that family members have the responsibility to provide economic, moral, and emotional support to their kin and relatives. Hispanic familism involves the expression of family

solidarity and the desire to care for the individual regardless of the cost (Weiler, 2007). The typical Hispanic family lives in multigenerational household, and they each contribute support and decision-making. Hispanic patients also include their family in their health decision-making (Gallaraga, 2007).

Among diabetes literature, the findings on the effect of familism are mixed. Some studies indicate the positive impact of family on diabetes management whereas others do not. Weiler and Crist (2009) suggested that the role of the family is vital to the family member with illness; however, the influence of the family can either undermine or strengthen diabetes management. For example, family and social gatherings have been the biggest challenge for Hispanic people with diabetes (Lindberg, Stevens, & Halperin, 2013). Hispanic family celebrations involve social pressure to overeat, making it difficult to adhere to diabetes prescribed diet (Caballero, 2011). Food does not only provide daily sustenance but also serves as the core element that binds Hispanic families and communities (Lindberg et al., 2013). Integrating a diabetes meal plan has been the base of cultural issues for many Hispanic patients; sticking with a diet different from their family diet has been a challenge (Awalom, 2014). For instance, Awalom (2014) observed that a Hispanic woman may be considered "self-indulgent" if she changes the family diet according to the medically prescribed diabetes meal plan. Thus, family support for diabetes dietary adherence is critical for diabetes self-care.

Although *familismo* is an important aspect of the Hispanic culture and family is the primary source of assistance in diabetes management, it can also render it difficult for individuals to make decisions concerning their health (Caballero, 2011). Hispanic

individuals suffering from diabetes may feel compelled to discuss diabetes treatment and lifestyle modification with their family members prior to adhering to a plan and weigh their opinions heavily (Caballero, 2011). Previous studies also indicate that Hispanics with diabetes face challenges, frustrations, and confusion in altering their diet and find difficulty in refusing offers of traditional food from family and friends that are not appropriate for the diabetes dietary regimen (Hu, Amirehsani, Wallace, & Letvak, 2013).

Findings from recent studies indicate that family members of individuals with diabetes provide emotional support, encouragement, and motivation to participate in physical activities and health diet (Hu et al., 2013). However, family members conveyed concern of not having adequate knowledge of diabetes to provide support to their diabetic family member (Arora, Marzec, Gates, & Menchine, 2011; Hu et al., 2013). Cultural influence has a principal importance in the Hispanic families, as the management of health is usually the concern of the entire family (Arora et al., 2011). It is within this cultural context that proposals for diabetes program tailored for Hispanic with diabetes must shift from that of individual responsibility to family responsibility (Weiler, 2007). Family networks have been reported to be the dominant source of help and advice for generations and have been the most important entity in the Hispanic culture (Awalom, 2014; Hu et al., 2013).

Fatalism or *Fatalismo* and Diabetes

Literature relating to Hispanic culture has suggested that Hispanic people have their own perceptions of the causes of illnesses (Colon, Giachello, McIver, Pacheco, & Vela, 2013). One of these cultural beliefs is *fatalismo*, which is the belief that individuals

cannot alter their destiny; it was their fate to have diabetes, and therefore they deem it futile to seek help to treat their diabetes conditions. Many Hispanics with diabetes have been observed to have fatalistic stance and see no reason to continue with diabetes management as they were doomed to suffer the complications anyway (Rustveld, Pavlik, Jibaja-Weiss, Kline, Gossey, & Volk, 2009). Research has shown that fatalistic beliefs to be a barrier in achieving glycemic control among Hispanic people with diabetes (Desai, Ramar, & Kolo, 2010; Walker, Smalls, Hernandez-Tejada, Campbell, Davis, & Egede, 2012). Findings from recent literature indicated that many Hispanic people with diabetes believe that their illness may be out of their control and it came from "higher beings"; thus, adhering to management prescribed plan may not help improve their diabetes condition (Desai, Ramar, & Kolo, 2010). Some believe that diabetes is a punishment from God (Caban & Walker, 2006), and God will decide of the outcome. Weiler and Crist (2007) noted that often an individual with diabetes is stigmatized as a result of the belief that diabetes is God's punishment.

This fatalistic belief that is engrained in them catalyses the conviction of helplessness preventing them from performing necessary behavior to avoid further health complications. Fatalism, along with the social stigma attached to diabetes influences the denial by some Hispanic individuals with diabetes about the reality of disorder and its complications (Caban & Walker 2006, Weiler & Crist, 2009). Caban and Walker (2006) noted these feelings of helplessness, prevented patients from adhering to diabetes self-management plans. These fatalistic beliefs are not merely confined with the diabetic individual, Castro-Riva, Boutin-Foster, Milan, and Kanna (2014) noted that even the first

degree relatives of Hispanic individuals with diabetes share similar beliefs, asserting that just by being Hispanic they are destined to have diabetes. Fatalistic beliefs are common among Hispanics with diabetes and their immediate families, which often impedes adherence to diabetes management treatment plan (Awalom, 2014; Castro-Riva, Boutin-Foster, Milan, & Kanna, 2014; Rustveld, Pavlik, Jibaja-Weiss, Kline, Gossey, & Volk, 2009). Further, patients who are exhibiting higher levels of fatalistic attitude may demonstrate correspondingly lower compliance in diabetes self-care (Walker, Smalls, Hernandez-Tejada, Campbell, Davis, & Egede, 2012). Recent literature also suggested that even though the patient's family may have adequate knowledge about the risks and consequences of diabetes, their fatalistic beliefs may influence their health decision-making and may impede them from adhering to diabetes management treatment (Castro-Riva, Boutin-Foster, Milan, & Kanna, 2014).

Such findings of the effects of cultural beliefs help illustrate the importance of better understanding each individual's conviction of their ethnic beliefs and how it affects diabetes treatment when dealing with the Hispanic population (Campos, 2006). Addressing these traditional beliefs through culturally focused diabetes intervention programs may help stem the higher rates of diabetes cases among the Hispanic population (Castro-Riva, Boutin-Foster, Milan, & Kanna, 2014).

Susto and Diabetes

Susto is a folkloric belief in the Hispanic culture that is attributed to the soul leaving the body as a result in an unhappy mood and sickness (NYS Office of Mental Health, nd). Individuals who suffer from *susto* also experience the feeling of inadequacy

in fulfilling their social roles. The context of *"susto"* is more popular among Mexican-American subgroup but it is observed cross-culturally at a lesser extent among other Hispanic subgroup (Hatcher & Whittemore, 2006; Mendenhall, Fernandez, Adler, & Jacobs, 2012). Research also indicated that *susto* is a more common practice among Hispanics in the lower socioeconomic status, especially among Mexican-Americans (Mendenhall, Fernandez, Adler, & Jacobs, 2012). Traditional ways of healing individuals with *"susto"* involves ritual healing practice in which traditional healers or "*curanderos"* are called upon to perform the calling back of the soul to return to the body (Acosta, 2014; Mendenhall, Fernandez, Adler, & Jacobs, 2012). "*Curanderismo"* is a traditional healing system practiced in the Hispanic culture that incorporates the use of herbs, massages, diet, prayer, and spiritual medicine (Wellness, 2014). Literature focused on the role of *"curanderos"* in diabetes management among Hispanics is limited (Melancon, 2008). One of the past studies focusing on the role of "*curanderismo"* in individuals diagnosed with diabetes was from Najim, Reinsch, Heohler, and Tobis (2003) indicated only 8% of Hispanics with diabetes used *"curanderos"*as an alternative to conventional modern physician.

Among low-income Mexicans *"susto"* has been found to be the ubiquitous etiologic reasoning for diabetes onset, and they believe that their diabetes conditions derived from experiencing "*susto"* a frightful event that cause a scare in individuals resulting in developing diabetes (Mendenhall, Fernandez, Adler, & Jacobs, 2012; NYS Office of Mental Health, nd). According to Hatcher and Whittemore, (2006) many Hispanic adults with diabetes believe that a frightful event has made them susceptible to

diabetes. The manifestation of diabetes after "*susto*" varies in time; it could take days or sometimes years before diabetes caused by *"susto"*develops (Hatcher & Whittemore, 2006). Wallace and Benyshek (2006) indicated that insufficient studies have focused on the relationship of "*susto"*and diabetes considering that literature reports 75% of Hispanics believe in the impact of *"susto"* as corroborated by Mendenhall, Fernandez, Adler, and Jacobs (2012). The higher percentage of *"susto"* believers warrant further investigation concerning the role of "*susto*" plays (Mendenhall, Fernandez, Adler, & Jacobs, 2012). Such exploration will better illuminate the putative relationship between *"susto"* and diabetes and may provide better information for health care providers to improve communication (Wallace & Benyshek, 2006).

Depression and Diabetes among Hispanics

Depression and diabetes frequently co-occur and are the most prevalent chronic diseases globally (Huang, Wei, Chen, & Guo, 2013). The co-morbidity of diabetes and depression has been reported to be as high as 33% in the Hispanic communities (Hansen & Cabassa, 2012). However, Hispanic immigrants have been documented to have lower cases of depression in comparison to their U.S. born counterparts and Non-Hispanic Whites (Martinez Tyson, Castaneda, Porter, Quiroz, & Carrion, 2012). Accordingly, Martinez et al. (2012) further suggested that Hispanic immigrants are less likely to seek mental health help when they are in a depression state.

In a study conducted by Mendenhall et al. (2012) the participants who were mainly immigrant Mexican women with type 2 diabetes spoke of social isolation, stress related to health, family, neighborhood violence, and immigration status as contributory

to their depression associated to diabetes. Cabassa, Hansen, Palinkas, and Ell (2008) suggested Hispanic people with diabetes are less likely to receive guideline congruent depression care than their counterpart non-Hispanic Whites.

Dietary Interventions

The Hispanic diet has become a focus of study in recent years because it was viewed to be the possible explanation for higher rates of obesity in the United States in comparison to non-Hispanic Whites (Martinez, 2013). Heuman, Scholl, and Wilkinson (2013) conducted a multi-method research approach with four focus groups, with total of 49 participants of Hispanic residents in rural West Texas. The authors' aims were to gather and analyze data concerning health literacy, knowledge of diabetes, diet and exercise habits, language preference and media use habits among Hispanic parents and adolescents. The authors observed five major themes that emerged from the study such as: susceptibility to diabetes, diet, importance of parental guidance, challenges to eating healthy, and lack of social support from a greater network. The participants in this study expressed a genetic predisposition influencing their risk of developing diabetes. Some also spoke of the fatalistic belief that diabetes is beyond their control and it is the "will" of higher power. English speaking Hispanic people who are more acculturated to mainstream U.S. culture also observed food consumption reflecting higher consumption of food with higher fats. The larger participants in this study the authors indicated were more likely to be obese and have diabetes in comparison to the less acculturated ones. Those participants who were less acculturated and Spanish speaking expressed their desire to eat healthy but also admitted that the ritual of eating high in carbohydrates

comfort food has been part of the culture for generations. This study suggests that those who are less acculturated Hispanics also have difficulty adhering to a diabetes compliant diet.

Physical Activity

The low level of physical activity along with poor diet has been attributed to increased rates in obesity in the United States (Ickes & Sharma, 2012; Ferrari, Siega-Riz, Evenson, Moos, & Carrier, 2013). The rates of obesity a contributing factor to T2D is higher among the Hispanic population than non-Hispanic whites (Ickes & Sharma, 2012). The rates of diabetes among Hispanics are 2 to 3 times more compared to non-Hispanic whites and Hispanics are more likely to die from diabetes (Ickes & Sharma, 2012). Research has consistently indicated the importance of exercise with respect to maintaining glucose control (Wheeler et al. 2014).

Incorporating physical activities with diabetes management regimen is especially advantageous for people with diabetes; it helps promote physiological changes that affect the liver insulin sensitivity (Wheeler et al. 2014). Ickes and Sharma (2012) further noted inactivity is more prevalent among the Hispanic communities. Some of the contributing factors to inactivity among adults include "low income, lack of time, and lack of motivation, obesity and advancing age" (Ickes & Sharma, 2012). Nyberg, Ramirez, and Gallion (2011) suggested inactivity among Hispanics immigrants has been attributed to heavy acculturation, as immigrant children navigate their way into the U.S. mainstream culture they are more likely to be sedentary which increases their risks for obesity. Addressing the lack of physical activity among Hispanic people with diabetes involves

understanding various influences in physical inactivity like social, cultural, economic, and environmental factors (Parra-Medina & Hilfinger-Messias, 2011). Furthermore, Wheeler et al. (2014) noted there is a lack of studies investigating the role of physical activities in T2D among Hispanic people with diabetes. Wheeler et al. (2014) suggested effective diabetes programs need to include strong physical activity components that are culturally and language sensitive diabetes education as a way to encourage physical activities among Hispanic immigrant people with diabetes and achieve improved diabetes outcomes.

Parra-Medina and Hilfinger-Messias (2011) conducted a study among immigrant Hispanic women in Texas and South Carolina on the influences of factors like social, cultural, economic, and environmental in physical activities among Hispanic immigrants. The study revealed lack of personal knowledge and limited English proficiency were noted as barriers to participating to physical activities among Hispanic immigrant women. Furthermore, the researchers also noted that among the Hispanic immigrant participants stated to have little knowledge or exposure to walking primarily to exercise. Concerns of not feeling safe in the environment where they reside or the sense of feeling not welcome were also noted as contributing factors to the lack of engagement in physical activity among recent Hispanic immigrant women.

In addition to the influence of environment participants also claimed dominance of their domestic responsibilities and workload was also revealed as contributing factors to non-participation in physical activities. The authors indicated among the recent immigrants social and cultural influences were noted as barriers, family responsibilities

like maintaining the order in the household along with the concerns of sustaining an employment preceded the desire of Hispanic immigrant women to engage in leisurely physical activities. Findings from Parra-Medina and Hilfinger-Messias (2011) indicated a need for interventions that culturally and linguistically appropriate programs addressing multiple levels of influence.

