TYPE 2 DIABETES SELF-MANAGEMENT: INFLUENCES ON NUTRITIONAL PRACTICES AND PHYSICAL ACTIVITY AMONG SPANISH-SPEAKING, LIMITED-ENGLISH-PROFICIENT HISPANICS

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ABSTRACT

CHERYL A. SMITH-MILLER: Type 2 Diabetes Self-Management Practices: Influences on Nutritional Practices and Physical Activity among Spanish-Speaking, Limited-English-Proficient Hispanics (Under the direction of Diane C. Berry)

The purpose of this study was to better understand the influences of and the relationships between the social environment, health literacy, diabetes knowledge, and self-efficacy of Spanish-speaking Hispanics with limited English proficiency on their type 2 diabetes self-management. This study used social cognitive theory as a theoretical framework and a mixed-methods design. Semistructured interviews focused on participants' diabetes self-management practices and personal and family experiences. Clinical measures indicated participants' current health status, and instruments were used to assess health literacy, diabetes knowledge, health behaviors, and diabetes, eating, and exercise self-efficacy.

Qualitative data procedures and analyses used a multistep process that began during the interview. Data reduction and analysis was performed using NVivo[®] V.9 qualitative software. Descriptive statistics and multivariate procedures described the relationships between health literacy, diabetes knowledge, self-efficacy, and diabetes self-management using IBM SPSS[®] V.19 software. The analysis culminated with qualitative and quantitative results linked in the results narrative that provided detailed descriptions of the type 2 diabetes self-management of Spanish-speaking Hispanics with limited English proficiency.

DEDICATION

This work is dedicated to my grandmother, Grace Armintha Eby (1913–1988).

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LIST OF ABBREVIATIONS

AADE	American Association of Diabetes Educators
ADA	American Diabetes Association
BMI	body mass index
CDC	
DKT	Diabetes Knowledge Test
HbA1c	glycated hemoglobin/hemoglobin A1c
HPLP II	Health-Promoting Lifestyles Profile II
IDF	International Diabetes Foundation
IRB	Institutional Review Board
NC	North Carolina
NIDDKD	National Institute of Diabetes and Digestive and Kidney Diseases
OMHHD	Office of Minority Health & Health Disparities
РНС	Pew Hispanic Center
RA	research assistant
SAHLSA	Short Assessment of Health Literacy for Spanish-Speaking Adults
SMBG	self-monitoring of blood glucose
S-TOFHLA	Short Test of Functional Health Literacy in Adults
T2DM	
UNC-CH	
US/U.S	
WtHR	

CHAPTER 1

INTRODUCTION

Statement of the Problem

Globally, an estimated 285 million people aged 20-79 years were living with diabetes in 2010 (International Diabetes Federation [IDF], 2010). In the United States (U.S.), Type 2 diabetes mellitus (T2DM) accounts for 94.3% of the 18.8 million diagnosed diabetes cases. Ethnic and racial minorities are disproportionately affected having prevalence rates 2-to-6 times those of non-Hispanic whites (7.1%), higher complication rates, and worse clinical outcomes (Office of Minority Health & Health Disparities [OMHHD], 2011). Hispanic populations have a high T2DM prevalence rate at 11.8%, second only to non-Hispanic Blacks (12.6%; Centers for Disease Control and Prevention [CDC], 2011b). Among Hispanic populations (i.e., Mexicans, Puerto Ricans, Cubans, Central and South Americans) the prevalence rate for Mexican Americans aged 20 and over is 13.3%, second only to Puerto Ricans at 13.8% (CDC, 2011b). When compared to non-Hispanic white adults, Mexican Americans have an 87% higher risk of being diagnosed with T2DM. Men and women of Mexican heritage suffer higher rates of end-stage renal disease, retinopathy, neuropathy, and lower limb amputations secondary to diabetes than other Hispanic subgroups and are more likely than non-Hispanic Whites to die from diabetes (Umpierrez, Gonzalez, Umpierrez, & Pimentel, 2007). Additionally, immigrant populations also experience higher T2DM prevalence rates and have greater difficulty with diabetes self-management than native-born populations (Creatore et al., 2010; Manderson & Kokanovic, 2009; Plockinger, Topuz,

Langer, & Reuter, 2010; Ujcic-Voortman, Schram, Jacobs-van der Bruggen, Verhoeff, & Baan, 2009). The largest U.S. immigrant population is from Mexico, comprising approximately two-thirds of the foreign-born population (Batalova, 2008b; Pew Hispanic Center [PHC], 2010). This immigration pattern is also reflected in North Carolina (NC) as the Hispanic population increased 394% from 1990 to 2002; the majority, 60%, immigrating from Mexico (Gill, 2010; U.S. Census Bureau, 2010).

Low levels of health literacy and diabetes knowledge, and lack of self-efficacy are thought to contribute to worse diabetes self-management and the resulting disparities in diabetes outcomes (PHC, 2010; Pleis, Lucas, & Ward, 2009; Rustveld et al., 2009). However, the relationship of these factors on Spanish-speaking, limited-English-proficient Mexican immigrants' T2DM self-management practices are only beginning to be studied.

Purpose

Barriers to Spanish-speaking, limited-English-proficient Mexican immigrants' successful T2DM self-management include low academic achievement in Mexico, lack of diabetes knowledge and self-efficacy, and low health literacy (PHC, 2010; Pleis et al., 2009). At the most basic level, literacy is an individual's ability to understand and use the dominate symbols of a culture (alphabet, numbers) to construct meaning (reading and writing). In the health care environment literacy is conceptualized as reading and numerical skills as well as the ability to access, understand, and act upon health information (Nielsen-Bohlman, Panzer, & Kindig, 2004; Peerson & Saunders, 2009). Consistent connections have been found between low health literacy and lack of diabetes knowledge (Office of Disease Prevention and Health Promotion [ODPHP], 2005; Rothman et al., 2005). However, findings regarding the relationship between low health literacy and high glycosylated hemoglobin (HbA1c) levels have been mixed.

Studies including Spanish-speaking subjects found a relationship between low health literacy and HbA1c levels (Schillinger et al., 2002) while research with only Englishspeaking subjects found no association (DeWalt, Boone, & Pignone, 2007; Morris, MacLean, & Littenberg, 2006). These results suggest health literacy alone may not account for the disparities in T2DM outcomes. Lack of self-efficacy, in the presence of low health literacy, may contribute to poor self-management practices in limited-English-proficient Hispanic populations (Bandura, 2004; Wen, Shepherd, & Parchman, 2004). However, to what degree health literacy, diabetes knowledge, and self-efficacy together relate to this populations' diabetes self-management practices has not been examined. Therefore, the purpose of this dissertation was to explore how the social environment influences T2DM self-management and clarify the relationship of health literacy, diabetes knowledge, and self-efficacy with Spanish-speaking limited-English-proficient Mexican immigrant's T2DM self-management (Figure 1.1). Specific study aims are:

Aim 1: Describe the diet practices and physical activity of participants related to T2DM self-management.

Aim 2: Describe how the social environment and vicarious learning influence T2DM self- management related to diet practices and physical activity.

Aim 3: Describe the relationships among health literacy, diabetes knowledge, self-efficacy, and diet practices and physical activity.

Aim 4: Examine the relationships among diabetes knowledge, health literacy, self-efficacy, and the social environment and T2DM self-management behaviors.

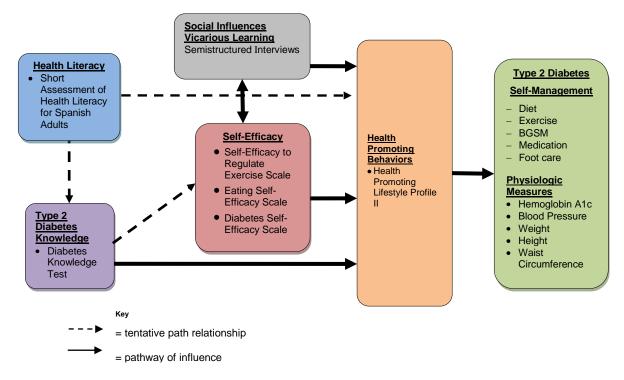


Figure 1.1. Model of study aims and measurement tools (bulleted items). BGSM = Blood glucose self-monitoring.

Prevalence

The number of new diabetes cases in the U.S. more than tripled from 493,000 in 1980 to over 1.7 million in 2010 (CDC, 2011b). In 2007, diabetes was the seventh leading cause of death in the U.S., and the fifth leading cause of death among U.S. Hispanics (OMHHD, 2011). The diabetes prevalence rate in NC increased from 8.4% in 2004 to 9.8% in 2010 making it fifteenth in the nation for adults responding, "Yes" to, "Have (you) ever been told by a doctor that (you) have diabetes?" (Behavioral Risk Factor Surveillance System, 2010).

Minority populations are disproportionately affected by higher rates of T2DM (CDC, 2011b; OMHHD, 2011). From 1997 through 2010, Mexican Americans had a 59% increase in age-adjusted percentage of diagnosed diabetes, the most of any Hispanic subgroup (CDC, 2011a). When examined by age approximately 17.9% of persons of Mexican heritage aged

45-64 years are diagnosed with T2DM compared to 11.4% of non-Hispanic Whites of the same age (CDC, 2011a). These higher prevalence rates have been attributed to a number of factors including biologic and physiologic differences, language differences, socio-economic and education levels, and access to health care services (Herman et al., 2007; Umpierrez et al., 2007). However, lack of diabetes specific knowledge was also identified as contributing to poorer T2DM self-management and worse clinical outcomes (Mann, Ponieman, Leventhal, & Halm, 2009).

Complications

Not only do diabetes prevalence rates vary among racial and ethnic populations, considerable differences exist in the management and the types of complications among these groups (Jiang, Andrews, Stryer, & Friedman, 2005). The complications of poor glycemic control occur at both the microvascular and macrovascular level, and result in a variety of consequences including cardiovascular disease, stroke, hypertension, retinopathy, blindness, renal disease, and nervous system damage (American Diabetes Association [ADA], 2012; NIDDK, 2011). Mexican Americans experience worse microvascular complications in the form of lower extremity disease, end stage renal disease, and have an 84% higher prevalence rate of diabetic retinopathy compared to non-Hispanic Whites (Karter et al., 2002; Umpierrez et al., 2007).

Population Identification

Efforts to gather accurate, comprehensive information about Hispanic populations are plagued by inconsistent identification, language barriers, incomplete data collection, uncertain immigration status, and distrust (Garcia & Marinez, 2005; Zambrana & Carter-Pokras, 2001). These inconsistencies limit the ability to track health status trends of Hispanic groups and especially those of recent immigrants (Hector et al., 2009; Lorant, Demarest, Miermans, & Van Oyen, 2007; National Center for Health Statistics, 2010).

Misidentification and inconsistencies in reporting Hispanic origin on death certificates, censuses, and surveys can lead to population under- and over-identification, mask health trends, and under or over represent disease prevalence, illness incidence, and estimated health risks (Borrell, 2005; Hunt & Bhopal, 2004).

The term *Hispanic* and *Latino* describe individuals or populations whose heritage can be traced to Spanish-speaking countries or who have immigrated to the U.S. from Mexico, Puerto Rico, Cuba, Central or South America, or other Spanish-speaking countries (Office of Management and Budget, 1997). Data classification using these terms in reference to T2DM suggest a homogenous population when, in fact there is a great deal of variability in prevalence rates and types of complications based on country of origin. For example, collective classification conceals the differences in T2DM prevalence rates among Hispanic subgroups: Cubans 7.6%, Mexicans 13.3%, and Puerto Ricans 13.8% (CDC, 2011b). In this document, *Hispanic* refers to non-specific populations as previously described and *Mexican* refers to persons living in the U.S. who have emigrated from Mexico or are of Mexican heritage.

Language

Language differences between patients and providers contribute to communication difficulties and hinder successful diabetes management (Umpierrez et al., 2007; Wilson, 2005). Persons with limited-English proficiency are described as those who have difficulty communicating in, reading, or understanding English because their primary language is not English (U.S. Department of Health & Human Services, 2003). English language skills are a significant issue for recently immigrated Mexicans because an estimated 75% have limited English proficiency (PHC, 2009). Lack of English proficiency is a marker for poor health status and presents a significant barrier to effective T2DM self-management (Nam, Chesla, Stotts, Kroon, & Janson, 2011; Martinez, 2007).

The majority of recent Hispanic immigrants from Mexico face significant obstacles related to language and literacy (PHC, 2009; U.S. Census Bureau, 2008). In NC, a reported 34% of Mexican immigrants speak English poorly or not at all and 49% report not speaking English very well, figures that exceed the national rates of 22% and 36% respectively (U.S. Census Bureau, 2008). Limited-English proficiency in combination with low literacy increase individuals' difficulties accessing health services, acting on health information, and self-managing chronic conditions such as diabetes (Ding & Hargraves, 2009; Garcia & Duckett, 2009; Sarkar et al., 2008; Sudore et al., 2009). In this research we targeted Spanishspeaking persons with limited-English proficiency in exploring their T2DM self-management (Martinez, 2007; Powell, Hill, & Clancy, 2007; Schillinger et al., 2002).

Literacy

Literacy encompasses a broad range of skills including the ability to identify, understand, interpret, communicate, and use printed and written materials in varying contexts (Barton, 2007; Brandt, 2001), skills that many individuals do not possess or have difficulty with (Kutner, Greenberg, & Baer, 2006). For Hispanic populations low literacy is a significant issue because 41% of U.S. Hispanics aged 20 and older do not have a high school diploma (Fry, 2010). Among Mexican immigrants, three to five percent do not have a high school diploma (Batalova, 2008a). The impact of lower educational status coincides with their T2DM self-management and glycemic control (Franzini & Fernandez-Esquer, 2004).

Overall Hispanic persons consistently report lower educational achievement and higher HbA1c levels than African Americans or non-Hispanic Whites (Goldman & Smith, 2002; Heisler, Piette, Spencer, Kieffer, & Vijan, 2005; Nielsen-Bohlman et al., 2004; Rosal et al., 2005; Smedley, Stith, & Nelson, 2003). For persons with low literacy, tasks required for successful T2DM self-management such as adjusting medication dosing based on blood glucose test results can quickly exceed their literacy skills (Cavanaugh et al., 2008; Osborn, Cavanaugh, Wallston, White, & Rothman, 2009; White, Osborn, Gebretsadik, Kripalani, & Rothman, 2011). Heightened anxiety and stress due to language difficulties, current health status, and low confidence may further impair their ability to self-manage. The following sections describe the constructs of the *Model Aims* and *Measurement Tools* as illustrated in Figure 1.1.

Health Literacy

Literacy is the ability to understand and use the dominant symbols of a culture (alphabet and numbers) to construct meaning (reading and writing; Barton, 2007; Brandt, 2001; Scribner & Cole, 1999). Health literacy is context specific and requires all the previous noted competencies as well as the ability to access, understand, and act upon health information (Nielsen-Bohlman et al., 2004; Peerson & Saunders, 2009).

Low health literacy is most often measured as reading ability and has been consistently associated with less diabetes knowledge (Gazmararian, Williams, Peel, & Baker, 2003; Hector et al., 2009). However, the association between low health literacy and poor diabetes self-management as evidenced by HbA1c levels has been less certain. Studies including Spanish-speaking participants found a relationship between health literacy and HbA1c levels (Schillinger, Barton, Karter, Wang, & Adler, 2006; Schillinger et al., 2002);

research with English-speaking participants did not find an association (DeWalt, Boone, & Pignone, 2007; Morris et al., 2006). Although the definition is broad, when the exploration of health literacy is limited to reading ability its psychological and social domains, and their influences on self-management behaviors, remain unexplored (Lerman et al., 2004; Parker, Baker, Williams, & Nurss, 1995).

Diabetes Knowledge

Successful diabetes self-management requires sufficient knowledge of the condition and its treatment (American Association of Diabetes Educators [AADE], 2012; Carbone, Rosal, Torres, Goins, & Bermudez, 2007). Although the benefits of diabetes selfmanagement education (DSME) on outcomes (e.g., HbA1c levels, weight) are well documented, the percentage of persons receiving DSME remains suboptimal, especially among racial and ethnic minorities, the poor, and the uninsured (Brown et al., 2005; Funnell, 2009; ODPHP, 2009; Peyrot, 2009). Diabetes knowledge is positively correlated with health literacy levels; persons with inadequate health literacy have significantly less knowledge about diabetes than those with adequate health literacy. However, the evidence linking health literacy, diabetes knowledge, and self-management outcomes among Spanish-speaking Hispanics is limited (Cavanaugh et al., 2008; Fransen, 2011; Hector, 2009).

Social Influences

Culture is the behaviors, beliefs, values, and ways of living shared by a social or ethnic group and is a social environment that includes family, friends, and neighbors (Bandura, 1986). Culture, past experiences, and attitudes inform individuals' T2DM selfmanagement practices (Rustveld et al., 2009). This study examined whether and how this environment influenced participants' T2DM self-management. Two components of Hispanic culture relevant to diabetes self-management and social cognitive theory are familialism (*familismo*) and fatalism (*fatalismo*). Familial traditions are central to Hispanic culture. Familialism subordinates personal interests and prerogatives to the needs and values of the family. Family members act as consultants for health-care decisions and serve as behavioral referents (Weiler & Crist, 2009). Family members also serve as models for T2DM self-management behaviors and influence beliefs about the etiology and course of diabetes (Alcozer, 2000; Caban & Walker, 2006; Comellas et al., 2010). Fatalism is the belief that an outcome cannot be altered, a perspective that can potentially undermine the value of long-term diabetes self-management (Rustveld et al., 2009). This belief may contribute to Mexicans experiencing more hopelessness related to T2DM compared to other Hispanic subgroups. It is suggested that this hopelessness is related to the high number of familial references for poor diabetes outcomes, stronger fatalistic attitudes, or both (Alcozer, 2000; Beard, Al-Ghatrif, Samper-Ternent, Gerst, & Markides, 2009; Caban & Walker, 2006).

Successful diabetes self-management requires lifestyle changes and adapting a number of new behaviors (ADA, 2012). Social cognitive theory proposes that a person's decision to engage in different health habits is based on evaluation of the expected costs and outcome expectations of these behaviors (Bandura, 2004). In this study, individuals' experiences with family members' course of diabetes self-management were explored, as well as the influence of these experiences on individuals' expectations for their own diabetes self-management.

Vicarious Learning

Vicarious learning occurs over time by observing referent social models' behavior and the consequences of this behavior (Bandura & Locke, 2003; Sarkar, Fisher, & Schillinger, 2006). Observation of others (e.g., role models, family members) diabetes selfmanagement practices can influence individual self-management practices (Alcozer, 2000; Bandura, 1998; Caballero, 2006; Hunt & de Voogd, 2005; Ingram et al., 2007). Vicarious learning experiences can improve or worsen an individual's self-efficacy to perform T2DM self-management behaviors, but exploring what has been learned from others can offer explanation of current, possibly incongruent, self-management practices (Bandura & Locke, 2003; Sarkar et al., 2006).

Self-Efficacy

Self-efficacy is the confidence an individual has in his ability to perform a behavior or accomplish a goal; the degree of self-efficacy influences the amount of perseverance and effort that will be made (Bandura, 1989). However, self-efficacy focuses on individual effort and as such may not be applicable for persons from cultures that privilege the group over the individual (Bandura, 2000). It is suggested that collective efficacy, or the belief in group or collective effort, may be a more appropriate theoretical construct in familial-centered cultures (Bernal, Woolley, Schensul, & Dickinson, 2000; Ingram, Ruiz, Mayorga, & Rosales, 2009).

Although self-efficacy is a mediating link between cognitive preparation (knowledge and skills development) and task performance, health literacy level does not appear to effect self-efficacy in diverse populations (Figure 1.1; DeWalt et al., 2007; Sarkar et al., 2006). Self-efficacy has been used as a framework in previous research on exercise (Allen, 2004), eating, and exercise behaviors (Bandura, 2004; Everett, Salamonson, & Davidson, 2009).

Self-Management

Optimal T2DM self-management decreases morbidity and saves billions of dollars in health-care costs (ADA, 2012; Dall et al., 2010; Minshall et al., 2005). Poor T2DM selfmanagement increases morbidity, strains the health care system, and decreases one's productivity and ability to contribute to society (ADA, 2012; Spector, 2009; Von Korff et al., 2005). Self-management are the actions and behaviors in which an individual engages to manage the symptoms, treatment, physical and psychosocial consequences and life style changes in order to maintain health and minimize negative outcomes in the future (AADE, 2012; Barlow, 2002). However, *prevention*, to minimize future negative health outcomes, in the absence of present symptoms, is not a universally held belief (Carlson, 2000).

Type 2 diabetes self-management typically targets four domains: nutrition and diet; exercise and physical activity; blood glucose monitoring; and medication. Each domain is multifaceted and complex. For example, nutrition and diet require knowing what foods are healthy choices, understanding portion control, and the timing of eating (AADE, 2012). Successful T2DM self-management depends on individuals' performance of regular exercise, daily medication adherence, diet and blood glucose monitoring, and foot care (ADA, 2012). One indicator of diabetes self-management is HbA1c or the average blood glucose during the previous two to three months, with a target HbA1c value of 7% or less (ADA, 2012; Dorsey, Eberhardt, Gregg, & Geiss, 2009; Kirk et al., 2008). However, only 49.8% of adults with diabetes meet the objective of a HbA1c < 7% and only 28.2% engage in the recommended level of physical activity (Saydah, Cowie, Eberhardt, De Rekeneire, & Narayan, 2007; Saydah, Fradkin, & Cowie, 2004). Successful diabetes self-management not only requires

knowledge of recommended behaviors but the consistent performance of these behaviors (Powell et al., 2007; Sarkar et al., 2006; Schillinger et al., 2006).

Culturally, time orientation can also shape self-management behaviors. Many Hispanic cultures focus on the present, not the future, a perspective that can impair the performance of behaviors that are intended to minimize future complications (Borrell, Dallo, & White, 2006; Caballero, 2006; Giger & Davidhizar, 2007; Leininger & McFarland, 2006). The consequences of successful diabetes self-management are not immediately evident making the benefits of daily adherence to nutrition and exercise recommendations difficult to appreciate and maintain (Mainous, Diaz, Geesey, 2008; Paz et al, 2006, Perez-Escamilla, & Putnik, 2007).

Diet and physical activity have been identified as the most difficult domains of T2DM self-management to initiate and continue (Allen, 2004; DeWalt et al., 2009: Glasgow, Toobert, & Gillette, 2001). While daily medication adherence is unrelenting, following a medication regimen appears to be easier than engaging in recommended diet and exercise behaviors (Lerman et al., 2004; Rustveld et al., 2009). As previously described, Spanishspeaking, Mexican immigrants with limited-English proficiency face unique barriers to achieving glycemic goals and successful T2DM self-management (ADA, 2012; Lerman et al., 2004; OMHHD, 2011; PHC, 2009). Barriers impede or obstruct progress and include low health literacy, lack of diabetes knowledge, or low self-efficacy (Ingram et al., 2009; Latham & Calvillo, 2009; Vega, Rodriguez, & Gruskin, 2009). Although these factors can exacerbate poor T2DM self-management practices, their relationships and affect on the selfmanagement practices of Spanish-speaking, limited-English-proficient Mexican-immigrant populations are largely unexamined (Mann et al., 2009).

Conceptual Framework

The theoretical foundation for this study was social cognitive theory. Social cognitive theory is based on reciprocal determinism and is represented in Figure 1.2. This model describes behavior as the result of continuous interactions between the environment, personal factors, and behaviors.

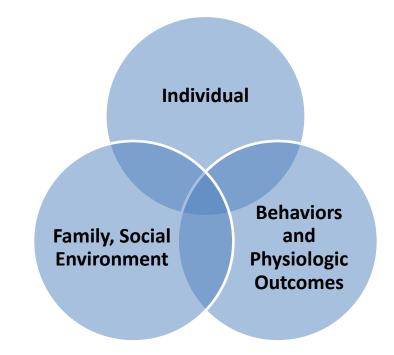


Figure 1.2. Model of the examined constructs. Individual includes personal attributes of knowledge and self-efficacy. Behaviors and physiologic outcomes represent diabetes self-management behaviors and outcomes. Family and social environment includes individuals' past and current experiences with diabetes management.

The following figure (Figure 1.3) represents how the relationships among Family,

Individual, and *Behavior* were conceptualized in the study, although the degree of association among the components is expected to vary among the 30 participants. The following section briefly explains how the constructs above were examined using a social cognitive theory framework.

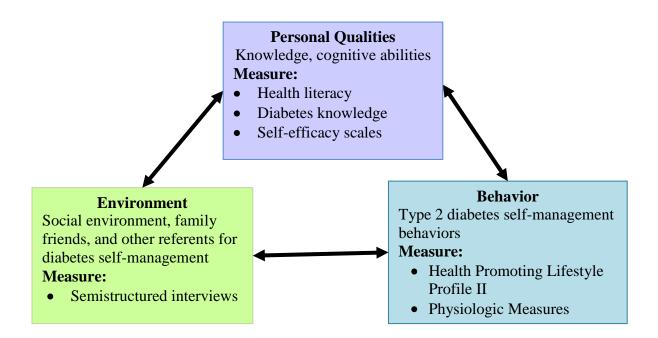


Figure 1.3. Reciprocal determinism and how these qualities were measured or explored (Bandura, 1986).

For the purposes of this study *environment* was limited to the social environment and the influence of family, friends, and other referents related to T2DM self-management. Semistructured interviews explored the ways in which participants learned about diabetes, their current social environment in relation to their diabetes self-management practices, and their vicarious learning experiences. Interview questions and probes were designed to explore how and to what degree participants' self-management practices were influenced by their social environment.

The personal qualities, knowledge and self-efficacy, were examined. Measurements focused on health literacy level and diabetes knowledge. Self-efficacy, identified as a predictor of the initiation and maintenance of behaviors, was measured with diabetes, eating, and exercise self-efficacy scales (Figure 1.1; Allen, 2004; Ingram et al., 2009). Health

promotion practices were examined using a health-promoting lifestyle profile instrument and the efficacy of current self-management practices were assessed with physiologic measures.

Summary

Chapters 2, 3, and 4 correspond to the review of the literature, methods, and research findings. Chapter 2 is a review of the literature that examines current research in reference to health literacy, self-efficacy, and Spanish-speaking Hispanics' T2DM self-management. A summary of the research and recommendations for future research are provided. Chapter 3 describes the challenges in recruiting minority participants into the research study and discusses the strategies that were employed to overcome these barriers, Chapter 4 describes the process of summarizing the mixed-method research findings. Chapter 5 provides a synthesis of the results, implications for future research and interventions to improve self-management and glycemic control in populations similar to the study participants.

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CHAPTER 2

LITERATURE REVIEW

Introduction

The prevalence of T2DM is increasing in both developed and developing countries (van Dieren, van der Schouw, Grobbee, & Neal, 2010). The rise is attributed to cultural and societal changes, aging populations, changing dietary habits, decreased physical activity, and increasing obesity rates (International Diabetes Federation [IDF], 2010). Globally, an estimated 285 million people aged 20 to 79 years were living with diabetes in 2010 (IDF, 2010). By the year 2034, this number is expected to increase to 438 million (Egede, 2010; van Dieren et al., 2010). Although public health programs promoting healthy lifestyle habits have been initiated, immigrant populations remain at higher risk for developing T2DM than native populations (IDF, 2010; Roglic et al., 2005). Investigators in Germany, Canada, the Netherlands, Australia and the United States (US) found immigrant populations experienced higher prevalence rates and had greater difficulty managing T2DM than native-born populations (Creatore, 2010; Manderson & Kokanovic 2009; Plockinger, Topuz, Langer, & Reuter, 2010; Choi, Chow, Chung, & Wong, 2011; Ujcic-Voortman, Schram, Jacobs-van der Bruggen, Verhoeff, & Baan, 2009).

Background

Native and foreign born Hispanics are the largest ethnic minority in the US; immigrants from Mexico comprise roughly two-thirds of the foreign born population (Pew Hispanic Center, 2010b). Hispanics aged 20 years and older, living in the US, have a diagnosed diabetes prevalence rate of 11.8%, higher than that of non-Hispanic Whites at 7.1% (National Institute of Diabetes and Digestive and Kidney Diseases, 2011). Diabetes prevalence rates vary among Hispanic subgroups with persons of Mexican descent at particularly high-risk. Of Mexicans aged 45 to 74 years and living in the US, 24% are diagnosed with diabetes, compared to 12% of non-Hispanic Whites (Centers for Disease Control and Prevention, 2010; Umpierrez, Gonzalez, Umpierrez & Pimental, 2007). Diabetes is the fifth leading cause of death for Hispanics in the US (Heron et al., 2009). Compared to non-Hispanic Whites Hispanics have higher rates of renal disease, retinopathy, neuropathy, and lower limb amputations secondary to diabetes (Umpierrez et al., 2007).

Effective self-management of T2DM, defined as glycated hemoglobin (HbA1c) less than 7% and maintaining a healthy weight through diet and exercise, can reduce or prevent these complications (American Diabetes Association [ADA], 2012; Sabaté, 2003). Mexican immigrants face substantial barriers to attaining this goal including low academic achievement in their country of origin, low health literacy, limited-English proficiency, lack of diabetes knowledge, and low self-efficacy (ADA, 2012; Batalova, 2008; Fry, 2010; Office of Minority Health & Health Disparities, 2009). Despite high prevalence rates and the size of the Mexican immigrant population in the US, we have insufficient knowledge of T2DM selfmanagement of limited-English proficient Hispanic immigrants (Saydah, Cowie, Eberhardt, De Rekeneire, & Narayan, 2007).

To clarify terminology, *Hispanic* or *Latino* is used in the literature to describe individuals or populations whose heritage can be traced to Spanish-speaking countries or who have immigrated to the US from Mexico, Puerto Rico, Cuba, Central and South

America, or other Spanish speaking cultures (Office of Management and Budget, 1997). Hispanic and Latino are ethnic classifications and are contingent on individuals selfidentifying; those same individuals may be of any race. In this article, the term *Hispanic* is used when collective data are provided and countries of origin are given when specific subgroup data are provided.

Health Literacy

Low health literacy contributes to disparities in self-care management and health outcomes among Hispanics with limited proficiency in English (Brach & Chevarley, 2008; Sarkar et al., 2010; Schillinger et al., 2002). Health literacy is the ability to access, understand, and act on health information. Commonly, researchers use reading ability as a proxy for the broader construct of health literacy (Nielsen-Bohlman, Panzer, & Kindig, 2004; Schwartzberg, VanGeest, & Wang, 2005).

The most recent National Assessment of Adult Literacy (NAAL) evaluated health literacy tasks in the clinical, preventive, and navigational domains (Kutner, Greenberg, Jin, & Paulsen, 2006). The evaluative materials were designed to represent real-world, healthrelated information, including health insurance information, medication instructions, and preventive health information. The clinical domain covered individuals' interactions with providers and performance of common tasks in the health care setting such as completing a patient information form, understanding medication dosing instructions, and following directions in preparation for a diagnostic test. The prevention domain addressed maintaining and improving health, disease prevention, recognition of signs and symptoms of health problems, and self-care and management of illness. The navigation domain incorporated activities related to understanding how the health-care system works and consumers' rights

and responsibilities within it. Examples include understanding what a health insurance plan's inclusions and exclusions mean, appraising one's eligibility for public insurance or assistance programs, and the ability to give informed consent for a health-care service.

The assessment found that 41% of Hispanics scored *below basic* health literacy, a level lower than any other racial or ethnic group (Kutner et al., 2006). Tasks at that level required locating straightforward information within simple texts such as circling an appointment date on an appointment slip or identifying how often a person should have a medical test based on information in a pamphlet. However, while the NAAL questions were orally administered in either English or Spanish, they were based upon written materials presented in English only; thus, respondents were not evaluated in their language of choice making this a major limitation of the NAAL.

For adults with less than a high school education, 49% had below basic health literacy; the number for those with a high school education was 15%. These disparities substantiated previous findings associating low academic achievement with low health literacy (Kutner et al., 2006). Overall, Hispanic adults had lower average health literacy than any other racial or ethnic group. With three in five Mexican immigrants having less than a high school education, they are at a particular high risk for low health literacy (Batalova, 2008).

Limited English-Language Proficiency

Low academic achievement is associated with poorer health status, and limited English language proficiency further exacerbates the effects of low literacy (Goldman & Smith, 2002; Kimbro, Bzostek, Goldman, & Rodriguez, 2008; Vega, Rodriguez, & Gruskin, 2009). *Limited English proficient* refers persons who, because of national origin, do not

speak English as their primary language and have a limited ability to read, speak, write, or understand English (Civil Rights Division, 2000; U.S. Government, 1964). Language skills are a significant issue because 75% of recently immigrated Mexicans have limited English proficiency (Pew Hispanic Center, 2009). Limited English language proficiency and low literacy increases individuals' difficulties in acting on health information and self-managing diabetes (Sarkar et al., 2010; Sudore et al., 2009). Although low literacy and lack of diabetes knowledge play a role in poor self-management outcomes, they are insufficient to explain all domains of diabetes self-management such as diet, exercise, self-monitoring of blood glucose (SMBG), and medication management (Latham & Calvillo, 2009).

Self-Efficacy

Self-efficacy is a person's confidence in his or her ability to perform a behavior or accomplish a goal, and it influences the degree of perseverance and effort a person will put forth (Bandura, 2004). Self-efficacy is an established predictor of the initiation and maintenance of health-related behavior changes in English-speaking populations and the same appears to be true among Hispanic populations (Ingram, Ruiz, Mayorga, & Rosales 2009). Although self-efficacy seems to be linked to Hispanics' initiation and maintenance of diabetes self-management, little is known about the applicability of self-efficacy research findings to Hispanics with limited English proficiency and low literacy (Bernal, Schensul, & Dickinson, 2000; Sarkar, Fisher & Schillinger, 2006). Therefore, the purpose of this review was to assess the state of the science with regard to literacy and self-efficacy as they relate to the T2DM self-management of Hispanics with limited English proficiency.

Methods

Research focusing on literacy, self-efficacy, T2DM self-management, and included Spanish-speaking participants was explored. The search was conducted using electronic databases, reference lists of selected articles, related citations, and government reports. The *Cumulative Index to Nursing and Allied Health, PubMed*, the *Cochrane* Library, and the *Education Resources Information Center* were searched for original research articles. The search was limited to articles published in English and the following search terms were used: *diabetes, literacy, self-efficacy*. To limit the search results all three search words were required to be positive, using AND in Boolean logic. The following Medline Medical Subject Headings terms were also used: *diabetes mellitus, literate, illiteracy, readability,* and *reading level.* No date restrictions were placed on the search. The full inclusion and exclusion criteria are summarized on Table 2.1.

Table 2.1

Included Studies	Criteria
Population	• Spanish-speaking adults with type 2 diabetes
Focus	 The relationship between literacy, self-efficacy, and self-management outcomes or domains (i.e., diet, exercise, self-monitoring of blood glucose, medication) The measures of the focus variables and outcomes were evaluated
Measures	 Literacy level determined using a validated instrument Numeracy Self-efficacy Physiological or reported self-management behavior
Publication Criteria	English languageNo unpublished dissertationsArticles in print

Literature Search: Inclusion and Exclusion Criteria

Excluded Studies	Criteria	
	• Focused on gestational diabetes or type 1 diabetes	
	• Focused on program development	
	• Used academic achievement level as a literacy measure	
	• Focused on instrument psychometrics	
	• Evaluated diabetes information or patient education materials	
	• Opinion pieces, commentaries, or editorials	
	• Focused on physician–patient communication	
	• Used an adolescent or pediatric population	
	• Focused on health-care access or utilization	

Reference lists of works selected from the online search were reviewed for additional manuscripts. The search results from each database and the reference lists were screened for duplicate manuscripts. This resulted in 43 titles and abstracts published between March 2001 and December 2011. All 43 titles and abstracts were screened based on whether the subject population included Spanish-speaking adults and examined the relationship of the literacy and/or self-efficacy on a diabetes self-management outcome (e.g., HbA1c level, weight, SMBG). A total of 24 articles were excluded after the review of titles and abstracts. Of those, six were excluded because they did not focus on literacy or self-efficacy (Abdoli, Ashktorab, Ahmadi, Pravizy, & Dunning, 2011; Cho et al., 2010; Levin-Zamir & Peterburg, 200; Seligman et al., 2007) or diabetes specifically (Carolan, Steele, & Margetts, 2010). Two unpublished dissertations and one review were excluded (Fransen, von Wagner, & Essink-Bot, 2011). Six studies were excluded due to a lack of Spanish-speakers in the study population (Fernandez et al., 2011; Khan et al., 2011; McCleary-Jones, 2011; Peek et al., 2009).

The remaining manuscripts (n = 19) were reviewed, and 14 did not meet the inclusion criteria. Wrong topics included focuses on physician–patient communication (Seligman et

al., 2005), instrument psychometrics (Gerber et al., 2006), health systems (Adams, 2010; Cavanaugh, 2011; Sarkar et al., 2008), and descriptions of the problems associated with low literacy (Nath, 2007). Studies that did not include Spanish-speaking participants were excluded (Delgadillo et al., 2010; Cavanaugh et al., 2008; Ishikawa, Takeuchi, & Yano, 2008; Ishikawa & Yano, 2011; Osborn, Cavanaugh, Wallston, & Rothman, 2010; Rosland, Heisler, Choi, Silveira, & Piette, 2010). Studies not measuring literacy status or self-efficacy were also excluded (Latham & Calvillo, 2007, 2009; Rosal et al., 2009, 2011). Figure 2.1 illustrates the process used to screen the articles.

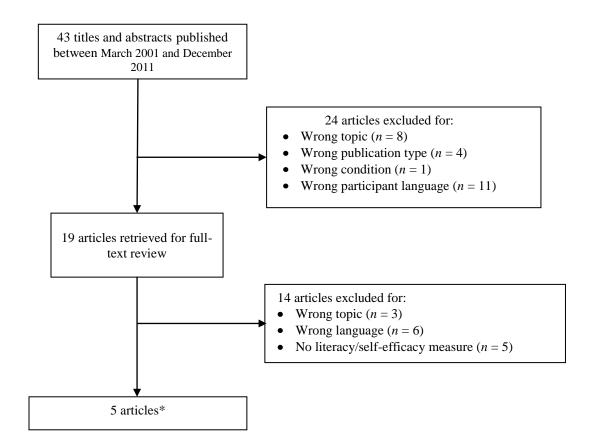


Figure 2.1. Flow diagram of the methods used to determine the included studies. *One study had outcomes published in two articles (DeWalt et al., 2009; Wallace et al., 2009).

Results

Five articles met the inclusion criteria and were included in the review (DeWalt et al., 2009; Gerber et al., 2005; Sarkar et al., 2006; Wallace et al., 2009; White, Osborn, Gebretsadik, Kripalani, & Rothman, 2011). Two of the five articles were based on results from the same study (DeWalt et al., 2009; Wallace et al., 2009). All four studies addressed literacy, self-efficacy, and T2DM self-management. See Table 2.2 for a summary of the articles.

Table 2.2

Summary Table

Author	Design	Data /Measures	Literacy Assessment	Age/Race/ Language	Number of Participants	Outcomes
Gerber et al., 2005	Randomized Control Trial Intervention Clinic-based multimedia diabetes education computer application Duration:1 year	 Intervention - computer use Control - standard of care Instruments: Adapted Knowledge Scale; self-reported Medical Care Scale; Self- Efficacy Scale; perceived susceptibility to complication Physiologic measures: HbA1c, BMI, BP 	English and Spanish versions of S-TOFHLA	 Intervention group (n = 122): 81 women; 31African American; 52 persons speaking only Spanish Recruited from: Five public clinics Location: Chicago, Illinois 	n = 183 Average ages Intervention group: Lower literacy: 57.7±11.7 Higher literacy: 49.4 ±12.0 Control group: Lower literacy: 60.4±10.8 Higher literacy: 51.8±11.3	 Intervention group: increase in perceived susceptibility with greatest increase among low-literacy participants. Low-literacy participants with baseline A1C ≥ 9.0% (n = 26): greater decrease in HbA1c in intervention group than control group Self-efficacy: trend toward greater improvement in self- efficacy for the intervention group
Sarkar et al., 2006	Cross-Sectional Observational Study	• Orally administered: Diabetes Self-efficacy Scale, Summary of Diabetes Self-Care Activities Questionnaire	English and Spanish versions of S-TOFHLA	 ≥ 30 years old 2 visits with the same physician n = 148 Spanish speakers n = 260 English speakers 165 Hispanics 51 Whites 	n = 408 Average age 58.1 ± 11.4	Each 10% increase in self-efficacy score reported optimal diet, exercise, SMBG, and foot care but not medication adherence. Associations between self-efficacy and self- management were consistent across race/ethnicity and literacy levels.

Author	Design	Data /Measures	Literacy Assessment	Age/Race/ Language	Number of Participants	Outcomes
DeWalt, et al., 2009	Quasi- experimental design, intervention study	 Literacy-appropriate patient educational materials and brief counseling sessions. Domain Specific: facilitated patient goal setting Non-clinical interventionist. Duration: 4-study contacts- baseline introduction session, telephone calls at 2, 4, and 12- 16 weeks Satisfaction questionnaire reference education guide 	English and Spanish versions of S-TOFHLA	> 18 years old 45% African American, 33% Hispanic n = 149 English speaking (NC) n = 77 Spanish speaking /80 (California) n = 85 English- speaking (Louisiana)	n = 250 Ages 29-93	Goal setting domains were diet and exercise. No differences in goal achievement by literacy or language
Wallace, et al., 2009		 Education guide and outcomes Initial structured interview Demographics Orally administered: Patient Activation Measure Diabetes Self-Efficacy Diabetes Distress Scale, Diabetes Self-Management Behaviors Diabetes Knowledge Pre-intervention physiologic measures: HbA1c and BMI 				 Spanish-Speakers: Diabetes-related distress declined more than for English-speakers Self-efficacy only improved for English-speakers. Literacy levels: Patients with marginal or inadequate literacy experienced similar benefits as those with adequate literacy.
White et al., 2011	Cross-Sectional Descriptive	 Examined the relationship between diabetes-specific numeracy and related outcomes among a sample of Latino adults. Orally administered in Spanish: 	S-TOFHLA	Eligible 18-85 years old Visual acuity Recruited from 1 Adult Medicine	n = 144 Average Age 47.8 (<u>+</u> 12.1)	Diabetes specific numeracy measure was significantly associated with acculturation but unrelated to self-

Author	Design	Data /Measures	Literacy Assessment	Age/Race/ Language	Number of Participants	Outcomes
		S-TOFHLA, Wide-Range		Clinic & 2 Federally		efficacy, self-care
		Arithmetic Test, Short		funded Community		behaviors, insulin
		Acculturation Scale, Perceived		health centers		use, and HbA1c
		Diabetes Self-Management				
		Scale, Summary of Diabetes		Recruited at		
		Self-Care Activities		Scheduled		
		 Demographics 		appointment		
		Age, gender, nationality,				
		diabetes type and length of				
		diagnosis, education level,				
		income, insurance status and				
		insulin use				
		• Physiologic measures:				
		HbA1c				
		BMI				

Literacy was assessed in all four studies with an abbreviated version of the 36-item, short version of the Test of Functional Health Literacy in Adults (S-TOFHLA; Baker, Williams, Parker, & Gazmararian, & Nurss, 1999). This test requires an estimated 12 minutes to complete, has English and Spanish language versions, and has two-parts with one section evaluating numeracy and the other evaluating reading comprehension using a modified cloze procedure (Taylor, 1953). The cloze procedure systematically deletes every fifth-to-seventh word in a passage; the modified version offers a choice of four words from which the reader selects the one that best fits the context of the sentence. Scores of 0 to 16, 17 to 23, and greater than 23 indicate inadequate, marginal, and adequate levels of literacy, respectively. All the studies used one-part of the instrument, focusing on reading comprehension and proficiency. Physiological measures taken in three of the studies were HbA1c levels and body mass indexes (BMI).