Wheeler et al. (2014) used En Balance program to assess the feasibility of culturally and linguistically sensitive diabetes education approaches to encourage increased physical activities among Spanish-speaking Hispanics in Inland Empire of Southern California. En Balance is a program that is culturally and language sensitive specifically tailored for Spanish-speaking adults. The authors conducted a 3-month assessment to test the impact of the program among 39 Spanish-speaking adults. The diabetes program En Balance was taught weekly for the first month by bilingual educators and those who missed attendance make-up classes were provided for them. The education stressed the importance of diet and exercise in their diabetes management regimen in order to achieve glycemic control. The participants were provided extensive education including personal instruction on how to use monitor as a way "to reinforce the principles of glucose control" (Wheeler et al. 2014). The participants were strongly encouraged to increase physical activity and modify lifestyle habits. After 3 months of the En Balance program the researchers noted a significant increase in moderate intensity physical activity energy expenditure, high intensity physical activity, significant reductions in total cholesterol and reduction in waist circumference.

The findings from Wheeler et al. (2014) indicated incorporating culturally and linguistically sensitive approaches in diabetes management programs particularly interventions that stress the vital role of diet and exercise can positively impact lifestyle changes among Spanish-speaking Hispanics with diabetes. In Wheeler et al (2014) study demonstrated the importance of culturally sensitive materials and the consistency of patient-health care provider relationship. Because of language and cultural barriers Hispanic immigrants with diabetes are deterred from adhering to necessary components in achieving glucose control. Patients with different cultural background from U.S. mainstream culture may feel discouraged to maintain diabetes adherence due to their lack of proficiency in the English language and understanding of the diabetes information provided.

Bautista, Reininger, Gay, Barroso, and McCormick (2011) surveyed 398 Hispanic participants in South Texas to assess the levels of and perceived barriers to exercise. Results from Bautista et al. (2011) challenged previous studies findings in South Texas and other Hispanic populations, fewer participants from this study reported not exercising at all, and a larger percentage did not meet physical activities recommendation at all. Furthermore, Bautista et al. (2011) noted similar findings from Parra-Medina and Hilfinger-Messias (2011) the female participants in both studies indicated “lack of time for exercising”, “very tired” and “lack of discipline to exercise”. These findings indicate that among Hispanic women traditional norms restrict them from engaging in physical activities.

In the Hispanic culture, Bautista et al. (2011) noted the role of the women is to care for their family and when women allot time for themselves it could be interpreted as being "selfish". Further, it is evident from both studies that Hispanic women have the tendency for self-deprecation and devaluing their own health. The authors also noted that the participants also reported that engaging in physical activities might not resonate well with their spouses or partners due to concerns of safety, jealousy or insecurity.

These issues of cultural challenges are also compounded by the lack of wider public exposure participating in physical activities in Hispanic communities. Findings from both studies confirm traditional gender role in the Hispanic culture play a significant aspect in health decision making of Hispanic women. As Wheeler et al. (2014) suggested interventions that are culturally sensitive, and the inclusion of the family unit can positively encourage physical activity levels as well as nutritional changes among Spanish-speaking Hispanic communities. Health education programs that are language sensitive especially tailored for those individuals who lack English proficiency may encourage change and consistency among Hispanic people with diabetes and lead to improved diabetes outcomes within this population (Wheeler et al. 2014).

Health Literacy

Low health literacy has been defined by Healthy People 2010 as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services to make appropriate health decisions" (National Institute of Health, 2014). Health literacy requires the individual to possess the skills and understanding of information and services used in order to make appropriate decisions.

According to Berkman et al. (2011) low literacy among minority populations like Hispanic and Asian Americans has been associated to the under reporting of health status in these segments of the U.S. populations. Furthermore, Sentell and Halpin (2006) indicated literacy "maybe an important factor in health disparities," thus eliminating its significant role has been erroneously attributed to other factors."

Health literacy requires the understanding the full meaning of words, "analyze information, and comprehend instructions, weigh risks and benefits" and ultimately being able to make decisions and take action (NIH, 2014). Low health literacy affects more than 90 million American adults, "where 43% of adults demonstrate only the most basic or below levels of prose literacy" the National Institute of Health (2014) reported.

According to the 2003 report of health literacy from the *National Assessment of Adult Literacy* about 66% of Hispanic adults have basic or below levels of health literacy skills and lower health literacy levels than any adults in any other ethnic groups (Kutner, Greenberg, Jin, & Paulsen, 2003). Paramount in effective diabetes care is the ability of the individual to understand the process of the various steps in self-diabetes management. Sentell and Braun (2012) suggested low health literacy and limited English proficiency has been associated to poorer health status of Hispanics (Latinos). The ADA (2013) noted those individuals with low health literacy who suffer from T2D have less diabetes knowledge and worse glycemic control in comparison to those who have higher health literacy.

Patients-Health Care Provider and Low Health Literacy

Rothman et al. (2004) conducted a randomized trial to examine the role of low health literacy on the effectiveness of diabetes self-care for individuals with diabetes. The study enrolled 217 patients aged 18 years and older with T2D and poor glycemic control. The patients in the control group received usual care from their primary health care provider and had not any contact anymore with the comprehensive disease management team. Meanwhile the individuals in the intervention group intensive diabetes management team consisting of three clinical pharmacist practitioners and diabetes care coordinator provided their usual diabetes care. Those samples from the intervention group were also provided one on one education session, counseling and medication management. The diabetes care coordinator contacted the intervention group 2 to 4 times a week.

Further the communication used to communicate with the intervention group was individualized and used technique that in accordance with their literacy level utilizing picture based information materials. Rothman et al. (2004) observed that those individuals with low health literacy when accompanied by comprehensive diabetes management program adhered to diabetes self-care to a greater degree than those individuals with higher literacy levels. Similarly, those individuals in the intervention group Rothman et al. (2004) revealed were more likely to follow through with diabetes management and achieve goals than those in the control group who have higher literacy levels. Rothman et al (2004) discovered the impact of taking time with the patients and allowing them to understand the process of self-diabetes care with less complex

approaches can assist individuals with diabetes with low health literacy achieve diabetes management goals and overcome barriers such as literacy issues.

In another study, Cavanaugh et al. (2009) included literacy-numeracy appropriate elements to a diabetes education program and observed significant improvement in glycemic control among the participants compared to those participants that did not include these components. Health literacy is an important predictor of improved glycemic control (Cavanaugh et al. (2009). The result from Rothman et al. (2004) indicate that literacy is more than the meaning of words but also involves time and active listening and using techniques that are appropriate to the literacy levels ensuring the individuals with diabetes comprehend the information being provided to them. Cavanaugh et al. (2009) also suggested that applying literacy components to diabetes management program could lead to improved diabetes outcomes. Although, in Cavanaugh et al (2013) indicated that after 3 months the intervention participants have much improved glycemic control during the period intervention delivery, the improvement declined after the program concluded.

Thus, findings from Cavanaugh et al. (2009) suggested that literacy-numeracy components and continued support from health care providers maybe necessary to achieve successful glycemic control among patients with lower literacy. Observational studies including literacy and culture-sensitive components in intervention program in ethnic minority populations like Hispanic people have also documented improved diabetes control among participants (Rosal et al., 2011).

In Rosal et al. (2011) and Cavanaugh et al. (2009) demonstrated the important role of health literacy and continued health care provider guidance in the much-improved

diabetic management outcomes of diabetic individuals. These theory-based studies observed significant improvements in self-management behaviors among participants in three key areas (Rosal et al. 2011). Furthermore, Cavanaugh et al. (2009) suggested strategies to sustain the improvements of diabetes self-management among individuals are necessary. Similarly, Rosal et al. (2011) added improving the knowledge and self-efficacy of diabetic individuals requires literacy-sensitive materials and strategies. Consistent interaction between patients and health care providers appeared to be a significant factor in achieving glycemic control among individuals with low health literacy levels.

In addition to low health literacy, Hispanics often concede to their fatalistic beliefs resulting to non-compliance of diabetes self- care and so, are unlikely to seek help or adhere to consistent diabetes management (Larkey, Hecht, Miller, & Alatorrem, as cited by Carranza, 2014). Carranza (2014) conducted a study among 16 Spanish speaking Hispanics (Latino) ages 39 to 79 that were diagnosed with T2D using descriptive qualitative study. The samples were a convenience sample and were recruited based on their low literacy level. The interview was done in structured manner due to the low level of literacy among the participants. The result showed about 62.5 % of the participants were able to report the symptoms of diabetes while the result of their patient's understanding of how to interpret nutritional label revealed 81.3% stated did not know how to accurately interpret nutritional label. The findings indicated that the greatest challenge of achieving glycemic control among this population was lack of time during

doctor's visit, lack of understanding on nutritional information, and resources are not linguistically appropriate (Carranza, 2014).

Furthermore, Carranza (2014) reported in addition to various factors like visual handicaps, literacy issues, and possessing elementary level of understanding, intricate nutrition labeling also hinder Hispanic people with diabetes from appropriately following required intake of carbohydrates per meal. Accordingly, Carranza (2014) also noted that Hispanic people experience inadequate time with health care providers leading to receiving unsatisfactory information necessary to properly manage their diabetes conditions. Findings from Carranza (2014) indicate a vital need in addressing literacy among Hispanic population in order to achieve better diabetes management outcomes. In consistent with Cavanaugh et al. (2009), Rosal et al. (2011) and Rothman et al. (2004), findings from Carranza (2014) indicate the importance of patient-health care provider consistent relationship and the time allotted to each patient to further explain information in a comprehensive manner to individuals with diabetes with low literacy levels. Further in consistent with Rothman et al. (2004), Carranza (2014) suggested developing culturally appropriate information along with the use of animated pictures to illustrate instruction on how to achieve portion control would assist Hispanic patients with low health literacy to comprehend diabetes management regimen with less complexity.

White, Osborn, Gebretsadik, Kripalani, and Rothman (2013) sought to learn more about the relationship of low health literacy with psychosocial factors like trust on health care provider, self-efficacy for diabetes care, and acculturation can influence diabetes outcomes among Hispanics with diabetes with limited resources. White et al. (2013)

further noted that health literacy might also influence trust on health care provider. Trust on health care provider is an important factor in achieving glycemic control. To achieve glycemic control that involves complex activities like monitoring blood glucose levels, managing insulin intake and oral medication, monitoring appropriate diet, and physical activities engagements (White, Osborn, Gebretsadik, Kripalani, & Rothman, 2013).

Each activity involved in diabetes management regimen requires knowledge, motivation and the ability to comprehend complex food labeling posing significant issues among those with low health literacy and psychosocial barriers (Carranza, 2014; White, Osborn, Gebretsadik, Kripalani, & Rothman, 2013). The findings from White et al. (2013) indicate among those Hispanics with diabetes, those with low health literacy were found to have greater trust in their health care provider, greater self-efficacy for diabetes care, and greater adherence to diabetes management regimen including general diet. The study results from White et al. (2013) challenge the findings from Carranza (2014), Cavanaugh et al. (2009), and Rosal et al. (2011) that higher literacy level does not associate significantly greater with diabetes self-care.

Furthermore, White, et al. (2013) suggested those individuals with higher literacy are more likely to verify the credibility of information received from their health care provider and explore other options beyond what is given during their visit with their physician. From White et al. (2013) study indicates that health literacy is not a barrier to diabetes self-care among low income Hispanics with diabetes. The White et al. (2013) study demonstrated that Hispanics people with diabetes, specifically those with low health literacy have greater adherence to diabetes management. The researchers noted

that those individuals with low health literacy are more inclined to follow diabetes management regimen and trust their health care provider without questioning the recommendations compared to those with higher health literacy individuals. The study has several limitations include a small sample size and may not apply to other more established Hispanic population and other Hispanics who speak English well. The study also did not gauge the length of time of the patient-physician relationship, ethnic and linguistic, or level of patient engagement.

The successful management of diabetes is often achieved through combination of lifestyle changes and doctor-patient relationship (Shaw, Huebner, Armin, Orzech, & Vivian, 2008). As Carranza (2014) observed the length of time spent by the health care provider with the patient impacts the necessary logistics of properly explaining appropriate diabetes management regimen. As Campos (2006) noted "improvements in health literacy" can be assisted by better patient-health provider communication, along with the provision of culturally appropriate information to patients. Further, Campos (2006) suggested that any efforts in enhancing health literacy among Hispanic people with diabetes should involve family members when it is appropriate. Family engagement is vital in Hispanic culture; their involvement is vital to their effective diabetes self-management care.

Theoretical Framework

As previously described, the foundation for this study is based on theory of reasoned action and theory of planned behavior (TRA/TPB). Understanding the influence of culture and ethnic beliefs to diabetes management regimen among Hispanic

immigrants comes from TRA/TPB theories. TRA/TPB is useful in investigating culturally specific attitudes, subjective norms, perceived control, and intentions related to diabetes management among Hispanic people with diabetes (Zoellner, Krzeski, Harden, Cook, Allen, & Estabrooks, 2012). One of this theory's constructs subjective norms is helpful in determining the influence of culture on disease management; it implies that a positive product demonstrates behavioral intent (Glanz, Rimer, & Viswanath, 2008, pp. 72-77). Further, Ajzen's (1991) as cited by Abraham and Sheeran (2003) TRA was specifically designed to predict an individual's accurate behavior that presents issues of volitional control.