A total of 553 Hispanic subjects participated in the four studies. Participants ranged in age from 29 to 93 years, and all had a diagnosis of T2DM. The key characteristics of study participants are presented in Tables 2.3 and 2.4. Exclusion criteria for all the studies were a history of psychosis or dementia, blindness, or poor visual acuity. These exclusions are common in research focusing on literacy and diabetes self-management due to their potential to interfere with accurate literacy assessment and the ability to self-manage diabetes. Assessing visual acuity can be significant when evaluating reading ability as low literate persons may attribute their reading difficulties to an inability to see the material or not having their eye glasses with them (Nurss et al., 1995). Additional variables measured by the reviewed studies were perceived susceptibility to complications, computer usage, self-management activities, patient activation, diabetes-related distress, diabetes knowledge, and

goal setting behavior. Specific information about the instruments is provided in the context of the study in which they were used.

Table 2.3

Characteristics	Sarkar et al., 2006	White et al., 2011
Title	Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy?	Development and Validation of a Spanish Diabetes-Specific Numeracy Measure: DNT-15 Latino
Participants' Average Ages (range)	58.1, <i>SD</i> <u>+</u> 11.4	47.8, <i>SD</i> <u>+</u> 12.1 (18-85)
Number of Hispanic participants	165	144
Spanish language preference	<i>n</i> = 148 (90%)	n = 90-130 (63% - 90%)
Literacy level		
Adequate	n = 198 (48.5%)	n = 95 (64%)
Marginal/Inadequate	n = 210 (51.5%)	n = 54 (36%)
Self-efficacy	74, <i>SD</i> = 18 (16-100)	22.8, <i>SD</i> <u>+</u> 6.4
Glycosylated hemoglobin	8.5%	8.1, <i>SD</i> <u>+</u> 2.3
BMI	NA days DNT 15 Lating - Disbates Nu	31, <i>SD</i> <u>+</u> 7.2

Note. BMI = Body mass index; DNT-15 Latino = Diabetes Numeracy Test-15 Latino

Table 2.4

Characteristics	Gerber et al., 2005	Wallace et al., 2009 and DeWalt et al., 2009
Title	Implementation and evaluation of a low-literacy diabetes education computer multimedia application	Literacy-appropriate educational materials and brief counseling improve diabetes self-management Goal setting in diabetes self- management: Taking baby steps to success
Participants' average ages (range)	Intervention Group Lower literacy: 57.7 ± 11.7 Higher literacy: 49.4 ± 12.0 <i>Control Group</i> Lower literacy: 60.4 ± 10.8 Higher literacy: 51.8 ± 11.3	56 (29–93)
Number of Hispanic participants-	161	83
Spanish language preference	<i>n</i> = 101 (63%)	<i>n</i> = 77 (93%)
<i>Literacy</i> Adequate	<i>n</i> = 109 (45%)	n = 142 (57%)
Marginal/Inadequate	<i>n</i> = 135 (55%)	<i>n</i> = 108 (43%)
Self-efficacy scores	Intervention Group Lower literacy: 0.73 ± 0.96 Higher literacy: 0.88 ± 1.32 Control Group Lower literacy: 1.00 ± 1.41 Higher literacy: 0.90 ± 1.14	Pre- 73.62 (<i>SD</i> ±16.73) Post- 77.91 (<i>SD</i> ± 16.02)
Glycosylated hemoglobin (range)	Intervention Group Lower literacy: 8.1%, $SD \pm 2.2$ Higher literacy 8.3%, $SD \pm 2.4$ Control Group Lower literacy: 8.1, $SD \pm 1.7$ Higher literacy: 8.3, $SD \pm 2.1$	8.6 (4.2 <u>+</u> 16.8)

Characteristics of Intervention Studies

Characteristics	Gerber et al., 2005	Wallace et al., 2009 and DeWalt et al., 2009
BMI	Intervention Group 31.0, <i>SD</i> + 7.9 (lower literacy)	34.7 (12.9–73.4)
	$32.9, SD \pm 8.0$ (higher literacy)	
	Control Group	
	29.8, $SD \pm 6.3$ (lower literacy)	
	33.5, $SD \pm 8.0$ (higher literacy)	

Quality Assessment

The quality of the articles was assessed with the modified Quality Assessment Tool for Quantitative Studies, a tool with demonstrated content and construct validity (Effective Public Health Practice Project, 1998; Thomas, Dobbins, & Micucci, 2004). Each study was scored according to the following standards: selection bias of sample, study design, confounders, blinding, data collection methods, and, if applicable, the number of participant withdrawals. A global rating of the papers was tabulated from the component scores, the study was then rated as weak, moderate, or strong (Table 2.5). No study was rated as weak.

Table 2.5

Global Ratings of Reviewed Studies

Moderate	Strong
Sarkar et al., 2006	Gerber et al., 2005
White et al., 2011	Wallace et al., 2009
	DeWalt et al., 2009

Cross-Sectional Studies

Two studies (Sarkar et al., 2006; White et al., 2011) were descriptive and crosssectional and their characteristics are in Table 2.3. Sarkar et al. (2006) examined self-efficacy and T2DM self-management and their relationship to literacy and ethnicity. A targeted recruitment strategy, utilizing a university hospital clinical database, identified potential English or Spanish speaking participants. Inclusion criteria required at least two visits to the same physician within a specified time period and at least one recorded HbA1c value (Sarkar et al., 2006). The minimum age was higher than that required by most studies at equal to or greater than 30 years. Measures included the S-TOFHLA and The Summary of Diabetes Self-Care Activities Questionnaire.

Sarkar et al. (2006) obtained results from 408 participants. For ethnicities, 18% (n = 75) were Asian/Pacific Islander, 25% (n = 100) were African American, 40% (n = 165) were Hispanic, and 12% (n = 51) were non-Hispanic White. Participants were uninsured (32%) or publically insured (Medicare 36%; Medicaid 23%) and 49% had adequate literacy. Overall, the mean self-efficacy score was 74 out of 100 ($SD\pm18$) and did not significantly vary across ethnicity or literacy category. This self-efficacy score indicates a moderate level of confidence in behavior performance as the self-efficacy scales range from 0-to-100. Higher scores reflect an increased belief in one's ability to perform a behavior.

The relationship between self-efficacy and the self-management domains were analyzed independently. Self-efficacy was significantly (p < .01) related to four of the five self-management domains (i.e., diet, exercise, SMBG, and foot care). There was no significant (p = 0.4) relationship between self-efficacy and medication adherence. However,

there was a strong trend (p < .08) toward higher medication adherence among African American and non-Hispanic White participants with higher self-efficacy scores.

Univariate models were used to further explore the influence of literacy, clinical characteristics (i.e. duration of diabetes, medication regimen, and presence of complications), sex, income, and race/ethnicity on the relationship between self-efficacy and self-management behaviors. Results showed that these factors did not affect either self-efficacy or the self-management relationship. The final multivariate model examined clinical characteristics, race/ethnicity, and literacy scores as covariates. The model indicated that for every 10% increase in self-efficacy scores, participants were more likely to report better self-management in diet (0.14 days more per week), exercise (0.09 days more per week), daily SMBG levels (odds increased 16%), and daily foot care (odds increased 22%). No significant interaction was found between self-efficacy and race/ethnicity or self-efficacy and literacy on self-management behaviors.

White et al. (2011) established the reliability and validity of a 15-item, Spanish language Diabetes-Specific Numeracy Measure (DNT-15 Latino) and examined the relationship between diabetes-specific numeracy and diabetes related outcomes. Spanish-speaking, self-identified Hispanic persons, 18 to 85 years of age, with T2DM (n = 128) or type 1 diabetes (n = 5) were recruited during a scheduled clinic appointment. The majority of participants were female (n = 93), of Mexican origin (n = 117), uninsured (n = 121), and had poor lipid (low density lipoprotein [LDL] = 110, $SD \pm 38.3$) and glycemic control (HbA1c = $8.1, SD \pm 2.3$).

Data collection occurred either before or after the clinic appointment. Questionnaires were administered orally in Spanish. Levels for LDL and HbA1c were obtained by chart

extraction. The BMI was calculated from the height and weight measures taken at the clinic appointment. The S-TOFHLA findings indicated 64% of participants had adequate literacy (Table 2.3). Numeracy, a component of literacy, was assessed using the DNT-15 Latino to examine specific skills related to nutrition, exercise, SMBG, and medication management. Self-efficacy was measured with the 8-item Perceived Diabetes Self-Management Scale (PDSMS; (Wallston, Rothman, & Cherrington, 2007). Total PDSMS score can range from 8 to 40 with higher scores indicating greater self-confidence in diabetes self-management. Additional instruments included the Wide-Range Arithmetic Test (Wilkinson & Robertson, 2006), a 12-item acculturation scale (Marin, Sabogal, VanOss Marin, Otero-Sabogal, & Perez-Stable, 1987), and the 14-item Summary of Diabetes Self-Care Activities Scale (Toobert, Hampson, & Glasgow 2000). The results demonstrated that diabetes-specific numeracy was associated with acculturation level, but not self-efficacy, self-management behaviors (diet, exercise, SMBG, medication adherence), HbA1c level, or insulin use (all P > 0.05).

Intervention Studies

Two studies examined the impact of educational interventions on diabetes selfmanagement, with one intervention resulting in two articles (DeWalt et al., 2009; Gerber et al., 2005; Wallace et al., 2009). See Table 2.4. Gerber et al. (2005) examined the impact of a one-year computer multimedia program on self-management, physiologic outcomes, knowledge, and self-efficacy among participants with type 1 or T2DM. Wallace et al. (2009) and DeWalt et al. (2009) used an uncontrolled intervention design to examine the impact of educational materials and a brief counseling session over 12 to 16 weeks.

Wallace et al. (2009) and DeWalt et al. (2009) examined two different components of an intervention study, based on social cognitive theory, focused on improving T2DM selfmanagement. Wallace et al. (2009) evaluated the feasibility and effects of diabetes selfmanagement support, in the form of educational materials and a counseling session, on a number of health-related psychological constructs, such as self-efficacy, across literacy levels. DeWalt et al. (2009) examined participant goal setting, problem solving, and selfreported behavioral change.

The research project was conducted at three academic internal medicine practices, one each in North Carolina (n = 85), Louisiana (n = 85), and California (n = 80). Participants were English or Spanish speaking, diagnosed with T2DM, age 18 years and over, and referred by their health-care providers. All Spanish-speaking participants (n = 77) were from the California site. Of the total participants (N = 250), 48% were uninsured (n = 120), 43% had less than a high school education (n = 108), and 57% had adequate literacy (n = 143). African American participants made up 44% of the sample (n = 112), and 33% were Hispanic (n = 83). A majority were female (65%; n = 162) and 92% (n = 230) completed the study.

Informed consent, baseline data collection, and goal setting occurred during the initial session. Structured interviews were conducted pre- and post-intervention. Instruments were orally administered at the pre-intervention and post-intervention sessions and included the Patient Activation Measure (13-items; Hibbard, 2004), Diabetes Distress Scale (17-items; Polonsky et al., 2005), Diabetes Self-Efficacy (8-items; Sarkar et al., 2006), Diabetes Self-Management (Heisler, Smith, Hayward, Krein, & Kerr 2003), S-TOFHLA (40-items; Baker et al., 1999), and the Diabetes Knowledge Assessment (9-items; Wallace et al., 2009). The

Patient Activation Measure assesses individuals' belief in the importance of their role in their own health maintenance, confidence, and knowledge to take action, initiative to take action, and persistence to continue performing these actions. A high score indicates knowledge of and involvement in preventive behaviors related to respondents self-care. Baseline HbA1c and BMI measures were extracted from participants' medical records. The initial, pre-intervention session was followed by telephone contact at Weeks 2 and 4 and exit interviews were conducted during Weeks 12 through 16.

The intervention consisted of a face-to-face introduction to the *Living with Diabetes*: *An Everyday Guide for You and Your Family* guidebook (Davis, DeWalt, Schillinger, & Seligman, 2007; Seligman et al., 2007) and a brief counseling session to develop an individualized action plan (Bodenheimer, Davis, & Holman, 2007) and facilitate goal setting. Participants identified the diabetes self-management domain (eating, exercise, medication, blood sugar monitoring) on which they wanted to focus and were assisted in developing an achievable goal related to the selected domain.

Upon study completion, participants demonstrated a significant improvement in knowledge (p < .001), self-efficacy (p < .001), activation (p < .001), and self-management behavior (p < .001). The effect sizes among these measures, pre-intervention to post-intervention suggests self-efficacy may have been the construct least affected by the intervention as results ranged from 0.42 (activation), 0.37 (self-care), 0.36 (total distress), 0.33 (knowledge), to 0.29 (self-efficacy). In addition, there were differences related to literacy and language for the diabetes distress and self-efficacy outcomes. Spanish-speaking participants expressed a greater decline in diabetes distress than did English-speakers (-8.3 and -3.8, respectively; p = .03), and self-efficacy levels significantly (p < .001) improved for

English-speaking participants but not for Spanish-speakers (+6.34 and –0.02, respectively; p < .001). This study demonstrated that focusing on behavior change, simplifying diabetes self-management, and concentrating on one domain, can mediate the negative effects associated with low literacy as well as improve self-management behaviors among those with adequate literacy.

DeWalt et al. (2009) described the interventions' effect on goal setting and achievement. Participants most often selected diet and exercise as their domains to focus on during the three-goal setting sessions. The specific goals varied from being one-time events (e.g., "I will look into a water aerobics classes and at least try one") to a daily behavior changes (e.g., "I will eat less fast food by cooking one meal a day"). A majority of participants achieved and sustained a behavioral goal at each of the follow-up contacts: 77% at 2-weeks (n = 185), 66% at 4-weeks (n = 153), and 59% at 12-weeks (n = 135). But only 33% of the participants achieved their goals at all three sessions. However, participants did make other behavior changes regardless of whether they achieved the selected goal. The length of time a participant was enrolled in the program was not a factor in goal achievement.

Satisfaction with the guide was also evaluated: 75% of participants indicated they would continue to use it, 81% would recommend it, and 75% would share it with others. The most helpful content was the diet (67%) and exercise (24%) information.

Gerber et al. (2005) recruited 244 English and Spanish-speaking participants, age 18 years or older with a self-reported history of type 1 or T2DM from five public clinics. Participants were randomized into a control (n = 122) or intervention group (n = 122). Both groups accessed the computer programs from kiosks situated in the clinic waiting areas. The control group accessed a multimedia application that provided diabetes-related multiple-

choice quizzes. The intervention group took part in the *Living Well with Diabetes*, a computer-based multimedia program that contained 19 lessons about diabetes self-management and related topics. Modules were based on Gagne's theory of instruction and every lesson had a specific self-care objective (Driscoll, 1994).

Baseline data were collected face-to-face. Measures included the short version of the Test of Functional Health Literacy in Adults (S-TOFHLA; Baker et al, 1999), a Diabetes Knowledge Questionnaire (Gerber et al., 2002), and a 12-item Diabetes Self-Efficacy Scale. The Diabetes Self-Efficacy Scale was modified from the original 26-item Insulin Management Diabetes Self-efficacy Scale (Hurley, 1990) with the Spanish version translated and validated by Bernal et al. (2000). Additional measures included the Perceived Susceptibility to Diabetes Complications, a Likert-style scale with response choices from 1 (lowest) to 10 (highest) (Lewis & Bradley, 1994). The self-reported medical care questionnaire mirrored the 2005 American Diabetes Association Standards for Medical Care and queried participants about their dilated eye exams, laboratory tests, and immunizations during the previous year (ADA, 2005). Response choices were "yes", "no", or "don't know". The S-TOFHLA scores were divided into two categories: lower literacy (score ≤ 22 ; inadequate-marginal), and higher literacy (score ≥ 23 ; adequate). Height, weight, and blood pressure were obtained from concurrent clinic data, and BMI was calculated from these measures. The HbA1c level was measured with a point-of-care finger stick. Additional data for intervention and control group participants included demographics, diabetes history, computer experience, physiological outcomes, and questionnaire responses.

Fifty-six percent of participants in the intervention group and 55% in the control group had low literacy. Participants with low literacy were more likely to be older, of Latino

ethnicity, Spanish speaking only, have a lower level of educational achievement, be uninsured, have low socioeconomic status, and use insulin. They were less likely to own or use a computer.

Participants received monetary incentives based on their computer use and progress in the program. Each participant's computer use on the clinic kiosks was tracked for 1 year and 183 (75%) of the participants completed the trial. All baseline measures were repeated at 1 year and compared. Overall results showed no significant difference between the intervention and control groups on diabetes knowledge, HbA1c, BMI, or blood pressure. However, low literacy, intervention participants with a baseline HbA1c of more than or equal to 9.0% (n = 26) experienced a greater decrease in HbA1c than those in the control group (-2.1% and - 0.3% respectively; P=.036) post-intervention.

Although there were no significant differences in self-efficacy, knowledge, or medical care between the intervention and control groups the intervention group reported a statistically significant increased perceived susceptibility to eye, kidney, or heart disease than those in the control group (intervention + 1.19 versus control +0.24; p < .009). A significant variation in perceived susceptibility and self-efficacy existed between lower and higher health-literacy participants as well, with the greatest increase in perceived risk among participants with lower-literacy (intervention 1.48 versus control 0.19; p < .016). Lower literacy participants in the intervention group trended toward greater improvement in selfefficacy than lower literacy participants in the control group (intervention 1.51 versus control 0.99; p < .13). Higher literacy scores were not correlated with improved self-efficacy or glycemic control (-0.9% intervention group versus -1.3% control group; p = .54) but they were positively correlated with computer use (r =.28; p < .005).

Discussion

The purpose of this review was to examine the research on literacy and self-efficacy and their relationship to T2DM self-management among Hispanic populations with limited English proficiency. This discussion will touch on the challenges faced in several different areas by the study population, how they were addressed in the selected studies, and the findings related to each topic.

Hispanic Populations

Ethnicity, as determined in these articles, was based on individuals' self-identification as a member of an ethnic group. Not all Hispanics self-identify as Hispanic but may consider themselves White, Black, or some other race (Pew Hispanic Center, 2010a; Weinick, Jacobs, Stone, Ortega, & Burstin, 2004). Persons of Hispanic ethnicity are a diverse, heterogeneous population (Borrell, Crawford, Dallo, & Baquero, 2009). Using one categorization, *Hispanic* or *Latino*, is nonspecific to countries of origin or heritage and ignores the differences in T2DM prevalence, self-management practices, education level, and medication usage that vary based on country of ancestry (Morgan, Buscemi, & Fajardo, 2004; Montoya, Salinas, Barroso, Mitchell-Bennett, & Reininger, 2011; Vigdor, 2009). In addition, distinguishing between recent immigration groups and established populations acknowledges the unique health care needs of each (Ding & Hargraves, 2009; Vega et al., 2009). White et al. (2011) acknowledged these differences in describing their study population (n = 144) both in terms of country of origin (78% were of Mexican origin) and level of acculturation (96% had low acculturation; Table 2.3).

Language

The number of Spanish speaking Hispanic participants in the four selected studies is estimated as ethnicity (Hispanic) or race and language (English, Spanish) were categorized separately (Table 2.3). Although, it may assumed that the Spanish speakers were a subgroup of those identified as Hispanic, such a categorization may be inaccurate because not all Spanish-speakers self-identify as Hispanic and not all Hispanic persons speak Spanish. The participants in the reviewed studies represented a number of ethnic or racial groups, ranging from seven (Asian/Pacific Islander, African American, Hispanic, White/non-Hispanic, Native American, Multiethnic, Other; Sarkar et al, 2006) to three (African-American, Hispanic/Latino, Caucasian; DeWalt et al., 2009; Wallace et al., 2009).

Comparison of English versus Spanish speakers in association with the other factors revealed language associated differences in the reviewed articles. DeWalt et al. (2009) found no difference in individual achievement of behavioral goals based on language or literacy level; however, within the same population Wallace et al. (2009) found variations in diabetes-related distress and self-efficacy between Spanish and English speakers. Sarkar et al. (2006) found self-efficacy associated across racial/ethnicity and literacy levels in their multivariate model but did not examine these variables in relation to language.

Health Literacy

Health literacy is an extensively explored topic (Nielsen-Bohlman et al., 2004) but much of the research has been restricted to English-proficient participants (McCleary-Jones, 2011; Cavanaugh et al., 2008; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). Requiring English proficiency results in a significant segment of the Hispanic

population being excluded from the research that has occurred related to literacy and health (Van Scoyoc & DeWalt, 2010; Kimbro et al., 2008).

Health literacy definitions include the ability to access, understand, and act on health information, and these broader constructs merit exploration beyond reading ability and the individual (Nielsen-Bohlman et al., 2004). Literacy is not only knowledge; it is a socially constructed, cognitive phenomenon requiring distinct skills for specific purposes in specific contexts (Barton, 2007; Gee, 2001; Ferdman, Weber, & Ramirez, 1994).

DeWalt et al.'s (2009) and Wallace et al.'s (2009) results are examples of the skill development that can occur through literacy sensitive interventions and provide evidence for the value of implementing a diabetes support program in a primary care setting. Such a program can be effectively executed by nurses to achieve the objectives set forth in the 2010 Affordable Care Act that encourage nurses to practice to the full extent of their education and training (Institute of Medicine, 2011). In addition, implementing such a program would fulfill health care systems, and providers' obligations to establish social environments where all patients can succeed regardless of language or literacy level.

Recruiting Methods

Gerber et al.'s (2005) 1-year intervention study was sufficiently powered (n = 183) to detect a 0.5% difference in HbA1c levels at 1-year. All other studies were sufficiently powered to detect differences between the groups or variables that each examined: Sarkar et al. (n = 408; 2006), White et al. (n = 144, 2011) and Wallace et al. and DeWalt et al. (n = 250; 2009).

All recruiting and participant selection in the studies occurred in conjunction with health-care facility use. Recruiting took place in waiting rooms (Gerber et al., 2005; White et al., 2011, through a hospital database (Sarkar et al., 2006), or through referrals by a health care provider (DeWalt et al., 2009; Wallace et al., 2009). These recruiting methods were sensible strategies for assessing the feasibility and efficacy of an intervention program (Gerber et al., 2005; Wallace et al., 2009). However, recruiting through only those sources targets a specific population, persons who utilize the health-care system, and may introduce bias because health-care users may have different characteristics or attributes than other persons in the community (Arcury & Quandt, 1999; Konfino, Mejía, Majdalani, & Perez-Stable, 2009).

Intervention

The two intervention studies differed greatly in the length of duration at 12 to 16weeks (DeWalt et al., 2009; Wallace et al., 2009) and 1-year (Gerber et al., 2005). No language or literacy level differences in reported behavior changes were noted for the 12 to 16 week intervention, but an exploratory analysis found differences in lower literacy populations for the 1-year intervention.

DeWalt et al. (2009) found that 73% of participants achieved and sustained at least two behavioral goals during the study period and knowledge, self-efficacy, activation, and self-care increased (DeWalt et al., 2009; Wallace et al., 2009). However, the 12 to 16 week duration may have been far less time than required to make and sustain the targeted T2DM self-management behaviors. In addition, this duration was inadequate to demonstrate significant improvements in most physiologic outcomes, improvements that can motivate and reinforce behavior changes (Bandura, 2001, 2004).

This study raises questions about effective invention duration and identifying those persons who may benefit the most from ongoing support and reinforcement. The frequency,

duration, and reinforcement of interventions are unexamined factors in diabetes selfmanagement as they relate to literacy level (Brown et al., 2005), factors that may be especially important for sustaining behavioral changes in low literacy populations (DeWalt et al., 2009).

Gerber et al.'s (2005) intervention and control groups experienced no significant change in HbA1c, BMI, or blood pressure. Participants with higher and lower literacy experienced comparable increases in knowledge and self-efficacy but, the lower literacy group, post-intervention, experienced the greatest change in *perceived susceptibility to complications* scores, suggesting an increased awareness of complications. Participants with the worse glucose control, HbA1c levels greater than or equal to 9.0% (n = 26), experienced the greatest improvement in values over the 1-year intervention. This finding is possible because it is generally easier to lower high HbA1c values, while lower HbA1c values are more difficult to improve upon (D. DeWalt, personal communication, April 14, 2012). Further exploration is required to identify the mechanisms by which these changes in selfmanagement occur (i.e., educational content, social support, reinforcement).

Measurement

All four studies used the S-TOFHLA (Baker et al., 1999) to provide a consistent measure of health literacy. Other measures varied. Diabetes self-efficacy was measured with the same instrument in two studies (Skaff, Mullan, Fisher, & Chesla, 2003). Gerber et al. (2005) used a modified version of the Insulin Management Diabetes Self-efficacy Scale instead (Hurley, 1990) and White et al. (2011) used the Perceived Diabetes Self-Management Scale (Wallston et al., 2007). White et al. (2011) and Sarkar et al. (2006) did not assess diabetes knowledge. Gerber et al. (2005) assessed adapted knowledge (Gerber et al., 2002)

and Wallace et al.'s (2009) diabetes knowledge measure corresponded to the *Living with Diabetes* guide.

Data regarding diabetes self-management activities were collected with the two different questionnaires (Heisler et al., 2003; Toobert et al., 2000). Gerber et al. (2005) did not collect information about self-management practices but rather measured physiologic outcomes. Measures unique to specific studies were the Diabetes Distress Scale (Polonsky et al., 2005) used by Wallace et al. (2009) and Gerber et al.'s (2005) use of the Perceived Risk of Complications (Lewis & Bradley, 1994).

Self-Management

Diabetes self-management includes medication management, SMBG, diet and exercise maintenance, and foot care (ADA, 2012). Examination of diabetes self-management domains, rather than only physiologic outcomes, is a recent phenomena not yet widely studied in the context of health literacy. Of the studies in this review, only one examined selfmanagement domains through self-management goal setting (DeWalt et al., 2009). Participants identified the need for goal-setting assistance with exercise and diet domains, indicating that these areas are the ones people believe are the most important to work on and as such may be areas in which to concentrate targeted interventions (Gerber et al., 2005; Wallace et al., 2009).

Self-Efficacy

Broader exploration of the constructs of self-efficacy in diabetes self-management is warranted. There have been efforts to examine the influence of self-efficacy in the presence of low literacy on diabetes self-management, but its measurement in the reviewed studies was limited. Although higher diabetes-self-efficacy scores correlated with better physiologic

measures, this finding is inconsistent across self-management domains (Sarkar et al., 2006). In addition, Wallace et al. (2009) showed statistically significant improvements in selfefficacy, but the improvement was only among English speakers—not Spanish speakers. Although the measured construct included mastery of experiences, other types of selfefficacy (e.g., exercise, eating) were not explored.

Recommendations

Although progress has been made in recognizing the disparities among persons with low literacy and limited English proficiency in relation to diabetes management and outcomes, uncertainty remains how differences affect self-management practices. As the studies here illustrate, self-management behaviors may be influenced by literacy level but that self-efficacy and social support (e.g. with goal setting) also play a role. To identify and gain a better understanding of the factors mentioned above the following six steps are recommended. First, broaden the examination of literacy to include the competencies of accessing, understanding, and using health information in relation to individuals' diabetes self-management. Second, examine the influence of social support in the context of literacy, especially among persons whose culture the family assumes a position of priority over individual interests. Third, explore exercise and eating self-efficacy, in addition to diabetes self-efficacy, among Spanish-speaking persons as differences in self-efficacy have been shown between English and Spanish-speakers. Fourth, examine cultural differences in relation to environmental and social aspects that may affect and inform individuals' diabetes self-management. Fifth, recruit participants with T2DM from community settings. Sixth, include persons with limited English proficiency, noting country of origin.

Conclusions

This chapter assessed the published literature on literacy and self-efficacy in type 2 diabetes self-management and their relationship to self-management practices among Hispanic persons with limited English proficiency. The included studies provide evidence that the pathway by which literacy level influences diabetes outcomes (i.e. HbA1c) is not a direct one. Interventions that considered literacy level and self-efficacy, targeted skill development (i.e., goal setting), showed a positive, but inconsistent relationship between improved self-efficacy and some, but not all, self-management behaviors. These differences appeared to be associated with language more than literacy. These studies demonstrate that the exploration of literacy as a multifaceted phenomenon, requiring specific skills and competencies, remains largely unexamined in relation to the T2DM self-management practices among Hispanic immigrants with limited-English proficiency.

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CHAPTER 3

METHODS

Introduction

Successful T2DM management (e.g. glycosylated hemoglobin [HbA1c] < 7%) depends upon an individuals' self-management regimen that includes regular exercise, daily medication adherence, diet, blood glucose monitoring, and foot care (American Diabetes Association [ADA], 2012). The research on literacy and self-efficacy in T2DM selfmanagement, and their relationship to T2DM self-management among Hispanic populations with limited English proficiency is sparse. Studies that have examined the influence of language and health literacy level on a given outcome have had varied results. At the conclusion of Gerber et al.'s (2005) study participants in the intervention who had lower literacy experienced an increased *perceived susceptibility to complications*, but no difference in behavioral goal achievement was found between subjects based on health literacy level (DeWalt et al., 2009). Wallace et al. (2009) found no differences in outcomes based on health literacy level but did on language, finding a greater improvement in *diabetes-related distress* and less improvement in *self-efficacy* among Spanish-speakers compared to Englishspeakers. Additionally, studies that have examined diabetes self-efficacy and diabetes selfmanagement have typically not explored the association of exercise and eating self-efficacy with physical activity and nutrition behaviors.

This chapter describes the procedures used in a mixed methods, descriptive study that explored the social influences and relationships of health literacy, diabetes knowledge, and self-efficacy on T2DM self-management among Hispanic immigrants with limited English proficiency. It details the research aims, philosophical assumptions, data collection procedures, and analysis of the study.

Aims

This study had four aims. The first was to describe the diet practices and physical activity of participants related to T2DM self-management among a Hispanic immigrant population with limited English proficiency. The second aim was to describe how their social environment influenced participants' T2DM self-management related to diet and physical activity. Culture, past experiences, and attitudes can inform and influence individuals' T2DM self-management practices (Caballero, 2010; Rustveld et al., 2009). Semistructured interviews were used to gain an understanding of these influences.

The third aim was to describe the relationships among health literacy, diabetes knowledge, self-efficacy, diet practices, and physical activity. We explored these factors with the following instruments: the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA; Lee, Bender, Ruiz, & Cho, 2006), the Diabetes Knowledge Test (Fitzgerald et al., 1998), the Self-Efficacy to Regulate Exercise Scale (Everett, Salamonson, & Davidson, 2009), the Eating (Glynn & Ruderman, 1986) and Diabetes Self-Efficacy Scales (Lorig, Ritter, & Jacquez, 2005), and the Health-Promoting Lifestyle Profile II (Walker, Kerr, Pender, & Sechrist, 1990).

The fourth aim was to examine the relationships among health literacy, diabetes knowledge, self-efficacy, and the social environment and T2DM self-management behaviors. This aim was addressed by integrating the qualitative data from the first two aims with the quantitative findings from the third aim at the results point of interface (Morse, 2010).

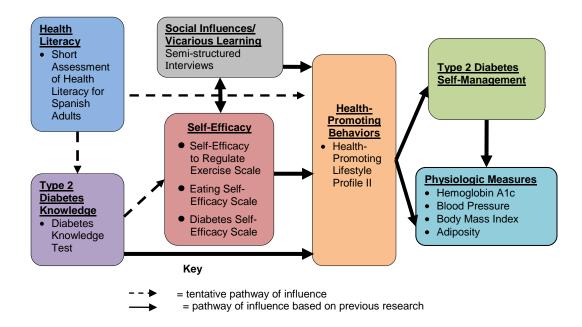


Figure 3.1. Model of study aims and measurement tools. Each bulleted item reflects how the different components were measured.

Philosophical Assumptions

Culture includes the behaviors, beliefs, values, and ways of living shared by a social or ethnic group (Random House, 2005). Culture affects individuals' T2DM self-management practices (Nam, Chesla, Stotts, Kroon, & Janson, 2011; Rustveld et al., 2009; Weiler & Crist, 2009). In this study, social cognitive theory informed the initial framework for exploring the social environment and familial influences on individuals' self-management practices (Bandura, 1977b). The social cognitive theory constructs focused on in this study were knowledge, as a personal attribute, self-efficacy, and vicarious learning (Bandura, 1977a).

Social cognitive theory distinguishes between cognitive knowledge and behavioral performance; knowing does not assure a behavior will be performed (Bandura, 1977b). In this study diabetes knowledge and health literacy are examined because both have been

associated with worse glycemic control and diabetes self-management behaviors (Osborn, Bains, & Egede, 2010; Schillinger et al., 2002).

Self-efficacy is an individuals' perceived capability to perform a course of action or behavior. It involves *generative capability*, which is a combination of cognitive, social, and behavioral skills that the individual can effectively organize to produce an integrated course of action (Bandura, 1977a; b). Measuring self-efficacy can help predict the likelihood an individual will initiate and maintain physical activity, healthy eating behaviors, or other health-related behaviors (Bandura 1977a; b). The success achieved through the performance of these behaviors contributes to the perseverance of an individual in continuing them (Bandura, 2004). The literature provides strong evidence that diabetes self-efficacy measures are accurate predictors of diabetes management among Hispanics; however, exercise and eating self-efficacy have not usually been explored in association with diabetes selfmanagement (Allen, 2004; Ingram, Ruiz, Mayorga, & Rosales, 2009).

Vicarious learning, another component of social cognitive theory examined in this study is information learned by observing family members or other referent individuals. It influences an individual's self-efficacy in performing the tasks and behaviors related to T2DM self-management (Bandura & Locke, 2003; Sarkar Fisher, & Schillinger, 2006). The prevalence of T2DM within the Hispanic population suggests that family members are likely to serve as models for T2DM self-management behaviors (Alcozer, 2000; Weller et al., 1999). A qualitative methodology of inquiry was used in this study to gain an understanding of the subjective social realities of Hispanics with limited English proficiency who were living with and self-managing T2DM (Huberman & Miles, 2002: Tashakkori & Teddlie, 2010). This method also acknowledged that persons living with T2DM have a perspective

about diabetes and its self-management that is different from that of health care providers. By seeking out their viewpoint, new perspectives of the phenomena were revealed (Charmaz, 2006).

Design

The study was a descriptive, correlational design that used a mixed methods approach for data collection and analysis (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007; Gorard, 2010; Morse, 2010). The qualitative data were collected using semistructured interviews and were considered the core component of inquiry. The quantitative data collection included instruments and physiologic measures (Morse, 2010). Figure 3.2 illustrates how the mixed methods approach combines the two types of data to answer the research aims.

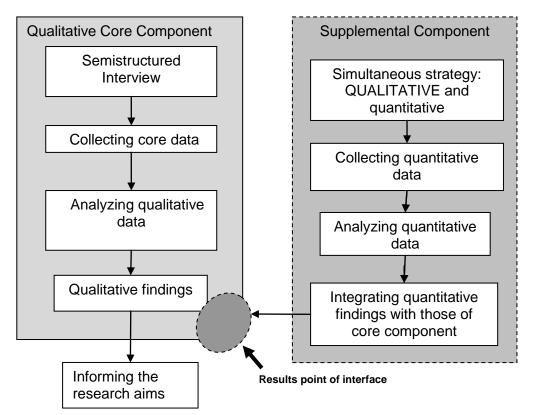


Figure 3.2. Overview of mixed methods. Adapted from Morse, 2010, p. 342 (In Tashakkori & Teddlie, 2010).

The variables of interest were the participants' social environments, personal attributes (i.e., diabetes knowledge, health literacy), self-efficacy (i.e., confidence in performing diabetes, diet, and exercise behaviors), and health-promoting behaviors. The University of North Carolina at Chapel Hill Office of Human Research Ethics Institutional Review Board approved the initial research plan and all subsequent modifications.

Population

The NC Hispanic population increased by 421,157 people between 2000 and 2010 (Ennis, Ríos-Vargas, & Albert, 2011). However, this increase was not evenly dispersed throughout the state. Sizeable gains for this population were seen in the Piedmont region, making it an appropriate area from which to recruit and conduct the study. Recruitment focused on two counties in the region, Orange and the adjoining Chatham county, that had estimated Hispanic populations of 5,273 (4.5% of the total population) and 4,743 (9.6% of the total population), respectively. The birth country-of-origin for 63% to 73% of this population was Mexico (U.S. Census Bureau, 2010). Both counties have rural and urban areas with a variety of employment opportunities; thus it was expected participants would also work in diverse settings.

This specific population required additional considerations in the recruitment effort. According to the Pew Hispanic Center, over 300,000 immigrants in NC are undocumented (Passel & Cohn, 2009). That number represents about half of all Hispanic immigrants living in the state, ranking NC at the eighth highest among all U.S. states for populations of undocumented immigrants. Therefore, establishing trusting, friendly relationships with community members was critical because of immigration status issues among this population (Arbona et al., 2010; Denzin & Lincoln, 2005). To address any fears or distrust from the

potential participants, recruitment efforts focused on social networks and institutions trusted by the study population. Institutions were identified through the research team's knowledge of the community and personal connections in the area. The recruiter and research assistant were bicultural, native Spanish-speakers, and were well-connected members of the community (Balcazar et al., 2006). The study team had also previously participated in three community-based research studies focusing on Hispanic immigrant women and their children (Berry et al., 2011). This previous experience facilitated recruiting efforts within the community and fostered confidence.

Recruiting

To reduce bias that could arise from recruiting participants from any one site, it was decided that potential participants would be recruited equally through informal (e.g., grocery stores, participant referral, businesses) and formal sites (e.g., churches, community centers). A flyer and a postcard were designed for the purposes of recruiting participants (Appendix). These were left at sites that targeted both genders such as mercados (Latino markets), grocery stores, locally-owned pharmacies, laundry mats, mobile home parks, English as a second language classes, and Latino community events. Personal visits were made to formal sites like social service agencies, health clinics agencies, community-based organizations and churches whose mission was to serve the Hispanic community. To include a sufficient number of males, emphasis was placed on sites in the community where males congregated or worked.

For informal settings, recruitment was achieved through face-to-face community outreach by the principal investigator to the managers and business owners of companies known to employ a high percentage of male workers: landscaping, environmental services,

painting, construction, Mexican restaurants, and auto parts stores. The auto parts stores were targeted because of both their location and customer base; they allowed recruiting postcards to be placed at their counters. To encourage snowball sampling each study participant also received recruitment postcards and was encouraged to distribute them to friends or neighbors who might know someone with T2DM. Utilizing these strategies, the target sample of 30 participants was recruited from the community over a 6-month period from June to December 2011. Four individuals contacting the research assistant were excluded from consideration because either they were non-Spanish speaking (n = 1), did not have a diagnosis of T2DM (n = 2) or were born in the U.S. (n = 1).

Screening

The research assistant/recruiter screened participants according to the following inclusion criteria: immigrant to the US, Spanish-speakers, limited English proficiency, diagnosed with T2DM over one year, and without co-morbidities that would preclude the performance of recommended diabetes self-management behaviors (i.e., blindness, peripheral neuropathy). Spanish-speaking language ability was specified in describing the population because a majority of Mexican immigrants living in NC do not speak English or do not speak it fluently (Table 3.1; Gill, 2010).

Table 3.1

Screening Criteria

Screening Questions	Yes	No	Answers
Spanish-speaking, limited English proficiency			Averaged score < 2.99
(*verify Short Acculturation and language scale)			
From what country are you? (Birth country)			Mexico
Have type 2 diabetes mellitus over 1 year?			Yes
Are you 21-60 years old?			Age between 21 and 60 years
Do you have any problems with seeing or walking?			No

Language skills and acculturation level were assessed using the Short Acculturation

level and Language Screening Scale (Table 3.2; Marin, Sabogal, VanOss Marın, Otero-

Sabogal, & Perez-Stable, 1987; Perez-Escamilla & Putnik, 2007). To be eligible for the

study, an averaged language and acculturation score (total score divided by four) of less than

2.99 was required.

Table 3.2

Language and Acculturation

Question	Only Spanish 1 point	Spanish better than English 2 points	Both Equally 3 points	English better than Spanish 4 points	Only English 5 points
In general, what language do you read and speak?					
What language do you usually speak at home?					
In which language do you usually think?					
What language do you usually speak with your friends?					

Pilot Study

A pilot study assessed the amount of time required for obtaining informed consent and data collection. Participants understanding of the interview questions and probes, comprehension of the study instruments, and burden were evaluated. Information learned from the pilot sessions was consistent throughout the remaining interviews. For example, the time required for data collection was confirmed to be approximately 90 minutes. The participants were not hesitant about having the interview recorded, and exhibited difficulty responding to the Likert-type scales, preferring to answer 'yes' or 'no' rather than selecting a number (i.e., 1-5, 1-10) to indicate a level of agreement. The principal investigator addressed this difficulty by making large, laminated cards of the scales. Additional explanation was also provided with each instrument (Lee, Jones, Mineyama, & Zhang, 2002).

Sample

A total of 30 participants, 19 female (63.3%) and 11 male (36.7%) were recruited from June 2011 to December 2011 from Orange and Chatham County, NC. Participants country of origin was primarily Mexico (83.3%; n = 25) with the remaining 16.7% (n = 5) from El Salvador, Guatemala, or other Latin American countries. One individual, born in Guatemala, had lived in Mexico for more than 15 years, and another had grown up in the border lands between Guatemala and Mexico. All were Spanish-speaking, had limited English language proficiency, and were diagnosed with T2DM. Educational achievement was low for a majority with 70% (n = 21) having a 9th grade education or less and 37.9% (n =11) completing their studies by age 12 (Table 3.3).

Table 3.3

Grade level completed	Frequency	Percent	Cumulative Percent
5th grade or less	10	33.3	33.3
6th grade–9th grade	11	36.7	70.0
High School (HS)	5	16.7	86.7
Graduated HS/GED	1	3.3	90.0
More than high school	3	10.0	100.0
Total	30	100.0	

Participants' Educational Achievement

Measurement

Data were collected one participant at a time. Participants received a thorough description of the study in Spanish and all questions were answered before consent. After consent the participants had physiologic data collected, the semistructured interview was conducted, and then instruments were administered. Childcare was available on site if needed. Participants received \$50 reimbursement for their time, travel vouchers, a record of all physiologic measures, a recipe booklet, and exercise information. The psychometrics for the instruments and the physiological measures are provided in Table 3.4 and a discussion of each study component follows.