According to TRA/TPB theory, a person's behavior is determined by his/her intention to perform a certain behavior (Ajzen, as cited by Glanz, Rimer, & Viswanath, 2008, p. 71). In addition, TRA/TPB behavior intent is the most pivotal determinant of an individual's behavior. Ajzen (2006) indicated that individual's intention to conduct a certain behavior is an amalgamation of attitude toward performing the behavior and subjective norm. The person's attitude towards certain behavior includes the following constructs: Behavioral beliefs, evaluations, subjective norm, normative beliefs, and the motivation to comply.

Furthermore, TRA/TPB (Glanz, Rimer, & Viswanath, 2008, pp. 72-75) suggested that people are rational being and consider the consequences of their actions prior to engaging in specific behavior. Thus TRA/TPB theories imply that human beings are rational and will systematically use information made available to them. For example, findings from Zoellner et al. (2012) revealed TPB approach provided critical information

on how cultural perspectives affect sugar-sweetened beverage (SSB) consumptions among at-risk population in rural counties in southwest Virginia. Zoellner et al. (2012) study was the first to use TPB in a qualitative study to understand the influence of cultural factors in the consumption of SSB. The results from Zoellner et al. (2012) indicating the role of cultural beliefs in SSB consumption among this at-risk population revealed critical information that will help for the development of appropriate intervention targeting the vulnerable population of Southwest Virginia. Furthermore, Zoellner et al. (2012) noted while TPB is widely used in quantitative studies, they often lack the "specificity on cultural and regional factors that are necessary for program planning."

TRA/TPB constructs help illuminate the influence of cultural and ethnic beliefs on diabetes management care among Hispanic people with diabetes. Zoellner et al. (2012) using theory-based approach in qualitative study can assist to further understand the illustrated usefulness of TPB in quantitative research in predicting behavior.

Narrative Research

Narrative inquiry explores the rituals, routines, and everyday lived experiences of people through their own narratives (Clandinin & Connelly, 2000). Narrative research is based upon the premise, that as people we give meaning to our lives through our stories (Trahar, 2009). Bochner (as cited by Trahar, 2009) suggested that narrative study is not necessarily the gathering stories about the past, but it is obtaining knowledge from the past. Andrews, Squire, and Tamboukou (2013) indicated that narrative research is not merely focused on the investigation on how stories are structured and the ways in which

they work, but also centered on who produces them and by what means. Narratives carry traces of history of human lives that we want to comprehend, describe and explain.

Further, Andrews et al. (2013) noted narratives research offers no rules about suitable materials or modes of investigation, or the best possible way on how to study the stories gathered from the participants. Narrative inquiry is collaboration between the researcher and the participant that requires them to think together (Andrews, Squire, & Tamboukou, 2013; Barton, 2003; Clandinin & Connelly, 2000). Narrative method will allow my study to explore deeper into the lives of Hispanic people with diabetes. Through reflexive analysis the use of narrative inquiry will generate new forms of knowledge about diabetes management among the Hispanic immigrant population. According to Clandinin and Connelly (2002) narrative inquiry has three commonplaces, which distinguishes narrative method from other methodologies. Commonplaces are dimensions, which are necessary to be explored during the process of the narrative inquiry (Clandinin & Connelly, 2000). The three commonplaces of narrative inquiry are temporality, sociality, and place; these are the mentioned dimensions, which will serve as the conceptual framework of the inquiry (Clandinin & Connelly, 2000). The exploration of commonplaces will allow the researcher to study the complexity of the lived experiences of the participants.

Oral History

Bornat (2012) states oral history as the combination of methods and sociology, which focuses on the importance of temporal context and memory by interviewing people about their past experiences. Oral history places value on the contribution of personal

experiences of the participants' understanding of the past and present day (Bornat, 2012). Oral history approach captures the detailed stories of life experiences of individuals, which involves in-depth interview through face-to-face interaction between the participant and the researcher (Creswell, 2013, p. 73; Raleigh Yow, 2005). Oral history reveals the daily lives of the participants of home and work, life stories and experiences that rarely transcribed in public records. Raleigh Yow (2005) further noted personal testimony allows the researcher to understand the meaning of artifacts in the lives of people. The in-depth interview in the oral history processes also reveals the images and symbols people use to express their feelings about their lived experiences, their daily lives and give them meaning (Raleigh Yow, 2005). Beverly (as cited in Creswell, 2013) suggested oral history framework advocate for Latin American women through *testimonio* (testimony), the stories of women would be interpreted through feminist approach. To attempt to interpret the stories of Hispanic immigrants with diabetes with meaning, oral history approach would provide a lens that shows how Hispanic women participants' voices are muted, multiple and contradictory (Chase, 2005 as cited in Creswell, 2013).

Summary of the Chapter

This chapter revealed the gap that this study sought to fill. The literature review looked at the background of cultural and ethnic beliefs and its influence in diabetes self-management. My search covered multiple search terms relating to the research questions and databases including PubMed, Medline, Google Scholar, and ProQuest. The chapter provided me an overview of the various sub-groups of Hispanics and their cultural and

ethnic beliefs, how cultural and ethnic beliefs play a role in diabetes self-management, and the theoretical framework governing this study. The review of previous studies also provided the theoretical framework for this study, how TRA/TPB fits into this research study. The chapter also discussed narrative oral history as the methodology appropriate for this study. Chapter 2 also provided the essential tool needed for the research method, which includes the research questions and the design rationale needed for this study. Chapter 3 of this study is focused on the research methodology and its rationale. Chapter 3 also discussed how participants were chosen, collection of data, instrumentation, ethical procedures, and issues of trustworthiness.

Chapter 3: Research Method

Introduction

The purpose of this study was to gain an understanding of the experiences of Hispanic immigrants living with diabetes. Diabetes continues to be the major cause of morbidity and mortality in the United States (NAHH, 2010). However, Hispanics have higher rates of deaths from diabetes than non-Hispanic Whites (NAHH, 2010). Gaining an understanding of the unique challenges of Hispanic immigrants with diabetes is important to achieve improved health outcomes and decrease the health disparities experienced by this segment of the population.

Investigating the lived experiences of Hispanic immigrants with diabetes by listening to their personal accounts can expand the literature on how culture and ethnic beliefs influence disease management among ethnic minority groups. The literature review suggested that there are only few studies focused on the influence of culture and ethnic beliefs on diabetes management. Considering that the Hispanic population is the fastest growing minority group in the United States, it is important to explore factors that may influence diabetes self-management among this segment of the population (Kposowa, 2013). The findings from this study can provide necessary information for health care providers to improve communication and understanding how culture and ethnic beliefs influence diabetes self-management in the Hispanic communities.

In this chapter, I describe the research design and explain why it was chosen over other research methods. I also discuss my role as a researcher along with the sample selection, sample size, the availability of the appropriate participants, and the setting of

the face-to-face interviews. This chapter also includes the data collection and data analysis procedures and credibility, transferability, dependability, and confirmability related to qualitative research are examined. Ethical issues including the protection of the participants' rights, privacy, and confidentiality is also addressed. Finally, a summary concludes of the chapter.

Research Design and Rationale

I chose narrative oral history as the best approach for this study to explore not just the individual's experiences living with diabetes but also the cultural, social familial, linguistic, and institutional narratives in which the participants' experiences were shaped, expressed and described (Clandinin, 2013). Narrative researchers study the participants' experiences in the world; both the living and telling of these experiences can be analyzed through listening and observing as well as through texts (Clandinin, 2013). Narrative inquiry is used to draw upon how the stories were constructed, why, and for whom and is used to explore the cultural influences of the narratives (Trahar, 2009). Narrative inquiry can be used to interpret the participants' subjective accounts of their personal experiences with diabetes (Clandinin & Connelly, 2000). Further, narrative inquiry can assist in shaping new theoretical understanding of people's experiences through collaboration between the participants and the researcher (Clandinin, 2013).

In this study, I used narrative inquiry as a window into the lives of Hispanic immigrants with diabetes. What personal stories do they share about their experience coping with diabetes? How do culture and ethnic beliefs influence adherence to diabetes management regimens? Narrative inquiry is based upon on the premise that identities are

constructed through personal stories. A narrative inquiry reflects upon human experiences and was well suited for the exploration of the influence cultural context can have on the disease management among Hispanic immigrants (Clandinin & Connelly, 2000). Through this method, I attempted to understand people's lived experiences and how these experiences have shaped their views.

Other qualitative approaches have been used to explore diabetes experience in other ethnic groups. Phenomenological researchers focus their analysis on the shared experiences of the participants. The purpose of the phenomenologist is to illuminate the experiences and perceptions of individuals and identify the events through how they are seen by the participants (Lester, 1999). Grounded theory is a method of inquiry where the researcher generates a general explanation of a process, event, or action formed from the views of many participants (Creswell, 2013). In an ethnographic study, the researcher looks for patterns indicating the group's mental activities such as knowledge, beliefs, attitudes, values, and other predispositions. Thus, the participants are those who have been around the group long enough or have interacted with the group enough to share certain working patterns that can influence behavior (Creswell, 2013; Whitehead, 2005). Case study research is an approach to study that involves exploration of a phenomenon using multiple data sources (Baxter & Jack, 2008; Creswell, 2013). The use of multiple data sources ensures that the issue is explored through various lenses rather than just one viewpoint, which allows the phenomenon to be understood in multiple facets.

Although it would have been beneficial to use other qualitative approaches, I wanted to focus the study on story and to explore the lived experiences and perspectives

of Hispanic immigrants with diabetes. I chose this approach due to its participant-centered focus and the paradigms under in which the methodology operates. My study design includes descriptions of data collection methods, data sources, and data analysis procedures. I also explain the positioning complexities of my role as a narrative researcher and procedures to monitor my bias.

Restatement of the Research Questions

The main research question for this study is: What are the perspectives of Hispanic with diabetes towards disease self-management?

The subquestions are:

1. What are the self-reported ethnic or cultural beliefs toward health care needs for Hispanics with diabetes?
2. What is the daily lived experience for immigrant Hispanic with diabetes?
3. What are the cultural and ethnic beliefs that may influence how Hispanic immigrants manage their own diabetes condition?

Role of the Researcher

In the role of researcher, my function was that of a facilitator who helped the participants to talk freely. The emphasis for me was to not have preconceived notions of what I expected to hear from the participants. My goal was to investigate what I could learn from their stories and how these experiences may influence their adherence to diabetes management as I interviewed Hispanic immigrants with diabetes.

Research Methods

Participants Selection

To understand the experience of Hispanic immigrants with diabetes, recruitment was based in the northern most borough of New York City and the third-most densely populated in the United States (U.S. Census, 2017). Recruitment was focused on Hispanic immigrants who are fluent in English and who do not seek regular treatment for their diabetes and those who have regular primary care provider. Flyers were posted in Hispanic community organization bulletin boards, churches, health care centers, supermarket bulletin boards, and personally handed to potential participants in the streets. A phone number along with e-mail address was provided alongside a message for potential participants in the study.

Due to the need to understand the unique cultural experience of Hispanics with diabetes, recruitment targeted only immigrants who have lived in the community in the last 15 years. I sought participants by using various techniques. Because I was trying to find specific experience and perspectives, I used purposeful sampling. It could be challenging to find Hispanic immigrants with diabetes who are comfortable with discussing their diabetes condition; thus, the snowball technique was used to find suitable participants. Snowball sampling is a technique of recruiting study participants through identification of initial subject who can provide names of other actors who can be potential participants (Atkinson & Flint, 2004). Other techniques that I used to find participants were (a) I placed notice in civic groups organizations newsletter, (b) posted advertisement in churches that have heavy Hispanic congregations, (c) I made contacts

with local health agencies, (d) I asked personal contacts who may know Hispanic immigrants with diabetes, and (e) I contacted faculty at universities and colleges who may know suitable participants for my study.

Inclusion Criteria

Criteria for inclusion for this research are as follows: Participants have to be

1. Hispanic immigrants who are fluent in English and who are living in Bronx New York, NY during the study period.
2. Hispanics immigrants who are characterized as diabetic with TD2.
3. Hispanic immigrants who are between the ages of 20 to 55 years old.
4. Hispanic immigrants who are either seeking regular treatment from a provider or Hispanic immigrants who are not seeking regular treatment for their diabetic condition.
5. Hispanics immigrants of intimate living together or in close proximity with strong emotional bond.

Exclusion criteria for being considered as a participant

1. Women with gestational diabetes
2. Women or men with diabetes who are over 65 years of age this is to avoid the experience of elderly with diabetes with multiple medical conditions,
3. Children with diabetes due to paediatric TD2.

Demographic information included number of years suffering from diabetes, educational attainment, gender, and English language fluency. The participants were residing in Bronx, New York. The participants were from ages 20 to 55 years old. The

participants' age group was chosen based from rates of diagnosed diabetes cases in the United States from the Centers for Disease Control and Prevention. The data indicated that from 1990 to 2009 the rates per 100 of diagnosed diabetes cases in the United States population increased by 217% for those ages 0-44 and 150% for those ages 65 to 74 (CDC, 2014). I have chosen the median age for my study.

The intent of the study is to explore the lived experiences of Hispanic immigrants with diabetes and how culture and ethnic beliefs influence disease management among this segment of the population.

Sample Size

When conducting in-depth face-to-face interviews, the sample size can be small in comparison to other types of qualitative or quantitative studies. Creswell (2013) noted that sample sizes could range from one individual to a group of people. For this study, I sought seven individuals who were willing to grant in-depth face-to-face interviews. The procedure of implementing narrative research focused on one or two individuals by gathering data through their stories, reporting individual's experiences and chronologically reporting these stories using their reported course of life stages (Creswell, 2013). Mason (2010) noted that there is a point when enough data is collected and any additional may not necessarily lead to more information. Mason (2010) further indicated that qualitative researched concern on the meaning and not focused on the generalized hypothesis. Furthermore, when the collection of new data does not shed any further light into the phenomenon under investigation, the concept of saturation has been reached (Mason, 2010). Additionally, analyzing a large sample is impractical and time

exhaustive. Thus, seven participants were all that necessary to allow for the detailed analysis in this study.