Table 3.4

Data Collection Measures and Psychometrics

Measures in Spanish	Psychometrics for English	Psychometrics for Spanish	
(Author) Knowledge			
Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA; Lee et al., 2006)	 No English version-correlation with the Test of Functional Health Literacy in Adults (TOFHLA) = .65 50 items 	 Cronbach's α = .92 Test-retest reliability = .86 50 items 	
Diabetes Knowledge Test for Mexican Americans (Garcia et al., 2001)	 Cronbach's α = ≥ .70 24 items 	 Cronbach's α = .78 Range 0-24, mean = 14.22, <i>SD</i> <u>+</u>4.32 24 items 	
Self-Efficacy			
Diabetes Self-Efficacy Scale and Spanish Diabetes Self-Efficacy Scale (Loring, Ritter, & Jacques, 2005) Eating Self-Efficacy Scale (Glynn & Ruderman, 1986)	 Cronbach's α (total scale) = .828 Range 1-10, mean = 6.87, SD = 1.76 Test-retest reliability = Not available^a 8 items Cronbach's α (total scale) = .92 Eating when experiencing negative affect (NA) subscale = .94 Eating during socially acceptable circumstances (SAC) = .85 7-week test-retest reliability = .70 	 Tested primarily with Mexican Americans Cronbach's α (total scale) = .85 (a = 147) Test-retest validity = .80 (n = 20) Cronbach's α (total scale) = .8894^b 25 items 	
Exercise Self-Efficacy Scale (Everett et al., 2009)	 Cronbach's α = .95. Item-total scale correlations = .59 to 0.84 18 items 	 Cronbach's α (total scale) = .8692^b 18 items 	
Diabetes Self-Management			
Health-Promoting Lifestyle Profile II (HPLP Spanish version) (Walker et al., 1990)	 Cronbach's α (total scale) = .94 Cronbach's α (6 subscales) = .79 to .87 3-week test-retest reliability (total scale) = .89 52 items, 6 subscales 	 Tested primarily with Mexican-Americans Cronbach's α (total scale) = .93 Cronbach's α (6 subscales) = .70 to .87. 2-week test-retest reliability = .8 52 items, 6 subscales 	

Physiological Measures	Reason for Use		
Glycated hemoglobin	Index of metabolic control (ADA, 2012)		
Blood pressure	Physiologic indicator closely associated with the adequacy of diabetes self- management (National Heart Lung Blood Institute, 2000)		
Body Mass Index (BMI)	BMI calculated from the height and weight, reliable method to determine body fatness (Flegal et al., 2009)		
Adiposity	Insulin sensitivity correlates with generalized and regional visceral adiposity (Goodpaster, Kelley, Wing, Meier, & Thaete, 1999)		

Note. ^aThe Stanford English Diabetes Self-Management study is ongoing, so this value is unknown at present. ^bData provided from a personal communication with D. Berry in 2010.

Physiologic Measures

Height was measured on all participants in street clothes without shoes, using a stadiometer, calibrated in 1/8-centimeter (cm) intervals. Height was measured twice and averaged. Weight on all participants was measured in a private room, in street clothes without shoes, to the nearest 0.1 kilogram using a Tanita[®] WB-110A Digital Scale. Body mass index (BMI) was calculated twice by entering height and weight (kg/m²) (CDC, 2007). In adults age 20 years and older, overweight was defined as a BMI between 25.0 and 29.9, and obesity was defined as a BMI equal to or greater than 30.0 (Allison, Fontaine, Manson, Stevens, & VanItallie, 1999; CDC, 2007).

Waist-to-height ratio (WtHR) is increasingly considered a recommended method for assessing central fat distribution and cardiometabolic risk, which includes T2DM risk (Ashwell, Gunn, & Gibson, 2012; Browning, Hsieh, & Ashwell, 2010). Waist circumference was measured in a privately screened area by two research assistants using a Figure Finder[®] measuring tape with lock following the procedure used in the Insulin Resistance Atherosclerosis Study (Novel Products Inc., Rockton, IL; Festa et al., 2000). All measurements were performed three times and averaged according to the National Health and Nutrition Examination survey procedures (CDC, 2007). The WtHR ratio was calculated using the measurements obtained above (Browning et al., 2010). A WtHR less than or equal to 0.5 is considered within normal value, a ratio greater than 0.5 indicates increased cardiometabolic risk. At present, there are no standardized parameters for higher ratios (Ashwell, 2011).

Using Lange[®] skinfold calipers, triceps, iliac crest, and subscapular skinfolds were measured on the right side of the body three times and averaged, also according to the National Health and Nutrition Examination Survey procedures (CDC, 2007). Totals of the skinfold thicknesses at the four sites were compared to the body fat content table developed by Durman & Womersley (1974; Beta Technology, 2005). Categories of healthy, overweight, and obese body fat percentages vary by age and sex as described below in Table 3.5 (Gallagher et al., 2000).

Table 3.5

Women - Age	Healthy Overweight		Obese	
20–40	21-33%	33–39%	Over 39%	
41–60	23-35%	35–40%	Over 40%	
61-79	24–36%	36-42%	Over 42%	
Men - Age				
20–40	8–19%	19–25%	Over 25%	
41-60	11-22%	22-27%	Over 27%	
61–79	13–25%	25-30%	Over 30%	

Gender Specific, Age-Adjusted Body Fat Percentage Recommendations

Blood pressure was measured with a Criticon[®], digital blood pressure meter (Welch Allyn 300 series). Measurement was taken on the right arm while participants were sitting, with their arm supported using an appropriately sized blood pressure cuff (Ostchega, Dillon, Carroll, Prineas, & McDowell, 2005). Participants were encouraged to relax and not talk during the measurement. Persons with diabetes are considered to have hypertension with blood pressure of 130/80 mmHg, parameters that are lower than those for persons without a diagnosis of diabetes (140/90 mmHg). Treatment with lifestyle or pharmacological intervention is recommended with repeated measure of a systolic reading greater 130 mmHg or diastolic reading greater than 80mmHg (ADA, 2012).

Point-of-care finger stick HbA1c was assessed with the CholestechTM (Hayward, CA) GDX point of care machine. This device is Clinical Laboratory Improvement Amendments (CLIA) waived and has National Glycohemoglobin Standardization Program (NGSP) certification (Bode, Irvin, Pierce, Allen, & Clark, 2007). Control and optics checks were performed as recommended by, and according to manufacturer instructions. All quality control results fell within the stated limits (9.5-11.6). Type 2 diabetes mellitus is diagnosed after two abnormal test results, taken at least days a part from one another, at a threshold of HbA1c \geq 6.5% using standard laboratory measures; the recommended maintenance level for HbA1c is less than 7% (ADA, 2012). Participants were provided with their HbA1c results and were urged to share these results with their health care provider. Universal precautions were followed during the procedure, as were standard biohazard disposal protocols (CDC, 2011).

Instruments

The research assistant verbally administered all instruments in Spanish and recorded participant responses. Verbally administering the instruments standardized the data collection process and ensured that participants understood all the items. This practice also minimized differences between participants' reading comprehension, cognitive processing skills, or physiological limitations such as difficulties with vision, or fine motor skills. Items were reread or clarified if requested or a participant did not appear to understand an item. Large, laminated cards illustrating the instrument scales were placed on the table in front of the participants during the session. At the end of the data collection session instruments were visually screened to assure all items were completed and a packet check sheet was used to verify all measures were collected.

Participants were asked demographic information on gender, age, nationality, last year of formal education completed, age at which formal education ended, country where they attended school, and current and past employment.

The 50-item Short Assessment of Health Literacy for Spanish-Speaking Adults (SAHLSA) is an orally administered instrument that evaluated comprehension of medical terminology and screened for low health literacy (Lee et al., 2006). A laminated card of each test item was given to the participant. Three choices were printed on each card; the *key* (correct answer), a *distracter*, and "I don't know". The research assistant read the *stem* item, or prompt, and the three choices. Participants were asked to select one answer from the three choices, for example–stem "*Obesity*", the three choices "*weight*" (key), "*height*" (distractor), "I don't know." Respondents were encouraged to answer "I don't know" rather than guess.

Scores range from 0-50 with one point awarded for each correct answer. Alpha coefficient was .92 and test-retest reliability was .86 (n = 201).

The Diabetes Knowledge Test is a 24-item tool that measures basic diabetes knowledge (Garcia et al., 2001). Answer choices are "yes", "no", "I don't know". An example of a question is, "Diabetes can be cured". Scores range from 0-24 points with one point given for each correct answer. Alpha reliability coefficient was .78, mean = 14.2, and $SD \pm 4.3$ with 201 persons with diabetes.

The Diabetes Self-Efficacy Scale (Lorig et al., 2005) measures perceived confidence in performing behaviors related to T2DM self-management. Using a Likert-type scale, participants responded to items like, "How confident do you feel that you can judge when the changes in your illness mean you should visit the doctor?" Item scores range from 1-10, with higher scores indicating more confidence in performing diabetes self-management related behaviors. The Alpha reliability coefficient was .85, mean = 6.8 (n = 147), and test-retest validity of .80 (n = 20).

The Eating Self-Efficacy Scale (Glynn & Ruderman, 1986) measures self-efficacy related to dietary patterns. This 25-item instrument asks respondents to rate their difficulty in controlling eating from 1 (no difficulty) to 7 (difficulty) on two subscales, negative affect (NA) and socially acceptable circumstances (SAC). Negative affect eating is related to emotional eating and the triggers that cause it (e.g., anger or anxiety). Socially acceptable eating is related to overeating at parties, family events, or holidays. Scores range from 25 to 175, with higher scores indicating more difficulty in controlling eating. Alpha coefficients were .94 for the NA subscale and .85 for the SAC subscale. Test-retest reliability was .70 in a sample of 600 women and men (Glynn & Ruderman, 1986).

Exercise self-efficacy was measured using Bandura's Exercise Self-Efficacy Scale with 18 questions on a 100-point scale, ranging in 10-unit intervals from 0 (cannot do at all) through intermediate degrees of assurance such as 50 (moderately certain can do) to 100 (completely certain can do) (Bandura, 2006; Everett et al., 2009). The item responses are added up and divided by 18 to calculate a total Exercise Self-Efficacy score (Bandura, 1997). A higher score indicates greater self-efficacy. Alpha coefficients of the total scale ranged from .86 to .92 in adult men and women (Everett et al., 2009).

The Health-Promoting Lifestyle Profile (HPLP II) Spanish version was used to measure health-promoting lifestyle behaviors (Walker et al., 1990). This 48-item, 4-point Likert-like scale questionnaire, with four response choices: 1 (never), 2 (sometimes), 3 (often or routinely), 4 (always) measures the frequency of health-promoting behaviors, six subscales include health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management. The instrument has been used with both minority and non-Hispanic white populations (Hulme et al., 2003). Alpha reliability coefficient for the total scale was .93 and alpha coefficients for the six subscales were .70 to .87, 2-week test-retest reliability was .86.

Semistructured Interviews

Data collection, in the form of semistructured interviews, was an intrinsic step in exploring participants' T2DM self-management. The interview guide was developed based on information seeking/knowledge acquisition, family influences or vicarious learning experiences, and self-management practices. A panel of experts in health literacy, qualitative research, diabetes, social cognitive theory, and cultural studies assisted in developing the questions and the interview format. Bilingual, bicultural consultants translated the questions

from English to Spanish. After translation, another bilingual, bicultural expert evaluated the interview guide for accurate communication of the concepts, acceptability, and cultural appropriateness (Denzin & Lincoln, 2005; Kvale, 1996). Any discrepancies found during this process were discussed and resolved among the members of the expert panel. Additional evaluation of the interview guide occurred during the pilot testing sessions.

In the final interview guide (Table 3.6) questions were grouped to reflect the theoretical components of the conceptual model (Figure 1.1) and were administered in the order in which they appeared. Additional probes were used to confirm information and clarify responses and were used as needed (Kvale, 1996). Interviews were conducted by the bilingual, bicultural research assistant, with the primary investigator present, lasted from 17.3 to 60 minutes, and were considered complete when the participant did not have anything more to say. Data saturation, or the point at which no new information about the phenomenon is obtained, was reached within 30 semi-structured interviews (Richards, 2005).

Table 3.6

Semistructured Interview Guide in English

Exploring Experiences with Type 2 Diabetes Self-Management Information seeking/Knowledge Acquisition

Probes: if the person mentions the clinic then ask for other places and persons such as family etc: How do they give you information? Do they tell you things? Have they given you any books or pamphlets?

- 2. Can you tell me about a time you received information about diabetes? From whom did you receive this information? What did you do with the information? How did you use it? Was it helpful?
- 3. What are things you think you need to learn more about your diabetes?
- 4. If you had a question about diabetes, who would you ask? Why would you ask them?
- 5. Tell me about anyone who helps you with your diabetes. How do they help you?

^{1.} I am interested in learning about how you get information about your diabetes. Tell me about a time when you first were learning about diabetes. Where did you get information about your diabetes? What is the best way for you to get information?

Family Influences/Vicarious Learning

6. Tell me about any family members or friends who have had type 2 diabetes.

Probes: What are memories you have of family members who have diabetes?

- 7. How did they do to manage their diabetes (food, diet, exercise/activity)? Tell me about their health now, how is their health doing now?
- 8. What did you learn from them about diabetes?
- Probe: think about people you know with diabetes. Are there things that they do for their health that you try to do also because you thought it was a good idea? Are there things that they do that don't work well?

Self-Management Practices

9. Tell me about managing your diabetes now. What do you do each day because you have diabetes?

Probe: What about food, diet, exercise/activity?

- 10. What do you have trouble with in managing your diabetes? What is most difficult about eating/exercise right?
- 11. What things do you think you do really well for your diabetes? What things do you find really hard to do, but you think you should?
- 12. How you feel about being able to do everything you need to do to take care of your diabetes? Do you have confidence you can do everything you need to do to take care of your diabetes? Tell me.
- 13. Tell me about the most important things you do to take care of your diabetes. Why are those things important? How do they help you?
- 14. Those are all my questions. Is there anything else you would like to talk about? Thank you very much.

Data Collection

Data collection was conducted in Orange County, NC at the United Church of Christ,

Chapel Hill, and the Carrboro Century Center, Carrboro. These sites were selected based on their proximity to public transportation, parking, and commitment to serving the Hispanic community. Both locations had private conference rooms suitable for conducting the interviews and taking the physiologic measures. Appointments were limited to two per day to assure interview quality and to prevent interviewer fatigue (Kvale, 1996; Morse & Richards, 2002). All appointments were scheduled for 2 hours, confirmed the day before, and based on the location, could be scheduled between 8:00 am to 5:00 pm, Monday through Saturday.

Quantitative Data Analysis

Data analysis was performed using IBM SPSS[®] V.19. A sample size of 30 was deemed sufficient to establish model fit and support final conclusions but is limited in generalizability (Salkind, 2010). Data was entered into SPSS[®] and was visually inspected for accuracy. Any questions about data entry were resolved by referring back to the original case file. Descriptive statistics (e.g., means, standard deviations, minimums, medians, maximums, frequencies, and percentages, as appropriate) were calculated on all questionnaires. The normality of the results from each instrument were assessed and while the results did not meet the assumption of normal distribution, these departures were within acceptable limits (Howell, 2002).

All Likert-style scales were truncated to a 1 to 5 or 1 to 10 during data collection due to the difficulty some persons have with broader ranges and number of choices (Bernal, Wooley, & Schensul, 1997; Lee et al., 2002; Marin & Marin, 1991; McQuiston et al., 2002). During data analysis, responses were recalibrated to the original 100-point scale. Lower scores on all instruments indicted either lower self-efficacy levels, lower health literacy levels, or fewer healthy habits performed. Higher scores indicated greater confidence levels, higher literacy levels, and healthier lifestyle habits. The Eating Self-Efficacy Scale was reverse coded to match the progression of the Exercise Self-Efficacy Scale and Diabetes Self-Efficacy Scales from the lowest to the highest level.

At the conclusion of data collection correlation coefficients were performed on (a) health literacy and self-efficacy measures of diabetes care, exercise, and eating; (b) health literacy and diabetes knowledge; (c) diabetes knowledge and self-efficacy measures of diabetes, exercise, and eating; (d) health literacy and selected physiological measures; and (e)

health literacy and HPLP II. Correlation procedures were used to assess redundancy between the instrument measures or independent variables. The goal is to have independent variables that correlate with the dependent outcomes (e.g. HbA1c), as illustrated in the proposed model, but have minimal correlation with one another (Green & Salkind, 2008). A high degree of correlation between instruments suggests redundancy, or that the measures have the same predictive value, in relation to the dependent variable. If different measures (e.g. SAHLSA and Diabetes Knowledge scale) quantify the same phenomenon, discerning each measure's affect on the outcome may be less precise than if the instruments were not correlated with one another.

Regression procedures were used to assess the relationships in the theoretical model (Figure 1.1): health literacy on T2DM knowledge; health literacy and diabetes knowledge on health-promoting behaviors; health-promoting behaviors on physiologic measures (adiposity, HbA1c, BP, BMI); physiologic measures on diabetes, exercise, and eating self-efficacy; exercise and eating self-efficacy on HPLP II nutrition and physical activity subscales; and lastly self-efficacy on T2DM knowledge. Linear regression also examined the relationship between health literacy and diabetes knowledge.

Data Immersion

Intimate knowledge of the data, or *immersion* in it, was requisite for recognizing the presence of similar terminology and identifying patterns and relationships between variables (Sandelowski, Voils, & Knafl, 2009). Immersion in the data began by the primary investigator being present during the interviews and reviewing the digital recording of each interview. The reviews assessed the quality of the recording, allowed additional note taking, and helped clarify any questionable content (Denzin & Lincoln, 2005). Reviewing the

interviews also contributed to data synthesis and interpretation because the interview sessions were interactive, which could cause details to be overlooked during the interviews(Denzin & Lincoln, 2005; Patton, 2002)?

Data immersion continued with the primary investigators' comparison of each translated English text interview with the Spanish digital recording for proofing purposes. There were multiple reviews of the English-language transcript during independent coding by hand, concurrent coding, and final electronic coding. This process facilitated developing a sense of the whole interview, validated the quality of the data, and transcription, and assisted in identifying patterns across participants' responses. During this process, attention was also paid to "silent" or missing topics that could be considered components to T2DM selfmanagement but that participants did not mention (e.g., foot care, nurses' providing information).

Qualitative Data Analysis

The qualitative component of the study explored T2DM self-management with the goal of understanding participants' conceptualizations of and subjective experiences with T2DM self-management. In this study, data analysis consisted of three concurrent processes: data reduction, data display, and verification using directed content analysis (Hsieh & Shannon, 2005; Miles & Huberman, 1994; Sandelowski, 2008). The interactions between these processes are illustrated in Figure 3.3 and they will be explained in the following sections. Directed content data analysis uses a predetermined theory as the basis for analysis. For this study, the social cognitive theory constructs of knowledge (i.e., personal attribute), self-efficacy, and vicarious learning provided the basis for initial codes and data generation (Baker, Parker, Williams, Coates, & Pitkin, 1996; Hsieh & Shannon, 2005; Patton, 2002).

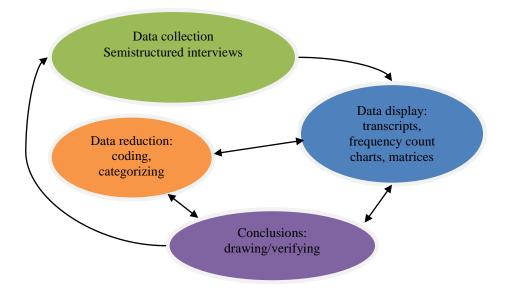


Figure 3.3. Components of qualitative data analysis. Adapted from Miles & Huberman, 1994, p. 12.

Data Display

The data display began as the interviews were translated and transcribed into textual form. Transcribed text was displayed in word processing software (Microsoft Office[®] V2007), and was double-spaced with 1-inch margins to provide room for notes and coding. The text files were exported into qualitative analysis software to organize, code, and facilitate analysis (NVivo[™] V9; QSR International Pty Ltd, 2010). Displaying the text in more than one format varied how it was visualized and facilitated its manipulation and analysis (Polit & Beck, 2004).

Data Reduction

The transcripts of each interview were considered *potential data*. The data reduction organized, integrated, and interpreted the potential data into a form that allowed analysis and synthesis. It is a process that continues as new understandings are realized. The initial coding was completed on the paper transcripts and concurrent coding was noted in the electronic

text. These data reduction methods resulted in two or three excerpts for the interviews that exemplified each category in the interview guide. Participant quotes were used to provide evidence of constructs, validate interpretation, or illustrate an important point in the final results.

Directed Content Analysis

The directed content analysis guided the coding process and analytical decision making about what textual elements to designate as *data* versus elements that were *nondata* (Sandelowski, 2008). Decisions about whether text qualified as data were guided by their relevance to the theoretical framework, social cognitive theory, diabetes self-management, or through the consensus of the two independent coders (CASM, DCB). The documentation of the steps in data reduction served as an auditable trail of the analytical decisions, an example of which can be seen in Table 3.7.

Table 3.7

Meaning unit	Condensed meaning unit	Code	Sub-category	Category	Theme
"it is really hard to take care of my diabetes when I'm working two jobs"	hard to take care of diabetes when he doesn't have much time	Time constraints in diabetes self- management	Barriers/Constraints in diabetes self- management	Diabetes self- management	Self- efficacy (diabetes)
"I can't afford to use blood sugar strips every day. That is why I only check it sometimes."	Can't afford test strips to check blood glucose every day	Financial constraints of diabetes self- management (1.26.12) <i>Review Note: Code</i> <i>as Diabetes Self-</i> <i>Management or</i> <i>Knowledge</i> ?			

Example of Directed Content Analysis

Note. The process is derived from Graneheim & Lundman, 2004.

Meaning unit refers to blocks of unedited text as spoken by the participant, which are identified because of their relevance to the topic of interest. Significant statements that were not considered relevant to social cognitive theory, knowledge, self-efficacy, or vicarious learning were noted by the individual coders, as can be seen in the second example on Table 3.7–Review Note. It was decided during team meetings whether these statements contributed to the development of new codes, definitions, or theoretical frameworks (Hsieh & Shannon, 2005). Field notes taken during the interviews preserved interviewers' observations and thoughts as well as participants' emotions, demeanors, postures, and other information not captured by the digital recorder. These notes do not appear in a transcribed text but assisted in interpretation and informed analysis.

The interview data was analyzed by comparing individual textual elements to other statements made during the interview. For example, as participants became more comfortable during the session they sometimes shared information that appeared to contradict earlier statements. Data reduction continued as the initial meaning units were identified, condensed, and the text that best represented the concepts was selected (Graneheim & Lundman, 2004). Identifying textual patterns assisted in accurately interpreting the content and facilitated sorting the data into appropriate codes and categories.

Categories. The study aims were primarily descriptive, and the data analysis was guided by the predetermined categories: knowledge, family influences or vicarious learning, and self-management. The codes within each category expressed similar concepts or understandings. New categories were created as new codes or differences were detected (Patton, 2002). For instance, during independent coding of the text *financial constraints* was noted as a possible category. During concurrent coding sessions, the researchers agreed that

this code was accurate and that it recurred across participant interviews. Participants referred to finances as interfering with self-management, thus a new category, *barriers*, was created to capture this and similar topics.

Codes. Directed content analysis guided initial coding in this study. Codes were the labels placed on blocks of text. This process helped reduce and sort sections of text into manageable units. The text selected for coding was based on its relevance to identified categories (i.e., exercise, eating). The codes were not static, as illustrated in Figure 3.3; when initial codes were inadequate for newly identified concepts, new codes were proposed and defined (Denzin & Lincoln, 2005). New codes emerged during the independent and concurrent transcript reviews. As they emerged, they were noted alongside the text in which they appeared and added to the codebook (Graneheim & Lundman, 2004). Using the previous example, if financial constraints were mentioned as interfering with T2DM self-management, additional exploration of this construct was warranted. Thus, previous interviews were scrutinized for references to finances. In cases when a new concept was identified, the previously coded material was re-coded. A codebook documented the descriptions and definitions of all the codes whether they were expanded, altered, or deleted (Hesse-Biber & Leavy, 2006).

Standards for the Quality of Conclusions

The following section follows recommended criteria for evaluating qualitative research findings and conclusions with a brief description of how these criteria were met in this study (Denzin & Lincoln, 2005; Miles & Huberman, 1994; Patton, 2002).

Objectivity and Confirmability

The goal of objectivity is that the research is conducted from a neutral point of view and one free from bias (Miles & Huberman, 1994). Two examples of the strategies employed in this research to enhance objectivity were: recruiting from multiple sites in the community, and conducting the interviews with the primary researcher and the bilingual, bicultural research assistant (Arcury & Quandt, 1999; Hesse-Biber, 2010; Tashakkori & Teddlie, 2010). Personal philosophy can also contribute to bias; this was minimized in this research by documenting observations and impressions in field notes and analysis memos. The process of documenting impressions heightens awareness of personal philosophical stance and values, allowing these internal positions to be scrutinized and discussed among the research team (Hesse-Biber & Leavy, 2006; Huberman & Miles, 2002). Objectivity was also balanced with friendliness and active listening during the interviews (Geanellos, 2005; Marshall & Rossman, 1999).

Participants can also introduce bias. Individuals may experience negative emotions (e.g., shame, anxiety) regarding their reading skills or in measurement situations, resulting in performance that is worse than actual ability (Brandt, 2001). Social desirability can lead participants to respond to interview questions or report self-management habits that are better than those they actually perform in a desire to please the researcher. In this study, a number of measures were taken to minimize the risk of participants responding in a socially desirable manner. Inadvertent reinforcement of participant responses with the use of value-loaded words such as *good* was avoided. A nonjudgmental posture and neutral facial expression was maintained. Keeping aware of body language and gestures was also attempted. In addition, particular attention was paid to the room and seating arrangement, and attire of the research

team because these factors can influence interactions during interviews (Alex & Hammarstrom, 2008; Johnson, Schofield, & Yurchisin, 2002; Kvale, 1996). The risk of bias was also minimized by data triangulation and the use of multiple quantitative measures to enhance the trustworthiness of the data (Hesse-Biber & Leavy, 2006; Tashakkori & Teddlie, 2010).

Debriefings at the end of each data collection session provided a checkpoint for validating impressions and clarifying the team's field notes (Patton, 2002). Collaborating on the codebook and definitions provided an auditable trail and a mechanism to check impressions. Staying close to the data by using the participants' own words, clarifying the concepts, reviewing coding strategies, and deciding on interpretations was accomplished throughout the project with independent coding, dual coding and concurrent comparison of independent coding during regularly scheduled meetings with the research advisor (DCB) and research assistant. Open discussions about the data or cultural differences also helped maintain objectivity.

Reliability, Dependability, and Auditability

Reliability, or quality control, in research methods and analysis is essential in assuring the trustworthiness of the research findings (Miles & Huberman, 1994). A number of measures were taken in this study to ensure its reliability, dependability, and auditability. Procedures for data collection were established, and the procedure for data collection was standardized and consistently used with all participants (i.e., review of study purpose, consent procedure, physiologic measures, interview, instruments). The same team collecting the data further enhanced reliability, and minimized inconsistencies that can occur when multiple data collectors are involved (Bloomberg & Volpe, 2008).

Auditability is possible with the availability of digital recordings of the interviews, printed transcripts, the codebook, field notes, and memos (Bloomberg & Volpe, 2008; Kvale, 1996). Notes in the paper transcript margins and in the electronic versions documented the thought process behind coding decisions and data interpretation (Graneheim & Lundman, 2004). The conclusions and interpretations are traceable to the original interview text with the use of a unique number sequence indicating case, and line number (e.g., C23- L567 = Case 23, line of text 567). Alterations in codes were documented with a description of why and how the definition changed or was deleted or added. Field notes provide a context of the interview, noting the scene and participant demeanor. Any impressions or thoughts were discussed with the research assistant at the close of each interview and documented as needed.

The primary investigator and research advisor jointly reviewed data reduction, coding, categorization, and links between the data and the interpretations of each interview. Any discrepancies arising from the independent reviews were discussed and reconciled (Munhall & Chenail, 2008).

Internal Validity, Credibility, and Authenticity

Credibility, the validity of a study, stems from whether the findings accurately reflect the data collected (Denzin & Lincoln, 2005). The measures that were taken to maintain the objectivity of the data collection sessions were already described. Each debriefing session assessed the research assistants' interviewing technique, evaluated participant responses, and addressed any cultural or conceptual differences. The internal validity of the collected data was maintained through the digital recordings, Spanish-to-English translations by a bilingual, certified translator, and transcriptions. The internal consistency of the data was also enhanced by the quantitative and qualitative data being collected from the same participants during the same data collection session (Onwuegbuzie, Slate, Leech, & Collins, 2009).

External Validity, Transferability, and Goodness of Fit

External validity, transferability, and goodness of fit are conceptual substitutions made for *generalizability* when referring to qualitative findings (Patton, 2002). They refer to how far beyond the study sample the conclusions may apply (Huberman & Miles, 2002). For this study, the characteristics of the sample were well defined, which allows cautious comparison with groups that share similar attributes and limits generalizability of the findings to populations or conditions for which they do not apply (Jezewski & Poss, 2002).

Utilization, Application, and Action Orientation

The utilization of qualitative research findings is also known as *pragmatic validation*. It refers to the extent to which research findings impact the participants and can be applied in the field (Hesse-Biber & Leavy, 2006; Kvale, 1996; Miles & Huberman, 1994). The potential benefit to study participants was considered in the research design. They were reimbursed for their time and received diabetes educational materials. Our experience reflected what other researchers have found in similar studies (Caban, Walker, Sanchez, & Mera, 2008; Shellman, 2004): a majority of the participants appreciated the opportunity to share their story in a safe environment, and having witnesses to their experiences and struggles with diabetes. The participants also received immediate feedback about their physiologic measures (i.e., BP, weight, HbA1c) and a record of those measures. They were also encouraged to share these results with their health-care providers.

The study results will be disseminated through a summary article for a local Spanishlanguage newspaper, and copies will be provided to each of the formal recruiting sites.

Presentations on the results are pending for two nursing conferences. In addition, the research findings will be disseminated to the larger academic community through publications in peer-reviewed journals with the goal of contributing to the body of knowledge about T2DM self-management. This information will not only inform health care providers about this populations' self-management practices but will help institutions seeking to improve their delivery of culturally competent care (Giger & Davidhizar, 2007).

Analysis Summary

In summary, the data analysis mirrored the mixed methods design with concurrent, independent, parallel analyses occurring for each data source (Figure 3.2; Morse, 2010). The sampling design of the study strengthened its internal consistency because the same individuals provided both quantitative and qualitative data. As results from each method were obtained, mixed analysis procedures were used to assure the analytic adequacy of the data for addressing the study aims and the constructs being examined (Hesse-Biber, 2010; Miles & Huberman, 1994; Tashakkori & Teddlie, 2010). The final processes involved blending the findings from each source to address specific research aims. The results of the qualitative analysis were used to extract specific, but perhaps unanticipated, factors that affected T2DM self-management. These factors were in turn used to inform specific quantitative analysis approaches of the data collected, which for example included subdivision of the population according to some criteria or suggest specific regression approaches.

Conclusions

This chapter provides a detailed model for conducting a mixed methods research study with a Hispanic immigrant population diagnosed with T2DM who have limited English

proficiency. Specific methods are delineated for a community recruiting strategy, data collection procedures, and analysis. Disseminating this information offers a framework to guide other researchers planning to work with comparable populations under similar circumstances.

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CHAPTER 4

FINDINGS

Introduction

Chapter 4 is divided into four sections. The first section presents an overview of the study aims and a detailed description of the sample characteristics. The second presents the quantitative data, section three presents the conceptual model and relevant statistical analysis, and section four the qualitative data.

Aims

The purpose of this study was to examine four aims using a mixed methods design. Aim 1 was to describe the participants' diet practices and physical activity related to T2DM self-management. Aim 2 was to describe how the participants' social environment and vicarious learning influenced T2DM self-management related to diet practices and physical activity. Aim 3 was to describe the relationships between health literacy, diabetes knowledge, self-efficacy, and T2DM self-management diet practices and physical activity. Aim 4 was to examine the relationships between diabetes knowledge, health literacy, self-efficacy, and the social environment and how they affected participants' T2DM self-management behaviors.

Sample

The study sample consisted of 19 female (63%) and 11 male (37%) participants recruited from Orange and Chatham counties in North Carolina (NC) from June 2011 to December 2011. The total sample of participants' age ranged from 27–86 (M = 45.0; SD_{\pm} 12.9) years of age and had 1–16 (M = 7.2; SD_{\pm} 3.9) years of education. Males were older

(Range 30-86 years; M = 53.2; $SD\pm14.3$) than females (Range 27-56; M = 40.3; $SD\pm9.4$) and had more years of education (Range 4-16 years; M = 9.3; $SD\pm3.7$) than females (Range 1-15 years; M = 5.9, $SD\pm3.7$). The participants' country of origin was primarily Mexico (n = 26; 83%), the remaining 17% (n = 4) were from El Salvador, Guatemala, or another Latin American country.

Quantitative Findings

The 30 cases in the data set were examined using IBM SPSS 19.0 as follows. The psychometrics of each instrument is described in Table 4.4, which appears later in this chapter. A brief description of each instrument and the findings related to them will be described in the following sections.

Physiologic Measures

Physiologic data included measurement of point of care hemoglobin A1c (HbA1c), adiposity measurements including skin folds, weight-to-height ratio (WtHR), and calculation of BMI. Table 4.1 describes the physiologic measures based on gender. Males and females had similar mean diastolic and mean systolic blood pressures. As a group, neither males nor females met the American Diabetes Association (ADA) 2012 Clinical Practice Guidelines goal of 130mm/Hg for systolic blood pressure; however, they both met the diastolic goals of below 80mm/Hg. Individually, the goal of 130mm/Hg for systolic blood pressure was met by 45% (n = 5) of the men and 74% (n = 14) of the women; the diastolic goal of below 80mm/Hg was met by 73% (n = 8) of the men and 100% (n = 19) of the women.

Table 4.1

Physiologic Measures by Gender	
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Value	Male Range	Male (<i>n</i> = 11) Mean (<i>SD</i>)	Female Range	Females $(n = 19)$ Mean (SD)
Systolic BP (< 130 desired)*	102–173	134 (22.7)	82–169	134 (22.2)
Diastolic BP (< 80 desired)*	66–92	74 (8.8)	47–83	64 (9.9)
HbA1c (< 7% desired)	5.7–11.4	7.4 (1.7)	5.1-12.1	7.9 (2.0)**
Adiposity Measures	22.9–39.6	27.9 (4.9)	23.7-41.9	34.3 (4.6)
– subscapular skinfolds	10–28	16.6mm (4.8)	14–35	22.7 (5.8)
 – iliac crest skinfolds 	8–40	16.5mm (8.4)	8–34	22.5 (6.8)
– tricep skinfolds	2–26	9.8mm (6.5)	4–25	15.7 (4.8)
– bicep skinfolds	4–26	9.8mm (6.0)	4–25	14.2 (6.2)
WtHR (50% desired)	0.50-0.74	0.56 (0.1)	0.43–0.73	0.60 (0.1)
Pounds	129.0–243.6	179.7 (35.0)	102.8–253.6	167.5 (38.6)
Kilos	58.5-110.5	81.5 (15.0)	46.6 -115.0	75.9 (17.5)
BMI (20–25 desired range)	24.4–38.2	29.6 (4.9)	20.1–43.5	32.7 (6.1)

Note. BP = blood pressure, BMI = body mass index, HbA1c = glycated hemoglobin, WtHR = waist-to-height ratio.

*Per ADA, 2012 guidelines. **One female participant HbA1c value missing.

As a group, neither males nor females in this sample met the ADA goal of an HbA1c 7% or below. Overall, women (7.9%) had slightly poorer metabolic control than men (7.4%). The goal of an HbA1c \leq 7% was met by 33% (n = 6) of the women (n = 18) and 45% (n = 5) of the men. Individually, 72% (n = 13) of women had a HbA1c \geq 7% compared to 55% (n = 6) of men who had a HbA1c \geq 7%. Both males (22.9–39.6) and females (23.7–41.9) had skinfolds (adiposity) ranging from normal to overweight. The majority of males and females in this study were either overweight or obese as evidenced by Table 4.1. As a population, the mean BMI in males (29.6) was in the overweight range however, in females the mean BMI (32.7) was in the obese range. Using gender-based referent points, 73% (n = 8) of males were within the normal weight range for their age, 18% (n = 2) had a BMI in the overweight range and 10% (n = 1) were in the obese range. This contrasted with 42% (n = 8) of the women who were within the normal weight range for their age, 26% (n = 5) were overweight, and 32% (n = 6) were in the obese range (Table 4.1; Table 4.2).

Table 4.2

Age	Underfat	Normal	Overweight	Obese
Women				
20-40 years	< 21%	21–33%	33–39%	> 39%
41-60 years	< 23%	23-35%	35–40%	>40%
61–79 years	< 24%	24–36%	36–42%	>42%
Men				
20-40 years	< 8%	8–19%	19–25%	> 25%

Gender-Based, Age-Adjusted Percentage Body Fat Recommendations Body Fat Chart

Age	Underfat	Normal	Overweight	Obese
41-60 years	<11%	11-22%	22-27%	> 27%
61–9 years	< 13%	13–25%	25-30%	> 30%

Note. Recommendations are reproduced from Gallagher et al., 2000.

The WtHR was calculated for the study population as an indicator of the distribution of body fat or central adiposity (Table 4.1). The weight categories were based on age and sex as described on Table 4.3 (Ashwell, Gunn, & Gibson, 2012). Male and female participants had higher than the desired 0.50 WtHR. Although the numbers within each group were small, the results pointed to weight related tendencies between men and women. There were fewer women in the overweight range compared to men, but more women were in the obese and highly obese categories than men.

Table 4.3

Waist-to-Height Ratio Categories—Gender Frequency in Each Category

Male Range	Males (<i>n</i> = 11)	Female Range	Females (<i>n</i> = 19)
0.35–0.43 (Extremely slim)	0	0.35–0.42 (Extremely slim)	1 (6%)
0.46–0.53 (Normal)	3 (27%)	0.42–0.49 (Normal)	1 (6%)
0.53-0.58 (Overweight)	6 (55%)	0.49-0.54 (Overweight)	4 (22%)
0.58–0.63 (Obese)	1 (9%)	0.54–0.58 (Obese)	4 (22%)
> 0.63 (Highly Obese)	1 (9%)	> 0.58 (Highly Obese)	9 (44%)

Note. Categories are reproduced from Ashwell et al., 2012, and Schneider et al., 2010.

Instruments

Instruments were collected on all participants and included the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA; Lee, Bender, Ruiz, & Cho, 2006), Diabetes Knowledge (Fitzgerald et al., 1998), the Self-Efficacy Exercise Scale (Everett, Salamonson, & Davidson, 2009), the Eating Self-Efficacy Scale (Glynn & Ruderman, 1986), the Diabetes Self-Efficacy Scales (Lorig, Ritter, & Jacquez, 2005), and the Health-Promoting Lifestyle Profile II (Walker, Kerr, Pender, & Sechrist, 1990). The tables below show the findings for the total sample (Table 4.4) and by gender (Table 4.5). The decision to examine the instruments based on gender was made because it appeared that men and women responded differently to some instruments. For example, the pattern of females' responses to the eating self-efficacy scale items seemed to be lower than males.

Table 4.4

Measures	Score Range	Cronbach's α (total scale)	Mean (SD)
Knowledge:			
Original Versions in Spanish			
SAHLSA (50 items)	19–49	0.92	38.4 (8.5)
- Inadequate score $(37\%; n = 11)$	≤ 3 7		
- Adequate score $(63\%; n = 19)$	> 37		
Diabetes Knowledge (0-24)	6–18	0.50	14.0 (2.5)

Instrument Psychometrics

Seij-Ejjicacy: Spanish Language Versions

Diabetes Self-Efficacy (8-items; 0-100)	41-100	0.79	75.7 (16.3)		
Exercise Self-Efficacy (18-items; 0-100)	30–93	0.94	50.9 (23.8)		
Eating Self-Efficacy (25-items; 0-100)	28-97	0.93	61.0 (19.8)		
Subscales – Socially Acceptable (10 items) – Negative Affect (15 items)	5–99 24–98	0.84 0.93	49.2 (19.9) 59.4 (18.3)		
Self-Management Behaviors: Spanish Language Version					
Health-Promoting Lifestyle Profile (52 items; 1-4)	2.0-3.0	0.97	2.4 (0.5)		
Subscales					
– Health Responsibility (9 items)	1.2 - 3.8	0.91	2.4 (0.6)		
 Physical Activity (8 items) 	1.1–3.6	0.88	2.3 (0.7)		
– Nutrition (9 items)	2.0-3.8	0.84	2.6 (0.4)		
– Spiritual Growth (9 items)	1.7-3.9	0.92	2.8 (0.7)		
 Interpersonal Relations (9 items) 	1.3-3.4	0.84	2.4 (0.5)		
- Stress Management (8 items)	1.4–3.2	0.86	2.3 (0.53)		

Table 4.5

Instrument for Sample by Gender

Instrument (Total Scale)	Male Range	Males (n = 11) Cronbach's α Mean (SD)	Female Range	Females (n = 19) Cronbach's α Mean (SD)
SAHLSA (0–50; inadequate is \leq 37, adequate > 37)	19–47	α = 0.99 37.9 (8.5)	20–49	$\alpha = 0.93$ 38.6 (8.7)
Diabetes Knowledge (1-24)	12–17	$\alpha = -0.31$ 15.0 (1.6)	6–18	$\alpha = 0.59$ 13.5 (2.8)

Instrument (Total Scale)	Male Range	Males (n = 11) Cronbach's α Mean (SD)	Female Range	Females (n = 19) Cronbach's α Mean (SD)
Diabetes Self-Efficacy (1-100)	44–100	$\alpha = 0.89$ 82.0 (16.8)	42–98	$\alpha = 0.69$ 72.3 (15.3)
Exercise Self-Efficacy (1-100)	10–99	$\alpha = 0.96$ 49.2 (25.4)	5–77	$\alpha = 0.91$ 49.2 (16.8)
Eating Self-Efficacy (25 items; 0-100)	54–93	α = 0.94 71.3 (16.4)	30–79	$\alpha = 0.88$ 54.9 (14.3)
Eating Subscales				
 Negative Affect (15 items) 	40–97	$\alpha = 0.96$ 71.6 (19.6)	28–92	$\alpha = 0.91$ 56.2 (18.1)
 Socially Acceptable (10 items) 	56–98	α = 0.79 70.8 (15.4)	24–88	$\alpha = 0.81$ 52.8 (16.8)
Health-Promoting Lifestyle Profile	2–3	$\alpha = 0.99$	2.0-3.0	$\alpha = 0.93$
(52 items; 1-4)		2.6 (0.50)		2.3 (0.5)
Subscales – Health Responsibility (9 items)	1.2–3.1	α = 0.93 2.6 (0.5)	1.3–3.8	α = 0.88 2.4 (0.7)
 Physical Activity (8 items) 	1.1–3.6	$\alpha = 0.78$ 2.6 (0. 7)	1.3–2.9	$\alpha = 0.80$ 2.0 (0.5)
Nutrition (9 items)	2.1–3.3	$\alpha = 0.62$ 2.7 (0.4)	2.0-3.8	$\alpha = 0.69$ 2.5 (0.5)
 Spiritual Growth (9 items) 	1.8–3.9	α =0 .75 2.9 (0.6)	1.7–3.8	$\alpha = 0.69$ 2.7 (0.7)
 Interpersonal Relations (9 items) 	1.9–3.1	$\alpha = 0.78$ 2.5 (0.5)	1.3–3.4	$\alpha = 0.75$ 2.3 (0.5)
 Stress Management (8 items) 	1.4–3.3	$\alpha = 0.78$ 2.6 (0.5)	1.5–3.3	$\alpha = 0.74$ 2.2 (0.5)

Note. SAHLSA = Short Assessment of Health Literacy for Spanish-Speaking Adults. There were 30 completed instruments.

Descriptive Analysis

The following sections provide a descriptive analysis of the instruments listed in Table 4.5 and a discriminate analysis that describes the attributes of the individuals in three HbA1c groups and concludes with a description of the revised conceptual model and the statistical procedures that were conducted using the model as a guide.

Health literacy. Educational achievement, or last grade of school attended, was correlated at a low strength (r = .47, p < .009, 95% CI [0.88, 5.53]) with the SAHLSA. The scores on the SAHLSA were categorized into one of two categories, *inadequate* (score ≤ 37) or *adequate* (score > 37). This instrument was verbally administered and assessed respondents' comprehension of medical terms. Descriptive analysis of the SAHLSA showed that 63% (n = 19) of the participants scores were in the adequate category and 37% (n = 11) were in the inadequate category. Despite differences in educational achievement between male and female participants, there was little variation among health literacy scores due to gender. Among male participants, 36% (n = 4) scored in the inadequate category and 64% (n = 7) in the adequate category. Female participants showed similar results with 37% (n = 7) in the inadequate category and 63% (n = 12) in the adequate category.

The distribution of scores were negatively skewed (M = 38.4; skewness = -1.1; kurtosis = 0.4) representing a tendency for scores to cluster at the higher end of the scale rather than normally distributed from lower to higher. This finding was not unique as health literacy instruments have a tendency to have a ceiling effect among higher scores (Macek et al., 2010; Weiss et al., 2005). Similar to other health literacy instruments the SAHLSA appropriately identifies individuals with inadequate health literacy, however, respondents

with adequate literacy scores tend to cluster at the higher level (score > 37; Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Chew, Bradley, & Boyko, 2004; Davis et al., 1993).

Diabetes knowledge. Diabetes Knowledge Test scores (n = 30) ranged from 6–18 out of a possible score of 24 (M = 14.0). Descriptive analysis indicated a somewhat negatively skewed distribution of scores with skewness of– 0.9 and kurtosis of 2.2.

SAHLSA and diabetes knowledge. Pearson correlation coefficients were computed to assure the SAHLSA (50-items) and Diabetes Knowledge Test (24 items) diverged on the constructs that each measured. The results were r(28) = .37; p < .05, which demonstrated a low correlation. This meant that each instrument measured independent knowledge-related constructs and could be considered as an independent variable in evaluating their association with health-promoting behaviors in the conceptual model (Munro, 2004; Trochim, 2007).

Healthy Promoting Lifestyle Profile II. There were items within the Health-Promoting Lifestyle Profile II (HPLP II) that prompted participants to ask for additional clarification. The questions revealed that some concepts were unfamiliar to many of the participants, such as working toward long-terms goals (Item 30) and feeling connected to some force greater than myself (Item 48). The subscale results: health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management are described in Table 4.4 for the total sample and with differences by gender in Table 4.5. The decision to examine these variables by gender was made because it appeared that males and females responded differently to some instruments, like the Eating Self-Efficacy Scale.

Self-efficacy. The descriptive analysis of the Self-Efficacy Scales distribution (0-100) indicated a higher level for Diabetes Self-Efficacy (M = 75.7; skewness = -0.5; kurtosis = -0.3), followed by Eating Self-Efficacy (M = 60.9; skewness = -0.2; kurtosis = -0.2

0.1), and Exercise Self-Efficacy with the lowest reported level of self-efficacy (M = 49.2; skewness = -0.2; kurtosis = 0.8).

Correlation coefficients were computed among the Diabetes Self-Efficacy Scale, Eating Self-Efficacy Scale, and Exercise Self-Efficacy Scale to assure they measured divergent constructs. The results are presented in Table 4.6 and show a statistically significant correlation between the Eating Self-Efficacy Scale and Exercise Self-Efficacy Scale (r = .42; p < .05). The correlation between the Diabetes Self-Efficacy Scale and Eating Self-Efficacy Scale (r = .35; ns) was higher than the Diabetes Self-Efficacy Scale and the Exercise Self-Efficacy Scale (r = .11, ns) but the strength of all the relationships, including eating and exercise, were considered to be low (Munro, 2004).

Table 4.6

Scale	Correlation Type	Diabetes	Exercise
Exercise	Pearson Correlation	0.11	0.11
	Sig. (2-tailed)	0.58	0.58
Eating	Pearson Correlation	0.35	0.42*
	Sig. (2-tailed)	0.58	0.02

Correlations between Self-Efficacy Scales

Note. 30 scales were completed. *p < .05 level (2-tailed).

Psychometrics for all the instruments were analyzed based on the results from this study population and were generally robust as described in Table 4.4.

Discriminate Analysis

To explore elements of the revised conceptual model discriminate analyses were conducted to determine whether any of the six instruments, the SAHLSA, Diabetes Knowledge Test, Diabetes Self-Efficacy Scale, Exercise Self-Efficacy Scale, Eating Self-Efficacy Scale, and reported Health-Promoting Lifestyle Behaviors estimated membership in one of three HbA1c level groups (≤ 6.99 ; 7.0-9.9; ≥ 10.0). The results of the overall model were statistically non-significant (Wilks' $\lambda = 0.43$; χ^2 (12; n = 29) = 19.8, p < .07) for predicting group membership; however, two independent variables contributed to the discriminant function (Table 4.7).

Table 4.7

	HbA1c Group and Mean scores (N = 29)		Tests of Equity of Group Means			
Scale	≤ 6.99 n = 13	7.00- 9.99 n = 12	≥ 10.00 n = 4	Wilks'λ	F	Significance
Diabetes SES	85.7	66.4	71.9	0.68	6.0	0.008
Eating SES	64.3	58.7	56.5	0.96	0.46	0.63
Exercise SES	52.1	49.1	36.3	0.93	0.95	0.39
SAHLSA	39.7	38.5	33.0	0.93	0.95	0.40
DKT	14.6	13.3	14.3	0.94	0.78	0.47
HPLP II	2.8	2.3	2.0	0.63	7.46	0.003

Discriminate Analysis of HbA1c Groups

Note. DKT = Diabetes Knowledge Test; HPLP II = Health-Promoting Lifestyles Profile II, SAHLSA = Short Assessment of Health Literacy for Spanish-Speaking Adults, SES = Self-Efficacy Scale.

The results (Table 4.7) suggest that the HPLP II and Diabetes Self-Efficacy were associated with HbA1c group membership. This same pattern held within the structure matrix correlation results with HPLP II (r = .75) and Diabetes Self-Efficacy Scale (r = .66). All other variables were below r = .30, which is considered the cut-off between important and less important variables (Garson, 2008).The cross validated classification results indicated that 59% of participants were classified correctly into the HbA1c groups. The prediction of group membership ranged from substantially better than chance at 85% for the HbA1c ≤ 6.99 group to moderately better than chance at 50% for HbA1c 7.0-9.9 group. However, the ability to estimate membership for the HbA1c ≥ 10.0 group was 0%; this lack of predictability was likely due to a small group number (n = 4) resulting in a ratio of sample size to number of variables that was not favorable for analysis. These results suggest trends among the HbA1c groups but sample size, particularly among the HbA1c >10 group, was not adequate to predict group membership.

The group with the best glycemic control (HbA1c ≤ 6.9) had higher health literacy scores (M = 39.7), diabetes knowledge scores (M = 14.6), self-efficacy scores (diabetes M =85.9; eating M = 78.7, exercise M = 56.1), and a higher HPLP II mean (M = 2.8) than the other two groups (7.00-9.9; > 10.00). Exercise and eating self-efficacy trended downward as HbA1c levels increased. Diabetes knowledge scores were slightly lower among the middle HbA1c group (M = 13.3) than those whose HbA1c was ≥ 10.0 (M = 14.3). Health-promoting lifestyle behaviors were less likely to be performed (*sometimes*, M = 2.0) among the HbA1c >10.0 group, compared to these behaviors being *often* (M = 2.8) performed among the HbA1c ≤ 6.99 group. This result indicates that the reported performance of health-

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promoting behaviors along with Diabetes Self-Efficacy Scale may estimate group membership.

Health literacy and diabetes knowledge. Health literacy and diabetes knowledge were the initial quantitative components of the conceptual model (Figure 4.1). To assess the conceptual model as well as explore the relationship between health literacy and diabetes knowledge, an independent regression of the SAHLSA on the Diabetes Knowledge Test (DKT) was conducted (Table 4.9). In the model summary, health literacy accounted for an estimated 11% of the variance in Diabetes Knowledge. A significant association was found (p = 0.04). See Table 4.8. This result suggests that health literacy level has a small ability to estimate an individual's diabetes knowledge and is consistent with the model that suggested a weak association between the two constructs.

Table 4.8

Model Summary: Health Literacy and Diabetes Knowledge

R	\mathbf{R}^2	Adjusted R ²	SE of the Estimate	ΔF	df1	df2	Significance Δ F
0.37 ^a	0.137	0.11	2.38	4.44	1	28	0.04

Note. The predictor was the Short Assessment of Health Literacy for Spanish-Speaking Adults score. The dependent variable was the Diabetes Knowledge Test score. SE = standard error.

Model	Unstandardized Coefficients		t	Sig.	95% C	95% CI for β		
	В	SE			LL	UL		
1 (Constant)	9.80	2.05	4.77	.000	5.60	14.		
Short Assessment of Health Literacy for Spanish- speaking Adults	0.11	0.05	2.01	.04	0.003	0.22		

Coefficients for the Health Literacy and Diabetes Knowledge Model

Note. The predictor was the Short Assessment of Health Literacy for Spanish-Speaking Adults scores. The dependent variable was the Diabetes Knowledge Test scores.CI = confidence interval, LL = lower limit, SE = standard error, Sig. = Significance, UL = upper limit.

Health literacy, diabetes knowledge and health-promoting behaviors. The next

step in the model was to explore the relationships between health literacy and diabetes knowledge with type 2 self-management diet practices and physical activity as measured by the HPLP II. The HPLP II is composed of six subscales and the score is based on how often a behavior is reportedly performed: *never* (1), *sometimes* (2), *often* (3), or *routinely* (4). The more often health-promoting behaviors are performed for the higher the HPLP II score. Specific information about the HPLP II and the subscales are described in the following health-promoting behaviors section.

The relationships between the SAHLSA, DKT, and the HPLP II, as illustrated in the conceptual model and were explored using linear regression procedures (Figure 4.1). The Table 4.10 model summary suggests that the SAHLSA and DKT accounted for 20% of the variance in the HLPL II. The SAHLSA reached significance at p = 0.049, 95% CI [0.00, 0.04] (Table 4.11; Munro, 2004).

Model Summary: Health Literacy, Diabetes Knowledge, and Health-Promoting Behaviors

Model	Adjusted R ²	SE of the Estimate	ΔF	df1	df2	Significance of Δ			
		Estimate				Γ			
1	0.20	0.45	4.55	2	27	0.02			
Note The predictors were the Dichotos Knowledge Test and Short Assessment of Health									

Note. The predictors were the Diabetes Knowledge Test and Short Assessment of Health Literacy for Spanish-Speaking Adults scores. The dependent variable was the Health-Promoting Lifestyle Profile II scores. SE = standard error.

Table 4.11

Coefficients for the Health Literacy, Diabetes Knowledge, and Health-Promoting Behaviors Model

Model	Unstandardized Coefficients		t	Sig.	95% Con Interval f	
	β	SE			LL	ŪL
1 (Constant)	13.54	1.87	7.22	0.000		
SAHLSA	0.02	0.01	2.06	0.049*	0.00	0.04
DKT	0.05	0.04	1.29	0.208	-0.03	0.12

Note. The predictors were the Diabetes Knowledge Test and Short Assessment of Health Literacy for Spanish-Speaking Adults scores. The dependent variable was the Health-Promoting Lifestyle Profile II scores. CI = confidence interval, DKT = Diabetes Knowledge Test, LL = lower limit, SAHLSA = Short Assessment of Health Literacy for Spanish-Speaking Adults, SE = standard error, Sig. = Significance, UL = upper limit. *p < .05

Health literacy (SAHLSA) and diabetes knowledge (DKT) were then examined in association with the specific HPLP II subscales, physical activity and nutrition. The results of the analysis (not shown) with SAHLSA and DKT as estimators of physical activity did not reach significance (R-squared = 0.02; adjusted R-squared = -0.05, F(2, 27) = 2.81, p = 0.75).

The adjusted R-squared = 0.23 suggested that SAHLSA and DKT accounted for 23%

of the variance in the nutrition subscale (Table 4.12). However, their relationship with the

nutritional subscale also did not reach significance at the p < .05 level (Table 4.13).

Table 4.12

Model Summary: Health Literacy, Diabetes Knowledge, and HPLP II Nutrition Subscale

\mathbf{R}^2	Adjusted R ²	$\mathbf{R}^2 \Delta$	ΔF	df1	df2	Significance of Δ F
0.53	0.23	0.28	5.32	2	27	0.01

Note. The predictors for the constant model were the Diabetes Knowledge Test and the Short Assessment of Health Literacy for Spanish-Speaking Adults scores. The dependent variable was the Health-Promoting Lifestyles Profile II nutrition subscale scores.

Diabetes knowledge reached near significance (DKT; $\beta = 0.06$. p = 0.050; Table 4.13) and therefore may be associated with reported nutritional behavior, 95% CI [0.00–0.127] but this cannot be assumed based on these results.

To validate the pathway described in the conceptual model a linear regression procedure was conducted with health literacy and diabetes knowledge in relation to HbA1c, WtHR and BMI (not shown). The model summaries and coefficients from these procedures

were non-significant at p < .05 level.

	Unstandardized Coefficients		t	Sig.	95% Confidence Interval for β	
Model	β	SE			LL	UL
1 (Constant)	1.13	0.45	2.5	0.02	0.20	2.05
SAHLSA	0.015	0.009	1.60	0.12	004	0.034
DKT	0.063	0.031	2.05	0.050	0.00	0.127

Coefficients for the Health Literacy, Diabetes Knowledge, and Nutrition Models

Note. The predictors for the constant model were the Diabetes Knowledge Test and the Short Assessment of Health Literacy for Spanish-Speaking Adults scores. The dependent variable was the Health-Promoting Lifestyles Profile II nutrition subscale scores. CI = confidence interval, DKT = Diabetes Knowledge Test, LL = lower limit, SAHSLA = Short Assessment of Health Literacy for Spanish-Speaking Adults, SE = standard error, Sig. = Significance, UL = upper limit.

Health-promoting behaviors. The HPLP instrument, the self-efficacy scales and the information shared during the interviews provided a comprehensive description of participants' diet practices and physical activities. The interview information and responses to the instruments were assessed for congruency during the data collection session, data entry and transcript review. For example, if during the interview the participant said she never exercised, it would be expected that her responses to the HPLP physical activity subscale items would be primarily *never* and *sometimes*, and responses to the Exercise Self-Efficacy Scale would be equally low. This assumption was true as monitoring during the data collection session confirmed congruent responses across interview and instrument responses. To explore the association between HPLP II subscales of interest and self-management outcomes, as illustrated in the conceptual model, correlation coefficients were computed among the six HPLP II subscales. This procedure ensured they diverged on the constructs measured. The results in Table 4.14 illustrate that the Nutrition subscale was highly correlated to Interpersonal relations (*r* = .80). The association between social situations and

diet management was also present in the qualitative data when participants talked about the challenges that social events and food presented for their diet management. Physical activity was moderately correlated with stress management (r = .63) a relationship that was also reflected in qualitative findings in participants' reported feeling less stressed after exercising (Munro, 2004; Trochim, 2007).

Table 4.14

Subscales	Health responsibility	Physical Activity	Nutrition	Spiritual Growth	Interpersonal Relations
Physical Activity	0.23				
Nutrition	0.52** (moderate)	0.47** (low)			
Spiritual Growth	0.56** (moderate)	0.46** (low)	0.70** (high)		
Interpersonal Relations	0.59** (moderate)	0.43* (low)	0.80** (high)	0.84** (high)	
Stress Mgt.	0.43* (low)	0.63** (moderate)	0.64** (moderate)	0.66** (moderate)	0.66** (moderate)

Correlations for the Six Health-Promoting Lifestyle Profile II (HLPL II) Subscales

Note. 30 HPLP II scales were completed. Mgt. = management. *p < .01, two-tailed. *p < .05, two-tailed.

Although the results indicated a significant statistical correlation among the HPLP subscales the strength of those relationships were defined as: 0.26 to 0.49 low, 0.50 to 0.69 moderate, 0.70 to 0.89 high, and 0.90 to 1.00 very high (Munro, 2004).

Health-promoting behaviors and HbA1c. To explore the ability of reported health-

promoting behaviors to estimate HbA1c as the next component in the conceptual model,

multiple linear regression analyses were conducted. The HPLP subscales Health

Responsibility, Physical Activity, and Nutrition were entered to assess their association with HbA1c. The three remaining subscales, Interpersonal Relations, Spiritual Growth, and Stress Management were not included in the analyses as they were not specific variables of interest in this study. The results of the first analysis appear in Table 4.15. The adjusted R-square = 0.24, accounting for 24% of the variance in HbA1c F(3, 25) = 3.97, p = 0.02.

Table 4.15

Model Summary: Health Responsibility, Physical Activity, Nutrition to HbA1c

R	\mathbf{R}^2	Adjusted R ²	<i>SE</i> of the Estimate	ΔF	df1	df2	Significance of ΔF
0.57	0.32	0.24	1.65	3.98	4	24	.02

Note. Predictors for the model were scores for the Health Responsibility, Physical Activity, and Nutrition subscales of the Health-Promoting Lifestyles Profile II. The dependent variable was glycated hemoglobin values. SE = standard error. *p < .05.

A significant association was found with the Nutrition subscale at p = .019 (p < .05),

95% CI [-4.07, -.406] suggesting that the reported performance of HPLP nutritional

behaviors (i.e., never to routinely) were associated with HbA1c (Table 4.16).

Model		Unstandardized Coefficients		Sig.	95% CI for β		
	β	SE			LL	UL	
1 (Constant)	13.54	1.87	7.22	.000	9.68	17.40	
Physical Activity	-0.49	0.57	-0.870	0.382	-1.66	0.68	
Nutrition	-2.24	0.89	-2.51	.019	-4.07	-0.41	
Health Responsibility	0.44	0.59	0.74	0.47	-0.78	1.65	

Coefficients for the HPLP II Health Responsibility, Physical Activity, Nutrition Subscales, and HbA1c Model

Note. Predictors for the model were scores for the Health Responsibility, Physical Activity, and Nutrition subscales of the Health-Promoting Lifestyles Profile II. The dependent variable was glycated hemoglobin levels.CI = confidence interval, LL = lower limit, SE = standard error, Sig. = Significance, UL = upper limit.

The second analysis focused on Nutrition and Physical Activity and their ability to estimate HbA1c. The adjusted R-square for Nutrition and Physical Activity suggests that they accounted for 25% of the variance in HbA1c, F(2, 26) = 5.80 (Table 4.17). The results of this analysis also indicate a relationship between nutrition and HbA1c. The association between nutrition and HbA1c was significant at the 0.05 level (p = 0.020) but, as with the previous analysis, Physical Activity did not reach significance (p = 0.382, ns). The 95% CI [– 3.52,–0.3] and coefficients for nutrition in this model indicates that reported nutritional behaviors are associated with lower HbA1c levels.

Model Summary: HPLP II Nutrition Subscale, Physical Activity Subscale, and HbA1c

R	R ²	Adjusted R ²	SE of the Estimate	ΔR^2	ΔF	df1	df2	Significance of ΔF
0.55	0.31	0.25	163	0.308	5.80	2	26	0.008

Note. The predictors were age and the scores for the Nutrition and Physical activity subscales of the Health-Promoting Lifestyles Profile II. The dependent variable was glycated hemoglobin values.SE = standard error.

Table 4.18

Coefficients for the HPLP II Nutrition Subscale, Physical Activity Subscale, and HbA1c Model

Model	Unstandardized Coefficients		t	Sig.	95% C	CI for β
	β	SE			LL	UL
1 (Constant)	13.08	1.82	7.57	0.000	10.05	17.55
Physical Activity	-0.50	0.56	-0.890	0.382	-1.66	0.66
Nutrition	-1.93	0.78	-2.49	0.020	-3.52	033

Note. The predictors were age and the scores for the Nutrition and Physical Activity subscales of the Health-Promoting Lifestyles Profile II. The dependent variable was glycated hemoglobin values. CI = confidence interval, LL = lower limit, SE = standard error, Sig. = Significance, UL = upper limit.

Self-efficacy. To examine the last phases in the conceptual model the association

between the Self-Efficacy Scales and the HLPL II Nutrition and Physical Activity subscales

were examined as the specific variables of interest.

Model Summary: Exercise Self-Efficacy, Eating Self-Efficacy, Diabetes Self-Efficacy, and Physical Activity

R	R^2	Adjusted R ²	SE of the Estimate	ΔR^2	ΔF	df1	df2	Significance of ΔF
0.61	0.37	0.29	0.51	0.37	5.17	3	26	.006

Note. The predictors for the model were scores from the Exercise Self-Efficacy, Eating Self-Efficacy and Diabetes Self-Efficacy Scales. The dependent variable was scores from the Physical Activity subscale of the Health-Promoting Lifestyles Profile II. SE = standard error.

Table 4.20

Coefficients for the Eating Self-Efficacy, Diabetes Self-Efficacy, and Physical Activity Model

Model	Unstandardized Coefficients		t	Sig.	95% CI for β	
	β	SE			LL	UL
1 (Constant)	0.432	0.51	0.85	0.40	-0.61	1.48
Diabetes SES	0.013	0.006	2.09	0.04*	0.00	0.03
Eating SES	0.015	0.007	2.24	0.03*	0.001	0.03
Exercise SES	-0.002	0.005	-0.32	0.75	-0.013	0.009

Note. The predictors for the model were scores from the Exercise Self-Efficacy, Eating Self-Efficacy and Diabetes Self-Efficacy Scales. The dependent variable was scores from the Physical Activity subscale of the Health-Promoting Lifestyles Profile II. SES = Self-Efficacy Scale, CI = confidence interval, LL = lower limit, SE = standard error, Sig. = Significance, UL = upper limit.

**p* < .05

Exercise Self-Efficacy, Diabetes Self-Efficacy, and Eating Self-Efficacy account for

29% of the variance in reported physical activity (Table 4.19). The results in Table 4.20

suggest that the association between Diabetes Self-Efficacy, Eating Self-Efficacy and

physical activity was significant.

The second analysis examined the relationship between Exercise, Diabetes, and

Eating Self-efficacy and the HLPL II Nutrition subscale. It would appear that Self-Efficacy

accounts for less of the variance in reported nutritional behaviors than physical activity: R-squared = 0.29; adjusted R-squared = 0.22, F(3,26) = 3.69, p = 0.025. The self-efficacy scales are estimated to account for 22% of the variance in the nutrition subscale and Table 4.22 would suggest that diabetes self-efficacy was associated with reported nutritional behaviors.

Table 4.21

Model Summary: Exercise Self-Efficacy, Eating Self-Efficacy, Diabetes Self-Efficacy, and Nutrition

R	R^2	Adjusted R ²	SE of the Estimate	ΔR^2	ΔF	df1	df2	Significance of ΔF
0.54	0.29	0.22	0.39	0.29	3.69	3	26	0.025

Note. The predictors for the model were scores from the Exercise Self-Efficacy, Eating Self-Efficacy and Diabetes Self-Efficacy Scales. The dependent variable was scores from the Nutrition subscale of the Health-Promoting Lifestyles Profile II. SE = standard error.

Table 4.22

Coefficients for the Exercise Self-Efficacy, Eating Self-Efficacy, Diabetes Self-Efficacy, and Nutrition Model

Model	Unstandardized Coefficients		t	Sig.	95% CI for β	
	β	SE			LL	UL
1 (Constant)	1.51	0.39	3.88	0.001	0.71	2.32
Diabetes SES	0.015	0.005	3.18	0.004	0.005	0.025
Eating SES	-0.005	0.005	-0.88	0.38	-0.015	0.006
Exercise SES	0.004	0.004	0.89	0.37	-0.005	0.012

Note. The predictors for the model were scores from the Eating Self-Efficacy and Diabetes Self-Efficacy Scales. The dependent variable was scores from the Nutrition subscale of the Health-Promoting Lifestyles Profile II. CI = confidence interval, LL = lower limit, SE = standard error, Sig. = Significance, UL = upper limit. SES = Self-Efficacy Scale.

These results suggest that the revised model describes the relationships between the constructs. Additional discussion of the model will be addressed in Chapter 5.

Quantitative Data Analysis Summary

The quantitative data analysis demonstrated the associations between health literacy, diabetes knowledge, self-efficacy, and health-promoting behaviors. Health literacy and diabetes knowledge informed health-promoting behaviors. Increasing the frequency of health-promoting behaviors contributed to improved diabetes self-management outcomes. Experiencing improved diabetes self-management and achieving diabetes self-management goals encouraged participants to maintain their performance of present behaviors and enhanced their confidence in their abilities to self-manage their diabetes.

Physiologic measures showed HbA1c levels above the recommended values with women's higher than the men's on average. Adiposity measures and weight values for males and females ranged from normal to overweight. The Waist to Height ratio, an indicator of central adiposity, showed that men and women exceeded the desired .50 ratio. The BMI calculations and skinfold measures for men and women also exceeded desired ranges. However, these measures differed by gender, 73% of the men were in the normal weight range compared to 42% of women while 10% of the men were in the obese range compared to 32% of the women. These differences in physiologic measures indicated women had poorer glycemic control and more overweight than men.

Qualitative Data

Interviews

The 30 semi-structured interviews were the primary qualitative data source. The length of the interviews ranged from 17.4 minutes (Case 1) to 60 minutes (Case 30), and

averaged35 minutes. The interviews were concluded when the participants had no more information to add. At the end of the data collection session additional information and impressions about diabetes self-management practices were obtained by clarifying information that was shared during the interview and asking participants if they had any questions.

The quality of the digital recording was reviewed after each interview; all were judged to be of good to excellent audio quality. A sample of four-interviews were transcribed in Spanish, translated, and transcribed into English by two independent transcriptionists to assess the reliability and consistency of the primary translation and transcription service, Transdual Forensics[®]. All subsequent interviews were translated directly from Spanish and transcribed into an English transcript. The content and accuracy of each translated transcript was validated by simultaneous review with each digital recording. The comparison of the audio recording and electronic transcript was conducted using DSS Player Pro Transcription[®]V2.0 transcription software with foot pedal. This procedure was also part of data immersion process. Memos were made during the reviews, which contributed to new understandings of what participants were saying and assisting in identifying patterns in the data.

Following the review and validation of the content, copies of the transcripts were printed, independently reviewed, and hand coded by me and another researcher. Concurrent coding was then conducted. It included reviewing the transcripts for content and theoretical elements. The semistructured nature of the interviews and the use of directed content analysis facilitated the coding process. Coder concordance on each transcript was initially 85%, but it reached 100% after the final concordance of evidence, following the evolving refinement of

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the codes, theoretical concepts, and definitions. Concordance was achieved on all coding after discussion of definitions and theoretical constructs. All participant names were replaced with pseudonyms.

Themes were developed in conjunction with the interview questions using directed content analysis. New themes were developed as new information was presented, as specifics were judged to contribute to the understanding of diabetes self-management, and as data was determined to be significant relative to other findings. A majority of the 36 themes that emerged from the data 75% (n = 27) had 15 or more sources.

The NVivo[®]qualitative data software program linked the coded text for each theme to the participant (i.e., source) from whom the statement originated. The number of coded references attributable to any one participant or theme was also tracked which allowed identification of data rich cases and topics. For example, seven sources specifically described good self-management practices they learned from family members, 30 participants were referenced as talking about friends or family members who had T2DM, and 30 participants made 228 references to *learning from family members*.

Data Analysis

As participants shared their feelings and thoughts upon receiving their diagnosis, concepts emerged from the data that had not been addressed in the original model. An unexpected process emerged early in the data collection – individuals receiving the diagnosis and delaying initiation of medication and other self-management behaviors. This disclosure prompted further exploration of the chronology of receptivity to initial diagnosis, participant response, and subsequent behaviors, which are described in the following sections.

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Diagnosis was viewed as a crisis. The participants receptivity to the news of diagnosis resulted in discomfort as a new self-concept (i.e., having diabetes) took shape. However, not all participants responded in the same manner; some participants experienced little reported discomfort with the diagnosis. Participants who were receptive to their diagnoses expressed it in the following ways:

Oh yes, it was hard, because like I said, I did not feel anything. I did not feel that it was going up or down, I did not feel anything, I could think I did not have it because I was not feeling anything. (Claudia)

It was a surprise. . . because I did not know. I was very slim and losing my hair. I mean I did not know why . . . that's what happened to me. (Alta)

I accepted it when they told me. (Maria)

One participant spoke of her diabetes diagnosis as inconsequential. Diabetes ran in her family; thus, having diabetes was normalized and her family experience facilitated the rapid

integration of the diagnosis into her view of self. Other participants were not as receptive:

I didn't want her to tell me I had it. (Claudia)

Well at first, I took it kind of light, right? Because I said, at first, 'No. He [physician] is wrong.' (Juan)

During the second stage participants described a process of *recognition*, or

ownership. They recognized that they had to make a choice. Recognition was clear in the stories of participants who initially denied ownership of diabetes diagnosis. They used terminology like *took it lightly* and *it was not important* in describing their responses to the diagnosis. This response was operationalized by not making changes in alcohol consumption, continuing regular diet habits, and taking medication on occasion or not at all. Participants who initially denied the significance of diabetes and the importance of treatment were prompted to acknowledge the necessity of treatment in one of two ways: by a family

member's insistence or by the appearance of physical consequences that could no longer be ignored (e.g., vision problems).

But when time passed I realized it is a very, very stubborn illness. It doesn't go away, It has to be controlled by it keeps getting worse with time because before, they were giving me pills and I didn't take them. I didn't take the pills. (Martin)

One participant shared that after his wife talked to him, he reflected on his health, his future, and his family, thus recognizing that he did have diabetes. His story exemplifies how family members and the social environment played a part in his transformation.

Grieving was a process that was evident throughout the interviews in varying degrees and occurred in four phases; all of which were expressed during the interviews. The first phase was described as numbress and panic, the second was pining and protest, third was disorganization and disrepair, and, the last was restabilization and reintegration (Boyd &

Myers, 1988).

Numbness and panic. Participants spoke of feeling paralyzed or stunned by the news

of diagnosis. This phase was typically transient in nature, lasting from hours to days for most

participants.

I knew it, but inside I was nervous, I had chills. I mean-you have it. They told me this all very calmly. (Jose)

Well, look, when they told me that I had diabetes. I didn't think anything because my sister had died from that–I thought, 'I am going to die.' And when they told me I started crying. I was screaming. (Silvia)

Pining and protest. Upon diagnosis, some participants reported they did not want to believe the doctor, silently arguing that the diagnosis must be wrong, that it could not be true. Participants admitted they occasionally felt sad about having diabetes, but were explicit in

communicating that they did not linger on these thoughts. Many conveyed that such thoughts

were counterproductive and unhealthy. However, it was important to distinguish this temporary phase from chronic depression, a condition that two women reported.

Disorganization and disrepair. This phase was when apathy and depression abounded. Sophia realized that, 'I felt badly. . . because I thought, 'I am never going to get better from that illness.' Maria shared that, 'having diabetes has given me a lot of depression. I still have depression because if it'.

Restablization and reintegration. The fourth phase was evidenced by participants' reports of recharging and regrouping. They discussed how they turned a corner, revising their perspective, having new–found hope for the future, and committed to diabetes self-management – thus demonstrating the integration of diabetes into their self-concept. Angelica and Roberto talked about their journey from diagnosis to restablization and reintergration:

I felt like somebody had died. I felt depressed but like we said "I put on the batteries." I remember it was around Christmastime, around this time. And I didn't eat anything. I was so afraid. And I felt that I was feeling fine I started eating. (Angelica)

So, with time, I started, started. . . . no soda, no tortillas, bread, and flours, little by little. I took me three months to come to terms with the illness [diabetes]. (Roberto)

In the sections that follow the qualitative findings from the three topic areas are discussed: *information seeking and knowledge acquisition, family influences and vicarious learning*, and *self-management practices*. The findings within each question are organized in the order in which they were explored during the interviews. Numerical percentages are provided when appropriate, in cases when words are used to describe the data the following interpretations apply: an overwhelming majority \geq 80%, a majority \geq 50%, some \cong 30%, and a few \cong 20%.

Information Seeking and Knowledge Acquisition

Question 1A: Initial diabetes knowledge acquisition. The themes that emerged when participants spoke about when they first learned about diabetes were *receiving the diagnosis*, *seeking medical care*, *awareness of the risk of developing diabetes, incorrect information*, and *lack of awareness about the disease trajectory*.

Theme 1: Receiving the diagnosis. The majority of the participants (n = 28; 93%) received their diagnosis of diabetes in the United States (US). Only two of the participants (7%) were diagnosed in their home country prior to immigrating. Many of the women first learned about diabetes because of gestational diabetes during pregnancy (n = 9; 47%). All the men and women reported they received their diagnosis of T2DM during a face-to-face office visit with a doctor except for two women who received their diagnoses over the telephone. They said receiving the news in this manner was traumatic. Elena said, "The doctor called me, she called me on the phone. . . I was crying. . . I couldn't talk to her anymore. It is really hard over the phone."

Theme 2: Seeking medical care. The reason many of the participants sought medical care was often due to physical problems, but these problems had not been identified or perceived as related to diabetes. Therefore, the participants did not suspect they had diabetes, often resulting in the diagnosis coming as a surprise:

One day I got sick, I went to a hospital . . . I had pain in my chest . . . but it was not my chest . . . it was diabetes. (Enrique)

I went for a check up to . . . get contraceptives . . . They told me I probably had sugar, they told me to come back the next day fasting to get test done and it came out at 500. (Pilar)

[A wound]. . . it wasn't healing and it wasn't healing and they started checking my sugar and it was at 360 and 300. That's when they diagnosed that I was diabetic." (Angela)

Others identified their physical problems as symptoms of T2DM and suspected they had diabetes but were reluctant to seek medical care. They sought medical care to receive confirmation for what they had already deduced. As Jorge explained,

Oh, [I went] because my vision was blurry, my hands were sweating and I was very tired. . . I had headaches. . . I did not want to go. . . I already thought I had it [diabetes].

Family members were also adept at recognizing the signs and symptoms of diabetes. Roberto shared,

I left from here to go visit my mamá. My diabetes started when I was here, symptoms started when I was working, so in Mexico my mamá wanted to know if I had diabetes. She sent me to the doctor to be checked.

Once the symptoms of diabetes were noted, many participants sought medical care at the

insistence of family members. Jorge said, "My wife told me, 'Make an appointment so you

know.' My wife made an appointment. We went." In other cases, family members had

limited experience and knowledge with diabetes that prevented them from recommending

appropriate action. In these instances participants reported turning to trusted others for

assistance. Melida recounted the physical problems that prompted her visit to her godfather,

All I know is that when I got sick . . . nobody knew what illness I had. . . I used to feel like fainting. . . . I would get very thirsty. . . . My vision started getting blurry. . . . I couldn't see . . . That's when I went to my godfather who cures. He is a spiritualist. . . He told me, take her immediately [to the hospital] but he didn't tell me that it was the sugar . . . just. . . that I had risk of sugar. . . I was hospitalized because my sugar was at 900 grams.

Theme 3. Awareness of the risk of developing diabetes. Participants' knowledge

about the condition and their risk of developing diabetes was often informed by family

members or acquaintances experienced with diabetes. Alicia said,

I didn't know much, I just knew that I had diabetes and that, that was it . . . that I was never going to get better, right? That is all I know but, because my mamá has diabetes too.

Marguerite's diagnosis was expected based on her family members' experiences. She shared,

'Ah', I said. 'Oh, it's only diabetes, no big deal! That's what I said. . . I said, 'It runs in the

family, what can I do about it?"

Participants who had not been exposed to T2DM were largely unaware of their risk for

developing it. Martin stated, "I didn't know. How could I have imagined I was going to get

that?" Claudia had never heard about diabetes and wasn't aware of her risk.

I did not know anything about diabetes. No, I had never heard of it. No one in my family had it, my mamá, my papá either, and my brothers, the majority, have already died. Only the one that lives in Los Angeles was diagnosed with diabetes. In Guatemala, we did not know anything.

Theme 4: Incorrect information. Confusion existed among the participants about

type 1 and T2DM, including whether one or the other condition required the use of insulin. Angelica' comment exemplified this confusion: "I am terrified of getting diabetes type 1 and having to inject myself." Eduardo was unsure if he was eligible to participate in this research study because he described himself as having type 1 diabetes. However, he only used oral medication, checked his blood glucose on occasion, and was diagnosed with diabetes in his late 20s.

None of the nine women who had a history of gestational diabetes were aware that it increased their risk for developing T2DM. The etiology of gestational diabetes may have contributed to their misconceptions about T2DM as Pilar's recounting of her experience after childbirth indicates. She said, "I did not have that [diabetes] anymore, it had gone away." Others cited ongoing environmental stress as the cause for their T2DM after gestational diabetes. Claudia shared, "I came over here [the US], I met a man who was drinking a lot and who was treating me badly and all that, and because of all that my diabetes came back." Some of the women talked about their diligence in taking care of their gestational diabetes, because they were afraid their baby would be born with diabetes. Anna said, "I was checking my sugar 4 times a day because the girl I was going to have could be born with diabetes." The breastfeeding information the women received also confused the issue; the women did not understand that diabetes was a metabolic condition. Isabel shared her thoughts on the connection:

When my baby was born, they told me that if I breastfed, maybe I would get rid of the diabetes, I could control it. So I breastfed my baby for a year . . . After I stopped . . . the diabetes came back. Then I got pregnant with my second child and then I could not control it anymore . . . I had diabetes all the time. Now I have it. Not long ago, it went up really high and they had to give me insulin.

Theme 5: Lack of disease trajectory awareness. The progressive nature of diabetes

was poorly understood by the participants. Eduardo attributed better control of his blood glucose level 20 years ago as a function of location. He explained, "In Mexico, well I was living in Guadalajara when the diabetes was detected . . . when I was in Guadalajara . . . my diabetes was well controlled. I took very little medicine. Elena expressed an understanding of the progression of diabetes, but she was unsure. She said,

I have a friend who injects herself in her stomach. She is more advanced because they only give me one kind of pills and with these pills it controls it. My friend, she gets some kind of injection which she puts here. Maybe she has it [diabetes] more advanced than I am, I do not know.

Carlos, diagnosed approximately 12 years ago, and attributed the change in his medication

last year to diet. He shared,

They told me I had diabetes . . . "We are going to give you pills for diabetes." Then I started taking pills and pills. When I got to the [*redacted*] clinic, they told me, "We are going to give you insulin.". . . But before one pill was enough for me. But . . . I take good care of myself, my nutrition is, it is not that great.

Question 1B: First thoughts at diagnosis. The themes that emerged from examining the participants' first thoughts when they were diagnosed were *everything changes, fear of death, disbelief, shock,* and *perseverance.* First thoughts at diagnosis emerged as a topic after observing that participants talked about accepting their diagnosis and letting it into their consciousness. The progression from shock to grief to resolve was not universal, but it was a common pattern among those who had delayed treating their diabetes for months or years after diagnosis.

Theme 1: Everything changes. The diagnosis of diabetes signified the end of a normal life and their views of self for many participants. Isabel described it like someone saying, "You have a normal life, no, [herself] you can't." Enrique stated that despite all the information he was given "they didn't warn me, you have to be careful all the time. I would have a different life (*laughs*). I have to be more . . . more careful . . . I cannot just go . . . outside and all." This statement also reflects the fear of injury that develops from understanding the detrimental effects diabetes can have on the body's ability to heal.

The diabetes diagnosis made participants shift their view of self from that of a healthy person to one who was not healthy. This changed self-view required the integration and assimilation of new aspects of identity, which was a struggle. Martin delayed consistent treatment of his diabetes for over 8 years. He described his refusal to accept his diagnosis and the change in his life: "I thought I was 100% healthy and suddenly I was told I was sick. I thought, I feel good, I am just thirsty, I just drink." This change process resulted in suffering and grief as the significant aspects of their former identities disintegrated, and many participants struggled to make meaning of their diagnoses. Women were more likely to talk about having depression after diagnosis, and they were also more likely to mention having

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chronic depression. Melida shared, "No, it has given me a lot of depression . . . To know that

I have that [diabetes], it gives me a lot of depression. I still have depression because of it."

Alicia described the symptoms she experienced:

I got depression and I started eating and eating and eating and eating, and because I was at home all the time. I spent all my time eating and eating and lying down [*laughing*]. Yes, I mean that's the truth.

Still others expressed quiet acceptance of their diagnosis. Anna recalled,

I felt badly, yes, I mean I felt badly . . . because I thought, 'I am never going to get better from that illness'. Aha, but the doctor told me that I was going to take the medication only for some time and that later on when the sugar got under control she was going to take me off of it, but I know that, that it was not going to be possible.

Theme 2: Fear of death. Death or dying in relation to diabetes was mentioned by

53% (n = 16) of participants. For many, thoughts of their deaths would be immediately

followed by fears for their children. Participants expressed this fear in the following manner:

So when they told me, "You have diabetes." I felt I was going to die. (Eduardo)

At the time when they tell you. . . it is like if they had told me 'you are going to die soon.' One gets scared. (Sylvia)

Yes, yes, I was afraid. I started thinking about my children. They are not very big. I thought, "If I die who will take care of them?"(Pilar)

I thought to myself, "Wow." I have this illness, and it is the hardest thing in life, because I tell myself, "I am going to die, no? "What will happen with my daughter?" (Alicia)

Theme 3: Disbelief and shock. Beatriz compared hearing the news of her diabetes

diagnosis to a physical assault. She said, "It is a strong blow when they tell you." Some

participants associated developing diabetes exclusively with being overweight and thus

thought themselves to be immune. Jorge admitted, "Being so slim I did not think I was going

to get it." Alicia was similarly confused, also believing that being thin was a protection

against getting diabetes. "I did not know, I was very slim and losing my hair, I mean I did not

know . . . why . . . that's what happened to me."

Participants recounted the manner in which their health-care providers delivered the

news. Being face-to-face in a private room communicated respect and awareness of the

significance of the diagnosis, although it did not lessen the shock of hearing it. Enrique

remembered the day he was diagnosed like it was yesterday.