The Narrative Interview Technique

Using the approach taken by Clandinin and Connelly (2000), first I needed to familiarize myself with the prevalence of diabetes in Hispanic immigrant communities. The process of narrative inquiry involves the informal collection of topics (Creswell, 2013). Then, following the review of the topics I have selected based on informal gathering, I have selected 7 individuals suffering from diabetes who have stories or life experiences to tell and I spent time with them gathering their stories through multiple types of information - refered to as "field text" (Clandinin & Connely, 2000).

My interview techniques followed Bauer's (1996) four phases of narrative interview process. These are: Presenting the initial central topic, Main narration, Questioning phase, and Small talk. In Phase 1, the context of the study was explained in detail to the participants. I sought their consent for their participation with the study as well as their permission to record the interview. During this phase, I established a timeline of the events by carefully formulating appropriate questions that would generate a chronological telling of the story. Bauer (1996) noted that this initial phase of the interview process should be experiential to the interviewee to ensure his/her interests and will likely proceed to a detailed account of the narrative. Phase 2 is the main narration part of the interview process. As the interviewer, I abstained from comments other than non-verbal gesture and restrict myself to active listening. Bauer (1996) noted that after the narration comes to natural end, I responded by proceeding to Phase 3. It was in this

phase where I asked questions concerning the event like "what is it like to adhere to diabetes management on a daily basis?" The purpose of the question phase was to elicit new material beyond the self-generating schema of the story given by the participant (Bauer, 1996). In phase 4, the recording was turned off, and the conversation was relaxed.

According to Bauer (1996), this phase of the data collection throws light on the more formal accounts of the participants earlier in the interview. This phase will be an important aspect of the interpretation of the data as this additional information can be crucial for a contextual interpretation of the participant's accounts of the event (Bauer, 1996). During this phase of the interview process I took notes to ensure that I would not miss any additional information that might be used for the interpretation of the data I collected.

Data Collection Procedures

The data for this study were collected through face-to-face interviews. I interviewed the participants by asking them a simple question and followed it with probes as the participants told their stories about their lived experiences suffering from diabetes. I anticipated that the interviews lasted about 30 minutes. The participants were given the opportunity to continue with their stories beyond 30 minutes. Since the focus of the current study was centered on one geographical location, I traveled to the location of their choice to make them more comfortable. To record the interview I used an application recorder on my iPad that is password protected.

After publication of the study all participants will be given a final transcript of the interview. The participants will be asked to comment on their contributions and provide further insights into the information they have provided. They will be given an opportunity as well to ask questions about how their responses will be used for further study and plans to share the work with larger audience, including further publications and presentation at conferences.

Data Analysis Procedures

NVivo 9 software by QSR International was used to assist with the organization of the interview transcripts. NVivo 9 software is a computer assisted data analysis software (CAQDAS) has been useful in assisting qualitative researchers in assorting, tracking and managing data (Baugh, Hallcom, & Harris, 2010). Baugh, Hallcom, and Harris (2010) further noted the use of CAQDAS can significantly assist qualitative researchers by freeing up amounts of time in managing data and can focus more time in deeper and richer analysis of the collected information. The interview was recorded via computerized application that transcribed the information into Microsoft Word. The transcribed data was hand-coded according to themes and categories. This method of the analysis is described by Glaser and Laudel (2013) as the search for "patterns in conditions and processes" and the integration of these processes. First, separating the themes and placing them into categories led to a better understanding of the logic underlying the initial steps of data analysis in qualitative inquiry (Glaser & Laudel, 2013). The search for patterns is the first step leading to linking the raw data to the research question. Glaser and Laudel (2013) explained that narrative interviews are often

conducted and analysed with the purpose of identifying structures of the whole text. It is imperative in narrative inquiry to note the chronology of the information provided by the participants. To obtain the data that provided answers to my research question, the use of hand coding was necessary to isolate the data most relevant to each specific research question. This process is recognizing parts of the raw data that contain information that answered each of the research questions. This is necessary in the analysis to categorize which theme information belonged to. I used the hand coding process to look for codes with a similar meaning, and developed a theme for the group.

Issues of Trustworthiness

Researchers, whether conducting quantitative or qualitative inquiry, have the obligation to demonstrate that the research was rigorous, and outcomes meet the quality assurance standards. Loh (2013) noted that the search for quality, especially the criteria in which to ensure quality in, that meant in positivist or postpositivist paradigms these criteria of credibility, validity, reliability, transferability, confirmability, and generalizability is essential for the study to be accepted into existing knowledge and to be suitable for use in variety of ways. Credibility requires evidence of taking the time to collect detailed accounts of the event under study and of using triangulation if necessary. In the current study, triangulation is the nonverbal expressions of the participants. I took notes of changes in body movement, posture, facial expression that may be incongruent with verbal statements, and I paid attention to the tone of voice that was incongruent with the participants' words.

Onwuegbuzie, Leech, and Collins (2010) explained that the voice of the participants is central in all interviews; however, nonverbal communication may come as valuable as the verbal ones for attaining a deeper shared meaning in which both the participant and the investigator increase their awareness of the contextual nature of the voice. Noble and Smith (2015) describes reliability as consistency in the procedure of the analysis, while validity refers to the integrity and the exactitude in which discoveries appropriately reflect the data collected. Dependability requires in-depth attention focus on the participants and keeping very detailed notes during the study. This process will enable future researchers to repeat the work, but not necessarily gain the same result (Shenton, 2004).

The in-depth coverage also demonstrates to the readers the extent to which proper research practices were followed. Included in this standard is information about how the research question was formulated, how participants and settings were selected, and how the decisions concerning the interview were made. Confirmability is determined when others have reviewed the study and agree about the interpretations of the study. Shenton (2004) noted that there are steps to be taken to guarantee the confirmability of the inquiry. The researcher must ensure that the findings are the results of the experiences and ideas of the participants rather than the characteristics and preferences of the researcher. Transferability allows what has been learned from the current study to be applied in other situations and conditions. Since qualitative study samples are generally small, generalizability is not feasible.

Ethical Considerations

Recruitment of participants was conducted through flyers and newsletter of Hispanic community organizations. The flyers had contact numbers and a detailed description of the criteria for sample selection. I also requested permission from religious organizations to post flyers on their bulletin boards soliciting participants, as well as asking their help in finding potential participants that may meet the criteria provided. A letter to the IRB of Walden University requesting permission to conduct the study was prepared and sent for approval. The Walden University approval number for this study is 11-30-16-0200130. The potential participants who agreed to participate in the study was formally notified in writing that their participation is voluntary, so that in case they wish to withdraw from the study they can do so at any time.

The document that was sent to the participants also contained a statement assuring them that their participation is completely confidential, that their identity will never be revealed to anyone, and that they can elect to conduct the interview under a pseudonym. I also assured the participants that all data collected from them would be stored in a safe place - locked file cabinet in my home. All raw data, however, would be kept for five years after the conclusion of the study, as required by the university.

Summary

This chapter reviews the processes used for conducting the inquiry. The purpose and research questions were restated. The rationale for choosing a narrative oral history inquiry as the most suitable means to study the lived experiences of Hispanic immigrants with diabetes towards disease self- management was explained. Sample

selection and the strategy for finding and recruiting participants for the study were also discussed. The chapter was concluded with a discussion of ethical concerns and the protection of the privacy of the participants. The results are presented in Chapter 4.

Chapter 4: Results

Introduction

The purpose of this study was to gain an understanding of the experiences of Hispanic immigrants living with diabetes, which is important for both managing and formulating policy for diabetes. The experiences and perspectives of the Hispanic population regarding diabetes management are critical to meeting the challenges of culturally sensitive, competent, and effective health care. This chapter presents the results of interviews with seven Hispanic immigrants with T2D. This study was designed to gain an understanding of how ethnic or cultural beliefs play a role in the management of their diabetes condition. In this chapter, I present the results of the study as follows: demographics of the study sample, setting of the study, and the data collection process. Also in this chapter is the process how data were collected, managed, and analyzed using NVivo 10 data coding software. The discussion of the themes and the evidence of trustworthiness of this research are presented with the summary of the results.

The study location was initially in New Jersey. I initially had many responses to my initial recruitment before the election of November 2016, but the organization that I contacted to assist me in the recruitment process stopped responding to my calls, and initial participants recruited for the study cited immigration status as the reason for withdrawing from the study. Potential participants did not clearly state their immigration status , and the rest of the potential participants did not respond to my calls to schedule an interview. The change of the study location was requested and approved by IRB from a city in New Jersey to a city in New York. The rationale for the change of location was

that it is a sanctuary city for immigrants; therefore, participants would not be afraid to participate due to immigration status. However, the final participants of this study all claimed U.S. citizenship.

The seven participants generated ample amount of insights of their lived experiences with T2D. In a qualitative study, there is a point when enough data are collected and any additional data may not necessarily lead to more information (Mason, 2010). Though 10 was the number of participants initially sought, there was no need to recruit more participants for this research because per the content analysis, data saturation was reached at the sixth interview.

The primary research question was What are the perspectives of Hispanics with diabetes towards disease self- management?

The following are the subquestions:

1. What are the self-reported ethnic or cultural beliefs toward health care needs for Hispanics with diabetes?
2. What is the lived experience on a daily basis for immigrant Hispanics with diabetes?
3. What are the cultural and ethnic beliefs that may influence how Hispanic immigrants manage their diabetes conditions?

Pilot Study

I conducted a pilot study with the first three T2D participants recruited from the flyer I posted through social media to test the feasibility of this research study. The pilot study participants consisted of two women and one man in their 50s, who had suffered

from T2D for 4, 15, and 25 years. I explained the purpose of the study as well as the need to test the questions with immigrant Hispanic diabetics living in Bronx, New York. I obtained consent from each of the participants. Each pilot study participant was interviewed privately in a coffee shop. All the research interview questions were tested for clarity and feasibility. Pilot study participants had no concerns or confusion answering the questions; thus, the study questions remained unchanged for the actual study participants.

Research Settings

The research settings were in various coffee shops in New York, conveniently located near the residents of the participants. I conducted the interviews in a private room away from other customers at the coffee shops to provide privacy to the participants. The participants spoke in low voices but audible for understanding and recording. There was no noticeable background noise during the interview and participants were not distracted.

Demographics

The seven participants in this study were from two Hispanic ethnic groups consisting of males and females, six (86%) Puerto Ricans and one (14%) Ecuadorian, all living in New York at the time of the study. The participants ranged in ages from 30 years to 55 years. Their years of living with diabetes ranged from 4 years to 25 years. Four of the participants (57%) were married with children, and three of the participants (43%) were single living with families or friends. One of the participants (14%) has been retired from work, one (14%) was forced to retire early due to diabetes, and one (14%) was actively searching for employment.

Table 1

Demographic Profile of Participants (N = 7)

Pseudonyms	Age	Gender	Marital status	Years with T2D	Ethnicity
Rocio	55	Female	Single	4	Puerto Rican
Juana	55	Female	Single	25	Ecuadorian
Manuel	54	Male	Married	15	Puerto Rican
Yvette	48	Female	Married	15	Puerto Rican
Luis	48	Male	Married	5	Puerto Rican
Celia	30	Female	Married	8	Puerto Rican
Ivan	51	Male	Single	2	Puerto Rican

Data Collection

The interviews lasted between 15-38 minutes, with an average of 20 minutes. There was enough time for the participants to tell their lived experiences and obtain for clarification of unclear information. Interviews were recorded using a secured digital voice recorder. The interview process was completed from March 2017 to July 2017. The recording of the interviews was later uploaded to a password-protected computer. I first manually transcribed each of the interviews and kept all the transcription in my computer locked with a password pending the appropriate time to destroy in accordance with Walden University's guidelines for handling the data as discussed in Chapter 3. Additionally, I took notes during the interviews, mostly on the facial expressions, and on points that were being emphasized by the participants. I took notes on other physical movements that could not be captured by the digital voice recorder. I anticipated that the

interview process would take longer than what I initially expected. However, the participants voluntarily and readily shared information without prompting.

Data Analysis

Data collection and analysis was undertaken by digitally recording of the interviews from the seven participants in this study. I first manually transcribed each interview then uploaded the digital recordings to online free web transcriber called oTranscribe. To ensure accuracy, I reviewed the transcribed interviews and recording interviews several times during the transcription process. Data were organized by research questions and with the alignment of interview questions to hand code into NVivo 10 software as detailed in Chapter 3. NVivo 10 software is a computer-assisted data analysis software (CAQDAS) that has been useful in assisting qualitative researchers in assorting, tracking and managing data (Baugh, Hallcom, & Harris, 2010). I entered the transcribed data into the NVivo 10 data coding software for further analysis and coding. I copied the interview scripts from the oTranscribe directly into NVivo 10 to auto code the interview data and generated important themes based on words frequency during the interview. I ensured that the coded themes represented the opinion of the participants.

Evidence of Trustworthiness

To establish evidence of trustworthiness of the study, I ensured that credibility, transferability, dependability, confirmability, and triangulation were established. All participants agreed to participate in the study with the understanding that the interview would be a one-time encounter. Participant checking of the transcript was not part of the process. However, I established clarity during the interview when necessary with follow-

up questions. The transferability was accomplished in the study by providing the rich account of the descriptive data, such as the context in which the research was carried out, setting, sample size, demographics, interview procedures, and excerpts from the interview guide. The dependability was accomplished in the study by using Hispanic diabetes educators/consultants to review the interview questions and protocol to minimize bias during the data collection. All interview questions were also pilot studied to ensure clarity and dependability. The confirmability was accomplished by analyzing the data as close to the time of the collection as possible. I employed a reflective, active listening approach throughout the interviews, repeating and rephrasing what had been stated as I took notes.