Well . . . he took me to a room and told me, "I do not have good news." . . . When you think you have a heart problem . . . and it turns out that you have diabetes . . . when they told me. I did not want to believe them, you know.

Theme 4: Perseverance. Some participants exhibited resolve and perseverance

shortly after receiving their diagnoses. Melida shared, "I have to keep going. What else am I

going to do?" Angelica described her progression from diagnosis to grief to reintegration:

Oh my God, [*laughing*] I felt like somebody had died. I felt depressed but like we say, 'I recharged'.... I was so afraid ... I didn't eat anything ... I just ate grilled meats, vegetables. I had a diet for a month, zero sugar ... and during this time it was hard for me, later on I was not afraid anymore ... I felt that I was feeling fine, I started eating.

Alicia shared how she pulled herself up and was strong because she knew she needed to be

there for her daughter:

I took all my strength and I told myself, "If I have this illness, I have to accept it, and keep going because my daughter is going to need me" . . . I said, "I am going to do it for her."

Some participants were pragmatic about the diligence required to successfully manage their

condition. Alejandro explained his reaction thusly:

And that's what you have to do, because if you don't, or like right now "I am okay" No, you shouldn't do that [think "I am okay"] because you are never going to be okay because they say there is no cure yet.

Question 2A: Receiving information about diabetes. This topic concentrated on the receipt of diabetes information and asked participants about their preferred way of receiving information. The themes that emerged were *information needs, individuals providing information* (e.g., physicians, nurses, nutritionists), *written materials in Spanish*, and *technology*. This exploration revealed that participants wanted to learn how to manage their condition, to receive information orally and in printed format, and that they trusted their health-care providers to give them accurate information.

Theme 1: Information needs. The desire for nutrition and diet information related to diabetes was high in the period after diagnosis. Participants also wanted to attend ongoing classes related to diabetes self-management. Office visits were less than ideal for receiving diabetes education; a few participants expressed dissatisfaction with the amount of time physicians spent with them during appointments. This perceived lack of time translated into feeling disrespected and communicated that the participants' needs were not important. Sylvia explained,

With Dr. [*redacted*], he is nice and he always has more time for you. The other? No She is always in a hurry. It is like . . . what seems important to me [does not matter], since I do not have my papers.

Detailed recommendations were preferred rather than general directives. Sylvia shared, "She only told me that I should go on a diet and get exercise . . . Doctors should give a person a little more information." Angela expressed similar thoughts:

She just told me if I lost weight my diabetes would be all right, that everything was going to be fine . . . But she didn't tell me how much [weight to lose] or anything like that . . . and they did the other test and I still had it [diabetes].

Classes were identified as an effective means of learning about diet and nutrition. Isabel said, "I took nutrition class and it has helped me a lot in how to prepare food with less fat, more exercise." The women with a history of gestational diabetes stated they attended diabetes classes when they were pregnant, but few mentioned attending a diabetes class since being diagnosed with T2DM. Only two of the men talked about attending a diabetes class, but most of the women reported meeting with a nutritionist. Jorge shared his experience:

They showed samples of food in little plastic plates. Well, I don't like vegetables but they showed broccoli, pasta, meats. But with time, I have been trying different foods, how much and what makes my level go high.

Rafael enthusiastically described the class he attended:

She [the instructor] even took us [to] the Wal-Mart over here, "You should buy from here. Don't grab food from the bottom. Grab the one from the upper part all the time, that's the best, but the one on the bottom is the one with the most fat. It is cheap but it is not good".

The classroom also provided the opportunity for discussion and information exchange.

Sophia mentioned this as part of why she would like to take a class: "To talk about diabetes would give me ideas. Because you hear different ways people do things, like what symptoms they have."

Theme 2: Individuals providing information. Doctor, nurses, and nutritionists were all mentioned as trusted sources for diabetes information. An overwhelming majority of participants liked receiving information face-to-face from a doctor, nurse, or nutritionist and all were viewed as having equal abilities to provide information. Jose said, "Yes, I like the nurse. You know, sometimes you trust them more."

Although men and women liked receiving verbal and printed information, they expressed a strong preference for information to be delivered in both formats. Anna said, in answer to how she wanted information delivered, "I think . . . by pamphlets. I also like for a person to explain it to me." Sylvia explained why she wanted both verbal and printed information:

I understand something better when it is written than for example on television. Many times, one does not really pay attention to what the doctor is saying. . . . and because you are thinking about other things during the consultation, such as, "Are you going to you check my blood or what? All they do is give me a sheet of instructions on how to keep my blood sugar lower, about the cholesterol and all that. Because whatever they tell you, you forget. But if you have the information on paper, you can go over it again.

She specifically described not receiving printed materials was viewed as a deficit. Sylvia

further explained:

At the clinic, they did not tell me anything or give me any information about anything. I asked them what I have to eat so that I don't feel bad, they never told me anything. They never gave me anything.

Providing printed information without a verbal explanation was also viewed negatively.

Melida said, "No . . . no she did not tell me anything. She gave me some paper, but she did not tell me anything."

Enrique shared the strategy he used for his physician appointment to make sure he

received all the information he could:

My girlfriend went with me. They told both of us, but at home she told me so I could understand better. . . .because when they talk to you, you are thinking about something else they told you. With someone, you feel calmer, and you hear it better.

Negative interactions even led some participants to discontinue their relationships

with health-care providers. Carmen was clearly upset by what she perceived as a lack of warmth and connection with her doctor, "They are cold. I mean when they say it [gave her the diagnosis], it is very cold. I even changed doctors because of how cold [unfriendly] she was." Angela did not connect well with the nutritionist she was initially seeing, "Yes, they referred me to a nutritionist but I have gone twice . . . but I don't like how the nutritionist treats me." Nadia shared:

When I found out I had diabetes, the doctor sent me to the nutritionist and I went. But, I did not like it because as soon as I arrived, she would ask me, "What did you eat last night?" So I would tell her. . . . she would only write it down. But she would not tell me anything! The only thing she would tell me is "exercise and lose weight". But how am I going to do it if you do not give me more information? So, I stopped going [*laughs*]. . . . After four years I started going to see her again. She was more . . . more knowledge[able] about diabetes because she had taken courses about diabetes and she was more able to help. That's when I said, "Ok, now I like it."

Most of the participants were comfortable communicating with their doctors, but barriers

were also mentioned. Angela shared that:

I got a note saying that my tests had come out very good. That's all. That's the only explanation she gave me. If I call to talk to her, I leave a message and she never returns the call . . . When I go [to the office] she's always in a hurry, she's always running.

Theme 3: Written materials in Spanish. The majority of educational sessions and

materials about diabetes were provided in Spanish to Spanish speakers. But that was not

always the case, and when it was not, it was a detriment to the participant's knowledge

acquisition. As Felipa described,

I had to go but I got really sleepy when I was there because everything was in English and many people were there . . . with diabetes and everyone understood everything they were saying, but I did not understand anything. That is when I got sleepy because I did not understand absolutely anything and I told my husband, "No, I am not going to go anymore"; I would rather stay sleeping I said because I get sleepy anyway being there.

Printed information was judged as useful because the participants liked to reference

it. Jose said, "I study it, I read it, it is very important." Alejandro held onto materials for a

long time: "I have a lot of things there from 7 or 8 years ago when . . . I like to keep things

like information. . . . I can say, 'Here is the information I was given.'"

Theme 4: Technology. A few participants used the Internet, independently or with

assistance, in their home to access diabetes information. Often, they used it to clarify

information they had received from their health-care provider. Some participants described

the process they went through:

Okay, they [the doctor's office] tell me not to eat carbohydrates." Oh, I don't know what carbohydrates are."... but there are certain things that one, I mean a lot of people in fact, what I knew was because of the internet, that beans are bad for diabetics!... How am I supposed to remember? No. It is hard. (Claudia)

I ask my daughter to look for some information in the computer. She looks for things, and then she tells me . . . because over there [clinic], they don't tell you anything. (Sylvia)

Information from the Internet was not accepted at face value but critically evaluated.

Angelica explained, "Sometimes the Internet is a good idea but there are contradictions . . .

[the] Internet confuses information sometimes so it is better to consult your doctor or have a

nutritionist.

Alejandro used the Internet as a means of social support and learning about others

who also lived with diabetes:

In the Internet, now you can find anything. Diabetes has a high mortality rate and unfortunately, now that I am here, I see a lot of Hispanics with it. . . . Ever since I was diagnosed, I have been using the computer to go online, because you get a lot -- you get stories, people who tell their story, people who are older. . . and now they are 70 years old. They are there . . . their lifestyle is very different . . . but they lived."

In addition, Alejandro regularly used Skype[®] to communicate with a nephew who was a physician in Mexico who was receiving training in diabetes. He said, "He gave me information about insulin and about many treatments that are coming out."

Televisions were used for exercising inside, playing exercise DVDs and for watching health-related programs. Beatriz explained how she used her television to improve her habits: "At home, since my daughter is a little overweight, I decided to buy [*unintelligible*] to exercise at home. This way it helps me and it helps her too." The use of media was also reflected in responses to the HPLP II Health Responsibility subscale item asking if participants watched TV programs about improving health, 23% (n = 7) reported they

routinely or often watched programs about improving health, and 67% (n = 20) reported they sometimes watched programs about improving health.

Question 2B: Applying information. Learning about self-management was only the first step. Participants were queried about how they applied the diabetes information they received. The themes that emerged were *nutrition, exercise, medication,* and *listening to their bodies*. Overall, making the recommended lifestyle changes was difficult, but a majority of the participants made an effort. Angela explained, "I tried more or less to take care of myself and other things but . . . I tried to avoid certain things." Other participants were selective in the recommendations they chose to follow. Ricardo shared, "I take a little from what they tell me [*laughing*] . . . because they prohibit so many things." Martin ignored his diagnosis at first and did not use any information that he had been given. In his words, "I didn't care . . . Back then I still wasn't aware of what it really [was] . . . not even having . . . symptoms . . . would I take my medication as I had to."

Theme 1: Nutrition. Many participants altered their eating habits, focusing on portion control or method of food preparation. Ricardo explained that he shifted to "just take one portion. . . Before I would eat five or six, seven, eight." Rafael shared that, "I don't eat fried things that much anymore." Food information sheets helped Lila know what she should eat: "If we don't know something, we look and look at the sheet to see what we are doing wrong or something. . . Sometimes I forget what I shouldn't eat."

The diligence required to follow the dietary guidelines often became more difficult to maintain as time passed. Sophia clearly described how difficult it was, "In the beginning it is easier, but later on it is hard because it has been too long. It is hard to have a strict diet." Alejandro admitted to difficulty sticking to a diet even though he knew what to avoid: "The

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thing is that I know what things I should not eat." Family members sometimes impeded women's efforts to change diet habits or cooking methods. Isabel shared how it was an uphill battle with her husband and son and how she advocated for change, "Sometimes I cook with another kind of oil but my husband and sons do not like it. I tell them we are changing things little by little, and they are going to get used to it."

Theme 2: Exercise. Exercise was not a favorite activity among the female participants, and it was a difficult habit to maintain if weight loss benefits were not evident. Alicia described, "I feel that I am fat because it does not go down. I have been walking over 3 years and exercising and I feel I am not losing weight." If their physician prescribed walking, the participants were more encouraged to pursue it. Lila related, "The doctor tells me to walk for at least 10 or 15 minutes . . . and I do . . . When I have shopping I walk."

Theme 3: Medication. Participants shared a commonly held belief among Hispanic populations that insulin makes diabetes worse and causes complications. Marguerite used insulin to manage her T2DM. At the end of the data collection session, she recounted that her mother-in-law had advised her, "No, no, don't take insulin," because her mother-in-law knew someone who starting using insulin and died 4 months later. Marguerite said she knew lots of people who think insulin is bad. Her mother-in-law—who has diabetes—took 30 pills a day, and she preferred taking those 30 pills a day to using insulin.

Despite this belief and warnings from others, an overwhelming majority of participants followed their doctors' instructions regarding insulin administration if they needed to take it:

I don't know because I used to take medication, but because the pill for my sugar was bad [i.e., ineffective] for me they started prescribing me injections and all that. (Alicia)

They told me, "You have to inject yourself insulin because you can't, because we are not able to control your sugar anymore with pills." (Melida)

Theme 4: Listening to their bodies. Over time, the participants became more attuned

to their physical cues and applied the information they had learned to their self-management

practices. Isabel described how she knew when to check her blood sugar level and acted upon

that information:

Sometimes when, I mean when I feel something, what one feels when it [blood sugar] goes up or down, when I feel dizzy or weak. That is when I check whether it went up or down because sometimes I don't even know it if went up or down . . . Sometimes, when I feel dizzy or tired and I check it, and it is because it either went up or down. That is when I look for that.

Question 3A: Current knowledge and beliefs. The first part of this question

explored participants' current knowledge and beliefs about diabetes. The themes that

emerged were overall health status and beliefs about the causes of diabetes, nutrition,

exercise, and taking care of themselves.

Theme 1: Overall health. Feeling different and not like other people was common

among the participants. Many wished they could return to feeling like their health was

normal. Anna described this feeling as "I think sometimes I do not have anything like this,

like I wish I did not have the sugar. I would like to be normal like before . . . but I am not

anymore."

Most participants tried to avoid stressful situations because they knew stress was

detrimental to glycemic control. Alejandro left a position because:

That job was stressing me too much and I feel that it contributed to my problem with diabetes a lot too because I had problems with the person in charge, with the manager. And now that I left I have felt really well.

Theme 2: Causes of diabetes. Most participants acknowledged that diabetes had a hereditary connection. Alta surmised, "You have it and you cannot get rid of it. It is a chronic

illness. One has it from birth, I don't know." How hereditary factors contributed to

developing diabetes was misunderstood however, Angela guessed, "I think it is hereditary

because when my mom was pregnant with me my dad was a diabetic already."

When asked, 36% of the participants (n = 11) attributed the cause of their diabetes to a very

intense emotional incident. This belief was often maintained despite the presence of other

risk factors. Carlos described what happened right before his diagnosis:

I was very fat, chubby . . . I came here [to the US] and one of my kids made me very mad, very mad, and that's when my sugar went up immediately. I went to the clinic and that's where they told me, "You have diabetes."

Although Jose was hesitant to say strong emotions caused his diabetes, he had no other

explanation for his sudden diagnosis after the news of his wife's pregnancy. He described

being told

"Your wife is pregnant." And then I felt like crying sadness and happiness at the same time. And from then on, I started feeling bad. And then I — I— the next day I get to work and she [a co-worker] tells me, "Jose what is wrong with you?" No, I feel bad. I feel really tired. And a nurse says to me, "I am going to check your sugar level." It was 350.... I mean, I don't know what happened; maybe I got diabetes because I was happy.... From that day on I started feeling sleepy, and I started urinating too much.... And it has not gone away since."

The belief that strong emotion causes diabetes often endured even when participants knew

the biomedical model of genetics and lifestyle risk factors. They simply viewed high

emotions as another cause of the disease:

Well, stress, anger, overconsumption of sugar, and if you come from a family of diabetics because it is hereditary, no? (Jorge)

I knew that you get it [diabetes] because one gets scared or because one gets mad. . . because one has a lot of weight, or a lot of sugar, is common. (Maria)

Pilar's statement exemplified how these views were reconciled: "I mean, there are many ways to get diabetes." Other participants were less certain about the causes of diabetes. Anna's showed her hesitance to give a solid answer:

Stress, gave it to me I believe, or maybe because my mom has the sugar too. I think that it may be hereditary, or I do not know. There are problems because then diabetes goes through the blood that is hereditary.

Theme 3: Nutrition. An overwhelming majority of participants knew the basic recommendations related to diet and nutrition, specifically decreasing sugar intake and not eating fatty or fried foods. Claudia explained her understanding: "Vegetables are healthier than fruits because fruits have a lot of sugar." They were also aware of the importance of limiting carbohydrate intake and that tortillas were carbohydrates. Alta described that sometimes she would have "just one, once in a while, but nearly none, because tortillas are bad for you."

Theme 4: Exercise. Despite knowing the need to exercise for diabetes self-

management, some participants expressed limitations about the amount and type of exercise they could perform. Enrique expressed vulnerability and fear related to exercise because of his diabetes:

With diabetes and football, if I break a finger or leg and if I bleed or something I don't know if I can control it or not. If I get hurt and another man who does not have diabetes [gets hurt], he will get better faster but I will have more problems. That's why I don't play. If I did not have diabetes, I would play. You sweat a lot too. My brother does not have diabetes and he sweats . . . but he does not feel bad. If I feel like that, maybe I will pass out, that's why I don't play sports. If I did not have diabetes, I would play more. Maybe I am a little afraid that something will happen.

Theme 5: Taking care of themselves. The phrase taking care was a common pattern

in participants' answers. To take care meant following your physicians recommendations,

taking medication, exercising and eating right. The participants described their methods of

taking care of themselves in various ways:

There are some people that, yes, they do [take] care. These young women I know, they have been pricked so many times, even on their fingertips, and from the insulin they inject, but they are very young. We talk a lot; they are like if they were my little sisters. We have a good friendship, good conversations. There are people who come to terms with it, and others who do not believe in diabetes, I feel that they are the majority . . . I knew that if you don't take care of yourself, you can die, the sensibility in your feet, cuts do not heal well. (Jorge)

I had never finished my medication before, I would say. . . but now I have to make an effort I said. And I mean now I take my medication. (Alicia)

These statements were in contrast with ones that described how other people or the

participants failed to take care of themselves in the past:

As a younger man, I used to drink too much. . . .I did not exercise. . . . and my diet was, well, full of carbohydrates, sugars I was weighing 72 kilos in Mexico, which is like 160 pounds." (Jorge)

But she [his mother] has insulin, she is getting insulin. She uses insulin. Aha, but my mom does not take care of herself, she, when one does not see her she eats sweet things." (Carlos)

Alicia gave the example of her sister as someone who did not take care of herself: "Well, she said she had it too [diabetes] but that she was not treating it. I asked her why she does not treat it, and she said that she did not like to take medications." Martin had no regret about his lack of self-management in the past. He explained, "I didn't think it was important . . . But what I have done, I have already done."

Question 3B: Additional knowledge needed. The themes that emerged related to

additional knowledge that participants needed to better manage their diabetes were

information about nutrition, blood pressure and blood glucose monitoring, and medication.

Theme 1: Information about nutrition. Many participants wanted a clearer

understanding of the portions of foods they should be eating and how to decipher a food

label. They also needed this information to be reinforced because it was difficult to remember:

Well, how to eat. What should I eat? What quantity should I eat? . . . Yes, I would like for someone to tell me what I can eat, what I cannot eat, what size of portion I should eat. Yes all that. (Claudia)

Angela recounted her nutrition class experience in relation to the difficulty of keeping track

of nutrition requirements:

Because if they tell you "No, don't eat this." or you have to pay attention and sometimes . . . one is dumb to read the labels, at least I don't know, I get confused when reading the labels. So I got tired and I didn't keep going.

The participants also expressed a desire for help developing strategies to deal with the emotional aspects of eating. As Alejandro put it, "Well more than anything what I need to learn is how to control my impulses with food. That's what I need . . . now it is hard for me to have that strong will."

Theme 2: Blood pressure and blood glucose monitoring. The most frequent

questions participants asked at the end of the data collection session were related to insulin use and dosing and the normal ranges for blood pressure and blood glucose. The overwhelming complexity of self-management was evident in this passage from Claudia's discussion of how her most common concern was fluctuating blood glucose levels. She hoped,

if someone could explain to me better what to do to make my diabetes better. I don't want to be all the time with it high or low, I want to be normal. Whether you eat or not, your sugar will go up or down. I don't know how one can get better. It affects everything, kidneys, liver, everything. . . . Yes, how to control it better, what do I have to do? Because I do not want to have it high all the time or whatever happens to me when it goes up. Ay, with everything that happens I don't even know how.

Many participants did not understand what caused their daily blood glucose levels to increase; others lacked an understanding of what the blood glucose results indicated.

Sometimes my diabetes goes up and down. One day I am fine, another one my level is high. (Roberto)

I don't know why my sugar is always high. (Sophia)

Like there are some things that are more . . . like the numbers. . . I cannot put all the numbers together. I only eat [something] and then I see [the level change], sometimes. I see it so I do not eat it anymore. (Enrique)

Theme 3: Insulin. Participants expressed a need to understand more about the role of

insulin and blood glucose control. Pilar wanted more information on "how to control it

[diabetes] in case the medication [insulin] does not work or something. What I should do.

What would help me." In addition, the connection between weight and insulin use was poorly

understood. Marguerite shared her frustration in trying to balance medication and trying to

lose weight:

They want me to lose weight, but mmm, I feel that when I take insulin, it prevents me from losing weight. I don't know what it is. As soon as I started taking insulin, I started gaining weight. Is it maybe because it controls my diabetes? Maybe it is . . . because before it was not controlled at all . . . I don't know . . . one question I have is can I lower the amount of insulin I take?

Question 4: Information givers. This question explored who participants would ask

if they had a question about diabetes. The only theme that emerged was credible

professionals.

Theme 1: Credible professionals. An overwhelming majority of the participants would ask a doctor, nurse, or nutritionist if they had a question about diabetes. If Carlos had a question, he would "call the doctor and ask her to look at this and that." Melida answered, "Just her [the doctor]. My family doesn't know anything about diabetes." Participants tended not to ask family members or friends questions about diabetes because they did not have the knowledge to answer. Exceptions were family members who were medical professionals,

successfully managing their own diabetes, or caring for someone with diabetes .Pilar trusted her mother because she also lived with diabetes, "My mamá, because she has it [diabetes]. My mamá or at the clinic, for sure, if I feel or have something I can ask them."

Barriers to seeking advice included the perceived lack of time physicians had for answering questions, poor communication skills on the part of the provider, feeling rushed and uncomfortable asking questions. The participants expressed this discomfort in a few different ways:

I want to know about my illness but in-depth . . . They just talk really quick and "Let's go!" (Elena)

Doctors use complicated words. I wish they would use simple language .(Juan)

It could be a neighbor or talk about that, about diabetes. Eh? For the doctor? I believe . . . sometimes I think I am very stupid to say, to ask. (Lila)

Question 5: Help with diabetes. Participants were asked to answer the question,

"Tell me about anyone who helps you with your diabetes?" The themes that emerged included *doctors for disease management* and *culturally defined boundaries*. This exploration also revealed a culturally grounded conceptualization of *help*. It was described in ways that were typically perceived as positive: encouraging physical activity as a family experience, making healthy family meals, et cetera. However, financial assistance was often not readily identified as help. Alta's request for clarification suggests she thought there was a difference between help through financial aid or other types of aid. She asked, "That helps me, or that buys me things?" Although, Claudia received occasional financial assistance from her sons, she did not initially recognize it as help:

No, no, they don't. . . . Yes, when I do not have money to buy the medicine, I tell Tomas, "Look I do not have money to buy medicine." He buys it for me *[unintelligible]*, he brings me money for the medicine. (Claudia)

Although uncommon, financial assistance was considered by some of the participants to be

help.

He gives me money for my medicine. . . [he helps me with] medicine and also food, but since he doesn't have diabetes, he buys whatever he wants *[laughs]*. . . he brings home food . . . because he knows how to drive. . . . it is very rare when I go with him [to the food store] now, he is helping me because he has a garden, and he is picking up lots of cucumber, tomatoes, chilies, it helps in controlling[my diet]. (Anna)

Theme 1: Doctors for disease management. Physicians were often mentioned as

people who would help participants with diabetes self-management. Family members (i.e.

child, wife, husband) were identified second. Participants shared how their physician and

family members helped them:

[My doctor] because he has . . . one assumes . . . the documentation, uh, at this fingertips, how to cure the problem of diabetes, or any other illness. . . . [then] my daughter. . . . Reminding me especially about the medicines . . . What I shouldn't eat . . . My daughter helps me a lot. (Juan)

No, I just go to the doctor at the clinic. . . . keeping it [diabetes] under control telling me this is the way it is. "Look, take care of yourself, and all that. And she reminds me so I don't forget. Things like taking my medication and all that. (Carlos)

I am the only one who goes to the doctor. I go by myself and consult with him and that's it, the doctor, he is the one. (Martin)

Theme 2: Culturally defined boundaries. Family members were identified second to

doctors as whom the participants turned to for help. The description of family members'

behaviors, considered by participants to be positive and supportive, are in contrast to how

these behaviors might be perceived from an Anglo-American point-of-view. Alejandro

speculated on how his wife would help him if she were in the US with him:

I need someone to push me.... She is going to decide what it is that I have to eat. Because she is going to say, "Eat this you are not well. You are not going to eat this because you should not eat it." That way I would do what she told me to and eat what is good for me and her or whatever is food for the both of us so we can have good health I don't, I don't do things because I am alone. Jorge also talked about his wife's helpful behaviors:

Oh, she knows I can only eat 4 tortillas, so I ask her, "Warm me seven or eight", and she says, "Oh yes? You can only eat 4 [and] it is 6pm."... She helps me a lot with my diabetes.

For Sylvia, her teenaged daughters were important sources of help:

"Yes," she tells me, "Mama, you don't need to be eating this," and when we go to the store, she looks for diet food. She tells me not to eat this because it is going to hurt me . . . She looks for something that does not hurt me. My daughters love me so much . . . [They say] "You should not drink coffee, you can't drink soda, you can't drink juice, you cannot eat pizza."

These behaviors would likely be perceived as negative, or nagging, by many Anglo-

Americans (Rosland, Heisler, Choi, Silveira, & Piette, 2010). For many of the participants,

they translated into love and being cared for. As Alicia put it,

Yes, because my husband tells me, "Don't eat that, it is going to make you sick." That was before, not lately. I tell him, "You don't love me anymore." And he says, "Why?" "Because I feel you don't take care of me anymore.". . . Before, he was like, "Take your medication, and don't eat that— it is bad for you". . . [She responds,] "Now you want me to die right?" [*laughing*] But I just tease him."

Information Seeking and Knowledge Acquisition Summary

The data suggested that many participants' educational achievement and experience with health care limited their individual capacity to comprehend and retain complex health information. These challenges were often mediated with family members' and others' assistance as well as receiving information in multiple formats. The printed materials reinforced verbal information and teaching, were used as reference material, and were often shared with other persons with T2DM. Physicians, nutritionists, and nurses were all mentioned as credible information sources and, for most participants, these professionals were participants' primary sources for information about diabetes. However, seeking information from these health professionals required having a satisfactory relationship. A status that was established by participants feeling respected – communicated by providers spending time with them – and showing a genuine interest in them and their problems.

A majority of individuals did not rely on family members or friends for information – unless those persons were perceived as knowledgeable, by either successfully managing their own diabetes or providing care for a family member with T2DM. Many participants served as community resources, providing information to family and friends about T2DM and often encouraging them to engage in healthier lifestyle habits, such as eating less fat, and being more physically active.

Family Influences and Vicarious Learning

Question 6A: Community knowledge of type 2 diabetes. This topic explored participants' knowledge of family members or friends who had T2DM and what their experiences were with the condition as well as how their communities reacted to the participants' diagnoses. The themes that emerged were *social situations with family members, diabetes and death,* and *helping others.*

Theme 1: Family members. Social situations presented challenges for adhering to dietary guidelines, particularly for women. This difficulty was also indicated in the Eating Self-Efficacy subscales; women had lower perceived abilities to resist eating in socially acceptable situations (M = 52.84) and in response to negative emotions (M = 56.16) than men (M = 70.82; M = 71.64, respectively; Table 4.5).

Participants who tried to follow the nutritional guidelines talked about changing how and when they socialized with family members to minimize the consequences of foodcentered situations. When asked if it was difficult to avoid the foods she knew were bad for her in social situations, Martha responded, "No, because I go to visit them when they're

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having a party, but I don't go to people's houses during the week Yes, I taste it [provided food]." The custom of scrutinizing guests' eating habits and applying social pressure to eat was described as commonplace in these situations. In the situation below, making healthy choices or being on a diet did not appear to be viewed as a positive behavior. Maria thoroughly explained these situations:

They give it to me and say, "Why don't you want to eat? Are you on a diet?" And I say, "No." I try it, and I leave the rest. I'll rarely finish it. Only if I haven't eaten well and I'm hungry, then I'll eat it, but if I'm not I'll think first . . . Like I said, we had two parties, one at my sister's and one at my cousin's, and I went and I ate a little at my cousin's and I didn't even finish everything on my plate because I would have been embarrassed to go to the other [party] and not eat. And I was able to do it; I didn't eat at the other one. I ate a little bit of gelatin so that they wouldn't say that I didn't eat.

The social pressure to eat was pervasive and not limited to women. Carlos described

how social gatherings had hindered his self-management efforts and the extreme to which he

went to avoid these situations:

To have control over oneself.... because that's why I don't go to parties anymore. Because sometimes at parties there is cake, and this, and that, and then you go there and sometimes people tell you, "Come and eat and grab this." And if one doesn't eat they start talking about one. So it is better not to move. One has to avoid all of that.

Theme 2: Diabetes and death. The seriousness and consequences of not managing

T2DM was well known in the community. Jorge said, "It is a deadly disease. If they do not

take care of themselves, it is deadly." Elena agreed, "I don't talk about it [diabetes] . . . It is,

that's like . . . thinking about dying." Felipa summarized many participants' feelings and

drew attention to the expectations often placed on healthy family members:

To me . . . I feel diabetes is a death sentence so to speak. I tell my husband that if something happens to me I want him to be all right. Now he has to take good care of himself so he doesn't get diabetes. I am very afraid of him getting diabetes.

Emotional support from family members often encouraged participants to stop

thinking about diabetes as a death sentence but rather as something with which they could

cope. Beatriz's brother offered a plan for her to learn about the disease and he provided a role

model for successfully living with it:

I told my brother, "I put you in charge of my daughter if something ever happens to me" since they already had given me the news. So I told him, "I put you in charge of my daughter." It is sad at the moment when you say something like that but at the same time you have to care for your family. He asked me, "What do you have?" And I told him, "This is what I got". So he said, "Let's see; let's research what we can do. My mother-in-law has it, and she has been living with the disease for 30 years and she is still alive."

Although Jorge compared having diabetes to cancer, his attitude was hopeful:

You can live more years, yes. I was thinking, well, I am 50 now. I can live 30 more years with my illness I will not live 200 years, no, the body gets tired . . . It is . . . it is, well yes, it is deadly, yes, but if you take care of yourself, no . . . Cancer is deadly. So is diabetes especially if one does not take care of oneself. I mean I cannot get rid of it . . . Diabetes has a high mortality rate, and unfortunately, now that I am here [in the US], I see a lot of Hispanics with it."

Theme 3: Helping others. A majority of the participants were viewed as lay experts

in their community, serving as resources for diabetes information. Their role was one of

teaching and advising for the collective good. They shared their knowledge, offered tips

about what worked for them, were brutally honest in their prevention messages (e.g. "You

are fat."), and provided motivation about weight loss, cooking, healthy eating, and exercise.

Participants described their role, and motivation for helping, in the following ways:

Oh yes, sometimes people come and ask me how it feels when one gets diabetes I tell them, "No, you feel dizzy, uh tired, and you have a dry mouth uh that's it. One feels badly. And you feel like using the bathroom. . . They ask me, "And how can one manage their diabetes? I tell them that the doctor told me, she explained to me in a piece a paper that one should not eat a lot of fat, uh, eat more vegetables, and less carbohydrates,I pass on information to them. (Lilia)

Yes, it was [*unintelligible*] classes, and that's why I can tell other people, "Don't eat this, eat this instead." . . . I tell them . . . Don't eat so much fried food."(Rafael)

Because it helps other people. I mean, I can explain it to other people who have the same problem I do. There are people who don't know anything about diabetes. It is nice to give information to people. (Carlos)

This assistance included providing supplies and information to family members in Mexico. Claudia described, "Everything I do over here [in the US], they do over there [in Mexico]. I send them medicine. When I know that something is good, I send it to them for them to have

it."

Advice about medication use was tempered with caution, but at the same time, the

participants used the opportunity to teach others about the differences between medications.

They also encouraged people to ask their doctors questions. Isabel related on experience she

had:

I met a man who has diabetes and he was asking me what medication I use. So I tell him, well, I tell him, "But you cannot use the same medication I am using. You really need to be asking your doctor if it is good for you. Because it may be appropriate for me, but not necessarily for you. He told me he was taking a medicine and the whole time he was sick to his stomach. "That's exactly what I am talking about", I told him. Ask your doctor to change your medication, because he knows your body, he can prescribe you one. Because maybe, the medication that fits me, may not fit you. It may not do anything, or it may do something bad, or make you sick.

The responses of family members' to the participants' advice often revealed the level

of misinformation that exists in the community about receiving medical treatment for

diabetes. Alicia described the typical reaction of her family members to her advice:

I tell them they should get it treated. I tell them [*unintelligible*] because it is bad and they say that . . . they say that the doctors over there [her country of origin] tell them that if they start taking medication for diabetes uh, then it is easier for their organs to degenerate. I don't know whether that is true or a lie because what I think is that if they don't take the medication that can happen to them.

Providing support for others offered benefits for both parties. Jorge explained this

relationship:

My brother-in-law has diabetesHe and I, we experiment. The other day, I asked him, "How did you feel?" "Well, like this or that." "And you, what did you do?" "Well, I tried this." "I did not drink this." He walks, he runs, and he does not drink sodas, and his level is very high.

The difference between culturally defined boundaries of Anglo Americans and Hispanics emerged again as participants described how they helped others. Their roles as community and family resources reflected the dynamics of *familismo* and collectivism. Familismo is a cultural construct that views the needs of the family as more important than those of the individual (Caballero, 2006). Collectivism is the connectedness an individual has with the larger community beyond that of the family, this connectedness often carries with it a strong sense of obligation (Bandura, 1986; Giger & Davidhizer, 2008). Both *familismo* and collectivism contributed to the participants' frustration when their advice went unheeded:

There are a lot of people who do not take care of themselves . . . It makes no sense. You don't love yourself, you don't value yourself. That makes me mad because if I talk to him, I always get the "I don't care about what you are telling me." These are people who do not value their life or their family, I don't know. To me, what is it about diabetes? It is that there are some people [who] don't . . . like nothing is important. (Jorge)

I have a sister who is extremely obese, she is fat and I think she has sugar [diabetes] and she says no, that I am crazy. And I say, "What do you have to lose? Go for a checkup." And I have another sister who is fat too, but she says she might have it. . . . But who knows? I say. "What do you have to lose? Just make an appointment and go for a checkup." I say. "That is what I used to think, 'I don't have that, I don't.' And now I have it," I say, because she is very fat, she is 200 and some pounds. (Pilar)

Because we would tell her [Nadia's mother-in-law], "The soda, it is very bad. Don't drink soda" or "Don't eat so much bread" "Don't eat all these things because you have diabetes." One would tell her and the only thing she would answer, "Anyway I will die. At least, I will die with a full belly." They would tell her, her children, "No, try to take care of yourself." But no, she did not try to take care of herself. No, she would not. She was contrary One would tell her, but she would not do it. (Nadia)

Question 6B: Family members with diabetes. This question examined participants'

memories of relatives who had diabetes. The themes that emerged were family members,

stigma and secrecy, care in the country of origin, and immigration-living apart.

Theme 1: Family members. Participants' answers on which family members they

remembered having diabetes covered a full range of relatives:

As far as I know, nobody . . . nobody was a diabetic.(Martin)

In my family, there are three siblings who have it, and my dad, and my paternal grandparents, and all my dad's siblings.(Angela)

My mamá has diabetes. And a brother too. My mamá got diabetes too, when I came here. She is in Mexico. My brother is also in Mexico. My brother does not know well how it started but with my mother it started suddenly my mother-in-law also has diabetes, but she is stubborn [*laughs*] and has severe diabetes. (Anna)

My mamá did not, my papá[n]either, and my brothers, the majority, have already died. Only the one . . . was diagnosed with diabetes, but just the one that lives in Los Angeles. . . . One of my sisters-in-law died from diabetes . . . My sister . . . has diabetes . . . type 2 . . . She suffers a lot She has had diabetes for 2 years, and my brother for a long time. My brother was in Guatemala, but he died . . . We really do not understand how he died . . . But yes, he was sick from diabetes. My other brother has had diabetes for 8 years now. Yes, there are one, two . . . four, we have four who have diabetes in the family. (Claudia)

Yes, my mamá, my grandpa, my grandma, too, and one of my uncles who died from it, too.... Now my mamá, she is suffering from it. They have just diagnosed her....I think my grandmother probably died from it. She said she had a tumor, but I [would] know if it was a tumor. (Alta)

My mamá and my sister, too. She [her mother] is doing badly. She is sick. I work a little, so I help her so she can buy her medicine over there [El Salvador]. Each month, I send her money so that she can buy medicine and food and clothes. . . . She has suffered a lot. . . . Last year in April, my brother died, and in April of this year, my sister died [*cries*]. She had diabetes, too. . . . My nephew took her to the hospital. She fell in[to] a coma, and she only lasted 3 days. Then she died because she got like a shock or a stroke. Her sugar went up to 300, and she was not able to stand it. So now, I do not eat anything sweet, because I don't want this to happen to me. My brother, also, he was told he had diabetes, but he was young. He was told he had it, but he did not give it any importance. (Sylvia)

He [an uncle diagnosed with diabetes] would tell us, "Take care of yourself. Do not eat too many sweets, too much sugar." We were young; how can you live without sweets? Coffee without sugar? What is a tortilla without chilies? [*laughs*]. (Jorge)

My papá was diabetic, and he in fact died as a consequence of this. . . Ay, very bad memories. My parents, both of them. . . Mostly my papa because I saw him, I saw him after being a man like me, tall and . . . very strong. . . . To be honest, it made me really sad seeing him like that in that depression. (Eduardo)

However, there were several issues that prevented participants from knowing if family members had diabetes. First, knowing if a relative has a condition requires a diagnosis. Many of their relatives who may have had diabetes did not seek medical care due to lack of desire or resources, and thus did not have a diagnosis of diabetes. Second, the stigma and resulting secrecy that surrounded the condition meant that some relatives never disclosed their illness to anyone other than their spouse, which will be discussed in the next section. Third, living in the U.S. and the resulting changes in communication with relatives contributed to participants not knowing about family members' health statuses.

Theme 2: Stigma and secrecy. Some participants had not told their parents or other family members of their diabetes diagnoses. Although her father had diabetes, Beatriz said she didn't want to burden him with bad news. She shared,

No, I have not told him. I have not told him. . . .I did not want him to feel bad. Since he is older I do not want to . . . give him such bad news, that's why I have not told him.

However, Jorge hypothesized about why a diagnosis of diabetes is not shared as he talked about his brother:

His wife told my mom that he has diabetes. She told her he was embarrassed about it . . . Well, my brother is embarrassed. . . People, out of shame, use any excuse. He said my mom would get eczema if he told her. But, the one who felt bad was her [because she heard this news from her daughter-in-law instead of her son].

Elena discussed similar reasons for keeping the diagnosis to herself, and why she didn't

know if anyone else in her family had diabetes:

Well, not as far as I know, because maybe a lot of people keep it quiet right? Because, I don't know, maybe they are like me? I don't tell my family, so they don't [react], "Ay, she has diabetes!" Do you know what I mean? Because it is, well to me, it is very sad; it is a shock.

She also shared how the subject of diabetes was broached with her friends. It brought up

reflections on whether it was perhaps her feelings that prevented her from discussing

diabetes. She explained,

My family doesn't have it. Friends, my girlfriends . . . we don't talk much about that maybe because it hurts us. We don't talk about diabetes. Just, we just say, "We have to take care of ourselves," and that's it. But I think we don't talk about it because it hurts to talk about it. Well, at least I hurt. And it hurts me to ask another person. Maybe that's wrong, but . . . I have only told Nina, but I don't talk about diabetes with other people because they make fun:"Ay, you have diabetes! Ay, you are going to die." Am I right? That's what we [Hispanics] think. And that's why one stays quiet and we don't tell. One goes to the clinic, and I hope they don't say, "Hey, you have diabetes, come here," and have them [other people] find out.

Theme 3: Care in the country of origin. As part of the discourse about family

members' experiences with diabetes, participants frequently referred to the health care that

was available to them in their countries of origin. Poverty was a barrier to accessing health

care services in those countries and it deterred participants from seeking medical care.

Several participants shared anecdotes about life with diabetes outside of the US:

My—no, they [her parents] don't have that, but my sister died of sugar, too, but she never went to the doctor because nobody knew. (Melida)

He [papá] passed away by himself. He did not want to be diagnosed. He was a very active person. He was always working. He did not want to stop. For him, it was going to be impossible to be like that. He did not want to be diagnosed, and he ended up the way he ended up. But he died working because his life was working. (Jose)

In Mexico, it is very difficult. It is very difficult because the doctor doesn't explain very much. . . . They [family members] don't really like to be talking to doctors. (Isabel)

When before my dad passed away, I remember he had like a small pimple in the upper back leg. He said it was just a small pimple, so he never went to the doctor because he said it would go away, but when finally he went, they told him it was gangrene . . . infected . . . so they sent him to the hospital in Aguascalientes, because he was seeing a family doctor, but there is nothing they could do because the gangrene had advanced quite a lot in his body. Even if they amputated his leg, he would not recover from the surgery because the gangrene had spread so much. (Marguerite)

He [her brother-in-law] usually walks a lot and runs. He exercises daily. But he has diabetes, anyway—that doesn't go away. . . . it doesn't right? And because medications and all that are more expensive, very expensive, yes. It is harder because there are very poor people who . . . have diabetes, too, but they are very poor, very poor. Sometimes, they don't have anything to buy medication or anything else. So he—my sister tells me that he works a lot outside, and she says that he gets very sick sometimes. (Felipa)

However, medical care was available for some of the participants' relatives. Similar to the

U.S. system, insurance status can improve access to the appropriate medications and health-

care services. A few participants talked about that circumstance as well:

And another one [a sister] who lives in El Salvador. They have their doctors because my brother over there has money. I have a brother who has, who has businesses. (Carlos)

And then you go to the clinic or to the hospital or to a private doctor, they just steal your money, "Yes, you have this," but they don't examine you well. They just steal your money sometimes. (Elena)

She [his wife] is better now, but I don't know what she used to get better because . . . she has insurance. She goes to the clinic, and they give her . . . a lot of medication over there. It looks like a pharmacy, she says, because they give her lots of them. (Alejandro)

Theme 4: Immigration. Immigrating to the U.S. dramatically changed the

participants' lifestyles. Distance from family members negatively influenced their

communication, limited the amount and accuracy of information they exchanged about health

statuses, and limited the emotional support they could provide one another. Immigration

status was often a permanent barrier to having physical contact with loved ones. They could

not go back and forth across the border. If they went back to their home country they would not be allowed back into the US. Many times they made a hard choice between their family or their children's future. Many of their children were born in the US. The effect of this separation was described in the following ways:

Over there, you have less stress because there aren't so many problems as you do here. You have family who helps you. (Angelica)

No, no, I have not seen her [her mother] in 9 years. (Anna)

Then my uncle has just died, and I have been here... so I did not know about his illness. My grandparents, I do not know how they died. I know that my uncle was sick from diabetes, and that's why he died. (Alta)

Oh, I just found out that one of my brothers. . . . I am the only one here. All my brothers are in Mexico. One of my brothers, who is older than me, has diabetes. . . . I found out when my mamá told me about 15 days ago he also has diabetes, but I don't believe he does takes care of himself. . . . Too bad we are too far away from each other, because if he had told me, we could have talked to each other. I have not been able to talk to him about it. I would have told him do this and that. (Jorge)

Question 7A: How family members managed. The themes that emerged when

participants were asked about how family members managed their diabetes were managed

well and did not manage well.