Presentation of Emerging Themes

The themes emerged from the NVivo 10 frequency transcripts acquired during the participants' interview session. The findings yielded six core themes from the interview questions: (a) knowledge of diabetes, (b) diabetes self-management (c) strong cultural beliefs, (d) social support, (e) lifestyle changes, and (f) strong cultural influence on diabetic self-management. The themes are arranged according to how they corresponded, and the interview questions were aligned to the research questions.

The main research question of the current study was "What are the perspectives of Hispanics with diabetes towards disease self- management?" The question addressed a broad perception of immigrants' diabetes self-management practices and potential outcomes. Several themes emerged during the analysis of the interview transcripts, but the two themes aptly aligned with the main research question: (a) knowledge of diabetes

and (b) diabetes self-management. The main research question themes correspond with the Interview Questions 1 through 8.

Theme 1: Knowledge of Diabetes

The first theme involved the exploration of knowledge and awareness of T2D. Interview Question 1 was "What do you know about diabetes?" Five out of the seven participants discussed some prior knowledge of diabetes but admitted to not recognize the seriousness of the disease. Participants expressed knowledge that the body needs the pancreatic hormone called insulin to lower blood glucose level. Five participants mentioned that decreased insulin production in the body or the inability of the body to produce required insulin leads to diabetes condition. Four participants acknowledged the risk of diabetes and its possible link to family genetics, or even poor lifestyle. Rocio said, "I know that you can develop diabetes from not eating proper food. I also know that it is likely you get diabetes because it runs in your family." Juana responded:

> I knew very little about diabetes before my diagnosis. Then I started gaining weight and I thought I was just eating too much carbs. At one point, I remembered thinking to myself, why I'm gaining more weight, sweating in the night arguing that my high blood sugar doesn't seem too dangerous.

Interview Question 2 was "How did you react when you learned you have diabetes?" The overall reactions from the seven participants ranged from surprise, hopelessness, acceptance, and no reaction at all. Manuel said, "Knowing about diabetes and its risk to my health was a surprise. But when I learned more about causes of diabetes, because of the way I used to eat, and my diet was so crazy. I used to eat

everything that was put on my face." Manuel also said, "I think my lifestyle was partly responsible for my diabetic diagnoses." Yvette said,

> My reaction was acceptance; I know we have it in the family and I had poor, healthy choices of food. So, I wasn't surprised. I know diabetes is deadly if you don't take care of it. I was surprised but not too surprising because of the history of diabetes in my family. It messes up your organs; it messes up your vision, it pretty much did with most of your organs.

Luis added, "diabetes could kill you, if you don't know of it but I was not surprised, I never used to exercise or follow a good diet."

Theme 2: Diabetes Self-Management

Interview Question 3 was "How important is diabetes management to you?" All seven participants emphasized the importance of diet and exercise as well as taking medications vital to controlling diabetes. Celia said,

> I know it is definitely life changing, it is not easy dealing with it, managing it is a lot of work, you have to take your medication, you have to make sure you are eating right, knowing what to eat and not to eat, so it is very hard.

Juana said, "The hardest part is that you would love to eat a piece of cheesecake, and the hardest is that you cannot eat because you know the consequences that follow behind that piece of cheesecake." Ivan said, "Diabetes management is important because especially now that I am approaching my later years, I need to have some kind of health to function." All the seven participants indicated that living with T2D has been a constant struggle. The seven participants also discussed their acceptance of diabetes conditions by

continuing with the management regimen and moving forward. The following are quotes representing the participants' statements about living with diabetes. Rocio discussed the difficulty managing his diabetes:

> It is very hard because you always have to think about what you were gonna eat and how it's gonna affect you, whether it is going to bring your sugar up high, sometimes you may not have the right food to eat you know. Maintaining proper diabetes self-management with the food intake and following a strict portion control has been a constant challenge to me.

Manuel said, "To self-manage, your diabetes is about being disciplined with the distractions of life. For me, it's a matter of getting used to it and having the necessary discipline and family support." Yvette said, "the hardest thing is taking the pills every day. I take Metformin, so to me, I find it very hard, and most medications make me sick."

Interview Question 4 was "What was the reaction of your family when they learned you have diabetes?" Five of the participants shared the acceptance that their families were not surprised because of their lifestyles. Six participants knew their vulnerability to diabetes because of family history. Two participants with less knowledge of diabetes in the family shared how shocked they were when diagnosed with T2D. However, the two participants shared prior unhealthy eating habits as potentially responsible for their diagnosis. Five participants knew family history and expected to inherit it. All the seven participants shared their family supporting the diabetic management. Rocio said, "From the time learned that I have diabetes, my family was

there for you. They help me go through it; they were not surprised that I was diagnosed with it."

Interview Question 5 was "Where do you get the necessary information about diabetes?" All except one of the participants admitted having in-depth information about T2D before their diagnosis. The seven participants reported to receiving the necessary diabetes information from the Internet, their health care providers, families, and friends. Juana said, "Diabetes was the last thing on my mind to think about managing it. I never had prior information about it, oh well, now I'm learning it from my doctor." Celia said, "I get my diabetes information from the hospital." Luis said,

> First I spent time on the Internet to dig for information. I just needed the basic information about diabetes before I continued the screening. I remembered getting all the poster from the hospital. When my doctor scheduled me for diabetic education was when I got the most necessary information about this illness. Other than this, I have a family friend who is a doctor who helped and other friends who have gone through this illness or know someone going through it. The diabetes information helps with the self-management.

Interview Question 6 was "How has diabetes affected your daily life?" All the participants discussed how self-managing diabetes continues to be a struggle. Rocio said, "I now depend on friends and family members to move around. I do my best not to miss my appointment like the diabetic education." All the participants expressed being mindful of their dietary food. Participants all shared how expensive is to live a life of diabetic

daily. All participants mention exercise as the important aspect of maintaining healthy diabetic daily life. Luis said,

> Sometimes taking medicine is difficult. God knows how tough to remember the exact time to take your daily medications. I have to explain to my 4-year granddaughter why I poke my hand every day. For me it's a miserable life but what can you do. You constantly weigh yourself or poke yourself to see what your numbers are. Sometimes, you want to socialize with friends, but you can't because you know yourself.

Manuel said, "For me, diabetes affects every part of my life, buying those medications are so expensive even if you are on insurance, you still have to pay co-payment. Not to talk about living a life of restriction. It's like you are in prison. So many things you can't do."

Interview Question 7 asked, "whom do you trust most to provide you advice about your diabetes management regimen? Why?" The seven participants all trust their health care providers and diabetes treatment center. Luis said, "I trust my doctor, and sometimes I go to the pharmacy." Rocio said, "Sometimes my friend talks about their medications and symptoms. Sometimes too we both have the same symptoms." Juana said, "For me, I trust my doctor and friend at the group diabetic treatment sessions." Manuel said, "Sometimes this illness can be frustrating, and you need to trust your health care provider. I call my doctor whenever I feel to do so. With diabetic self-management, you have to trust your health care provider."

Interview Question 8 asked, "If you have a relative or friend who was just diagnosed with diabetes, what advice would you give that person?" All participants felt obligated to provide advice and guidance to friends and family members newly diagnosed with Type 2 diabetes. Each participant ended the interview segment by offering advice about diabetes self-management adherence, diet, exercise, and going for lab screening early in life if there was a known case of diabetes in the family. Ivan said, "If I have a friend or family that is newly diagnosed with diabetes, I would tell them not to stress the fact that they have diabetes, but to eat better and exercise." Juana said, "I would tell my friend or family member diagnosed with diabetes to take care of himself or herself because diabetes comes with a lot of diseases that can sneak up on us." Manuel said, "First, see a doctor, make sure to eat right, and measure everything which people do not like to do, walk a lot, measure everything, move and do not sit around. Diabetes self-management is a lot of work trust me no one prepares for it. You have to live with it." Yvette said,

> My advice is the same as the doctor gave me. You gotta watch what you eat. Just take certain things in stride you know. You gotta eat no salt, no sugar, like certain things you gotta cut out of your diet, if you want to take pills then take the pills, try not to go to insulin because insulin is a lot harder. You gotta take insulin before you eat before you go to bed. That is the main thing you gotta follow the regimen if you don't do it then it's gonna hurt you in the long run.

Theme 3: Strong Cultural Beliefs

Subquestion 1 helped to explore the cultural beliefs of the Hispanic immigrant practicing self-diabetic management. The common cultural belief theme emerged from this research sub-question one in alignment with (IQ) 9-18. This theme explored the cultural beliefs.

Interview Question 9 asked, "What is *susto?*"and interview Question 10 asked, "Do you believe in *susto?*" The participants discussed cultural beliefs and traditional practices that affect the everyday management of their Type 2 diabetes condition. The seven participants knew what *"susto"* was and 3 of the participants believed that *"susto"* may have caused their diabetes condition. Manuel said, "*Susto* is something that my culture believes, that it may be the source for some illnesses." Luis said, "My parents and grandparents all believed in "*susto*" that it might cause most of the illnesses, including diabetes." Manuel said, "My culture believes in the traditional folk healing, and in that "*susto*" may have been the factor of diabetes to some." Juana said, "I believe that "*susto*" was the cause of my diabetes."

Interview Question 11 asked, "What is "*fatalismo*?" and Interview Question 12 asked, "Do you believe in *fatalismo*?" The seven participants acknowledged the belief in "*fatalismo*". Three of the participants believed that their fate was predetermined and there was nothing to do to change it. Manuel said, "with what am learning now from my doctor, I guess I was the person in the family to have it. I think too my culture eat so much carbs and so little of vegetables. I go crazy with pasta (laughs)." Juana said, "I believe in *fatalismo* as a practicing Catholic, things were predetermined to happen, and

you just can't run away. Here I am facing it." Luis said, "My entire family is Catholic, and they believe in *fatalismo*. This illness was bound to happen, I have heard of the *curandero*, I tried to go but did not follow up on it."

Interview Question 13 asked, "What is '*curandero*' and Interview Quesstion 14 asked, "Do you believe in *curandero*?" All the seven participants reported the knowledge in "*curandero*." Manuel said, "I know a few friends who got healed of this diabetes by the traditional witch doctor. Luis said, "I believe somewhat." Rocio said, "Witch doctor can heal if you believe it and do the cleansing." Ivan said, "*Curander*o is a common practice in the Hispanic community. They can cure the illness like diabetes." Juana said, "*Curandero* can cure illness but the food we eat brings the illness back. I believe I was cured, but it came back when I started eating so much carbs." Three of the participants believed "*susto*" and "*fatalismo*" may have played a role in the development of their diabetes and that "*curanderos*" may have helped somewhat in the management of their diabetes.

Interview Question 15 asked, "Have you sought help from "*curanderos"* regarding your diabetes?" Three of the participants acknowledged seeking help from a "*curandero"* for a cure for the diabetes illness. Yvette stated, "My sister went to consult the "*curandero"* on my behalf two weeks ago, for my diabetes illness." Ivan stated, "We have "*curanderos"* here in New York, and I know some people in my circle who sought their help". Celia stated, "*Curanderos* works for you if you believe them." Interview Question 16 asked, "What are the things that the "*curanderos*" advise you about managing your diabetes?" Three of the seven participants shared that the *"curanderos"*

offered some herbs and prayers to cure their diabetes. The other two reported that "*curanderos"* offered them a prayer and recited the rosary two times a day. Rocio said, "I have sought the help of "*curandero*" and gave me some teas and herbs, also told me to pray, because God is the only one that has the healing power." Juana said, "I met with the "*curandero*" who gave me herbs, teas and some rituals to cleanse diabetes off me."

Interview Question 17 seventeen asked, "Is diabetes a hot illness?" Two of the participants affirmed that diabetes is a hot illness, and "*curanderos"* are good in curing such illnesses. Yvette stated, "It's all about food and your history." Celia said, "Is like every Spanish family has one person with diabetes." Three of the participants believed "*susto*", and "*fatalismo*" played a role in the hereditary of diabetes and engaged in traditional practices like seeking "*curanderos"* to assist in healing their disease. All the participants acknowledged strong self-reported ethnic or cultural beliefs toward health care needs to self-manage their diabetes.

Theme 4: Social Support

Subquestion 2 helped to explore a broad perception of Hispanic immigrants' diabetes self-management practices on a daily basis including the role of family members as social support. Two common themes emerged namely: social support and lifestyle changes. SRQ2 themes correspond with Interview Questions 18-27. This theme explored the family support. Interview Question 18 asked, "what are the things that your family advises you about managing your diabetes?" All the seven participants acknowledged social support including family support. Rocio said, "I have strong family support all the time." Juana said, "I don't know what I would have done without the family support. You

can say they are my social support. Our family meet, and we socialize, talks about life. It's not always about diabetes. They know I have serious diabetes and they want to support me as much as they can." Manuel said, "My wife and I, we cook together she reminds me to take medications and eat per doctor's advice." Ivan said, "Our Hispanic family stick together, we support each other, diabetes is just too much to let one family member go through. The support has been very helpful."

Interview Question 19 asked, "Who helps you maintain your diabetes management regimen?" All the seven participants acknowledged getting help from health care providers, family and friends for their diabetes management regimen. Yvette said, "My husband gets me through this struggle every day". Luis said, "For me, my doctor and my family are the ones helping me." Juana said, "Diabetes self-management is hard without family support. I am lucky to have this support. It is good to have the doctor that helps you maintain your management regimen. My roommate, most of the time, reminds me to take my medication. Sometimes when we have a question, we call the nurse or the doctor on call. For me, this is huge social support."

Interview Question 20 asked, "Other than family members, do you have any other social support assisting you in your diabetes management?" All the participants except one acknowledged having other social support for the diabetes self-management. Luis said, "I attend the Spanish diabetic treatment support group at the hospital every other week. It's really helpful." Celia said, "My fiancée and my family are my support group. They offer Spanish group at the hospital for those with diabetes, but I don't go that often." Ivan said, "I'll say, my doctor and nurses. Sometimes I call the helpline if I can't

get my doctor." Yvette said, "My husband was the most reliable social support system (laugh)."

Theme 5: The Lifestyle Changes

This theme explored the lifestyle changes. Interview Question 21 asked, "Of the things that you do to manage your diabetes, what is the hardest and Interview Question 21 asked, "What is the easiest?" All the participants shared their sudden lifestyle changes. Despite the awareness of diabetes long-term health risks, adjusting to the diabetic lifestyle continues to be a challenge to all the participants. Luis said, "Living with diabetes is the worst thing I will not wish on my enemy. It changes your whole normal life. My hardest thing is to monitor my blood sugar." Manuel said, "I can't eat what normal people eat without thinking of my blood sugar. When I go to the community event, I have to be mindful of what I eat, check my blood sugar, it's embarrassing. But what do you do? It's your life. For me, it was just not eating what normal people eat." Celia said, "I don't have the freedom to live a normal life, constantly going for check-ups, taking my medications sometimes is hard, I can't do exercise that much because of my condition, so I rely more on the medication. Taking these medications can be hard. Sometimes, whenever, my sister comes, she takes me for a walk." Luis said, "It is not fun taking medications before you eat or going to bed." Yvette said, "I don't sleep well. I wake up like four times to use the bathroom." Ivan stated, "Checking my blood sugar every day is a pain." Rocio said, "Controlling my diet has been hard." Yvette said, "Following the portion meal is hard and taking my medication." Despite the awareness of

diabetes long-term health risks, adjusting to the diabetes lifestyle continues to be a challenge to all the participants.

Interview Question 22 asked, "Are there any positive impacts that have occurred in your life that may have been indirectly influenced by your diabetes?" All the participants reported being aware of type 2 diabetes. All the participants have had support groups. Manuel said, "My situation is getting better with my medication regimen. Now I know what not to eat." Yvette said, "Since my diagnosis, my husband and the rest of my family have become closer." Luis stated, "I have learned more about diabetes, and taking care of myself more. I think you could say the awareness of this disease and knowing the right food to eat now has been influenced by my diabetes diagnoses."

Interview Question 23 asked, "Have you improved your overall health?" Five of the participants expressed, their health improved considerably because of the lifestyle changes they have made after their diagnosis of diabetes. Luis said, "I have my diabetes condition under control, and I don't need to visit my doctor as frequently as I used to, I can have some social life now without making excuses to avoid them." Manuel said, "I will say that some days I have the energy and some days I don't." Yvette said, "You can't say you are improving something that you have to live with the rest of your life, it's hard because I still struggle on this and I'll do continue to deal with it for the rest of my life. But, I strive hard to follow the daily diabetes self-care because I want to see my daughter get married someday."

Interview Question 24 asked, "Have you been eating better?" Six out of the seven participants acknowledged following the dietitian's recommendations. Ivan said, "Yes, I

eat well." Yvette said, "I follow my dietitian's recommendation, and sometimes I crave for sweet food. Overall, I feel better, but you never know with the flu season." Manuel said, "It's hard to control what you eat when you go to family or community festivals with lots of food." Juana said, "Some days I crave for cake, chocolate and rice. These are hard to avoid. They are cheap at the stores, they are all over the place. I say that I am struggling with getting my diet in control." Rocio said, "I spend a lot more when I buy fresh fruits and veggies, I can't do it all the time, but I eat better." Interview question (IQ25) twenty-five asked, "Have you lost any weight?" Six participants acknowledged weight lost and attributed it taking the recommended medications, family support, social support, and adhering to the dietitian's recommendations. Juana said, "I lose and gain weight, it is hard to keep it up, but I am trying my best." Ivan said, "I've lost weight, and my lifestyle has been improving. I feel good, but I still have to take my medicine and monitor my blood sugar."

Interview Question 26 asked, "How often do you visit your doctor for your diabetes" and Interview Question 27 asked, "Do you visit your doctor for regular check-ups?" All the participants discussed that part of maintaining a healthy lifestyle is to visit the doctor for regular check-ups. Manuel said, "I used to see my doctor every six weeks, but now I see her every eight weeks." Juana said, "I missed my appointment last week, but I will call to reschedule. Otherwise, I see my doctor every month because of the cut on my right leg. So, to monitor my lifestyle, I must visit my doctor regularly." Rocio stated, "I see my doctor every three months, and if I need to refill my medication then I'll go to the pharmacy." Ivan said, "I used to see my doctor all the time, but now I learned

how to self-manage, you know, watching it on my own." Six participants affirmed visiting their doctors for regular check-ups and one participant admitted to only seeing the doctor when it was necessary. Juana said, "I visit my nutrition (nutritionist) regularly for my weight check-ups and well-being." Manuel said, "I don't miss my regular check-ups." Yvette said, "I go to my doctor regularly, like every three months, I go with my husband because he too has diabetes." The participants agreed that regular doctor visits help with the diabetes education including the health risks awareness and the motivation to self-manage diabetes new lifestyle changes.

Theme 6: Strong Cultural Influence on Diabetes Self-Management

Subquestion 3 helped to examine the cultural and ethnic beliefs that may affect diabetes management regimen? The strong cultural influence on diabetic self-management theme emerged from the interview questions (IQ) 28-32 aligned with this sub-research question. This theme explored the combination of traditional and western medication use as part of self-management plan.

Interview Question 28 asked, "How does your cultural or ethnic beliefs influence your diabetes management regimen?" All the seven participants expressed strong support for traditional remedy used in combination with the western medications to diabetes self-care. Juana said, "I believe *susto* is responsible for my diabetes. I have gone to *curanderos*, (witch doctors) I also went to *santeria* (worship of the saints) for cleansing and to manage my diabetes." Rocio said, "A long time ago, I did go to see a *curandero*, he offered me like herbs, you know some remedies that I could try, but nothing helps, you know. I take both the traditional herbs and my medication, and it works for me. It is

hard you know, but I just followed the order of the *curandero*, he told me if I change my intakes ahmm if I eliminate certain drinks everyday intakes and drink some teas and some stuff he has given me, that it will help your, my diabetes or bring down my sugar levels down." Similarly, when asked if "*susto*" may have caused her diabetes condition, Rocio said, "I believe *susto* caused my diabetes."

Interview Question 29 asked, "Do you believe that your diabetes condition is caused by *susto*?" Three of the participants associated their diagnoses to "*susto"* and "*fatalismo*." Three of the seven participants believed their diabetes to have the connection with "*susto*" and "*fatalismo*." Four of the seven participants stated to know "*susto*" and "*fatalismo*" because of some of their family member's beliefs. Interview Question 30 asked, "Do you believe that your diabetes condition is because of *susto*?" Ivan said "Yes, I believe so. *Susto* caused my diabetes condition. We know this and believe it in the family. I believe that certain things in life are the acts of God like diabetes, and there is just nothing you can do about it that is "*fatalismo*", but I still take my medications from the doctor. It works for me." Juana said,

> Unfortunately, there are things in this world that you were meant to have, I believe that I was meant to have diabetes and there is nothing I can do about it. I was born into it; my parents had diabetes. Therefore, I was meant to have it too. I've done the cleansing through the "*Santeria*." Perhaps my parents or somewhere in the past something happened that I was meant to have diabetes too.

Interview Question 31 asked, "Does *fatalismo* prevent you from doing the things that you should do to manage your diabetes?" The seven participants expressed that

"*fatalismo*" has no restriction. Rocio stated, "No *fatalismo* is just a belief that one was predetermined to have this illness. It does not prevent me from seeking help from my doctor." Ivan stated, *"Fatalismo* is at the back of my mind, sometimes I think that I was destined to have diabetes." Interview Question 32 asked, "Do you seek advice from your family about your diabetes condition?" The participants reported having received advice on diabetes self-management from families. Luis stated, "My mother checks on me every day to make sure I'm following my regimen." Rocio said, "My sisters send me a message every day to stay strong, take my medications, take the recommended diet and pray because the higher being is the only one who can heal all of our illnesses." Each participant ended the interview by offering advice on diabetes self-management adherence including medication, diet, and exercise. Three of the participants continue to believe that *"susto"* play a role in the development of their diabetes condition and when this happens there is nothing much that can be done since they are predestined to have diabetes "*fatalismo."* These cultural beliefs play a strong role in the self-diabetes care management of some of the participants.

Summary

Participants of this study of Hispanic immigrants living in the Bronx in New York with type 2 diabetes, although not a representative of other diabetics from similar ethnic backgrounds, depicted a variety of health seeking behaviors of the overall population of type 2 diabetics in the Hispanic communities. The exploration of the daily lived experiences of the Hispanic immigrants with type 2 diabetes provided insights into the feelings and reactions of the participants with type 2 diabetes and their reasons for

choosing to combine traditional management approaches and modern practices for their diabetes conditions. In the interviews, participants revealed their emotional reactions to their diagnosis ranged from negative to positive and mixed feelings.

The six themes that emerged were: knowledge of diabetes, diabetes self-management, strong cultural beliefs, social support, lifestyle changes, and strong cultural influence on diabetic self-management. The participants discussed the importance of acquiring diabetic knowledge which helped them develop better lifestyle changes needed to maintain diabetes self-management also with social support and cultural beliefs. In the interviews, the participants also discussed their aims when skipping their restricted diet and that was to fulfill their social and family obligations. Essentially, the participants also recognized that non-adherence to the daily diabetes self-management regimen can have physical consequences and contributes to their emotional frustrations.

Three of the participants discussed the continued use of home remedies and alternative medicine *"curandero"* in their daily diabetes self-care, including the belief that "*susto"* and *"fatalismo"* play a role in their diabetes condition. Two of the participants believed in combining natural remedies obtained from a "*curandero"* with their prescribed diabetes regimen and attributed their diabetes diagnoses to some events that occurred in their past. However, neither one of the two participants expressed their preferences of traditional medicine to the physician prescribed diabetes regimen. One participant believed in self-managing his diabetes condition and expressed that only his beliefs in God can help him with his illness. The rest of the participants believed in

following prescribed diabetes self-care regimen to achieve glucose control and attributed their diabetes diagnoses to heredity and poor lifestyle choices.

The participants offered advice to newly diagnosed patients to include the regular health check-ups, consulting with health care provider and following the prescribed regimen and dietary adherence. Finally, all participants reiterated the need for the newly diagnosed patients to balance the culture and their self-management well-being.

The connection between the six emerged themes from the data collection and analysis for this study will be discussed in chapter 5. A discussion of findings, limitations, and the implications for social change, and recommendation for future study will be also presented in Chapter 5.

Chapter 5: Discussion, Recommendations, and Conclusions

Introduction

Through this study conducted to understand the experiences of Hispanic immigrants living with diabetes, I found the following themes: (a) knowledge of diabetes, (b) diabetes self-management (c) strong cultural beliefs, (d) social support, (e) lifestyle changes, and (f) strong cultural influence on diabetic self-management that may influence the daily management of the disease unique to this segment of the population. The information gathered can inform health care providers, policy makers, and assist future health promotion efforts in developing culturally sensitive approaches to treating Hispanic immigrant diabetes patients.

The nature of the study was qualitative and included oral history narrative approach (Clandinin & Connelly, 2000). Narrative design involves the explorations of daily rituals, routines, and every day lived experiences of people through their own narratives (Clandinin & Connelly, 2000). The purpose of the study was to elicit the daily lived experiences of Hispanic immigrants living in New York as well as to gain understanding on the influence of cultural and ethnic beliefs in their daily diabetes management regimen.

Key Findings

Seven diabetic Hispanic immigrants living in New York agreed to participate and answer questions about living with T2D. The narrative stories about living with T2D revealed challenges and victories in their daily lived experiences with the disease. Six (85%) of the participants were actively seeking management assistance from their

respective health care providers. Only one (15%) of the participants opted for a holistic diabetes management regimen.

The participants discussed their fears of going blind, losing limbs, having kidney disease, or having a stroke from their diabetes condition. Despite of awareness of the health consequences of T2D, one participant (15%) admitted of being unable to control alcohol and food intake during family festivities and six participants said they try to avoid social celebrations as much as possible. The participants described their difficulty in following a strict regimen of taking their medication. Concerns were mitigated by strong family and social support with six participants (85%) mentioning family members and friends who assisted them. Faith in God was mentioned by one participant (15%) as his source of support and assistance. All participants said their motivation to diabetes self-care came from family participants. Only two participants (29%) said that their motivation to diabetes self-care came from their health care providers because they value their knowledge of their diabetes condition.

Three of the participants (43%) shared the continued home remedies, and alternative medicine including the *curanderos* as part of their diabetes management regimen. Two of the participants (29%) believed that an event that may have given them a fright or *susto* was a contributing factor to their diabetes condition. These two participants also believed that their diabetes condition was a will by a "higher being" or *fatalismo* and it could not be avoided. The four most common health beliefs about how to manage their T2D conditions were the importance of following a diet regimen like

portion control, adhering to daily medications, exercise, and natural remedies like special herbs or teas that the *curandero* instructed them to take.

There was not much difference between the men and women regarding the participants who said that they were motivated to take care of themselves because of their family. It was noted that the women were more inclined to believe in the efficacy of traditional remedy where two females (29%) continued to seek help from *curandero*. One of the males (14%) believe that "only God" had the healing power to help him with his diabetes condition. Six of the participants (86%) continued to visit their health care providers for regular check-ups while one (14%) resigned to follow his own regimen and only goes to the diabetes clinic when it is necessary. Additionally, one participant (14%) said that the diabetes management regimen provided by the health care provider was confusing, and his personal approach in managing his diabetes comes with his beliefs in God.