Theme 1: Managed well. Many participants had memories of good self-management

practices among their relatives who had diabetes. They included diet, medication, and exercise practices. The diet changes mentioned were decreasing sugar intake, not drinking sugared sodas, increasing vegetable consumption, and increasing water intake. Changing food preparation habits was another component of self-management mentioned, specifically using less lard and oil. Medication management involved taking medications as prescribed. The exercise most often mentioned was walking. Anna and Pilar shared their family members' practices:

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My mamá takes pills and . . . she exercises a lot. Every day, she goes out to run. My brother also takes pills. It is well controlled. He thinks because he works, he does not have to exercise, but the doctor tells him he needs to exercise. . . . "You need to run and move." (Anna)

I look at her [her mother] having trouble. She does it in her arm [injects insulin], on her leg, on her tummy, anywhere, because she has been like that for many years. Yes, a lot, she is hurt. . . . she is on a diet. She drinks a lot of water. She does not drink sodas. She does not eat a lot of fat. And she exercises . . . a lot She walks a lot. (Pilar)

Theme 2: Did not manage well. The consequences of poor glycemic control

discussed by participants were organ disintegration, microvascular complications (e.g.,

amputations, renal failure), and macrovascular complications (e.g., heart attack, stroke).

Relatives' complications could not be attributed entirely to poor self-management, because

economics played a significant role in access to food, health-care services, and medications

in the countries of origin for many participants' family members. However, poor

management modeled by family members clearly guided some of the participants' self-

management practices:

Sometimes I lay down, and I forgot to take my medicine, so I remember when my dad got sick. I remember that when we got my dad out of bed, he could not even move. Because he was not taking his medicine. So then, I get out of bed to go take my medicine. (Isabel)

My mother-in-law died from diabetes, so, well, then you try to do what you are told, and well, if you are able to achieve it, then you do it. . . . The memory from my mother-in-law is that her body would swell up a lot. . . . And what she was told was not to drink soda. Because when she was drinking soda, she would swell up more. People would tell her, "Don't drink that. It is going to hurt you; drink something else.""No! Anyways, I am going to die," she would say. "At least, I will die drinking it." That's not a solution. What you try to do when you have diabetes. . . I mean you are told not to do something, and then you do the contrary. . . . You must try not to do it. (Nadia)

Other reports of poor self-management by family members and friends included not seeking

regular medical care, using home remedies, using alcohol, and not taking medications:

I have lots of friends who have diabetes, too. Some treat themselves, and others say, "I don't know." That's a different way of thinking than me, I don't know. I have a friend who is very sick, and he does not want to take the pill he is being given because he does not like them or for other reasons or not liking an injection. (Roberto)

Well, my sister, the one who died, she used to complain a lot, that she was really thirsty and that her vision was very blurry sometimes and she really wanted to go to the bathroom. . . . I would tell her, and . . . my mom would tell her—"Daughter," she would say, "I am going to take you to the doctor to see, to get your blood checked out to see if it is the same illness your uncle has." And she started arguing; you could not even tell her that. She would grab her purse and went to her place. She never let them cure her, or take her to the doctor. She never let them do it. (Melida)

My other brother, he does not take care of himself. He drinks and smokes. He is almost dying, and then he doesn't see it. The other one . . . he drinks, he watches what he eats and what he does. (Carlos)

Well, she said she had it [diabetes], too, but that she was not treating it. I asked her why she does not treat it, and she said that she did not like to take medications. (Alicia)

There was also a propensity for managing diabetes through recurrent hospitalizations.

This pattern occurred when the participants' friends or family members with diabetes

engaged in minimal to no self-management behaviors; thus, the only time their condition was

managed was when they were hospitalized. There was obvious frustration on the part of

participants due to this practice because of the poor self-management habits it represented, as

can be seen in the following excerpts:

No, they [her nieces and brother] still don't. These are people who are always in the hospital. Their diet is really bad. Yes, they eat a lot of fat and a lot of candy.... There are some people who are always in the hospital. (Angelica)

It [blood glucose level] gets really high, and she [her sister] has to go to the hospital, but she is not careful. And when she gets there, she is told her sugar is really high and they don't let her go until they see she is taking insulin. She just gets it while she is in the hospital. When she leaves, she stops using it; that's why she gets sick again. I told her to take metformin because that's the one the doctor gave her, but she said her stomach didn't tolerate it. So she isn't doing anything. When she goes to the hospital, it takes a while for her to get discharged, but she still doesn't pay attention. (Angela) I speak with my sister, and I explain to her. She tells me, "I forget to take my medicine," so I tell her, "That's the problem! When you eat a big plate of a kind of food you know you are not supposed to eat and you do not take your medicine, then you need to have an insulin shot. Your levels go down, but the following day, it is the same thing. Or tell the doctor that he prescribes you insulin if you cannot take pills." She always is at the hospital. It is very expensive in Mexico. . . . Each time I talk to her, she has been admitted at the hospital. I tell my mom, "I do not understand why, I have *never* [emphasis hers] been admitted to the hospital because of my diabetes." (Isabel)

She [her sister] is, she is controlling it . . . but she goes to the hospital often. . . . Because it goes up, it goes down sometimes. (Pilar)

Question 7B: Status of family members' health. Family members' health statuses

were unknown in some cases because many of them did not receive regular medical care in

the absence of symptoms, and even with the presence of symptoms, they may not have

sought medical advice. Alta said, speaking of her siblings, "Well, who knows? I don't know

since they have not been checked out. I cannot tell you whether they are okay or not." In

other cases, there were obvious health issues for family members:

She [her sister] tells me she feels really badly. She throws up, she has nausea, she is dizzy. She has lost weight. Her diabetes is quite bad. (Sylvia).

He [her father] does not say much, either. I know he gets sick sometimes in Mexico. . . . He is very, very skinny now . . . and something happened one day, and he was hospitalized very ill because he got something like diabetic shock or something like that? (Felipa)

In the end, he [her father] had to have dialysis. He lost his vision, and more than anything, that last thing was when they did the . . . dialysis. . . . He lasted over a year but . . . he would get sick very often. (Angela)

Question 8A. Diabetes practices learned from family members. Two themes

emerged when the participants were asked what they learned from family members about

caring for diabetes: positive and negative.

Theme 1: Positive. Some of the positive lessons participants' took from their family

members with diabetes included using complementary medicines in conjunction with

medical treatment and emphasizing foot care. Complementary therapies recommended by

family members included using massages, coffee, tea, grasses, green tomatoes, nopales (i.e.,

cactus), chamomile water, hibiscus flower, and cucumbers. Several participants described

their family members' recommendations of what to drink:

My sister got sick often because of the sugar. . . Once, she fell and hurt her hand, her foot, and she had a massage. You know that in Mexico, you do that. . . . Sometimes, they say eating . . . nopales helps. They say it is good for diabetes. (Elena)

Ah, well they tell me about [a] nopale[s] shake, or the chamomile water—no, from a flower. (Sophia)

Well, I have always seen what they have done and what they took and I did that, too. They would say to me, "Look honey, take this," because you know that over there, you cure yourself with grass in teas. And maybe you have heard about yerbamora [*sic*]? It is an herb that is sold, and an herb that is bitter so I would make shakes with that herb, and I drank those shakes, green tomato, green tomato shakes, and all that. I would see them do it, and I did it too. Yes, that, too, because, sometimes because you know that cucumber. . . . My uncle made cucumber shakes and drank it too. No, I did that, and they got rid of the pills. I was controlling it with shakes for 4 months. After that, my sugar went up again, and they gave me the medication again. (Melida)

Participants also learned about foot care from family members or from observation of others

with diabetes. However, foot care was not mentioned frequently and always mentioned in the

context of protecting the feet to prevent amputation.

From this uncle, I learned a little about sensitivity in feet. He would show us. He lived for a long time I think, no? From 20 to 72, it is quite a lot. (Jorge)

Well, [I learned] to take care of myself. Protect the feet. Be careful when cutting one's toe nails. . . .The wife of one of my uncles just lost her leg. One of her toes got smashed, and she never wanted to go see the doctor. . . . Because one has to take care of the feet, dry them, put cream on them. (Carlos)

Memories and observation of family members encouraged diligence in self-

management, as several participants recalled when asked what they learned from their family

members:

Well, that I have to take care of myself. . . . In Mexico, there is a saying . . . "A diabetic person who takes good care of himself lives longer than a health[y] person who doesn't have diabetes." (Eduardo)

To eat healthy food. I mean I see their mistakes, and I try not to. . . . I learned from their mistakes. . . . We have to see other people and how they act and learn the good things and avoid things that are bad. . . . I am not saying that I am smart, but I know what is good for me. (Angelica)

That you have to take care of yourself, that not because things are good today, because things will be the same tomorrow. Diabetes is like a bit at a time. . . . For me, that's what I learned—that you cannot leave it unattended. (Marguerite)

My mother, my neighbors . . . more than anything, from her I learned that I have to take my medicine and keep control. I have my young children and have to keep going, to fight. From her, I learned to take the medicines to have—control diabetes. To not follow the example of my friends or neighbors who do not want to take their medicine. (Roberto)

Theme 2: Negative. The negative lessons learned from family members with diabetes

were ones that encouraged the use of complementary or natural therapies to the exclusion of

medical treatment. Another was the belief that pharmaceutical company drugs were harmful.

Carlos shared, "Because the-the medication, uh, helps, but it makes one ill, too. There are

medications that are really bad. It damages the kidneys, the liver." Maria expressed her belief

that too much medication was harmful,

One or two tablets a day, because I felt that my blood [laboratory results] came out the same if I took one or I took four. I said, "Why am I going to take so many if so many pills are going to harm me?" (Maria)

Natural remedies or plant-based treatments were considered safe and were generally

preferred to prescription medications by family members. However, despite this belief most,

of the participants were hesitant to accept family members' advice about diabetes

medications. They trusted their health care provider instead and explained why:

They may give you some advice about health, but my family members... I don't trust them too much.... [*laughs*] I mean, they are not doctors! [*laughs*] I think it is like... we say a lot of things like, "I have this and that problem," then [they say]

"Buy this and that."... Sometimes, whatever works for you does not necessarily work for me. We don't have the same organisms. What someone else takes can kill you. (Isabel)

She [her sister] takes care of herself with things that are natural. She takes care of herself with tea. She drinks tea in the morning, and that lowers her sugar...but[*laughs*] I don't think tea will lower your sugar. I mean, if your pancreas is not producing enough insulin, how is a tea going to work for you? [*laughs*] I mean, that's what I believe, but I do not know. (Marguerite)

But she is not careful. I think I watch it even more. I, at least, take my medications even though they may be bad for you, but I take it anyway. (Angela)

Family Influences and Vicarious Learning Summary

Family members provided both poor and good examples for T2DM self-management; both of which informed participants' self-management in positive ways. Participants learned from family members' who were good examples of self-management, as well as those who suffered the consequences of poor self-management. Many participants said medical care in their country of origin was expensive and their relatives did not have the money to buy medication or to access health care services. Some shared stories of family members who routinely managed their T2DM with hospitalization. Family members' beliefs about medications or self-management were not viewed as credible when those beliefs conflicted with those of participants' health care provider.

Self-Management Practices

Question 9: Daily self-management. The interview questions related to the daily self-management habits of participants were general in nature. For example, "Tell me about managing your diabetes. What do you do each day because you have diabetes?" This topic area specifically addressed individual self-management practices. Quantitative findings, when appropriate, are integrated into the narrative. The themes that emerged from these

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queries included *eating*, *alcohol*, *exercising*, *glucose monitoring*, *weight*, *medication*, *complementary therapies*, *symptoms*, and *foot care*.

Theme 1: Eating. There were several measures participants took to eat better and control their diabetes. Eliminating added sugar from the diet was the most often reported strategy for improving nutrition. Drinking carbonated drinks was a habit many women reported they had stopped. Anna said she drank "lots of Coca-Cola. When I was going to work, I would take one very cold, and when I was thirsty, this is what I would drink. Now when I see one, I do not know how I feel [*laughs*]." An overwhelming majority of women reported that if they drank an occasional carbonated beverage, it was sugar-free or diet, but they had primarily switched to drinking water. Male participants talked about how sugared carbonated drinks were bad, but they did not talk about carbonated drink consumption as frequently as the women did. Enrique, one of the male participants, reported stopping drinking horchata, a rice milk beverage with spices and a lot of sugar,

Before, I would drink horchata. We would go out to eat, and that's what I would drink. Now I don't drink that anymore. For food, there is nothing really that I want to eat. It is more drinking water, not the horchata. . . . Before, I used to yes. Things changed, everything changed.

The participants limited fruit consumption because of the sugar content, ate more salads and whole grains, limited portion sizes, and avoided eating at night. Reducing the amounts of fried foods and fast foods they ate was also mentioned. Alta described her dietary changes: "I go for walks, I drink water, and I eat vegetables. Salad, well not much. . . . Apples, grapes, peaches when in season."

The participants also talked about the physical consequences of eating certain foods, and they usually paid attention to the effects of it. Some adjusted their diet accordingly and were avoiding those foods, but others did not. The participants shared their successes and

setbacks with making nutrition changes:

No, I do not drink soda, nor do I drink diet soda because, although it is diet soda, it makes my sugar go up. And rice and banana, potato—I have to eat very little because then I feel it when my sugar goes up. Also, if I eat beef, even barbecue, I feel bad. I feel that I don't digest it well, although it is barbecue and little fat, I don't feel that I digest it well. (Anna)

I feel chills in my body. I take a little bit of cold water for my chills. Then my kids give me lots of water. I have lots of water at home. Water is what we drink. Water is the best for you, not soda. I only drink water. . . .But once in a while, I drink a Coca-Cola[®] because I am used to drinking it, but it hurts me so it is better to avoid it. When I eat things like . . . sweet things, I get a headache that lasts me for 12 hours, and I cannot get rid of the pain. It hurts for 12 hours, it hurts a lot."(Sylvia)

Eating patterns also changed as the participants learned how specific foods affected their

blood glucose levels. Carlos explained a switch to more snacks of smaller portions:

[I] eat a little bit often to—to avoid feeling full at once and instead eat little by little to avoid the sugar levels from going up. . . . And before, I used to get full and that is why my sugar went up, but today I don't. I already learned because one has to learn first. (Carlos)

Sometimes, the change to a healthier diet benefited the entire family. That was what

happened for Enrique's household:

Once in a while, I eat meat but more or less, I eat the sandwiches with grilled meat and things like that. Whatever I have to eat, she makes it. My mom . . . she, more or less, has changed, too, because she . . . cannot cook for me, then for [his son], then for her. She cooks for everyone. Yes, the same food for everyone, yes. . . . Before, she was putting salt on everything and the oil was different, but now we are all like this. She has to make the food that way. The food is better that way.

However, participants weren't always able to change their diet habits. The foods

identified by the most participants as difficult to avoid were corn tortillas and bread. Many

participants addressed the problem by reducing portions rather than by eliminating them from

their diets entirely. Fruits and potatoes were also frequently mentioned as challenges to

avoid. Other challenges were late night eating, overeating, and eating the wrong foods.

Claudia's account exemplified the dichotomy of knowing what to do versus doing what you know:

[I eat] more fruits than vegetables . . . yes . . . but I eat broccoli, carrots, potatoes, but the potatoes are bad. Potatoes, beans, and rice are bad for diabetes. And potatoes are very good! [*laughing*]. . . . Well, like I said, eat vegetables. Yes, you can eat a little bit of meat or a piece of fish, but the meat, too much meat is bad and a lot of chicken is bad, too. I love beef and chicken. But I eat just little pieces of chicken; I am not too addicted to it. To eat lots of meat. . . . When I make pork leg, I make tacos for my sons. Last night, I had lots of leftover[s], so I ground it, and I put some cheese, and I made tacos. Tortilla is also bad because it contains lots of flour. I like tortillas. I eat three, but it depends on the meal. The night before last, with the leftover pork leg, I lost count a little. I ate, and then I remembered, so I could not eat anymore. (Claudia)

For some participants not being able to plan ahead contributed to difficulties with food.

Planning ahead is a multi-step process that requires organizational skills, a budget or money,

and transportation (Cherrington, Ayala, Scarinci, & Corbie-Smith, 2011; Kieffer et al., 2004).

For participants without these assets the privilege of choice is limited. Many of the

participants expressed being unable to plan meals ahead of time, or simply not doing so:

Many times, it is difficult to plan it. When I plan it, they will eat meat, vegetables, but when I do not plan, I end up preparing whatever. These are possibly foods that will hurt me and them. More than anything, to plan for a good meal, it is difficult for me. (Isabel)

For instance, when I don't have anything else, I make potatoes or eggs or things like that but broiled or just a little egg. (Alicia)

But I try to drink water. I try not to eat a lot of tortillas—two tortillas, because I like tortillas. . . .but I try not to eat much . . . fat, I mean like pork and all that. I try a little. Sometimes I have to eat something, and I eat it. That's it. (Felipa)

Theme 2: Alcohol. The majority of the men used alcohol (n = 7; 63%) and they

discussed it as a habit they were trying to stop. The female participants did not identify

alcohol as a problem. Jorge listed it among the changes he was making: "I also try not to

drink so much, I am not that young anymore." Despite efforts to avoid it, alcohol

consumption was part of the male participants' social interactions with other men, but they

still tried to reduce their personal use. Jorge explained,

Now I have a friend, a good friend, we connect a lot. We used to drink a lot together when I first got here. Not anymore—he knows. Sometimes a Friday or Saturday, he says, "Let's get a beer." [I say,] "I'll come with you." I don't say, "No." I go with him. "I will drink water, but I will come with you." Sometimes he gets a liter of beer. I don't even finish my glass of beer.

The men also spoke honestly about the amount of alcohol they consumed. In recounting his

uncle's drinking habits, Jorge reflected on his own,

He did not stop drinking, so he would drink and the day after he would inject his insulin. . . I guess I did the same thing the other day. I drank about five or six beers. I went home. They drove me home. It was around 6 or 7 in the afternoon.

The other male participants could also admit that they still drank, at least in part. They

shared,

I have to be careful. . . . For example, like not drinking [alcohol]. . . . I drink less now, . . .Just a little bit, not much.(Ricardo)

Beer . . . I used to drink it. Now I don't. I still drink—I don't say I don't. I drink one beer, right now. Yesterday, I had two. Right now, not even one. . . . And sometime[s], I drink one or two beers but drink a lot . . . no. No, because it is bad for me. (Alejandro)

Although, the male participants were cutting down on their drinking, they gave

accounts of other men with diabetes who drank:

This guy I know, he drinks a lot. He drinks all the tequila that gets put in front of him, and he is skinny. I don't know if he injects insulin. What's the point of injecting yourself, what's the point of drinking? You are like a drug addict. You drink, and to get rid of it, you drug yourself. (Jorge)

I don't want to do what they do, because there are a lot of people who have diabetes and they are drinking beer. (Rafael).

Theme 3: Exercise. The descriptions participants provided of their physical activities were typically below the minimum recommended amount of 150 minutes per week (ADA, 2012). Strength training, also recommended by the ADA, was never mentioned.

Difficulties with exercise were also reflected in the scores on the Exercise Self-Efficacy Scale. It had a lower mean score (M = 49.2) than the Eating (M = 61) or Diabetes (M = 75.7) Self-Efficacy Scales, meaning that participants had the least amount of confidence about exercise. The participants' mean score on the physical activity subscale of the HPLP II was also the lowest among the five other subscales at 2.3 (Table 4.4). On average, this score indicates that participants, performed exercise behaviors 'sometimes'. A prevalent attitude toward exercise was that physical labor sufficed for meeting the recommended requirements. A few of the women explained,

[I] clean my house, that's it. And often, because me . . . the little one is always throwing movies, books, and throws everything. (Pilar)

No, I mostly exercise at work, because there is exercise [at work].Working, I go up and down stairs, vacuum, I mop, then I go home, and I do more. I feel that I exercise a lot. Because I get home around 4 or 5pm, and I take care of my kids and my home. I walk all day, up and down. I barely sit down. All day, I am constantly moving. (Nadia)

Two men, Jose and Roberto, and two women, Alta and Anna, said they ran for exercise and exercised on a daily basis. Jose said he ran every day, but when he didn't "I walk between an hour and a half and 2 hours." Roberto shared, "I walk, I run. Or sometimes in the evening, with my colleagues from work, I go play a little soccer." Bicycling was used for exercise and transportation. Beatriz said, "[Every day, I] . . . walk . . . and if not, I ride my bicycle. Every day for about 30 minutes. . . . It is like transportation from home to work."

Walking was by far the most popular physical activity. Some participants walked to the store, or they walked in combination with public transportation. Claudia shared, "I walk from the bus stop to the [employer's] house. . . .I walk about 45 minutes round trip."

However, the frequency and duration of participants' exercise varied greatly. Some

participants walked daily, but others walked two to three times a week. The duration ranged

from 10 minutes to about 1 hour for most of participants. Pilar said, "My ankle hurts . . . but I

do walk. . . . It could be three times a week . . . about 1 hour. . . . Sometimes, I go to the store

walking slowly, you know? But we go to the store." Sylvia used indoor mall facilities for

walking because she felt safer inside. She would go for:

Like 2 hours, sometimes more. But here, last year we used to go to the park . . . but we stopped going because one day, we saw two huge snakes and so we stopped going like we used to. Two huge snakes like this, very big! We left. Oh my God! It scared us. . . . I tell my daughter, "Better take me to the mall to walk," because it is cool over there and I can walk 2hours and feel nothing. But I walk outside, then I feel out of breath.

Having an exercise partner (e.g., another adult, a dog, a child) and family support

often facilitated the participants' physical activities:

The man I live with goes to run every day, so I go with him. (Alta)

I am always, I always am doing something like exercising and things.... I have a dog, too, so I walk him, and he makes me walk. I walk, if not I mow the lawn or something. I move a lot. I don't stay seated much all day. (Enrique)

Yes . . . in the afternoon when I am done cleaning and it is around 7 . . . I go walk for 1 hour . . . with my husband.(Alicia)

My daughter helps me a little when I tell them to help me to do this so I can go take a walk. She's the one who helps me a little more, because that day that I told her I had to come, she helped me. I was overwhelmed. She helped me to give the children breakfast while I bathed. And in the afternoon, sometimes when I tell her I want to go take a walk, she takes care of them. (Maria)

But my son, yes, he tells me, "Let's walk and run outside." He wants to in the afternoon. Many times, it is me. I just have them in the house. . . . They are always ready to walk. (Isabel)

Maria described how her goals for weight loss and exercise were initially not met, but

with perseverance, she began to see results:

I began to exercise almost every day, and I was starting to give up because *lpound a week* [emphasis hers]! And I said to my daughter, "1pound a week isn't fair with everything I do!" [*laughs*] And my daughter said to me, "Mommy, you look the same to me."And it took like a month to take effect since it was more because of the exercise. I was already convinced it wasn't going to do anything. . . . And now she tells me, "Mom, now I see the results in you." [*unintelligible*][*laughs*] But yes, that was what was bumming me out, that made me not want to go, because I don't lose weight quickly.

Maria also noted the stress reduction and mental health benefits of exercising outdoors, as

did other participants:

I feel better when I exercise than when I don't. When I don't do it, I get really angry. Sometimes, I nag them. It's not their fault if I don't take the time. (Maria)

I sometimes get my bike, and I go for a walk. That's when I feel bad, and then I feel well. (Rafael)

Exercise, per se, is very good for diabetes because . . . it's like . . . you relax a lot. When you walk, you relax exercising, and you think less about your problems. When you walk, you relax, and you stop thinking for a while. You do not forget about problems, but . . . yes. (Nadia)

Some participants accepted that exercise was not optional; it was part of what they needed to

do for their health. Maria explained, "Sometimes you tell yourself you can't, but you have to

find the time to exercise." Carlos discussed the benefits to his health from walking:

I go for walks, too . . . not more than 1 hour. . . . It is good for the circulation, too. . . . If one is always sitting down, one ends up in a wheelchair. One has to exercise. . . . we have to follow the doctor's instructions.

Weather, and its influence on exercise behavior, was evident in participants'

responses during the study period. During June, July, and August, when daytime

temperatures averaged 90 °F, 94 °F, and 91 °F, respectively, 20 of the interviews were

conducted. Enrique expressed how the heat affected how long he exercised: "When it's hot

about 30 minutes, because it is very hot." But in the winter months, cold and the darkness also negatively affected the outdoor exercise participants performed. Nadia explained,

Now that it is still light out, I walk very often, but when it gets dark earlier, sometimes I get home and it's really dark so I can only walk for a little bit. Right now, about two, three times a week, yes, yes, I go around my subdivision.

Depression also negatively affected motivation to exercise, even in the presence of

family support. Maria, who felt depressed at the time, said she would be "lying down

watching television, and my husband said, "Let's go for a walk." I said, "No, no, I don't want

to walk. I don't feel like walking."

Participants gave lots of reasons for why they did not exercise. Several participants

described exercise as just not something they did as part of their normal routine, but there

were barriers that also deterred them:

I don't do activities or exercise, because I don't have time. . . . [*laughs*] Excuses, but sometimes because I don't have time and because I am lazy. . . . I walk a lot at work and I say no more. . . . But I am trying to reestablish my routine again. (Angela)

I don't feel like doing it every day. (Rafael)

To begin with, there are no sidewalks here. . . . Whenever I walk, cars run over me. And this is a town where it is cold for 6 months.(Angelica)

I exercise a little. I walk a little but not much because sometimes work absorbs me. (Eduardo)

Not daily, not daily, but I do it more or less. . . . I am not going to lie to you; I do not do it daily. No, no. But yes, I do, I walk as much as I can . . . I walk for about 10 minutes. And when I go buy something, I walk too. . . . Then my neighbor says, "I can give you a ride." I say, "No, no, I want to walk." (Lila)

Some women participants said belonging to a fitness club would help them exercise

but that financial constraints and babysitting prohibited them from joining. Men and women

participants talked about how much they walked as a part of daily activity in their country of

origin and how there activity patterns changed when they immigrated to the US.

Theme 4: Glucose monitoring. The participants expressed several issues related to home blood glucose monitoring and their diabetes self-management practices including hypoglycemic and hyperglycemic episodes and practices related to glucose monitoring. Many individuals with diabetes, including some participants in this study, do not check their blood glucose levels whether or not they use insulin, which is a concerning but not unique practice (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000; Skelly et al., 2005). The participants shared their resistance to monitoring blood glucose levels:

I believe it got low because, I don't know, because I don't test myself. . . . [I use insulin] in the morning and in the afternoon. But sometimes, I do not know, it gets really low. I don't even check it anymore. Sometimes I check it, other times I do not because sometimes I do not want to know about the sugar. Sometimes I feel desperate. I do not want to stick myself. I do not want to know about my sugar. (Anna)

Well, I have not checked it, it may be bad or good, I don't know. I always inject the medicine [insulin], for example I inject it." (Alta).

Other participants were regimented about checking their blood glucose levels and used the

results to guide other self-management activities:

I take it every day. This morning it was 91.... Once a day, I measure the sugar—in the morning, while fasting. So during the day, the only thing I do is control the food and that's it. And then in the morning, I see how I wake up and okay.... If I see if [it] went up ... I lower it [the food intake] a bit. (Martin)

When sometimes it goes to 400, 500, that's when I get the insulin. And then when it is at 280 or 200, 100 and some, I just take my pills, nothing more. (Melida)

It is like I want to fall if it gets down to 70. I have to be around 100. . . . And if I go over 250, I feel bad again. (Rafael)

Yes, I have a glucometer. . . . [How often I check] it usually is 3 times a week. Now last week, I was checking it every day . . . but I was seeing that it was almost the same, . . . I am going to stop. (Eduardo)

Hypoglycemia was commonly mentioned; many participants had learned the signs

and symptoms of it, and they had instructed family members as well. Some female

participants made a point to carry candy or sugar tablets with them in case of a hypoglycemic episode. Isabel shared why she took up the practice:

When your blood sugar level gets too low.... The first time my blood lowered, it came down to 80. I felt so bad! I felt very dizzy. I was very thirsty, very hungry, sweating, and I did not know where I was! I told my husband, "I feel bad, I feel bad." ... He asked me, "What's wrong? What's wrong?" and I said, "'I don't know.... So he said, "Here, have some soda." So I drank soda... And so the doctor told me it was good to have something in your bag, always have something sweet in your bag. Because if you ... let your blood sugar go much lower, you can end up in the hospital. Thank god, I have never been in the hospital because of my sugar. My husband now knows. (Isabel)

Theme 5: Weight. There were a few subthemes associated with weight and self-

management practices for participants. They included weight loss in Mexico, weight gain in

the US, awareness of being overweight, and that exercise helped manage weight. Weight

gain since immigrating to the US was attributed to using an automobile instead of walking.

Participants who were overweight were aware they were overweight; 24 (80%) of the

participants had a WtHR greater than 0.51%. The benefits of weighing less for diabetes

management were well known, but the previously mentioned difficulties with food,

depression, and stress made weight loss challenging. A few of the women talked about the

way it felt to be overweight instead of in shape:

And when I returned [from a trip to Mexico], I gained almost all of it back. I didn't even want to weigh myself, because I felt like my clothing was cutting into me. I was very depressed, and I went to see the doctor. I couldn't even explain how I felt but crying, I told her. So she said, "Either you take care of yourself or I'm going to make you an appointment with the psychologist because with your diabetes you can't have that much depression." On my own, I began to take control. (Maria)

One feels better [thinner] than when you are overweight, because when you are overweight, everything bothers you and you feel bad.... One feels better when you are slimmer.... When you simply exercise, you walk a little, and then you get tired quickly because you are overweight. (Nadia)

Theme 6: Medication. When discussing medication, the participants brought up financial constraints in buying medication, self-adjusting dosages based on how they were feeling, a belief that taking too much medication was bad, and not understanding that they would need to take medications for life.

Despite some family members' opinions about the dangers of insulin, most

participants who used it did not express any problems. Alta shared, "Yes, I inject myself,

that's the way things are." But medication costs, the cost of office visits, and having no

insurance were financial hardships for many of the participants. In addition to her financial

constraints, Anna lived in rural Orange County and did not drive. She said, "I tell my friends

who live close to the clinic . . . just order it [insulin]. But yes, it is a problem."

Self-adjusting oral medications was a common practice among many participants.

They described various reasons for changing their dosages:

[I manage] only by taking my medicine like the doctor tells me. One pill in the morning and two pills before I go to bed, so three pills in total. Sometimes it bothers me, and I do not take them. In 2 weeks, I do not take them, and I start feeling pretty badly, so I start taking them again. (Sylvia)

She [a health-care provider] gave me some pills to take but never . . . never explained it to me [*laughs*]. That was a problem between me and her. Because she told me I was going to start taking pills and . . . and . . . it seemed like too many to me. She gave me . . . four a day of 500 mg, but it was too many for me. So I told myself, on days I eat less, I'll take three and on days I eat more, I'll take four. And that's what I did. (Maria)

When I get there, they check my blood. I am okay . . . everything is fine. Sometimes, there are 3 days when I don't take my pill . . . And sometimes, I go to the clinic and I tell them, "I haven't taken my pill for 3 days because I'm out," and they say, "It's not important. "It is fine," they say."Here is the pill," and that's what the doctor tells me. [I say,] "I haven't taken the pill because I don't have it, and I haven't come because I know I am coming to the clinic, and that's when I get a refill.""No, it's fine," and that's it, that's all she tells me. She doesn't tell me anything. (Elena)

The idea that participants may have been taking too many pills is informed by the belief that prescription medications were harmful. But insulin therapy was also considered an optional therapy by some of them. Melida stated that she had tried to stop using it, but her provider told her,

Well, that I had to have it. I told her, I didn't want to use insulin anymore, and she says, "Yes, you have to use it . . . because the sugar is not getting under control with the pill, so you have to use insulin."

Theme 7: Complementary therapies. Herbal therapies were preferred to prescription

medications by the participants. There were often comments made about a diabetes cure, a notion reinforced by a belief that certain herbs and teas in Mexico make the diabetes go away. As discussed previously, complementary therapies recommended were consuming nopales, chayote squash, cinnamon, aloe vera for foot pain, Herbalife[®] for weight loss, and vitamins. They also considered consultation with a naturist. Claudia described her experience using herbal therapies:

But one day, when I was looking at medicine as usual and I saw some pills made of . . . How do you say it? . . . made of . . . cinnamon pills, then I read what it was for, and it said it was to control sugar and for bad circulation. I have been taking them for 4 days. I take one early and one at night. . . . The other day, I found a pill for weak bones. . . . I bought it, and "Yes!" it worked for me. I was looking at this other medicine. I looked at it, and it said it was for bad circulation. This is what I have in my feet, bad circulation. Then I told myself, in the name of God, I will take them. I lose nothing by taking them, and yes, I have felt better.

Because they hoped for a diabetes cure, it was disappointing when natural remedies failed, and participants returned to using pharmaceuticals. Melida felt that her diabetes was controlled with natural treatments in Mexico, and she lamented, "Here, I just have my pills and insulin."

Theme 8: Symptoms. The symptoms participants discussed were hypoglycemia,

peripheral neuropathy, hyperglycemia, and visual problems. Anna described how she felt

during a hypoglycemic episode: "I feel very cold. That time, I had just injected insulin, and I felt sweat and then very cold. I was like shaking, then they gave me something sweet and it was under control and I felt good." Claudia shared her peripheral neuropathy symptoms, "Just pain in my legs . . . that's all." Martin's problems were visual, and he said, "My vision, double vision. I can see with this one. . . . With this one, I can see better. . . . This has been caused by my sugar."

Theme 9: Foot care. There was limited mention of foot care among the participants. Its absence suggests that a majority of participants were not aware of its importance, that it was not a priority for them or that it was not part of their routine. Anna mentioned it briefly regarding attending a nutrition class, "And that's where they talked about washing your feet and so many things." Rafael shared what he had learned, "Most important is that the feet are the most delicate part."

Question 10: Difficulty with self-management. The themes that emerged in respect to self-management difficulties were *eating*, *cultural context of food*, *exercise*, *weight*, *financial constraints*, *lack of transportation*, *predisposition toward diabetes*, *planning and organizing*, and *work environment*. Several of these themes have been addressed under other topics and will be briefly addressed in this section.

Theme 1: Eating. Participants' expressed difficulty with changing eating habits, and they also admitted to a degree of clandestine consumption of contraband items. Juan hid transgressions from his daughter: "I'll hide a soda so she doesn't see it—I'm not going to drink it there!" Participants also preferred to eat fruits over vegetables, with their high sugar content fruits are recommended to be consumed in limited amounts. Juan said, "Apples,

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oranges a little, I like them. Mmmm. . . . There are so many fruits!" Alicia confided, "Fruit is what I like the most [*laughing*]. Yes, I love fruits."

Wives were supportive of husbands' needs for a healthier diet, but the same was not always true when the situation was reversed. Family members were also not always supportive of the women's efforts to eat healthier. For some female participants, the solution was to prepare two meals: one for herself and another for the family. This practice resulted in a constant comparison of the diabetic diet with a normal diet, a comparison that inevitably left the participant wanting and feeling deprived. Anna and Marguerite shared examples of how family members refused to change their habits or expectations for meals:

I don't get along well with the diets [*laughs*]. I prepare food for everyone, and then it's time to prepare my own and I don't feel like it, or sometimes because . . . it bothers me that my diet has so many vegetables, so many vegetables, and it bothers me, and I see what they are eating. I tell you, when I prepare food, and my husband, because he does not have diabetes, he wants to eat fat, things that are bad for me. He eats it in front of me, and I wish I could. Sometimes I fail! [*laughs*]. (Anna)

Bread or tortillas. That is a meal for him. Because if I, if I give him a salad with chicken, roasted chicken, that is not a meal for him. He'll tell me, "That's not what I call a meal." So anyways, I have to cook. . . .Vegetables, they eat them but they do not eat many, not many. (Marguerite)

Theme 2: Cultural context of food. Reducing consumption of American-style foods

such a pizza or hamburgers were not identified as a major difficulty for most participants. They had more trouble giving up the typical high-fat, high-carbohydrate Mexican diet comprised of rice, beans, and tortillas. Indeed, most of the complaints about eating the recommended foods centered on their lack of *sabor*, or *rica*, taste or richness. Although some participants found the transition challenging, they also championed acclimating to new tastes and new ways of seasoning food. Carlos described becoming acclimated to a new diet:

Because one is used to, one is Latino, one eats foods that are more . . . one likes to eat heavy meals. . . . It is very hard for us to avoid them. . . . In the beginning, I found it

difficult because one is used to eating sweets. And then you don't eat that many sweets, and it is still very difficult for me to eat diet things because diet food does not have any flavor. But one gets used to it. I already got used to eating without salt because I started eating with lime.

The cultural association participants had with food made eating habits the most difficult to

change. For some it was their last connection to home and their cultural heritage.

You know that one comes with a pattern from Mexico that you don't get educated and we keep doing the same thing with the children and we want to start changing and it is very hard. And I have to do it because I don't want my children to be like me. (Angela)

I boil things and grilled things to avoid the illness (diabetes) right? I regularly eat meats with salsa . . . because I am Mexican. (Alejandro)

For some participants, avoiding Hispanic foods were not the only dietary problems. Pilar

described her enjoyment of both Chinese and American fast foods and how she did not want

to give them up:

I love Chinese. . . . I can't stop eating Chinese. At least once a week, but I eat so much. . . . But when I do, it [the blood glucose level] really goes up because of the fat. I get very dizzy . . . and I get nausea. . . . Temptation is strong. Sometimes, even twice a week, [it's] not Chinese but Burger King, McDonald's, but that has fat, too. . . . I love spicy food. . . . Ay, I feel really happy when I feel full.

Theme 3: Exercise. The female participants frequently made statements throughout

the interviews that suggested they anticipated weight loss to occur quickly through exercise. When it did not occur at the anticipated rate, they terminated their exercise behavior. The goal of exercising for the women was primarily to lose weight. When weight loss was not congruent with outcome expectations (i.e., did not occur at an acceptable rate), the women became discouraged and stopped exercising. Isabel explained her problems with exercise: "[It's] the thing I am not able to do. Because I tried—I walked and I ate less, but I never managed to lose any weight. So . . . [*trails off*]." Her statement succinctly describes how her outcome expectations (i.e., weight loss) not being met and the outcome—she stopped exercising.

The men more often described exercise as something they did to improve their diabetes self-management. Carlos said, "Exercise is good, because if one's sugar is high and one exercises, it goes down." The women seldom mentioned the affect exercise had on blood glucose levels.

Theme 4: Financial constraints. A lack of resources contributed to female

participants' trouble in managing their diabetes. Male participants did not express the same transportation or financial limitations as the women did. A few female participants lived in rural areas, combined with the inability to drive, this situation limited access to health care services. Anna shared "the lack of money to buy medicine. . . . there is no bus and I do not know how to drive."

Theme 5. Work environment. The work environment and hours influenced whether good self-management practices could be followed. Angelica explained how work interfered with diabetes self-management for her and many others:

I know people who work 2 shifts and are diabetic. These people, who are just like me, do not have time to drink water and see what they are going to eat. What do these people do? They drive by McDonald's because they work 16 hours. "Come here" [into McDonald's] I go there; I am hungry; that's what I grab. I have done the same thing knowing that it is bad for me. Sometimes I forget to eat because I have so much work. And other times, when I remember, I have McDonalds in front of me and I grab that because I haven't eaten in many hours.

Jose described the challenges in trying to manage his diabetes and working outdoors. He

feels uneasy injecting insulin since he works in construction and it is a very dirty

environment. Jose said:

At work, there is a lot dust, lots of construction so I cannot inject myself. I have to wait until I get home. It is a little complicated. In the morning if I have time, I can

inject myself or I take the medicine with me, but in the afternoon as I was telling you, I am very dirty, so I cannot inject myself. Yes, usually yes. I bring my water but now with this heat, one gallon of water is not enough to be 8 hours outside. I am working and with this heat outside, if I do not find water, I have to drink whatever I find. For example, soda makes my sugar go up quite a bit, it goes up pretty fast. I also feel the tiredness from work, all that, yes.

Some participants had shared their condition with work colleagues; however, given the stigma that surrounds this condition participants may have been reluctant to draw attention to the fact they had diabetes in the interest of keeping this information from coworkers.

Question 11: Successes in self-management. Participants were asked what diabetes

practices they were able to perform well. The themes that emerged about what participants

performed well in their management were eating, exercise, weight and other habits, and how

they planned to continue *balancing the disease*.

Theme 1: Eating. Eliminating soda from their diet and switching to water was

viewed as a major accomplishment for many of the participants. Others made significant

changes in their eating habits with the assistance of their family members. Jorge shared the

help his wife gave him in changing his habits:

She tells me, "Look, do this or try that." Then she put signs on the fridge to show me where the food is: "This can help you. Try this."So I try, but yes, I have eaten too many tortillas because it is so difficult to not eat them. I do not eat bread; I eat whole wheat, Mexican bread roll[s],—not sweets. If I want something sweet, I bought some Splenda[®]. At my job, there is some Splenda[®]. I sweeten everything with Splenda[®]. I don't drink regular milk. I drink 2% milk. I do not much put too much milk in my shakes. I make a shake of oats with water, and I put two or three strawberries or [an] apple in it. I do it because it fills me, and it helps me with cholesterol.

Sophia could not share any self-management practice she did well. She said, "I think that I just do well when I am hospitalized [*laughing*].Yes, they don't give me salt over there. I don't think there is something I do well."

Theme 2: Exercise. A number of participants remarked on how often they exercised

and how regularly:

On weekends, in the morning, my daughter and I, we go walk . . . for about 45 minutes. (Marguerite)

During the week, a minimum of three times a week. . . .I walk for 1 hour. I exercise for more or less an hour every day. . . .When they [his children] go back to school, my wife and I, we walk for an hour, and we go four or five times a week. (Roberto)

Several participants noted how much better they felt and how their mood improved when they did well with exercise:

Exercise is good. (Enrique)

If I am upset, angry, I go run, walk, and I come back calmed down. (Jorge)

[I]began to lose more weight, but also since then, I exercise almost every day. I rarely miss a day. Even on Sunday, whatever the day, I take a walk. I feel better when I exercise than when I don't. (Maria)

After I run, I feel like a new person. I think about the future. . . . I put a focus on what's ahead. I motivate myself. (Jose)

Theme 3: Weight and other habits. Despite the challenges and difficulties they face,

participants were making changes for better health. One accomplishment was weight loss for a lot of participants. Alicia lost 40 pounds and said, "Yes . . . I used to weigh 250 pounds." Examples of other habits participants changed are quitting smoking (Martin), getting regular checkups (Rafael), using salt-free cooking (Sophia), taking medications as prescribed (Ricardo), cutting down on the amount of alcohol drank (Alejandro), and moving the whole family to a healthier diet (Roberto).