Interpretations of the Findings

The interpretation of the findings is organized according to the literature reviewed in Chapter 2 and the TRA/TPB, which provided the theoretical framework of the study. I also present the limitations, implications, and conclusions.

Sample Population

The objective of the sample strategy was to obtain various groups of Hispanic immigrants with T2D in New York. I could only recruit two Hispanic ethnic groups, Ecuadorian and Puerto Ricans. Obesity and inactivity are risk factors for acquiring T2D (CDC, 2016). The Office of Minority Health (2018) reports that Hispanics are twice more

likely to be diagnosed with diabetes than non-Hispanic Whites. The CDC (2016) estimated that there are 12.2% Hispanics in the United States who suffer from diabetes. All participants in the sample reported that prior to their T2D diagnosis they followed no dietary restrictions. Four of the participants reported values that they were obese at some point prior to their diabetes diagnoses. On the other hand, all the participants in the sample reported healthy weights. In this study, all participants reported that they have adequate access to health care and sufficient social support. None of the participants reported to having financial difficulty that would prevent them from acquiring proper food with high nutritional value.

Knowledge of Diabetes

The Hispanic participants in this study reflected on how they have realized they had diabetes after their diagnosis, and they recognized the relationship between heredity and diabetes. I asked the participants what they knew about diabetes and what their reaction was after they were diagnosed. The stories about how they became aware of their diabetes conditions were like those in a study by Gonzalez, Vega, Rodriguez, Tarraf, and Sribney (2009) where participants indicated low level of diabetes awareness. These findings suggest that the level of health promotional efforts and prevention in this segment of the population is lower in comparison to the rest of the population in the United States. It should be noted, however, that in the current study most of the participants were diagnosed with diabetes more than 5 years ago.

It was evident that the participants in the current study who regularly visit their health care provider have strong knowledge of their illness. In the interviews, the

participants discussed adherence to diabetes self-care like food portion control, physical activities, and monitoring glucose levels as factors that contribute to better health outcomes. The participants also discussed their desire to learn more about their disease and continue to search for as much information on their own via Internet and read educational pamphlets provided by diabetes treatment clinics. These stories coincide with participants in a study by Low, Tong, and Low (2014), where participants geared their help-seeking behavior toward rebalancing their quality of life and continuing living normally. Participants' reactions from the current study after their diagnosis revealed that most of them have mixed feelings towards their diagnosis. Three participants expressed concerned about passing their disease to their children. The three participants also discussed how they are educating their family members about lifestyle changes like eating well and the importance of physical activities to avoid diabetes diagnosis.

The stories of how diabetes affected participants' daily lives supported Hu, Amirehsani, Wallace, and Letvak's (2014) research where the participants discussed their experiences living with diabetes as suffering. The participants in the current study perceived diabetes not only as physical but also emotional suffering. The participants expressed the challenges in taking their daily prescribed medication and the constant monitoring of their glucose levels. The participants in this study also discussed the physical symptoms being associated to diabetes were primarily pain and blurry vision and the emotional impact of their disease was described as feelings of despair and isolation from their family and community. In Hu et al.'s study, the Hispanic participants conveyed that their emotional suffering came from being isolated from family members,

as the families lacked diabetes knowledge. In the present study, the Hispanic participants discussed how family members were helpful in giving them advice on what not to eat but not during social gatherings and celebrations. The study participants in the current study also described the abundance of food during festivities and not being able to enjoy food with family members and friends was particularly stressful in the management of their diabetes. The cultural value that promotes family and a sense of community is more important than the individual needs in the Hispanic culture (Hu et al., 2014). Understanding these cultural aspects in the daily lives of the Hispanic diabetics may help remove barriers to self-management of diabetes.

Diabetes Self-Management

Diabetes self-management is important in achieving favorable health outcomes (Hu, Wallace, McCoy, & Amirehsani, 2014). Following a strict dietary regimen, doing physical activities, taking diabetes medications, and monitoring glucose levels can improve diabetes outcomes (Hu et al., 2014). In the present study, six participants indicated that taking their prescribed diabetes medication was a very important part of their daily diabetes care regimen, which was consistent with the study by Hu et al. (2014). Most of the participants also suggested that they kept regular appointments with their health care providers to obtain prescription and check their diabetes self-management progress. However, one participant chose holistic approach incorporating traditional remedies to manage his diabetes condition, which coincides with Weller et al.'s findings (2017). Two of the participants indicated combining natural remedies like

drinking certain types of teas and herbs obtained from a *curandero* and medicine prescribed by their health care provider in their daily diabetes self-management.

Regarding how important diabetes management to them, participants also discussed their concerns about the long-term health consequences that are attributed to the disease, noting that heart disease, blindness, amputations, and kidney disease could arise. It was evident from the responses that preserving health was important for the study participants. This was consistent with Low, Tong, and Low's (2014) findings that indicated participants were motivated to achieve quality life by adhering to a management plan. In the current study, being able to have a normal life without experiencing physical difficulty is the hope that all participants wish to achieve. Adhering to strict diabetes self-care and avoiding the ill effects of diabetes were motivation in their help-seeking behavior.

Strong Cultural Beliefs

The exploration and understanding of cultural or ethnic beliefs and how it influences diabetes self-management in the Hispanic immigrant population is one strategy that may help bridge the gap in both cultural competence and health promotion efforts (Concha, Mayer, Mezuk, & Avula, 2016). The participants of this study reflected on the perceived causes relating to their diabetes diagnosis. In the stories on how the participants acquired diabetes, they described a variety of causes relating to heredity, health behaviors, and emotions. Two participants described how an event in their lives have precipitated their diabetes condition. Five of the participants spoke of their heredity as the cause of their diabetes diagnosis. The participants have described how they were

predestined to have diabetes due to their genetic make-up. In the present study heredity and stress were the recurring themes throughout the interview, and when asked to explain, participants identified genetics "my whole family have diabetes" and stress "city life is stressful" as the main contributors to diabetes. These findings are consistent with the results from Concha et al. (2016).

Previous studies have revealed that Hispanics are 3 times more likely to experience diabetes-related complications, disability, and mortality (Concha et al., 2016). In the 2015 morbidity and mortality report, the Hispanic population continues to suffer substantial disparities in receiving quality care (as cited in Concha et al., 2016). These disparities remain to contribute to nonadherence to the regimented daily diabetes self-care. Given that the Hispanic populations are the fastest growing ethnic groups in the United States, the need for culturally and linguistically appropriate treatment and management approaches are necessary to improve long-term health outcomes in this segment of the population (Calzada & Mora, 2011; Rustveld et al., 2009). The current study revealed that the participants value the role of their health care professionals and the encouragements influenced their adherence to diabetes self-care. This finding is consistent with previous studies where cultural competency is necessary among health care professionals to deliver much improved disease treatment and management strategies in the Hispanic communities.

Social Support

Family and social support play an important role for Hispanics suffering from diabetes. A finding of interest in the present study is that the study participants had a

network of assistance from their family and communities. Hu et al. (2014) noted that involvement of family and community is an important intervention strategy for Hispanic people with diabetes. The participants described how family and peers have assisted them in the many lifestyle changes challenges they face in managing their diabetes. In the stories regarding who helped the study participants with managing their diabetes, social support, including peer and family involvement, was related to improved health eating habits, glucose control, improved knowledge, and better self-management. In this study, the participants described the support they receive came from variety of forms such as assisting in planning their meals, companionship in their daily walks, and psychological support. Marquez et al. (2016) also noted that social support for physical activities has been noted to have influence in weight loss. In the current study, the participants discussed participation of their family members and friends in physical activities boosted their motivation in their increased daily exercise.

The Lifestyle Changes

Previous studies have mentioned that the high rates of obesity in the Hispanic communities may be associated to lifestyle factors such as improper nutrition, high caloric intake, and inadequate physical activities (Ramar & Desai, 2010). Evidence from previous studies has indicated that lifestyle changes like following a healthy diet, achieving modest weight loss, and regular exercise can reduce the risk of complications of T2D (Chong et al., 2017). The participants in the current study discussed engaging in physical activities and following a healthy diet improved their health. The participants described diabetes as burdensome diseases that affects everything that they do.

The participants explained the overwhelming impact of the sudden lifestyle changes to their emotional well-being such as regular medical appointments, adherence to daily diabetes medication, and engage in self-care behaviors including constant monitoring of glucose levels, dietary changes, and increased physical activities. Strategies in managing diabetes entail more than the clinically prescribed guidelines, they also include their social networks interactions. Living in constant awareness of their diabetes condition has impacted their social life. The participants also expressed how diabetes have restricted their lives and lost spontaneity caused by the regimented diabetes management. The participants described their difficulties in dealing with their diabetes conditions in a daily basis but also expressed that the necessary lifestyle changes they have made improved their overall health and provided them confidence in managing diabetes. The participants understood that following a regimented diabetic self-management can lead to long term better health outcomes. These findings were consistent with those of Thomas, Ashcraft, Owen, and Phillips (2017). However, unlike the study by Thomas, Ashcraft, Owen, and Phillips (2017), the participants in the current study did not mention financial difficulty as a factor in the challenges in managing their diabetes conditions.

Strong Cultural Influence on Diabetes Self-Management

There are many factors associated to achieve effective diabetes self-care. Besides sufficient knowledge of diabetes, factors such as cultural or ethnic beliefs can influence the decision to follow self-management regimen. In the current study the participants demonstrated awareness in following prescribed regimented diabetes self-care can lead to

better health outcomes. However, three of the participants admitted to augmenting their prescribed diabetes self-regimen by combining with variety of teas, herbs and prayers. This finding is consistent with those by Juckett (2013). Juckett (2013) reported that herbal therapies play a major role in Hispanic disease management. Although, most of the participants believed that medications recommended by their health care provider were important to control their diabetes, one participant expressed to seeking the help of a "curandero" for health advice in addition to regular medical appointments.

Three of the participants also expressed beliefs in "susto" where their diabetes condition was caused by intense emotion that happened in their past. This finding was also reported by Caballero (2011). Majority of the participants also discussed how diabetes was part of their lives due to heredity and could not be avoided. Five of the participants conveyed their beliefs that they were simply destined to get diabetes because of who they are (fatalismo). One participant described his diabetes as a will from a higher being and that only a higher being can diminish his suffering from it. This finding was also reported by Moreira, Hernandez, Scott, Murillo, Vaughan, and Johnston (2018).

All participants described the challenges in following dietary restrictions, overeating and cooking is part of their culture and family history. The participants also spoke of their inability to avoid overeating during celebrations. Proper nutrition and diet is important for the effective management of type 2 diabetes, but from some aspect of the Hispanic culture can make challenges to adhere to prescribed diabetes diet. The participants in this study expressed sufficient knowledge about their disease condition, but also described the difficulty of adhering to regimented self-management care due to

family and social obligations. The participants also conveyed seeking advice and encouragement from their family members. Caballero (2011) noted involvement of family members is an important motivator for disease self-management but can also influence the independent health decision making of the diabetes patient.

Limitations of the Study

This qualitative oral history study allowed me to observe the content and meanings of the study participants' words and phrasing of ideas. This study was limited to the diabetic Hispanic immigrants in the Bronx in New York. By nature of the population from which the sample was selected, it did not include all the different Hispanic subgroups with diabetes living in Bronx in New York. The sample was also limited by the fact that only Hispanic immigrants who spoke English fluently were selected, the sample did not include a representation of diabetics from Hispanic immigrants who did not speak English. Non-English speaking Hispanic immigrant participants might have different lived experiences of living with type 2 diabetes. The current study investigated the daily struggles of the Hispanics of Puerto Rican and Ecuadorian descents, limiting its generalization to other Hispanic subgroups in the United States. The sample was also limited to those Hispanic immigrants who choose to participate in the current study and narrated their stories.

In narrative oral history research, there are usually other alternatives to gather data or information. It is possible to have used observations, videos, illustrations and other different types of written documents like diaries. However, in this study only

interviews were conducted. But the use of videos would have made the participant uncomfortable considering that the location of the interview was in public place.

Finally, another limitation was, I am not of Hispanic descent, my beliefs and experiences were different than those Hispanic immigrants with diabetes living in Bronx, New York. Also, to allow for privacy, I was the only person other than the participant during the interviews. It might have been possible that I have misinterpreted some of the information that was conveyed to me. However, during the interview, whenever something was not clear, I asked for clarification by requesting the participant to re-state what was said. Although, I listened to 100% of the interviews, it remains possible that I missed some information.

Recommendations

Despite the limitations, this study has several strengths where the recommendations were based. As with nature of the qualitative studies, the strengths of the current study were capturing the rich personal experiences through the participants' own narrations of their stories living with type 2 diabetes. Although the findings of the qualitative methods using narrative oral history in the current study do not represent the average opinion of Hispanic immigrants, however, it allows the generalization of the concepts of the daily challenges of regimented self-disease management. The plan was to gather information about the lived experiences of the Hispanic immigrants living with diabetes in Bronx, New York and highlight the importance of culture or ethnic beliefs in disease management to provide policy makers and health care providers materials to assist this segment of the population in dealing with the increasing epidemic of diabetes.

Although the study participants ranged in ages, the average age was 55 years of age was somewhat old on the end of the spectrum. A study with younger Hispanic immigrants who are newly diagnosed with the disease is recommended to obtain as comprehensive of an idea of the knowledge, health care beliefs and daily challenges facing this segment of the population. A future study with all Hispanic immigrant subgroups with diabetes is recommended since the current study was limited to only two Hispanic immigrant subgroups in the Bronx, New York. Additional studies that explore other Hispanic immigrants with type 2 diabetes around the country is also recommended to determine if their daily lived experiences with the disease is similar or different. Past studies in Hispanic immigrants in rural areas have been limited. A future exploration of the daily lived experiences of Hispanic immigrants in rural areas in the United States is recommended to get an idea of their health care beliefs or emotional status dealing with diabetes self-care. The current study indicated that the participants were knowledgeable about their diabetes condition and its long-term health consequences, however, this perhaps was attributable to their accessibility to diabetes care centers which are numerous in numbers in urban areas. It was also evident from this study that the participants had acquired knowledge of diabetes after their diagnosis. Thus, studies which address the knowledge of diabetes and its association to other health complications among the general Hispanic immigrant populations are necessary.

All participants in the current study acknowledged that diabetes is high among the Hispanic populations, and most perceived that the higher prevalence of the disease is associated to traditional Hispanic food which are high in carbohydrates and family

heredity. Participants in the current study discussed their challenges in following dietary restrictions, particularly during family gatherings or social celebrations. It might be beneficial for this segment of the population to tailor diabetes education specifically for family members and the diabetes sufferers to improve self-management interventions. Educating family members about diabetes self-care can ease the strain that they may feel coping with the lifestyle changes and the progression of diabetes. Family members may also benefit from diabetes education programs and decrease the likelihood of them developing diabetes through improved diet and regular physical activities. Organized community events focusing in the education of diabetes self-management by promoting healthy eating and proper food choices may be beneficial for Hispanic immigrant communities. Recruiting the participation of local grocery stores to participate in diabetes education program to promote responsible food choices by providing readily prepared food customized for diabetes sufferers would be beneficial to communities most afflicted by the disease.

The importance of faith was also well established by the participants of the current study in terms of coping with their disease. All participants of the current study acknowledged as practicing Christians, a study with other faith beliefs maybe necessary to determine if faith is an important factor is recommended.

The participants also acknowledged of augmenting their regimented prescribed diabetes self-care by incorporating natural remedies supplied by "*curanderos",* as Juckett (2013) reported herbal therapies play a major role in Hispanic disease management, it is recommended that a further exploration of the use of certain herbs and teas can decrease

glucose level. In this study, 3 participants admitted to using natural remedies and prayers were included in their daily diabetes self-management and treatment. It is recommended that health care providers and diabetes educators need increased awareness of this phenomenon and its implications.

Implications of the Study

The incidence of type 2 diabetes has been steadily increasing in the United States (Livaudais, Thompson Islas, Ibarra, Godina, & Coronado, 2011). Among Hispanics, diabetes has been the 5th leading cause of deaths, and more likely to develop diabetes than non-Hispanic whites (Hu, Amirehsani, Wallace, & Letvak, 2014). Hispanics also suffer from higher rates of diabetes complications than non-Hispanic whites (Hu, Amirehsani, Wallace, & Letvak, 2014). Previous diabetes studies indicated that Hispanics have poorer diabetes self-management skills, a key component in achieving glucose control, preventing other health complications associated with the disease, and improving better health outcomes. The current study explored the influence of culture and ethnic beliefs that may contribute to poorer effective diabetes self-management. Identifying cultural factors that are possible barriers to improved diabetes self-care and developing programs that are tailored specifically for this segment of the population, may play a role to achieving better health outcomes among Hispanic immigrant populations.

Collaborating with community grocery stores by offering specially prepared food for diabetics may help promote responsible food choices. To achieve better disease self-management, health care providers and communities must form a combined effort to

deliver culturally sensitive health education efforts acceptable for both the diabetes sufferers and their families.

Social Change Implications

It was evident from the current study that the participants' family and friends play a critical role in aiding the daily diabetes self-care regiment. With most the participants in this study describing the importance of family and friends' support, suggests that family and their extended support network provide a positive influence to effective diabetes self-management. Some of the participants also discussed that family and friends' behavior can sometimes be harmful, particularly during social celebrations. One participant described the non-supportive behavior of family members by offering food that were unhealthy and non-adherent to the diabetes diet restriction. The narrative stories of the participants describing their daily lived experiences highlighted one important finding that was also noted in previous studies by Reyes, Reimer, Parker, Mullier and Laroche (2017) diabetes sufferers relied support from both their health care providers and family members. While participants in the current study indicated the important role their health care providers play in their daily diabetes self-management regiment, they also expressed their heavy reliance on the recommendations of family members and friends' advice.

Theory of reasoned action (TRA) and theory of planned behavior (TPB) suggests that perceived norm describes the social pressure that one's feel to perform a certain behavior. Fostering behavioral changes through family and peer involvement can assist in much improved diabetes self-care. While the success of diabetes self-management protocols is based on the strict adherent behaviors of the diabetes patients, it is also

important to note that family and their extended support network play a vital role in achieving improved glucose levels.

Cultural influences play a critical role in diabetes self-management among Hispanic immigrants (Hu, Wallace, McCoy, & Amirehsani, 2014). Diabetes self-management education and interventions with considerations of cultural beliefs with greater emphasis on targeting family and friends are needed, so that they are better equipped to support their loved ones with diabetes. Providing family members and friends sufficient knowledge about diabetes self-management can ease the strain why the sudden lifestyle changes are necessary and how these daily routine modifications be best implemented with their support through responsible food choices and participating in the required physical activities (Baig, Benitez, Quinn, & Burnett, 2015). For example, during family and social celebrations, instead of preparing the traditional Hispanic food usually served during festivities, family and friends can collaborate in offering food choices that follow the diabetes dietary guidelines. Carefully designed education programs tailored for diabetes sufferers' family and friends particularly those at higher risks for developing diabetes can benefit through improved lifestyle changes (Baig, Benitez, Quinn, & Burnett, 2015).

With 3 participants revealing their beliefs that their diabetes condition may have precipitated by a tragic event in their past *"susto"* and admitted augmenting their prescribed diabetes self-management regiment by combining herbs and teas, health care providers who are caring for diabetes sufferers should be mindful how these traditional remedies can have adverse effect in their diabetes conditions. Health care providers must

formulate strategies in establishing trust to encourage diabetes sufferers to share traditional remedies they incorporate with their prescribed diabetes self-care. Understanding the underlying cultural or ethnic beliefs that might be instrumental to some of the non-adherent behaviors of diabetes sufferers may potentially increase trust in their health care providers and health educators, leading to much improved self-management and behavior change. For example, 1 participant discussed the continued use of a *"curandero"* in addition to regular medical appointments. It is important for health care providers to understand the importance of *"curanderos"* in their patients' diabetes care. Respecting the patients' beliefs in alternative therapy may lead to gaining more trust and respect (Brown, 2005).

In this study, 1 participant stated that the power of healing emanates from a higher being, this is in contrast with modern health care. This finding suggests the importance of faith and spirituality for the Hispanic immigrant populations. Health care providers may want to consider including the concept of spirituality in their practice and health educators may want to incorporate these cultural values in their health promotion efforts. Additionally, policy makers may want to enlist the aid of churches to participate in diabetes screening programs.

As previously stated, the participants in the current study were aware of diabetes and its other health complications, the importance to adhering to strict regimens and maintain favorable glucose levels. Understanding and incorporating cultural beliefs could achieve a much-improved diabetes self-management practices among this segment of the population. The participants in the current study also acknowledge having no prior

comprehension about diabetes until their diagnosis. Health promotion efforts and diabetes screening programs may need enhancement and be more widespread. With the steady increase of diabetes incidences in the Hispanic populations, policy makers, health care providers and health educators could partner with churches, community organizations and local groceries to promote healthy lifestyle through responsible food choices and regular physical activities (Livaudais, Thompson Islas, Ibarra, Godina, & Coronado, 2011).

In this study, there were concerns expressed by the participants concerning food choices at local grocery stores. For example, 2 participants discussed the abundance availability of food that are high in fat and carbohydrates in the local grocery stores and the prohibitive prices of vegetables and fruits. This information, provided insights that local grocery stores could collaborate with local government officials to avail food that are in adherent to diabetes dietary guidelines at affordable prices. Capitalizing in this idea, local grocery stores could provide a section of their stores dedicated to prepared food that are in accordance to diabetes dietary guidelines. The availability of diabetes friendly food in the local grocery stores could motivate people to eat healthier and lessen the stress of perusing the stores to search for food that are appropriate diet for diabetes sufferer.

Finally, previous studies suggested that there were some significant improved health outcomes when fruits and vegetables were prescribed to diabetes patients (Bryce, et al, 2017). Similarly, participants in the current study discussed how responsible food choices improved their overall health. This finding underscored the importance of fresh

fruits and vegetables in diabetes diet. Government and farmers could foster partnership in providing the opportunity for urban communities to obtain healthy foods at affordable prices and teach the importance of nutrition in health (Bryre, et al, 2017).

Conclusion

As previously stated this study was guided by the theory of reasoned action (TRA) and planned behavior (TPB). This theory was used to explore the lived experiences of Hispanic immigrants with type 2 diabetes in the Bronx, New York. Theory of reasoned action (TRA) and theory of planned behavior (TPB) suggests that perceived norm describes the social pressure that one's feel to perform a certain behavior and the subjective norm is the perception that others who are important to the diabetes sufferer believe that adhering to diabetes regimen leads to much improved health outcomes (Fishbein, as cited by Albarracin, Johnson, Fishbein, & Muellerleile, 2001). Finding from the current study illustrated that the current health behavior of the participants was habitual and triggered by the presence of diabetes conditions among family members and friends. Fostering behavioral changes through family and peer involvement can assist in much improved diabetes self-care.

Diabetes is a disease that affects not just the individual but an entire family. The complexity of diabetes makes it challenging for the individual sufferer to know everything about the disease. Family members can provide concrete support as well as emotional support by acquiring adequate knowledge about diabetes. However, family members and friends should not attempt to manage diabetes for the diabetes patient but rather inquire how to best assist their loved one. Accordingly, family members and

friends should understand that people with diabetes don't have special food, healthy food choices for everyone is the same for diabetes sufferers. Responsible food choices, healthy eating habits, and regular exercise must be adopted by the entire family.

It requires an entire community to tackle the daily challenges of diabetes. The participants from the current study indicated that their strong social support have been their strong motivation in following diabetes strict regimen. This suggests that formulation of diabetes education programs that involve family and friends and inclusion of family and friends during doctor's visit can help improve effective diabetes self-management.

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Appendix A: Interview Guide

Initial Questions for the Participants:

1. How do your cultural or ethnic beliefs influence your diabetes management regimen?
2. What do you know about diabetes?
3. How did you react when you learned you have diabetes?
4. How has diabetes affected your daily life?
5. What is *susto*?
6. Do you believe in *susto*?
7. Do you believe that your diabetes condition caused by *susto*?
8. What is *fatalismo*?
9. Do you believe in *fatalismo*?
10. Do you believe that your diabetes condition is because of *fatalismo*?
11. Does *fatalismo* prevent you from doing the things that you should do to manage your diabetes?
12. What is *curandero*?
13. Do you believe in *curanderos*?
14. Have you sought help from *curanderos* about your diabetes?
15. What are the things that the *curandero* advises you about managing your diabetes?
16. What was the reaction of your family when they learned you have diabetes?
17. Do you seek advice from your family about your diabetes condition?
18. What are the things that your family advises you about managing your diabetes?
19. Who helps you maintain your diabetes management regimen?
20. Other than family members, do you have any other social support assisting you in your diabetes management?
21. Of the things that you do to manage your diabetes, what is the hardest and the easiest?
22. How important is diabetes management to you?
23. Are there any positive impacts that have occurred in your life that may have been indirectly influenced by your diabetes?
24. Have you improved your overall health?
25. Have you been eating better?
26. Have you lost any weight?
27. How often do you visit your doctor for your diabetes?
28. Do you visit your doctor for regular check-ups?
29. Where do you get the necessary information about diabetes?
30. Whom do you trust most to provide you advice about your diabetes management regimen? Why?
31. If you have a relative or friend who was just diagnosed with diabetes, what advice would you give that person?

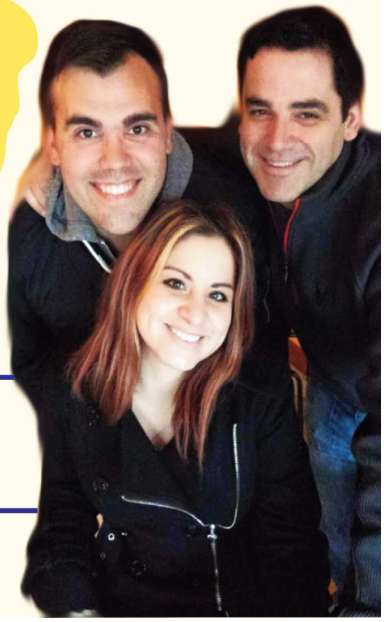
Appendix B: Flyer

TYPE II DIABETES RESEARCH

if you have been diagnosed with TYPE II DIABETES,
YOU MAY BE ELIGIBLE TO PARTICIPATE IN A RESEARCH STUDY!
THIS STUDY IS for a DISSERTATION

IN ORDER TO PARTICIPATE FOR THE STUDY YOU MUST BE:

- characterized as diabetic with TYPE II Diabetes.
- between the ages of 20 to 55 years old.
- Hispanic immigrant who has lived in the USA for at least 10 to 15 years.
- living in Bronx, NY during the time of the study.
- currently seeking regular diabetes treatment from a healthcare provider or no regular treatment for your diabetic condition.
- fluent in English.



If you or someone you know maybe interested in participating, please contact the number below.
If you qualify, you will receive all study related documents.
This will only take 30 minutes of your time.
A gift certificate will be provided for your time.