Theme 4. Future balancing the disease. Participants made changes in anticipation of future benefits, such as reducing their risk of developing complications and improving their health and their families. Martin used to smoke and "now, no, nothing." Rafael makes sure he sees his health-care provider regularly and said "I go to, for check-ups every 3 months."

Sophia made dietary changes and said "I don't cook too salty either." Ricardo understands the importance of taking his medications "I take my medication like I am supposed to."

Alejandro has balanced his alcohol intake and said "now if I drink I have one or two beers. I

don't feel bad but it affects me. . . . I feel I am more careful with my health now." Roberto has

made changes for all of his family by making "the same foods for everyone and my sons eat

healthy."

Question 12: Self-efficacy and self-management. The participants were asked to

describe how much confidence they had in their abilities to manage their diabetes. Two

themes emerged: control and family support.

Theme 1: Control. A few men and women were pragmatic and resolute about being

able to control their condition. They described their convictions:

One has to take care of oneself. First of all, the diet. . . . I have friends who tell me, "No, I drink a beer, beer levels out my sugar." How is it going to level it out? Beer has alcohol, has sugar. And one says that fruit—because fruit, the sugar is natural but it is still sugar. The body, what the body does not want anymore is sugar. Even an apple has sugar. And that hurts them. Fruit is very good. . . . Even if I still want to eat more, but I don't eat anymore. Even if I still feel like eating, I don't. One has to trust in oneself, to have control over oneself. Because I used to like wine and beer, but when I found out I was ill, I said, "That's it." I did not drink beer; I did not have a drink again. (Carlos)

I feel I have the necessary knowledge, because in 4years, I have stayed the same with high and lows right? But that I can have control over it. I have never had to go to the hospital to receive treatment for diabetes. (Angelica)

Yes, I have confidence. Every goal you set for yourself, you reach it. I'm going to try to do this and that today, and I will do it. (Beatriz)

Many participants said their level of confidence was affected by the unpredictability

of their blood glucose levels, a circumstance that distracted and frustrated them. They sought

absolutes in a situation where there were none. Although Claudia felt confident self-

managing her condition the unpredictability of blood glucose levels were frustrating:

Yes, by controlling it, by taking medicine when you are supposed to. Sometimes, you cannot do it, you want to do better but you cannot. The sugar either goes up or down; I cannot predict whether it will go up or down. Sometimes it goes up, and sometimes it goes down. If it goes down, it is not a problem because I know how to get it back up, but when it goes up, you don't have anything to bring it back up. You eat sweets, and it will hurt you. (Claudia)

Failing to control their blood glucose levels, to do everything (e.g., diet, exercise) 100%

correctly all of the time, contributed to feelings of decreased self-efficacy for many

participants:

Well no. . . I don't do it well. Because I don't do everything right especially when it comes to food. Because it is hard [*laughing*]."Sophia

Well, not a hundred percent, but yes, somewhat, because I already proved it. I think about how I do not want to die. [*laughs*] Because I want to be healthy. Well, how can I say that I don't want to die, how am I going to say that and if I don't take care of myself, then I am taking myself in the opposite direction from what I think (Maria)

Theme 2: Family support. Participants mentioned family and children as the most

important reasons for taking care of themselves. Both men and women who had young

children in their lives (n = 10; 30%) cited them as motivation to control their diabetes.

Several described the importance of sticking with their self-management practices to make

sure they would be there for their children:

Even though sometimes, one does not want to take medications anymore, but one does it for the children. (Carlos)

Yes, yes, I have a lot of confidence. My children give me this confidence from being so young. My son is 2 years old, and my daughter is 4 years old. If I don't take care of myself, I mean they have their momma, but it is not like having two parents together. They give me confidence in myself so I can come to terms with it, survive it and try to rest. (Jorge) That's what I'm afraid of. I don't want to get sicker, to have my eyesight go bad because I know that diabetes can sicken some organ or some part of the body, and I want to stay whole, for my children. (Maria)

Question 13: Most important self-management behaviors. The participants were

asked what behaviors they performed were the most important to their diabetes self-

management and why. The themes that emerged were what behavior I perform and why it is

important.

Theme 1: What I perform. The participants frequently described taking their

medication to be their most important self-management behavior because they feared

complications and the burden they would be on their family if they did not take it:

I will take all my medication, because I think it would be nice if one just died and that was it, but one leaves problems here. I don't take my medication and all the sudden I have a heart attack, a stroke, and then you are going to struggle. I am the one who is going to suffer. I think the one who is in a wheelchair or is ill suffers more because if they [family members] don't care, they are going to leave me there [*laughing*], and they are going to continue living their lives, right? That is something I am afraid of, that is why I take my medication. (Alicia)

The citing of medications as the most important self-management behavior was followed by eating well and exercising. Martin summarized this order of importance: "The main one is to take the medication on time. . . . Another one is to have an adequate diet to avoid having high sugar levels. . . . and that's it."

Theme 2: Reasons why what I perform is important. Eduardo did an excellent job

summing up the reasons that he performed the self-management behaviors that he did:

Well, being disciplined, being . . . look toward the future . . . I have a 6-year-old son who I want to see when he is a man. I would like to see . . . my biggest dream is to meet my son's children. Right? So in order to meet that goal, I have to take good care of myself to be able to get there. My daughter is already 21, and I know sooner or later, she soon will . . . get married and have her family, but my son is just beginning. Yes, it is good for me. I mean it is my incentive to behave. (Eduardo)

Appearance, Financial Issues, Environment

Question 14: Other issues related to diabetes. Participants were asked to discuss other issues they had that were related to diabetes. The themes that emerged regarding general health related issues were *appearance of the disease, co-morbidities, and finances.*

Theme 1: Appearance. Juan asked, "So one cannot tell that I have diabetes?" He was also pleased when the research team assured him that no, we could not tell he had diabetes.

This remark was revealing because it voiced a concern about 'looking like a diabetic' and expressed the idea that one may be identified as having diabetes based on appearance. This statement reflects the importance of a healthy image, presenting as a normal, healthy person. This question also suggests that looking like a person with diabetes is undesired.

Theme 2. Comorbidities. Effectively treating comorbidities with diabetes usually means taking more medications. Most participants did not welcome that demand. Managing diabetes was difficulty enough, but taking medications for another condition made their resistance to taking medications worse:

Because to be honest, one gets tired of taking medications. I am bored of taking medication, so many medications every day. I don't, I don't just take the one for diabetes. I take many kinds of medications, all kinds of pills. (Carlos)

There is a lot of medicine that they say is good, but these are medicines that are not given to you at the clinic. Because I told you that they gave me a medicine, but I hardly take it, because I do not believe it is effective for depression. . . . She [her doctor] told me to keep on taking my current pill. I told her, "Okay, that's fine, but I won't take it often."I can take one now and one later on tomorrow afternoon and that's it, but taking two early in the morning, and two in the afternoon? No. (Claudia)

Theme 3: Finances. The economic downturn negatively affected employment status,

social services, and health-service delivery for many health-care providers. These changes

affected many of the participants and their self-management practices:

When one is poor and one does not have money to buy good things. But we try to look for ways to eat less fat, beans once in a while, rice, and eat that way. (Carlos)

Okay... and so they ask me, when were you born, what is your date of birth? They ask me, "Do you want to see someone now?" I say, "Yes." Okay, then they tell me I have to pay \$25 *now* [emphasis hers] in order to have a consultation! And I tell them, "It's that now I do not have it." So they tell me, "Come back when you have it." They don't let you see someone. And if I don't have \$25, they don't let you see someone. I won't get a consultation [*crying*]. Twenty-five dollars for a consultation, and then after the consultation, when you come back, you have to pay for medicine in addition to that. So for them, I really need like \$100, and sometimes I do not have it. Before, I could be seen without paying, and if I did not have the money, they would give me the medicine anyways.... They would tell me, you can pay it later. (Sylvia)

Financial constraints could also mean that the participants had to stay in the US to remain healthy. The cost of insulin and other medications in their home countries made it financially unfeasible for some participants to return to their countries of origin. Melida described the price differences:

I mean, because here—here it is \$50 because the insulin bottle costs at least \$40. But here you get it. But in Guatemala [it] is really expensive, so I say, "What can I do?" Because I wish I didn't have to use it anymore, because in my country that's hard. And I am alone. I don't have a husband.

Self-Management Practices Summary

Most participants reported making changes in their diet – reducing fat, carbohydrates, and decreasing sugar consumption. Food preferences were often influenced by cultural traditions, but a majority cut their portion sizes, changed their cooking methods, and stopped eating foods that were bad for them. Women had difficulty maintaining a healthy diet and engaging in physical activity, often citing home and family obligations as interfering with the performance of these behaviors.

Family member support and intimate involvement in individuals' self-management practices made an important difference in their ability to successfully manage T2DM.

Engaging in behaviors that had previously not been part of participants' behavioral repertoire or culture (e.g., eating salads, being physically active) was challenging and did not become easier over time. However, when family members also adopted these nutritional and physical activity behaviors, participants felt supported and expressed less difficulty in T2DM selfmanagement. Alcohol consumption was cited as a challenge for T2DM self-management among a majority of the men. Although complementary treatments and remedies were mentioned by participants as diabetes treatments, these approaches were not used in lieu of medications for a majority of persons. Children were most often cited as the motivator for participants to successfully manage their diabetes. Participants said they wanted to see their children grow up, that they did not want to become disabled or be a burden for their families.

Summary of Findings

This chapter presented the findings revealed by this mixed-methods research study exploring Spanish-speaking, Hispanic immigrants' information seeking and knowledge acquisition, vicarious learning, and self-management practices related to T2DM. The quantitative data were analyzed using descriptive statistical procedures and discriminate analysis to describe the selected groups. The qualitative findings were derived from coding and analyzing individual interviews following the procedures described in Chapter 3. Following the qualitative research tradition, extensive samples of participants' quotations were included to accurately portray their realities and situations.

The findings indicate that receiving a diagnosis of T2DM was a traumatic moment for a majority of the participants, and that grieving over the loss of their former healthy selves was a recurrent issue. The participants faced significant barriers to successful T2DM management and men and women differed in the challenges each experienced. During the

interviews, women reported greater difficulty changing exercise and eating habits than men did, a finding that was supported by the quantitative results. Men, despite their efforts to change diet and exercise, often reported difficulty lowering alcohol consumption, an issue not addressed in the quantitative instruments. For a majority of participants, their children provided powerful, ongoing motivation for successful diabetes management and continued diligence. An interpretation and discussion of these findings, the theoretical model, and the research aims are presented in Chapter 5.

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CHAPTER 5

DISCUSSION

Overview

The purpose of this study was to explore information-seeking and knowledge acquisition behaviors, family influences and vicarious learning, and how they related to diabetes self-management practices among Spanish-speaking, Hispanic immigrants. The findings will be discussed as they apply to the theoretical model and research aims, limitations of the study will be identified, and future directions and implications for practice will be given.

This chapter discusses the quantitative and qualitative data analysis results as they pertain to the study aims and in conjunction with the conceptual model. The data analyses are described in relation to the revised conceptual model (Figure 5.1). The model illustrates how transformative learning theory and social cognitive theory serve as frameworks for diabetes self-management beyond a cognitively based approach (Bandura, 1977; Boyd & Myers, 1988). The strength of the revised model is in its acknowledgment of the emotional, psychological, cognitive, and social aspects of living with diabetes and its depiction of the mechanisms by which these factors are associated with diabetes self-management efforts.

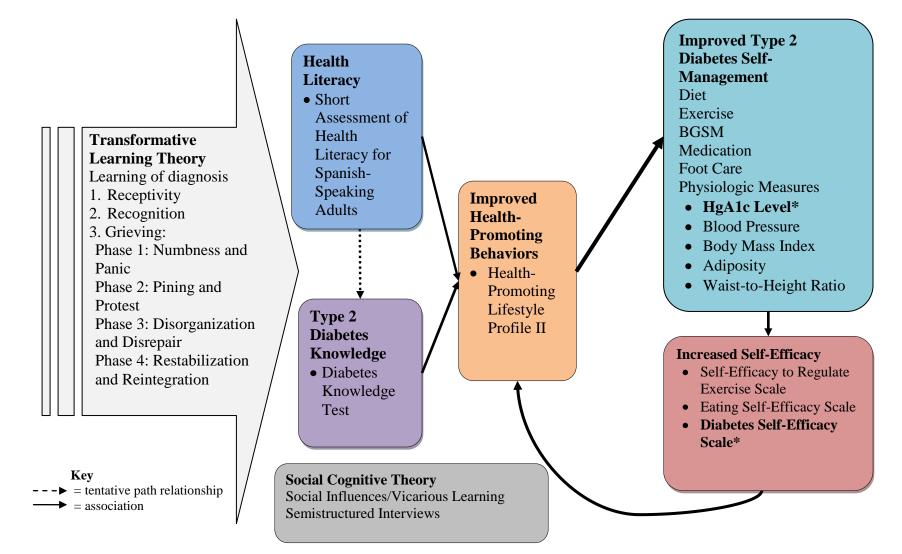


Figure 5.1. Revised theoretical framework model. The transformative learning theory facets are adapted from Boyd & Meyers, 1998 and used with the permission of the Taylor & Francis Group. Each bulleted item reflects how the different components were measured. BGSM = blood glucose self-monitoring, HbA1c = glycated hemoglobin. * = statistically significant with HPLP.

Data Analysis: Transformative Learning Theory

The reviewing and coding of the qualitative data revealed that for most participants, receiving the diagnosis of T2DM was an intensely emotional and psychological experience. Individuals' perspective and concept of self changed; this disorienting dilemma prompted reflection, and resulted in an expanded consciousness and behavioral changes (Mezirow, 1981). Based on the interview data and the language used by the participants, Boyd and Myers' conceptualization of transformative learning theory – self as the total personality and psychic being of an individual – was determined to be the most accurate framework for understanding participants' experience of receiving a diabetes diagnosis (Boyd & Myers, 1988).

Participants talked about the expanded awareness and change in self-perception they experienced before they engaged in diabetes self-management behaviors. The change in self-perception that occurred as an outcome of transformative learning is described as "a commitment to an altered way of being with one's self in the world" (Boyd & Myers, 1988, p. 276). Cranton (2006) summarized, "Transformative learning has to do with making meaning out of experiences and questioning assumptions based on prior experience, by definition, transformative learning leads to a changed self-perception" (p. 8).

Boyd and Myers' model of transformative learning theory focuses on the individuals' interior experience and uses three activities of *discernment* as the primary orientation to transformative change: *receptivity*, *recognition*, and *grieving*. Assimilating a diabetes diagnosis as part of their identity resulted in varying degrees of grief as significant aspects of participant's former healthy identity disintegrated. Although described as a linear process previously experienced stages of the grief process were revisited when participants' condition changed, such as progressing from oral medication to insulin.

Grieving included the phases of numbness and panic, pining and protest, disorganization and disrepair, and restabilization and reintegration (Figure 5.1). These steps are similar to those followed by participants who had received a diagnosis of cancer (Charmaz, 1991/1997) and are reminiscent of the stages of the theory of grief (Kubler-Ross, 1997). The phases of transformative learning theory in relation to the experiences of participants are more fully described in Chapter 4 and are briefly addressed in the following sections.

Receptivity

Participants often used the phrases "accepting the diagnosis" or "bringing it into consciousness" in association with their diagnoses. These words evoked a process of making meaning, suggesting that the news required integration and assimilation into their lives. This openness to new, and possibly unwelcome information about ones self, is defined as receptivity in transformative learning theory (Boyd & Myers, 1988). A majority of participants related that receiving the diagnosis of diabetes was an intensely transformative moment in their lives. Many participants vividly remembered the exact moment in time they were told they had diabetes "as if it was yesterday".

In contrast, several participants experienced little reported discomfort and readily accepted the diagnosis. One woman spoke of her diabetes diagnosis as inconsequential. Diabetes ran in her family; thus, having diabetes was normalized, and her family experience facilitated the rapid integration of the diagnosis into her life.

Recognition

When the individual came to understand they had a diagnosis of diabetes and that it was true, valid, and permanent – recognition occurred. Some participants came to this realization immediately. For a few, it took weeks, months, or years. The participants incorporated what they

could into their lives in their own time. A few participants "took it lightly", which they described as not making changes in their alcohol consumption, continuing their regular diet habits, and taking their medication only on occasion or not at all. Participants who initially denied the importance of the diabetes diagnosis were prompted to acknowledge the necessity of treatment in one of two ways: by their family members' concern or by complications of diabetes they could no longer ignore such as a progressive loss of vision. Of interest, one participant reflected on his health, his future, and his family after his wife voiced her concern for his health. The positive role of family and the social environment was very important in helping participants come to the realization that they had diabetes and they needed to make changes in their lives. This finding was similar to Kubler-Ross's (1997) grief stage of *denial*, which is defined as temporary and can be either a conscious or an unconscious defense mechanism in response to reality.

Grieving

Grieving was described by the majority of the participants as a series of steps they needed to go through, including an initial feeling of numbness and panic. Then anger was evidenced by pining and protest. Next came a feeling of disorganization and disrepair as they tried to incorporate themselves into their new reality, and finally, they reached a sense of restabilization and reintegration as they came to terms with their diagnoses and what it meant to have diabetes.

Phase 1: Numbness and panic. Many participants' immediate response of numbness and panic related to the meaning of the diagnosis in the context of their previous experiences with family members and friends who were diagnosed with diabetes and died. Individuals felt "numb, paralyzed, stunned, and shocked" when they were told. A few participants felt "panic" and "fear" and "cried for days". Several participants thought they had been given a "death sentence". For most participants this phase was transient in nature, lasting from hours to days.

Phase 2: Pining and protest. After getting over their numbness and panic, many participants felt anger at the diagnosis and grieved for the loss of their healthy self. Several participants reported initially that they did not want to believe the doctor and silently argued that the "diagnosis must be wrong". Some participants wanted to turn back the clock of time so they could do things differently and return to their life before the diagnosis. The diagnosis of diabetes also brought on feelings of intense sadness and sometimes depression as participants tried to come to terms with the fact that everything was forever changed.

These feelings were similar to Kubler-Ross's (1997) descriptions of the grief stages following denial: *anger*, *bargaining*, and *depression*. Anger can be evidenced by a time of irrational feelings of rage at the unfairness of the situation and the diagnosis. Bargaining is evidenced by self-negotiation for an opportunity to change aspects of a person's life. Depression brings forth an understanding of the reality of the diagnosis, a self-examination of life, and a new understanding of mortality (Kubler-Ross, 1997).

Phase 3. Disorganization and disrepair. Disorganization and disrepair was evidenced by participants feeling their lives were out of control and "broken". Nothing was the same and it would never be the same again. They now had to incorporate changes into their lives that did not feel intuitive. Diabetes self-management in Mexico was very different than in the US. The changes they had to make in their diet, exercise, and medications were foreign to their lifestyles. Culturally, participants ate differently, exercised differently, and their prescription medications were different. All of these changes, undergirded by low health literacy and a language barrier, made it so much more difficult. This phase frequently manifested among participants in compulsive eating, inactivity, excessive sleeping, and a lack of desire to participate in family activities. For most participants, this period was also transient lasting weeks or months.

Phase 4. Restabilization and reintegration. Restabilization and reintegration was defined by many participants as the expanded awareness and changed self-perception they experienced just before they began performing diabetes self-management behaviors. *Changed self-perception*, an outcome of transformative learning, is described as "a commitment to an altered way of being with one's self in the world" (Boyd & Myers, 1988, p. 276). Integrating the diagnosis of diabetes into their self-perceptions was integral to initiating diabetes self-management behaviors. After reaching this phase, participants acted in ways that best fit their desires (e.g., staying healthy) and values (e.g., being there for their family). This finding was similar to Kubler-Ross's (1997) grief stage of *acceptance*, a stage that brings an understanding and a sense of peace regarding the diagnosis and mortality.

Transformative learning results in a personal paradigm shift that is achieved through a journey of self-discovery (Mezirow, 1991). The participants in this study were forced upon this journey as a result of their new diagnosis of diabetes. Each participant experienced the journey as an intensely personal process that was uniquely theirs as evidenced by his or her stories. Despite restabilizing and reintegrating, the majority continued on their personal journeys toward diabetes self-management in an environment that many times did not take their health literacy, language barriers, cultural barriers, and socioeconomic barriers into account.

Transformative learning theory (Boyd & Myers, 1988), with its foundation in educational and constructivist understanding, has been utilized in health-related research exploring participants' adaptation to chronic illness and other life-changing health events. The participants' stories in this study are similar to other research that used transformative learning theory to frame the experiences of persons living with arthritis (Dubouloz, Laporte, Hall, Ashe, & Smith, 2004), cancer (McAndrew, 2004), traumatic brain injury (Kroupa, 1996), and stroke (Kessler,

Dubouloz, Urbanowski, & Egan, 2009). Sutton, Raines, and Murphy (2009) used transformative learning theory to understand participants' responses to initial weight loss after bariatric surgery, which was also described as a dramatic and life-altering experience (Sutton et al., 2009). The majority of participants in all of these studies, and the participants in this study, experienced paradigm shifts in relation to their new realities.

This is the first study to examine the diagnosis of diabetes in a Spanish-speaking population that has interpreted the finding using transformative earning theory as a framework, which adds to the literature. From a foundation of recognizing the patterns of transformative learning theory in the participants' responses, the research aims will be discussed along with the other components of the conceptual model.

Aim 1

To describe participants' diet practices and physical activities related to type 2 diabetes self-management.

The participants' descriptions of their eating and exercise habits were detailed in Chapter 4. This section discusses how the analysis and coding revealed patterns in the participants' experiences and the influences of the social environment on their individual practices. This section discusses diet and physical activity as they relate to diabetes self-management and the factors that influenced these activities.

Dietary Practices

The ADA dietary guidelines recommend a balance of carbohydrates, proteins, and fats that meet patients' metabolic goals (ADA, 2012). Carbohydrate counting is encouraged as a mechanism to achieve glycemic control. Specific recommendations include limiting alcohol consumption to one drink per day and keeping saturated fat intake to less than 30% of the total

caloric intake. In this study, participants described their difficulties with managing their diet after being diagnosed with diabetes. Decreasing carbohydrates, fat and sugar, eating more vegetables, decreasing fast food intake, and cooking differently affected them in many ways. A traditional Mexican diet is typically high in carbohydrates and fat and includes tortillas, beans, and rice. Some participants equated changing their diet to changing their cultural identity for themselves and their families. Similar to our study's results, Montoya, Salinas, Barroso, Mitchell-Bennett, and Reininger (2011) found a strong connection between food and culture for Mexico-born Mexican Americans in their secondary data analysis comparing the food preferences of US- and Mexico-born Mexican Americans.

Similar to Sofianou, Fung, and Tucker's (2011) findings, participants in this study often mentioned that being Mexican or Latino influenced their food preferences and that maintaining new dietary habits did not become easier over time but continued to be a daily struggle. Sofianou et al. conducted a secondary analysis of the 2003 to 2006 National Health and Nutrition Examination Survey (NHANES) database. Like Montoya et al. (2011), they explored dietary patterns based on nativity but also examined duration of U.S. residency among Mexican American immigrants. They found that Mexico-born Mexican Americans, living in the US for less than 15 years, preferred traditional Hispanic foods such as tomatoes or tomato-based products, tortillas, beans, and legumes. Their findings also suggested that Mexican Americans might avoid diet patterns that include frequent consumption of fresh fruit and some kinds of vegetables.

These diet patterns and food preferences were evident in this study as a majority of participants expressed unfavorable attitudes about increasing their vegetable intake and eating tossed green salads. Their attitude toward vegetables contrasted with their reported love of fruit

and difficulty refraining from eating too much. These specific dietary preferences were also evident in Grimm and Blanck's (2011) study, providing evidence that these opinions are neither unique nor limited to the participants in this study, but are prevalent among Spanish-speaking Hispanics. Using a subsample of 11,141 Spanish-speaking Hispanics from the 2009 Behavioral Risk Factor Surveillance System, Grimm and Blank (2011) found Spanish-speaking Hispanics more likely to eat fruit and drink fruit juice and less likely to eat vegetables than non-Hispanic Whites or English-speaking Hispanics. These results corroborate that the eating preference expressed by a majority of the participants in this study – fruit preferred to vegetables – is not unique one.

Montoya et al. (2011) also found that Mexican Americans born in Mexico were more likely to rate eating five servings of fruits and vegetables each day as important compared with Mexican Americans born in the US. A closer examination of actual diet practices by Colon-Ramos et al. (2009) revealed that fruit and vegetable consumption by Mexican Americans living in California was less than the recommended five servings a day. Moreover, beans were more likely to account for participant's' fruit and vegetable servings, particularly among men. They also found men less likely to eat green salad, a tendency also found in this study. The majority of participants in Caban, Walker, Sanchez, and Mera's (2008) qualitative study were Puerto Rican immigrants, but their findings were similar to this study's results concerning diet. Both men and women felt their culturally preferred diet made it difficult to follow recommended dietary guidelines and that reducing fat and calories in preparing traditional meals was considered a significant change (Caban et al., 2008).

In this study, traditional foods had increased cultural and emotional significance because of the participants' separation from family members and their countries of origin. Diabetes self-

management requires the elimination of or reduction in the consumption of traditional foods and this change represents a loss of cultural identity and traditions. A female participant in Caban et al.'s (2008) study discussed the importance of eating traditional foods, "It feels like home when you eat rice and beans" (p. 123). In a similar study with Mexican immigrants diagnosed with diabetes, a participant shared how having to change his diet affected him deeply, "I was sad because I could no longer eat what I used to eat. . . . I felt I was losing my traditions" (Cherrington, Ayala, Scarinci, & Corbie-Smith, 2011, p. 284).

Despite these attachments and acknowledgements of their preferences for traditional Hispanic foods and fruit, and their distaste for vegetables, participants in this study reported making dietary changes based on the advice of their physicians and nutritionists. However, it is clear that their dietary habits often differ based on nativity and language (Caban et al., 2008; Grimm & Blanck, 2011; Montoya et al., 2001; Sofianou et al., 2011). Although, these similarities cannot predict a specific individual's behavior, they provide context for the broader social environment in which participants were trying to change their diet and give credence to the daily challenges they face.

Physical Activity

Current physical activity guidelines for individuals with diabetes suggest 30 minutes of exercise on most days of the week (ADA, 2012). Though participants expressed awareness of their need to be physically active, many did not engage in regular daily exercise as recommended in the ADA guidelines. Most participants described their physical activity as a part of their daily lifestyle. For example, walking to the store, using a bike to get back and forth to work, house cleaning, caring for children, and performing physically demanding labor, such as construction work, was considered exercise. These findings were similar to a study by Berry et al. (2009) of

focus groups composed of men and women from Mexico. They found that many participants did not own a car in their home country, walked to the market and to work daily, and did not have a regular form of exercise. For many, physical activity was woven into their activities of daily living; joining a gym and working out was not something usually done in their culture (Berry et al., 2009). It was a foreign concept.

Women in this study were less likely to exercise on a regular basis compared with men, and when they did exercise, they liked to walk or dance with other women using community parks and community centers that were trusted and felt safe. Similarly, Berry et al. (2011) reported that women from Mexico in their study formed walking groups with other women from the study and enjoyed group cardio kickboxing and zumba classes held in a local church where they felt safe and could relax and enjoy the company of other women.

The support of family members was also mentioned as a great motivator for promoting physical activity in this study. Participants who reported that they exercised daily discussed how family members' support, exercising with them, helped them "keep on track" and provided encouragement to "keep going". This finding was similar to findings from a study by Berry et al. (2009) wherein men and women both felt the support from their spouses for walking more and from their children for going outside to play. Being physically active together, as a family, was important and very difficult to do because of the men's work schedules (Berry et al., 2011).

Another finding in this study was that both men and women equated physical labor with exercise. Men believed that if they had a physically demanding job in construction, then they got all the exercise they needed while they were at work. Women thought that housework – going up and down the stairs, sweeping, doing laundry – and caring for their children was physical labor and they got all the exercise they needed while caring for their family. Other researchers have

found similar beliefs among participants who were of Latino origin (Cherrington et al., 2011; Evenson, Sarmiento, Tawney, Macon, & Ammerman, 2003; Mainous, Diaz, & Geesey; 2008; Russell et al., 2010). Cherrington et al. (2011) conducted interviews with men and women from Mexico currently living in North Carolina and found that men felt the physical labor of their jobs was all the exercise they needed and that women felt housework and "chasing" after the children was all the exercise they needed. Evenson et al. (2003) interviewed women from Mexico, also living in North Carolina, and found that the majority (63%) did not engage in vigorous activity at least 3 days a week. Russell et al. (2010) conducted focus groups with urban Spanish-speaking participants with diabetes and found that vigorous, purposeful exercise was not a part of their lives. Mainous et al.'s (2008) secondary analysis using the 1999 to 2004 NHANES III database of Hispanic adults diagnosed with diabetes also found that Hispanics with limited English proficiency were less likely to exercise in their leisure time than were more acculturated participants.

Participants reported that the biggest challenge to their diabetes self-management was regularly engaging in sustained physical activity. The difficulty participants expressed with exercise were also present in Ingram et al.'s (2009) findings on Mexican Americans who had graduated from a diabetes education program. The program graduates did not take advantage of the free passes they had been given to a walking track thus prompting a 12-week walking intervention that was followed by focus group sessions. Similar to the findings in this study, participants' feelings of mastery related to exercise positively influenced continued physical activity and reported the benefits of exercise—it made them feel better, reduced their stress level, and increased their overall feelings of well-being.

The value of social persuasion in promoting exercise cannot be underestimated. Participants in this study described how important social persuasion was in their decision to increase their physical activity. Comparable to Ingram et al.'s (2009) findings, several participants in this study reported that they increased their physical activity because they had been instructed to do so by their physicians. The power of social persuasion was also noted in Vaccaro et al.'s (2012) study with Mexican American participants. Participants who were advised by their physician to exercise increased their physical activity more than participants who were not.

Men and women also expressed different attitudes toward exercise. In this study men talked about the need to keep active to avoid becoming debilitated and were likely to describe exercise as something they did to improve blood glucose control. Unlike in D'Alonzo and Fischetti's (2008) study, female participants in this study did not describe exercise as unfeminine. They conceptualized exercise as a method of weight control and a few mentioned the role of exercise in controlling their blood sugar levels, which was similar to D'Alonzo & Fischetti's findings.

Many of the female participants' outcome expectation for exercise was weight loss. Like in Evenson et al.'s (2003) study, when women's expectations for weight loss were not achieved, they were inclined to stop exercising. This response supports the assumption of social cognitive theory that continued performance of a behavior, particularly one that is not enjoyed, hinges on whether outcome expectations for that behavior are met (Bandura, 1997). The practice of regular exercise being dependent on weight loss is concerning because this mind-set brings a risk of losing all the other benefits of exercise, which include lower blood glucose levels and lower blood pressure.

Summary

Participants' dietary practices and physical activities were informed by their cultural heritage and traditions. Their food preferences often ran counter to the recommendations for a diabetic diet; however, most participants made significant changes in their portion sizes, diet, and food preparation methods. Altering their eating habits and becoming more physically active was difficult and presented an ongoing challenge. Many participants equated physical labor to exercise and believed that the physical work they performed was all the exercise they needed. Women talked about exercising in reference to losing weight, and men emphasized the effects of exercise on blood glucose levels. Men also reported exercising more often than women did.

Aim 2

To describe how the participants' social environments and vicarious learning influence type 2 diabetes self-management related to diet practices and physical activity.

In this exploration, work and family obligations emerged as factors in the social environment that negatively affected participants' diabetes self-management practices. The obligations upon each individual and social environment in which they lived differed in their influences on male and female participants' diabetes self-management practices. In some circumstances, they had a positive influence, and in others, they had a negative influence.

Diet Practices and Family

The social environment, which mainly consisted of parties and family gatherings often centered on food, made diet control difficult for many participants. However, in the home, families were often willing to change their diet and food preparation methods in deference to the individual who had diabetes. In many cases, family members took on an active role in assisting the participants' diabetes self-management efforts. Similar to this study, Cherrington et al.

(2011) examined the barriers to and facilitators of diabetes self-management among Hispanic immigrants with diabetes and found similarities and differences between men and women. As in this study, women cited social barriers (i.e., obligations of home and family) and men most often cited work as interfering with diabetes self-management practices (Cherrington et al., 2011). Laroche et al. (2009) conducted semistructured interviews with Hispanics and also found that most participants' children facilitated their exercise practices and healthy food choices. The children were also willing to make healthy diet changes to help their parents.

Male participants and most of the female participants reported receiving emotional support from their significant others for food preparation and dietary management. However, Carbone, Rosal, Torres, Goins, and Bermudez's (2007) results differed, reporting instances when wives did not prepare meals that took their husbands' diabetes into account. Some gender differences were noted in this study, but no male participants described wives who did not make an effort to assist them. Many times, their wives were the men's "strongest" supporters. In contrast, several female participants in this study said their husbands or boyfriends were not supportive and refused to try new foods or foods prepared in a healthier way. In most cases, this required the women to prepare two meals, a traditional meal for their family and a healthier rendition for themselves. Similarly, Cherrington et al. (2011) found that husbands of Hispanic immigrants born in Mexico were not willing to change their diet to accommodate the needs of their wives diagnosed with diabetes, which left their wives with the choice of preparing two separate meals. Gallant (2003) found similar gender differences regarding levels of social support and chronic illness self-management.

Help and Family

The participants in this study conceptualized what it meant to be provided with help managing their diabetes in several ways. For the majority, help was described in the context of what their family did to assist them in self-managing their diabetes and included problem solving and encouragement. For others, it related to financial assistance in purchasing food and medications. Participants felt that family members showed love and care when they helped them with decisions regarding food, exercise, and taking medications. If family members did not become intimately involved with participants' diabetes self-management, they felt as though family members did not care and felt "sad". Several men shared that they would do "better" if their wives lived with them in the US instead of in Mexico. They believed they needed "someone" to push them "to do better". These findings were similar to Spanish-speaking men who reported receiving and appreciating the support provided by their wives in both Caban et al. (2008) and Weiler and Crist (2009). Weiler and Crist (2009) found that male and female Spanish-speaking participants appreciated and valued family support that included reminders like "Oh. . . I haven't seen you take your medicine today" or "I haven't seen you take your shot, your insulin" (p. 289).

However, in other studies attitudes toward family members' support differed between English- and Spanish-speaking Hispanics. In Caban et al.'s (2008) study, English-speaking, Caribbean men reported that they had not received social support from anyone and they "didn't want any." Family support was also perceived as negative among the English-speaking men in Rosland, Heisler, Choi, Silveira, and Piette's (2010) study. Participants said that family members nagged and criticized them about their diabetes self-management. These differences in perspective may be due to language and acculturation, because the Spanish-speaking participants

in this study, Weiler and Crist's (2009) study, and Caban et al.'s (2008) study appreciated and valued family member involvement.

Another aspect of help was the advice participants provided to family members, neighbors, and coworkers about diabetes and diabetes prevention. Family and friends seeking participants' advice provided evidence the other valued their knowledge and expertise. Participants' willingness to provide assistance demonstrated their desire to help and teach others about diabetes. This involvement and openness about their condition within their communities illustrated how participants gained status as lay-experts.

Physical Activity

Participants mentioned that family members who exercised served as positive role models and prompted them to exercise. Many participants felt their spouses, girlfriends, boyfriends, and children encouraged them to be active. In contrast, Ingram, Ruiz, Mayorga, and Rosales (2009) reported that no participants, prior to the study intervention, discussed having a role model who influenced their exercise patterns. However, after the walking group intervention, participants referred to the positive examples other group members provided for regular exercise.

Similar to what Evenson et al. (2003) found, neighbors also provided participants in this study vicarious learning opportunities about exercise. Women who knew people who exercised or who had observed people exercising in their neighborhood were more likely to meet exercise recommendations or report physical activity. However, this experience may have limited transferability across cultures. A male participant in Cherrington et al.'s (2011) study recounted - that he witnessed American neighbors walking every day of the year. However, he believed

exercise was not part of Hispanic culture and could not envision himself walking every day despite this example.

In this study, if male participants exercised, it was often in the context of playing sports such as soccer with other men. If females exercised, it was in the context of walking or zumba dancing with other women. This preference reflects the value and need to employ collective efficacy in promoting exercise behavior among Hispanic women, an approach that is supported in the research that has targeted Hispanic women (Berry et al., 2011; Ingram et al., 2009). Additionally, female participants faced additional barriers to physical activity that men did not. Domestic responsibilities, household chores, childcare, and working outside the home often prevented women from having the time to exercise. Women's' obligations to homes and families were also found in the work of Evenson et al. (2003) and Russell et al. (2010). Female participants who were stay-at-home mothers had difficulty finding childcare so they could be free to exercise. This further supports how the cultural environment can limit access to activities that promote positive diabetes self-management.

Work Environment

Similar to the findings of Cherrington et al. (2011), the work environment often negatively impacted the diabetes self-management efforts of male participants. The majority of men worked in construction or landscaping, and these jobs were performed in extreme temperature and dirty environments. Several men discussed how difficult it was to carry enough water for the day, check their blood glucose levels, and inject insulin if needed. In addition, they did not have a choice about when to take their breaks. These working conditions left some men no option but to alter their medication regimen and to consume the drinks and packaged foods from the snack trucks that frequented the construction sites. For those using insulin, a disruption

in their self-management regimen (e.g., not eating, becoming dehydrated, consuming sugared drinks) could place them at increased risk for hypo- or hyperglycemia. Further complicating the situation was that several men had not told coworkers they had diabetes, secrecy that could limit an appropriate response in an emergency. In addition, their workdays were long and they often felt tired and exhausted at the end of the day; a reason the men did not feel like exercising.

Barriers

Women reported performing health-promoting behaviors less frequently than men did as evidenced by the participants' HPLP II scores. Financial constraints were often cited as negatively affecting the women's abilities to self-manage diabetes. Their lack of financial resources and transportation often required them to depend on others for medication and getting to clinic appointments, and it may have contributed to less frequent health-promoting behaviors.

The study revealed how participants' social environments contributed to successful diabetes self-management or impeded participants' efforts to manage their diabetes. The preservation of traditional gender roles contributed to some female participants having primary responsibility for meal preparation but little choice in determining the menu. When family members refused to adapt a healthier diet, this communicated a lack of concern about the women's health and wellness. This situation was not the experience of the male participants who were much more likely to receive support from significant others and family members.

Vicarious Learning

Observations of family members' diabetes self-management habits provided most participants with vicarious learning experiences. These observations, both positive and negative, informed participants' current diabetes self-management behaviors in positive ways. Most of the examples originated from poor diabetes self-management, and participants vowed not to engage

in the same behaviors. Their shared memories included relatives who never went to the doctor, who did not take their medication, who did not like talking to doctors, and who suffered horrid deaths. For most participants, these memories strengthened their resolve to take care of themselves.

Summary

The social environments could facilitate or hinder participants' diabetes self-management efforts. Women experienced more challenges to successful diabetes self-management than men. Family members' involvement with participants' diabetes self-management contributed to their feeling cared for and valued. Participants voiced confidence in their abilities to manage diabetes with family members' support. They also took pride in the fact that their families would benefit from adopting healthier eating and exercise habits. These findings align with the constructs of social cognitive theory that predicted that past experiences, vicarious learning, and current social environments would inform participants' diabetes self-management practices.

Aim 3

To describe the relationships between health literacy, diabetes knowledge, self-efficacy, and type 2 diabetes self-management, diet practices, and physical activity.

In this study, we measured health literacy using the SAHLSA (Lee, Bender, Ruiz, & Cho, 2006), the DKT (Fitzgerald et al., 1998), the Self-Efficacy Exercise Scale (Everett, Salamonson, & Davidson, 2009), the Eating Self-Efficacy Scale (Glynn & Ruderman, 1986), the Diabetes Self-Efficacy Scale (Lorig, Ritter, & Jacquez, 2005), and the HPLP II (Walker, Kerr, Pender, & Sechrist, 1990). Physiologic measures were taken as indicators of diabetes self-management. The instruments and measures, along with the findings, are described in Chapter 4. In this section, the associations among the components of the conceptual model are discussed.

Health Literacy

Participants' comprehension of medical terms was quantified with the SAHLSA and the semi-structured interview questions were crafted to provide information about participant's information seeking and knowledge acquisition behaviors, and the role of family members in these activities.

SAHLSA. A majority of participants in this study demonstrated adequate health literacy (SAHLSA scores of \geq 37). The SAHLSA effectively identifies respondents with low health literacy but has a ceiling effect for higher scores, meaning that the higher scores have a tendency to cluster at the end of the scale, giving the instrument limited ability to differentiate among those with adequate literacy (Shadish, Cook, & Campbell, 2002). The participants in this study were representative of the educational achievement level found among many recent Hispanic immigrants (Batalova, 2008; Cherrington et al., 2011; Fry, 2010). The average female participant in the study had a sixth-grade education, and males averaged a ninth-grade education. All participants had attended school in their countries of origin. Participants' difficulties related to literacy level were evident when they reported they did not understand their medication regimen, how much weight they needed to lose, or had questions they felt their physician had not spent enough time answering.

No statistically significant association was found between health literacy level and HbA1c level, however, this result should be cautiously interpreted to avoid a type 2 error or erroneously concluding no association exists, when in fact, one does. Although this finding is similar to Bains and Egedes' (2011) and Jahanlou and Karami's (2011) recent studies these studies also had small sample sizes. Bains and Egedes's (2011) study with 125 low-income, English-speaking participants found no association between health literacy and glycemic control.

Likewise, Jahanlou and Karami (2011) studied 256 Iranian participants and found that literacy level had no relationship with glycemic control. These results were in contrast to Schillinger, Barton, Karter, Wang, and Adler's (2006) study, with 395 participants, that showed literacy level mediated the relationship between education levels and HbA1c levels such that individuals with higher literacy had better glycemic control.

Health literacy skills. Key concepts of health literacy are individuals' capacity to access, understand, and use health information in self-management. These skills and competencies were communicated in the responses provided during the semi-structured interview.

Most participants' primary source for information about diabetes was their physician. If they had a question outside a regular clinic visit, attempts to contact their physician for an answer were often unsuccessful. Therefore, access to physician-provided information usually required an appointment, depended upon having transportation to the clinic, and having the financial resources to pay for the visit.

Participants' also relied on the Internet for health information and accessed this information independently or with the assistance of computer literate children. Questions about knowledge acquisition revealed the degree to which families were involved in participants' self-management and the level of assistance they needed to manage their condition. The findings in this study were similar those of Roland et al. (2010) who found family member involvement facilitated participants' self-management and paralleled Laroche et al.'s (2009) results that children, who were bilingual and computer literate, helped their parents with diabetes self-management.

Participants' descriptions of their experiences in clinical settings provided information about the socially constructed aspects (i.e., communication with health care providers) of literacy

(Barton, 2007; Schillinger et al., 2003). Although health literacy did not have a direct relationship with HbA1c in this study, participants' lower overall literacy and poorer literacy-related skills were suggested in reports of "not paying attention", "thinking about other things", in difficulties like "not remembering", and becoming "confused" in clinical situations or when trying to use nutrition information. Castro, Wilson, Wang, and Schillinger found these difficulties to be common among low literacy persons, their 2007 study provides evidence that the use of medical jargon contributes to these difficulties (Castro et al., 2007). Meeting participants' need to receive diabetes-related information in multiple formats may help compensate for these learning difficulties.

Health Literacy and Self-Efficacy

The discriminant analysis table (Chapter 4, Table 4.7) illustrates the differences between the HbA1cgroups based on instrument measures. This analysis showed that the group with HbA1c levels equal to or less than 6.99 had higher health literacy levels than the groups with worse glycemic control. However, it is also important to note the differences in self-efficacy scores among these groups. The group with better HbA1c levels had appreciably higher diabetes, exercise, and eating self-efficacy scores than the other two groups. This connection between selfefficacy and HbA1c control is well supported in the literature and will be discussed in the next section.

Self-Efficacy

Among the eating, exercise, and diabetes self-efficacy measures, diabetes self-efficacy was the only measure associated with the health-promoting behaviors of physical activity and nutrition. A result that suggests participants' physical activity was solely part of diabetes selfmanagement. The role of diabetes self-efficacy in this study is similar to that found in Sarkar,

Fisher, and Schillinger's (2006) results that showed diabetes self-efficacy was associated with the diabetes self-management domains of exercise and diet. Wallace et al.'s (2009) intervention study also reported participant experienced improved diabetes self-management behaviors and self-efficacy.

Although exercise and eating self-efficacy were not associated with health-promoting behaviors, the use of these measures allowed specific problem areas to be identified. Exercise self-efficacy scores were no different for men than they were for women with both in the middle range. Though physical activity level was not quantified in this study, participants who expressed not having the time, energy, or motivation to exercise were consistent in reflecting this information in their exercise self-efficacy responses. This consistency contrasted with Evenson et al.'s (2003) study that found that women with higher levels of self-efficacy were less likely to meet physical activity recommendations or report more activity than women with low self-efficacy. This suggests that regardless of activity level, women who were active did not believe they could do more than what they already did, but women who were inactive believed they could do more.

The positive influence of small successes on behavioral performance was supported in this study by the participants' descriptions of their behavioral changes, their feelings of accomplishment, and increased levels of confidence. The participants provided evidence that small successes fostered continued behavioral performances (e.g., weight loss, exercise), a construct supported within the structure of social cognitive theory (Bandura, 2004) and presented in the revised conceptual model (Figure 5.1).

Additionally, when participants ate well, had consistent blood glucose readings in the normal range, or lost or maintained their weight, they felt successful and confident in their ability

to self-manage their diabetes. When they ate poorly, had inconsistent blood glucose readings, or gained weight, they felt unsuccessful and ineffective in self-managing their diabetes. These feelings were similar to those expressed by participants in Carbone et al.'s (2007) study who became discouraged when they were unable to achieve positive results with diet, physical activity, or blood glucose control. In this study, the unpredictability of blood glucose levels negatively affected many participants' confidence levels regarding their diabetes self-management activities. Participants clearly engaged in what Bandura (1977) described as self-evaluation.

The women in this study wanted to see weight loss from exercising and were discouraged when weight loss was not as quick or lasting as they envisioned it to be. Similarly, Evenson et al. (2003) found that when the women's expectations for weight loss were not met, they were strongly inclined to stop exercising. These outcome expectations reflect the social cognitive theory tenet that when outcome expectations are met, participants will experience a sense of mastery and achievement and are thus much more likely to continue performing the behavior (Bandura, 1977, 1997). Thus, meeting diabetes self-management goals was difficult to accomplish because many women expressed frustration about receiving only general diabetes self-management instructions like "lose weight,""exercise more," or "eat fewer carbohydrates" without any guidance about how to achieve these goals. The complexity of setting diabetes self-management goals and the enormity of the task overwhelmed many of them.

Some participants established exercise and weight-loss goals, but others lacked the skills to independently establish similar self-management goals. Goal setting was a foreign concept to many participants in Carbone et al.'s (2007) study as well. Participants were unaware of and disinterested in goal setting as a means to manage their diabetes. DeWalt et al. (2009)

demonstrated the value of teaching goal-setting skills and coaching in enhancing diabetes selfmanagement behaviors. Not only did goal setting in their study result in improved diabetes selfmanagement, it fostered individual efforts to initiate other healthy behavior changes (DeWalt et al., 2009). Some participants in this study discussed goal setting as they talked about making changes (e.g. changing the cooking oil they used) and their plans for next steps (e.g. using less oil, using fat-free milk).

Physiological Measures

Physiologic measures of adiposity, blood pressure, and HbA1c were indicators of participants' diabetes self-management practices. When compared with the information shared during the interviews (e.g., eating less fat, exercising), the results of these measures were inconsistent with the outcomes that would be expected from performing the reported behaviors. As a group, all participants were overweight as indicated by skinfolds, ranging from normal to overweight size, BMIs, and WtHRs (Ashwell, Gunn, & Gibson, 2012). However, a majority of the male participants were within the normal weight range for their age. Only 18% (n = 2) had a BMI in the overweight range, and 10% (n = 1) were in the obese range. This is in stark contrast with the women's measures: less than half were within the normal weight range for their age, 26% (n = 5) were overweight, and 32% (n = 6) were in the obese range. The central adiposity measures, the WtHRs, were concerning because they exceeded the recommended ratio of 0.50 for 83% (n = 25) of the participants, denoting an overweight to obese status. The adiposity measures reflected the differences between men and women that were also apparent in the Eating and Exercise Self-Efficacy Scale scores. The ADA standard for HbA1c levels of less than 7% was met by 45% of the participants (ADA, 2012).

Summary

The conceptual model accurately depicts the relationships between health literacy, diabetes knowledge, self-efficacy, and health-promoting behaviors. Health literacy and diabetes knowledge informed health-promoting behaviors. Increasing the frequency of health-promoting behaviors contributed to improved diabetes self-management outcomes. Experiencing improved diabetes self-management and achieving diabetes self-management goals enhanced participants' self-efficacy in their abilities to self-manage their diabetes and provided incentive to maintain their performance of present behaviors.

Aim 4

To examine the relationships between diabetes knowledge, health literacy, self-efficacy, and the social environment and how they affect participants' type 2 diabetes self-management behaviors.

Knowledge

Diabetes knowledge and health literacy were associated with the HPLP II, reported frequency of health-promoting behaviors. Although diabetes knowledge and health literacy were not directly related to HbA1c levels or other outcomes (e.g. weight, adiposity, BMI) in this study the sample size may have been insufficient to reveal any relationship. The lack of association between diabetes knowledge and HbA1c values here contrasted with Bains and Egede's (2011) findings that showed diabetes knowledge and perceived health status were the most important factors associated with HbA1c. However, they did not find an association between health literacy and HbA1c levels.

The quantitative findings suggest that diabetes knowledge is associated with healthpromoting behaviors, particularly health responsibility. Improvements in diabetes knowledge

may contribute to more frequent health responsibility behaviors, a relationship that could occur because increased diabetes knowledge enables individuals to ask questions of their health-care providers and gives them the confidence to do so. In Micklethwaite, Brownson, O'Toole, and Kilpatrick's (2012) study increased diabetes education, along with diabetes self-management skills and case management, enhanced the participants' goal-setting skills, and improved HbA1c levels.

Participants in this study acquired diabetes knowledge primarily from their physicians and depended on them for up-to-date information, a common practice among low literacy populations. A few participants had a friend or family member they would ask about diabetes, but only because they believed these family members were knowledgeable about diabetes. Few participants had attended a diabetes education class even though they had been diagnosed with diabetes in the US, where the ADA (2012) recommendations for diabetes education are well established. However, work schedules, lack of transportation or childcare, or a limited number of classes taught in Spanish may have prevented class attendance. Whatever the reason, it is clear that the individuals who may have benefitted most from diabetes education were not receiving it.

Although participants demonstrated a lack of understanding about their diabetes medication this finding is not uncommon or restricted to Hispanic populations, as Aikens and Piette (2009) and Mann, Poineman, Leventhal, and Halms (2009) reported. In contrast with other studies, participants did not express fear or resistance to using insulin (Caballero, 2006; Heisler et al., 2007; Karter et al., 2010). They talked about the common Hispanic belief that diabetes could be treated or cured with natural remedies such as grasses or herbs but denied believing this themselves. Moreover, a majority expressed faith in their health care provider's expertise and knowledge with regard to diabetes care and management and used prescribed medications rather than natural remedies to treat their diabetes.

Self-Efficacy

Diabetes self-efficacy was associated with exercise and nutrition behaviors. One diabetes self-management domain that may be immune to self-efficacy is medication adherence. Although medication adherence was not measured in this study, participants discussed the difficulties they had in obtaining their medications because of financial constraints and lack of transportation. Sarkar et al. (2006) assessed participants' medication adherence and found this area to be the one domain with which diabetes self-efficacy was not related. The proposed reasons for this lack of association were that the costs of medication and lack of access to health care negatively influenced adherence. These problems were often mentioned by the participants in this study in explaining why they did not consistently take their medication. These findings suggest that improving medication adherence requires broad, creative solutions.

DeWalt et al. (2009) implemented a successful intervention based on the tenet that reaching expected outcomes fosters the continuance of behavioral change. Personal accomplishment builds a sense of self-confidence, a belief in self and improved self-efficacy. In this study, when outcome expectations were not met, both male and female participants became discouraged in their efforts. Many participants said their level of confidence in performing diabetes self-management activities was negatively affected by the unpredictability of blood glucose levels, a reaction that correlates with Bandura's (1977) standards for self-evaluation. This self-evaluation can result in harsh personal judgment. This continued evaluation concerning a perceived failed goal can be a source of distress and contribute to depression (Bandura & Locke, 2003); a state that some participants expressed feeling in this study. Harsh self-evaluation

and its negative effects hold particular importance in how they may prevent exercise behaviors and curb weight loss efforts of women in this population. Harsh self-evaluation in combination with prescriptive diabetes self-management guidelines could also have contributed to some participants feeling inadequate and unable to manage their diabetes.

Social Environment

Participants reported that the social environment negatively affected their diet management because of the central role food plays in these situations, an association that may be reflected in the high correlation found between the HPLP II nutrition and interpersonal subscales (see Chapter 4). The pressure to eat in social situations is pervasive among Hispanic populations. Mexican migrant workers in Arizona (Weiler & Crist, 2009) and Puerto Rican and Caribbean immigrant populations in the northeastern US (Caban & Walker, 2006; Caban et al. 2008) also reported that the pressure to eat in social situations was detrimental to their diabetes selfmanagement efforts.

Alcohol. Moderate alcohol consumption can be part of a diabetes self-management program and is addressed in the ADA guidelines (ADA, 2012). However, a majority of the male participants in this study identified excessive alcohol consumption, more than six beers in one sitting, as a problem in their diabetes self-management on many weekends. The belief that alcohol consumption is synonymous with celebrating life, particularly among Mexican Americans, means that participating in social gatherings results in alcohol being consumed (Giger & Davidhizar, 2008).

Alcohol and its metabolic effects (Bantle, Thomas, & Bantle, 2008) and alcohol and its connection to diabetes risk (Imamura, Lichtenstein, Dallal, Meigs, & Jacques, 2009) have been explored. However, in the qualitative studies that focused on diabetes self-management and

included Hispanic participants with limited English-proficiency, there was no references to alcohol consumption (Caban et al., 2008; Carbone et al., 2007; Cherrington et al., 2011; Ingram et al., 2009; Russell et al., 2010; Weiler & Crist, 2009). This omission may be due to a number of reasons: excessive alcohol consumption may not have been an issue for the participants in the Hispanic subgroups in the aforementioned studies, the focus group setting may have made the topic awkward to discuss, or men recruited from health-care settings were different from those recruited from community settings.

Weiler and Crist (2009) also used a bilingual interviewer and researcher team in their semistructured interviews. The participants discussed the challenges of food in social situations, but did not mention alcohol consumption. In this study, the topic of alcohol consumption was not part of the original interview guide but was raised by the participants. It is uncertain whether this topic arose because participants felt comfortable discussing the issue with the research team or because the population was unique. However, it is unlikely that the study population differed dramatically from other study populations given the number of common attributes present.

Stigma. The stigma associated with the diagnosis of diabetes negatively influenced participants' self-management behaviors. Although, being stigmatized because of their diagnosis was not a concern of all participants, it is a persistent phenomena among Hispanic populations (Arcury, Skelly, Gesler, & Dougherty, 2004; Jezewski & Poss, 2002; Weiler & Crist, 2009). Some study participants believed that other people would hold them entirely, or partially, responsible for having diabetes. Therefore, to avoid the shame that can accompany having diabetes, they kept their diagnoses a secret. This secrecy contributed to delayed treatment and hindered diabetes self-management in the workplace.

The stigma of being seen as unhealthy and abnormal (i.e., having diabetes) contributed to some participants' victimization by persons selling diabetes cures and remedies. One participant talked about the coffees and teas he bought from a vendor who told him these concoctions would treat his diabetes. Unfortunately, individuals attempts to correct what is perceived as a failing and the unscrupulous purveyors of cures who take advantage of these individuals is not new, limited to diabetes, or restricted to this study's participants. Rather, snake oil salesman and their ilk all have a long-standing presence in American society (Goffman, 1963/1986).

Vicarious Learning

Participants' observations of the diabetes self-management behaviors of families and community members provided a multitude of vicarious learning opportunities (Bandura, 2004). Even participants who had limited exposure to diabetes before their diagnoses observed acquaintances' behaviors and learned from them. In situations when diabetes self-management practices were poor and negative consequences were witnessed, participants consciously tried to avoid the same behaviors. In cases when diabetes self-management practices were good and positive consequences were witnessed, participants tried to emulate them. Another example of family positively influencing participants' behaviors was their expressed desire to be a good example for their children.

Culture. Vicarious learning as a mechanism to learn new behaviors may have limited cross-cultural applicability for exercise behaviors. Although Latino participants in Cherrington et al.'s (2011) study witnessed Anglo Americans exercising in their neighborhood, they considered this behavior to be more of an oddity than one to emulate. Culture also informed attitudes about physical activity in D'Alonzo and Fishchetti's (2008) study on female, Hispanic, undergraduate college students. Despite the differences in age and education between D'Alonzo and

Fishchetti's participants and the female participants in this study, family obligations were cited by both groups as a barrier to exercise.

Summary

The examination of the relationships in the study showed that diabetes knowledge and health literacy were associated with health-promoting behaviors and that the performance of health-promoting behaviors was associated with diabetes self-management outcomes. The performance of health-promoting behaviors was influenced by participants' current social and physical environments. Compared to the men, the women averaged a lower level of confidence in eating self-efficacy, which was also suggested by their adiposity and weight measurements. Diabetes self-efficacy and eating self-efficacy were associated with the performance of healthpromoting behaviors although exercise self-efficacy was not. Women and men expressed lower levels of confidence in being able to exercise than they did for diabetes self-efficacy and eating self-efficacy but gender-related differences were identified in the Eating and Exercise Self-Efficacy Scales. For these participants weight control and HbA1c control were problem areas for diabetes self-management. Cultural influences suggest that interventions designed to promote exercise may have greater success if facilitators (*promotoras*) or leaders have backgrounds similar to the participants.

Limitations

Although this study had limitations for statistical analysis precautions were taken to minimize the effect of any violation of assumptions for regression procedures, including assessing the independent variables for high correlations, excluding highly correlated variables from the analysis, and limiting the number of independent variables included in analysis (Cohen,

Cohen, West, & Aiken, 2003; Munro, 2004; Trochim, 2007). Some relationships achieved statistical significance and suggested associations among the variables and others did not.

In this study physiologic outcomes indicated diabetes self-management practices but these measures may have been influenced by factors other than those that were examined (e.g., financial status, medications, comorbidities). However, this does not minimize the fact that weight control, blood pressure control, and glycemic control were identified as challenging areas for individuals' diabetes self-management among the study population and does not detract from the clinical importance of the results.

All responses to instruments, information about diet and exercise, and interview data were self-reported. Self-reports may provide an imperfect estimate of current behaviors but data was collected using a variety of sources. The study was cross-sectional, and therefore, causal inferences cannot be made. The targeted population was recent Hispanic immigrants, mainly from Mexico, with limited English proficiency. These characteristics limit the generalizability of these findings to Hispanic populations who do not share them. Specifically, these findings may not be applicable to participants from other parts of Latin America or the Caribbean or to persons who are bilingual.

Strengths

This study examined health literacy in relationship to diabetes self-management in a population not previously studied. The participants were recruited from the community rather than through health-care facilities or managed care systems. The population was diverse with participants having relationships with health-care providers from a variety of sites or having no consistent relationship with a health-care provider. Unlike previous studies, there was no requirement for a preexisting HbA1c laboratory value.

All instruments were administered orally, and the answers were recorded by the research assistant. This procedure strengthened the quantitative results in a number of ways. First, the comprehension of each item on every instrument was enhanced by participants being able to ask for clarification if they did not understand the item, thus standardizing the concepts and enhancing the reliability and consistency of the results. Second, orally administering the questionnaires minimized the potential for test-taking abilities and reading abilities to affect the responses, which is an important consideration for low-literacy populations. This study also used three self-efficacy measures and found that the disease-specific self-efficacy measure provided targeted information. The Eating and Exercise Self-Efficacy Scales enriched the information by identifying gender-based differences in those domains of diabetes self-management. Additionally, I was present for all of the interviews. Research assistants were active members in the local Hispanic community, which fostered a trusting relationship between participants and the research team.

Conclusions

The findings have immediate implications for practice. This section provides a discussion of the relevant implications of this study and concludes with recommendations for clinical practice and future research.

Diagnosis

Receiving the diagnosis of diabetes was a traumatic event for the participants and often stimulated a transformative process that resulted in the incorporation of this new aspect into their self-perceptions. Some participants summarily denied their diabetes diagnosis at first, refusing to treat their condition on a consistent basis for weeks to years. These participants began treatments only after being urged to do so by a family member or because physical symptoms became too

serious to ignore. This finding was unexpected, adding to the richness of the data and expanding our understanding of receiving a diagnosis of diabetes.

Knowledge

Despite the fact that a majority of participants had adequate health literacy they lacked the knowledge or expressed misinformation about the nature and causes of diabetes, indicating that health literacy level is a poor predictor for what individuals understand. A majority of participants had not attended a diabetes class and did not receive any ongoing education on diabetes other than the information provided by their physicians. Many participants lacked adequate knowledge about diabetes, with the greatest deficits in medication dosing and effects. The level of diabetes knowledge appeared to be the best estimator of health responsibility and nutritional behaviors as assessed by the HPLP II (Walker et al., 1990). Health literacy level did not carry the same weight as diabetes knowledge in estimating health responsibility or nutritional habits. As illustrated in the model, neither diabetes knowledge nor health literacy was directly related to HbA1c levels. This finding, in addition to the qualitative data, suggests that literacy may exert its influence in other ways. Although not associated with glycemic control, health literacy level has value as a demographic descriptor and awareness of an individual's literacy level facilitates the design and development of interventions that meet their unique needs.

Social Influences

Diabetes self-management, as indicated by the nomenclature, is typically framed as an individual effort (Fransen, von Wagner, & Essink-Bot, 2011). However, among these Hispanic participants, the influences of culture and family are such that the term *diabetes collective management* may be more appropriate (Bandura, 2000). Given the study findings, the focus on the individual or diabetes self-management needs to shift to one that is inclusive toward family

members, an approach that may be more culturally suitable and effective for Hispanic patients. This shift toward inclusivity means encouraging family members to attend diabetes education classes and physician appointments. Increasing family involvement will allow family members to learn about diabetes and gain a better understanding of what they can do to support their loved one.

Participants did not like feeling rushed during appointments with their doctors. The minimal time given to them in appointments was equated with inattention to their problems, a lack of respect, or both. Despite the desire for more time with their doctors, longer clinic appointments are unlikely to occur in the current health-care environment. Having nurses and ancillary personnel take a larger role in the management of patients with diabetes would result in improved contact with health personnel, allowing Spanish-speaking, Hispanic immigrants to discuss current challenges and successes more easily.

The participants were largely silent on the topic of nurses' involvement in diabetes selfmanagement, suggesting that nurses were minimally engaged. This offers an opportunity for increased nursing participation and for nurses to work to the full extent of their practice: casemanaging patients with diabetes, meeting with them face-to-face, and providing ongoing support (Institute of Medicine, 2011). DeWalt et al. (2009) and Micklehwaite et al. (2012) provided detailed frameworks for implementing programs that include goal-setting strategies, monitoring, follow-up telephone calls, and coaching, which have demonstrated positive results.

Diabetes Self-Management

Few of this study's participants had participated in a diabetes education class. Some had been hospitalized because of their diabetes, and many shared stories about other Hispanics they knew who were hospitalized because of their diabetes. These findings align with the 2010 NC

Behavioral Risk Factor Surveillance System survey that found that 75% of Spanish-speaking Hispanics had never taken a diabetes self-management class and that they were hospitalized due to diabetes more often than English-speaking, Hispanic persons (NC Department of Health and Human Services, 2011).

The quantitative findings in this study suggests that if an individual improves their nutrition, physical activity, or stress management habits from never performing to either sometimes or routinely performing, they can lower HbA1c levels. These findings warrant further exploration about the degree of change needed, the length of time needed to see benefits, and the extent of behavior change that can occur if these efforts are encouraged by a nonfamily member such as a nurse or physician.

Physiologic measures. A higher percentage of women were overweight or obese than men. There were also differences between men and women on the Eating and Exercise Self-Efficacy Scales; women had lower levels of self-efficacy on both these measures. This suggests not only an association between self-efficacy and the physiologic outcomes, but that interventions targeting improving self-efficacy may increase self-management related behaviors and contribute to improved diabetes outcomes.

Recommendations

Communities. In this study, participants often viewed themselves as lay experts on the subjects of diabetes and diabetes prevention. Given the culturally grounded resistance to exercise and stigma associated with diabetes, promotoras or community members should be involved in any intervention. Promotoras can serve as cultural brokers and as examples in the community to promote exercise and other healthy habits (Ayala & San Diego Prevention Research Center Team, 2011).

A number of studies have utilized promotoras to gain access to the local Hispanic community and to facilitate intervention studies (Ingram et al., 2009). Promotoras have been successful as lay health advisors and research assistants, roles in which they assist in building trust between the community and the researchers (Berry et al., 2011; Gerber et al., 2010; Ingram et al., 2007; Sudore & Schillinger, 2009).

Clinical settings. Maintaining diabetes self-management dietary behaviors is difficult and does not become easier over time. Most participants repeatedly managed social situations that centered on food and faced day-to-day challenges presented by cooking and eating. The findings here and in other studies suggest that foreign-born participants' preferences for traditional Hispanic food remain, despite changes in behavior (Montoya et al., 2011; Sofianou et al., 2011). This underlying desire suggests that Hispanic participants with diabetes may benefit from receiving acknowledgement of the difficulties of changing habits and from diet reinforcement that honors their cultural traditions and meets their educational needs.

Family members' participation in the clinic visits of Hispanic patients with diabetes should be encouraged. This involvement fosters successful diabetes self-management in the home as family members become informed about diabetes and patients benefit from receiving clarification on information that was forgotten or not understood. Family involvement may also decrease the chance that individuals deny their diagnoses or do not treat their condition for an extended period of time.

Health-care professionals. Health-care providers' views of diabetes self-management, particularly for populations similar to those in this study, need to shift from prescriptive, paternalistic guidelines to ones that promote success in small steps. Because participants shared their frustrations at not meeting glycemic, weight, or exercise goals, it became apparent that

prescriptive approaches contributed to the harsh self-evaluation of their efforts, normative comparisons to others, and subsequent feelings of inadequacy. Supportive, realistic goal setting would assist participants in achieving their goals and provide the support needed to succeed.

New paradigms of care delivery in the clinical setting are needed for improving and supporting patients' diabetes self-management. Although participants complained about the small amount of time their physicians spent with them, longer physician clinic appointments are unfeasible in most health care environments today, however, increased nursing participation in patients' diabetes self-management is a fiscally realistic alternative. In addition, few clinics have the resources for onsite, bilingual diabetes educators. Thus, case management and diabetes education present opportunities for increased nursing involvement with this population. Initiating these changes could have added benefits for patients on two levels. One, they would spend more time with a trusted professional, and two, they may experience improved outcomes because of consistent, one-on-one, diabetes self-management assistance. Improved outcomes could result in savings in health-care dollars (Micklethwaite et al., 2012). Research opportunities exist for developing and examining new models of nursing practice in the outpatient setting as well as for analyzing the financial benefits of increased nursing involvement in managing patients diagnosed with diabetes.

Diabetes education. For patients similar to the study participants, the quantitative data suggests that increasing individuals' diabetes knowledge may result in improvements in diabetes self-management. Comprehensive, ongoing, diabetes education in group and one-on-one settings is needed for this population. Family participation in diabetes education should be encouraged because family member involvement can assist individuals who have lower health literacy and enhance their support system.

Medication. To meet the deficits in diabetes knowledge that were mentioned during qualitative data collection, medication-specific instruction needs to be provided for each individual and should include a literacy sensitive explanation of how it lowers blood glucose levels. The self-adjustment of medications and the importance of taking medication according to the dose and schedule prescribed would also be useful topics. A discussion of beliefs about diabetes medications and natural remedies is also recommended to clarify any misconceptions or misinformation. Research is needed to assess the benefits of increasing diabetes knowledge for improving diabetes self-management domains and physiologic outcomes.

Nutrition. Based on this study's findings, nutritional information should be reinforced and include reading nutritional labels. Developing individualized exercise and weight recommendations is also warranted for this population. Group discussions of effective coping strategies in social situations, addressing alcohol consumption for men and food consumption for both genders, are also needed. In addition, teaching stress management skills is warranted because the quantitative findings indicated that better stress management was associated with lower HbA1c levels.

Physical activity. Exercise as a group activity needs to be reinforced as a means to enhance glycemic control and lower HbA1c levels, not just as a method of losing weight, especially for women. Increased exercise behaviors are unlikely to occur by teaching participants about the benefits of exercise. The findings from this study, and from the others previously mentioned, suggest that cognitive approaches to exercise are unlikely to result in any change in physical activity but that including exercise groups or walking or exercise interventions with the involvement of promotoras can be an effective tactic for promoting exercise among women.

Implications for Research

The integration of transformative learning theory into the conceptual model provided new insights into why participants delayed treatment, which may have been dismissed as denial. Denial marginalizes and oversimplifies a phenomenon that was determined to be a foundational shift in individuals' views of self and their world. The prevalence and chronicity of diabetes risks overlook the profound effect the diagnosis has on individuals' ways of life and views of self.

Although transformative learning theory framed the experience of diagnosis for the participants in this study, opportunities exist for exploring whether other populations experience the diagnosis of diabetes in a similar manner. It is unknown whether the experience of diagnosis was so profound among these participants because of the tragic experiences of their family members, the pervasiveness of diabetes in their families, being so far from their home countries and their extended families, or for some other reason. Based on the participants' stories, we know they revisited phases of grief and experienced feelings of loss for their old ways of life, but we do not know to what degree or extent this occurred. We are also unaware of what changes in their conditions or medications represented for the individual in the context of transformative learning.

Another question that warrants exploration is whether an individual's progression through the stages of transformative learning can be facilitated through targeted counseling sessions, family involvement, or other means. Intervention research that targets the Hispanic population needs to be conducted at outpatient clinics and community settings to develop and evaluate innovative, effective practices for facilitating patients' diabetes self-management. Establishing sustainable, cost-effective interventions for use in these settings could result in reduced health-care costs and improved patient outcomes.

This study explored participants' health literacy skills and competencies (i.e., accessing, understanding, and using health information) in relation to their diabetes self-management. The results indicate that intervention research is warranted in evaluating the feasibility and effectiveness of comprehensive programs that include nutrition education, cognitive behavioral topics (e.g., maintaining diet in social situations, dealing with stress), self-efficacy, and exercise among Hispanic immigrants with diabetes. Evaluation of whether such activities facilitate diabetes self-management must be conducted as well as examinations of the dosing, effective duration of each session, session frequency, and program duration needed to produce measurable physiologic or psychological benefits such as improved self-efficacy. Assessing the feasibility and sustainability of these interventions is essential for assuring that effective programs can be maintained once the research is completed and can be implemented in diverse settings.

Summary

This research study described the diabetes self-management practices of Spanishspeaking, Hispanic immigrants in the context of health literacy and the social environment using common themes presented by the participants. The study identified challenges to successful diabetes self-management in each of these areas, and it revealed opportunities for intervention and improving outcomes. The utilization of transformative learning theory in conjunction with social cognitive theory offered new insights into the participants' experiences of diagnosis and living with diabetes and presented opportunities for innovative research. While the results were drawn from the unique contributions of individual participants and should not be used to generalize among persons, the conclusions were based on common themes that arose from the experiences of this subset of the Hispanic population.

APPENDIX A

RECRUITING MATERIALS

Flyer



Postcard

¿Usted o alguien que conozca tiene diabetes tipo 2?

Estamos reclutando a personas hispanohablantes de México, entre 21-60 años, con diabetes tipo 2 para participar en un UNC estudio de investigación sobre el manejo de la diabetes. Durante su participación se le hará una entrevista sobre el manejo de la diabetes, se le medirá la presión arterial, peso, altura, y nivel de glucosa en la sangre. Solamente una visita que durará 2 horas.

Usted recibirá \$50 e información sobre la diabetes. Para más

información, por favor llame o texto a (919) 259-9281

APPENDIX B

CONSENT FORMS

English Version

University of North Carolina-Chapel Hill Consent to Participate in a Research Study Adult Participants Social Behavioral Form

IRB Study #_<u>11-0592</u>_

Consent Form Version Date: July 14, 2011

Title of Study: Type 2 Diabetes Self-Management: Influences on Nutritional Practices and Physical Activity among Spanish-speaking, Limited-English-Proficient Hispanics

Principal Investigator: Cheryl A. Smith-Miller, RN, M.Ed., BSN, BA
UNC-Chapel Hill Department: Nursing
UNC-Chapel Hill Phone number: (919)818-0734
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Co-Investigators: None

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Email address: dberry@email.unc.edu

Funding source and/or Sponsor: none

Study Contact telephone number: (919)818-0734

Study Contact email: csmith@unch.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty, still receiving the American diabetes information and \$50.00.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or

staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to learn about what Spanish-speaking Hispanics know about type 2 diabetes, how they learn about type 2 diabetes, and how they take care of their type 2 diabetes.

You are being asked to be in the study because you are 21-60 years old, have had type 2 diabetes over 1 year, and speak Spanish.

Are there any reasons you should not be in this study?

You should not be in this study if you have cognitive or physical impairment or significant comorbidities (e.g., kidney disease, heart disease) that prevent you from responding to instruments, independently self-managing or performing recommended type 2 diabetes self-management behaviors. If you are under age 21 or have gestational diabetes you should not be in this study.

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 30 people in this research study.

How long will your part in this study last?

It will take about 2 hours to participate in this study. We may want to call you later if you have questions. Would we have your permission to call you if we have question in the next few months?

_____Yes, you have my permission to call me if you have questions.

_____ No, you do not have my permission to call me if you have questions.

What will happen if you take part in the study?

We will ask you to complete the:

- Short Assessment of Health Literacy for Spanish-speaking Adults
- Diabetes Knowledge Test
- Diabetes Self-efficacy
- Eating Self-Efficacy Scale
- Exercise Self-Efficacy Scale
- Health-Promoting Lifestyle Profile II (HPLP Spanish version)

We will perform a blood test, measure weight, height, blood pressure, waist, and measure skin thickness at three places: on your back (under your shoulder blade), on the back of your arm and at your waist. Lastly, we will have an interview when we will ask you questions about how you obtain information or knowledge about type 2 diabetes, what you have learned from your family about diabetes, and about what you do to manage your diabetes.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. This study will provide new information about type 2 diabetes.

What are the possible risks or discomforts involved from being in this study?

There may be uncommon or previously unknown risks. You should report any problems to the researcher. During this study there is the risk of:

Emotional distress/embarrassment: a small degree of emotional distress and embarrassment may exist related to weight and adiposity measurements. Calipers used in the adiposity measurements at the midriff, tricep, and subscapular areas apply a slight pressure to the skin.
Finger-stick HbA1c: small risk of bruising and momentary pain will be expected from the

finger-stick site. There is a finger stick blood test we will ask to perform. The test is like the blood glucose test you may perform at home. The test could hurt or bruise your finger. Cherie is a registered nurse and has been trained in how to perform this test and has extensive experience. She will wear gloves and a new lancet will be used with each person.

Confidentiality: small risk confidentiality breach if participants are seen entering the site and meeting with the researcher and the research assistant.

How will your privacy be protected?

Your name or telephone will not be in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for

purposes such as quality control or safety.

Only the research team will have your name and telephone number.

Your information will be kept in a locked file or password protected computer inside a locked office. All of your papers and the recorded interview will have a case number, no name. Digital recordings will be transcribed and kept until all analysis is completed. Recordings will be maintained in a digital file on a password protected computer. Your name will not be recorded on the tape.

The typed transcripts will be kept in a locked file cabinet inside a locked office.

Check the line that best matches your choice:

_____ OK to record me during the study

_____ Not OK to record me during the study

What if you want to stop before your part in the study is complete?

You can withdraw from this study at any time. You will still receive the patient education information from the American Diabetes Association in Spanish, \$50.00 reimbursement for time and travel expenses and documentation of any physical measures. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

Will you receive anything for being in this study?

You will be receiving patient education information from the American Diabetes Association in Spanish, \$50.00 reimbursement for time and travel expenses and documentation of physical measures at the end of the data collection session.

Will it cost you anything to be in this study?

Any childcare costs will be a cost for you.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu **Title of Study:** Type 2 Diabetes Self-Management: Influences on Nutritional Practices and Physical Activity among Spanish-speaking, Limited-English-Proficient Hispanics **Principal Investigator:** Cheryl A. Smith-Miller, RN, M.Ed., BSN, BA

Date

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Printed Name of Research Participant

Signature of Research Team Member Obtaining Consent Date

Printed Name of Research Team Member Obtaining Consent

Spanish Version

University of North Carolina-Chapel Hill Consentimiento para participar en un estudio de investigación Participantes adultos Formulario de conducta social

Nº de estudio del IRB <u>11-0592</u>

Fecha de la versión del formulario de consentimiento: 14 de julio, 2011

Título del estudio: Autocontrol de la diabetes tipo 2. Influencias en las prácticas de nutrición y actividad física entre hispanos hispanohablantes con capacidades limitadas en inglés

Investigador principal: Cheryl A. Smith-Miller, RN, M.Ed., BSN, BA

Departamento de la UNC-Chapel Hill: Enfermería

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Origen del financiamiento: No hay

Número telefónico del contacto del estudio: (919)818-0734

Correo electrónico del contacto del estudio: csmith@unch.unc.edu

<u>¿Cuáles son algunas de las cuestiones generales que usted debe saber sobre los estudios de</u> investigación?

Se le solicita que participe en un estudio de investigación. La participación en este estudio es voluntaria.

Puede negarse a participar, o puede retirar su consentimiento para participar en el estudio, por cualquier motivo, sin sufrir sanciones y aún así recibirá información educativa para el paciente en español de parte de la Asociación de la Diabetes de Estados Unidos y \$50.

Los estudios de investigación están diseñados para obtener nueva información. Es posible que esta nueva información ayude a las personas en el futuro. Es posible que no reciba ningún beneficio directo por participar en este estudio de investigación. También pueden existir riesgos asociados con la participación en estudios de investigación.

Los detalles sobre este estudio se analizan a continuación. Es importante que entienda esta información de modo que pueda decidir en forma fundamentada acerca de la participación en este estudio de investigación.

Se le entregará una copia de este formulario de consentimiento. Debe preguntar a los investigadores mencionados anteriormente, o a los miembros del personal que los asisten, cualquier consulta que tenga acerca de este estudio en cualquier momento.

¿Cuál es el objetivo de este estudio?

El propósito de este estudio es obtener información sobre lo que los hispanos hispanohablantes saben sobre la diabetes tipo 2, la manera en que se informan sobre la enfermedad y la manera en que la controlan.

Se le está pidiendo que participe en este estudio porque tiene entre 21 y 60 años de edad, ha tenido diabetes tipo 2 durante más de un año, y habla español.

<u>Existe algún motivo por el que usted no deba participar en este estudio?</u>

No debe participar en este estudio si tiene impedimentos cognitivos o físicos o comorbilidades importantes (p. ej., enfermedades del riñón, enfermedades del corazón, etc.) que le impidan responder las preguntas de los instrumentos de evaluación, autocontrolarse independientemente o comportarse de acuerdo a lo recomendado para el autocontrol de la diabetes tipo 2. Si usted es menor de 21 años o tiene diabetes de gestación, no debe participar en este estudio.

¿Cuántas personas participarán en este estudio?

Si decide participar en este estudio, será uno de entre aproximadamente 30 personas en este estudio de investigación.

<u>¿Cuánto tiempo participará en este estudio?</u>

La participación en este estudio dura aproximadamente 2 horas. Es posible que deseemos llamarlo más adelante para hacerle preguntas. ¿Nos autoriza a llamarlo si tenemos preguntas en los próximos meses?

_____ Sí, doy permiso para que me llamen si tienen preguntas.

_____ No, no doy permiso para que me llamen si tienen preguntas.

¿Qué ocurrirá si participa en este estudio?

Le vamos a pedir que responda las preguntas de los siguientes instrumentos de evaluación:

- Evaluación breve sobre conocimientos de salud para adultos hispanohablantes
- Prueba de conocimientos sobre la diabetes
- Autoeficacia en el tratamiento de la diabetes
- Escala de autoeficacia en la alimentación
- Escala de autoeficacia en el ejercicio físico
- Perfil II de Estilo de Vida Promotor de la Salud (Health-Promoting Lifestyle,
- HPLP) (versión en español del HPLP)

Vamos a hacerle un examen de sangre, pesarlo, tomarle la presión, medirle la estatura y medirle el grosor de la piel en tres partes: en la espalda (bajo el omóplato), en la parte de atrás del brazo y en la cintura. Finalmente le haremos una entrevista con preguntas sobre la manera en que usted se informa o adquiere conocimientos sobre la diabetes tipo 2, lo que ha aprendido sobre la diabetes de parte de su familia y lo que hace para controlar su diabetes.

¿Cuáles son los posibles beneficios por participar en este estudio?

Puede haber riesgos poco comunes o hasta ahora desconocidos. Usted debe reportar todo problema al investigador. Este estudio implica los siguientes riesgos:

Angustia emocional o vergüenza: Puede sentir una pequeña medida de angustia emocional o vergüenza relacionada con el peso y la toma de medidas de adiposidad. Los calibradores con que se mide la adiposidad en la cintura, el brazo y la espalda aplican una ligera presión sobre la piel.

Pinchazo en el dedo HbA1c: Se espera un pequeño riesgo de magulladura y dolor momentáneo en el punto en que se pincha el dedo. Vamos a pedirle que nos permita tomar una muestra de

sangre pinchándole el dedo. Este examen es como el examen de glucosa en la sangre que es posible que usted se haga en su casa. El examen puede causar dolor o magulladura en el dedo. Cherie es enfermera registrada y tiene capacitación y una gran experiencia en este examen. Se pondrá guantes y utilizará una lanceta distinta para cada persona.

Confidencialidad: Hay un pequeño riesgo de falta de confidencialidad si se ve a los participantes entrar al lugar y reunirse con el investigador y el asistente de investigación.

<u>¿De qué manera se protegerá su privacidad?</u>

Su nombre y su número de teléfono no se consignarán en ningún informe o publicación sobre este estudio. Aunque se harán todos los esfuerzos posibles para mantener la privacidad de los registros de la investigación, a veces la ley federal o estatal exige la revelación de los datos, incluso los datos personales, contenidos en tales registros. Esto es muy poco probable, pero si en algún momento se requiere esta revelación, UNC-Chapel Hill tomará las medidas permitidas por la ley para proteger la privacidad de los datos personales. En algunos casos, es posible que los datos sobre usted obtenidos en este estudio de investigación sean revisados por representantes de la universidad, patrocinadores de la investigación u organismos del gobierno para propósitos tales como el control de calidad o la seguridad.

Sólo el equipo de investigación tendrá su nombre y su número de teléfono.

Sus datos se mantendrán en un archivador con llave o en una computadora protegida por contraseña en una oficina con llave. Todos sus papeles y entrevistas grabadas tendrán un número de caso, no su nombre. Las grabaciones digitales serán transcritas y se conservarán hasta que se complete el análisis. Las grabaciones se mantendrán en un archivo digital en una computadora protegida por contraseña. Su nombre no se grabará en ninguna cinta.

Las transcripciones mecanografiadas se conservarán en un archivador con llave en una oficina con llave.

Marque la línea que corresponde a su decisión:

_____ Acepto que se me grabe durante el estudio

_____ No acepto que se me grabe durante el estudio

¿Qué pasa si usted desea retirarse antes de que el estudio termine?

Usted puede retirarse de este estudio en cualquier momento. Aún así recibirá información educativa para el paciente en español de parte de la Asociación de la Diabetes de Estados Unidos, los \$50 de reembolso por su tiempo y sus gastos de viaje y la documentación de las medidas físicas que se le hayan tomado. Los investigadores también tienen derecho a terminar su participación en cualquier momento. Esto puede deberse a que usted tenga una reacción inesperada o no haya seguido las instrucciones o a que todo el estudio haya sido interrumpido.

¿Recibirá algo por participar en este estudio?

Va a recibir información educativa para el paciente en español de parte de la Asociación de la Diabetes de Estados Unidos, \$50 de reembolso por su tiempo y sus gastos de viaje y la documentación de las medidas físicas al final de la sesión de recolección de datos.

¿Le costará algo la participación en este estudio?

Todo gasto de cuidado infantil corre por cuenta suya.

¿Qué sucede si desea formular preguntas sobre este estudio?

Tiene el derecho de preguntar, y que le respondan, cualquier duda que tenga acerca de esta investigación. Si tienen preguntas o inquietudes, deben ponerse en contacto con los investigadores mencionados en la primera página de este formulario.

<u>¿Qué sucede si usted desea formular preguntas sobre sus derechos como participante de</u> una investigación?

Toda investigación realizada con voluntarios humanos es examinada por un comité que trabaja para proteger sus derechos y su bienestar. Si tiene preguntas o inquietudes acerca de sus derechos como sujeto de una investigación, puede ponerse en contacto, de manera anónima si lo desea, con el Institutional Review Board (Comité de revisión institucional, IRB por sus siglas en inglés) al 919-966-3113 o por correo electrónico a IRB_subjects@unc.edu. -----

Título del estudio: Autocontrol de la diabetes tipo 2. Influencias en las prácticas de nutrición y actividad física entre hispanos hispanohablantes con capacidades limitadas en inglés
Investigadora principal: Cheryl A. Smith-Miller, RN, M.Ed., BSN, BA

Acuerdo del participante:

He leído la información proporcionada más arriba. He realizado todas las preguntas que tengo en este momento. Acepto voluntariamente participar en este estudio de investigación.

Firma del participante de la investigación

Fecha

Nombre del participante de la investigación en letra de imprenta

Firma de la persona que obtiene el consentimiento

Fecha

Nombre de la persona que obtiene el consentimiento en letra de imprenta

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