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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

Mexican-Born Immigrant Decision-Making About
Self-Management of Type 2 Diabetes

By

Virginia Lynn Hart-Kepler

A dissertation presented to the

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Self-Management of Type 2 Diabetes

DISSERTATION

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Abstract

Mexican-Born Immigrant Decision-Making About Self-Management of Type 2 Diabetes

Purpose: This study explored how English-speaking Mexican-born immigrants with diabetes 2 (T2D) made decisions about diabetes self-management (DSM).

Background: Little is known about the self-care decisions of Mexican-born adults living in America with T2D. This information is needed so that health care professionals (HCPs) might better support patients' DSM. T2D is a serious, multi-system disease, effecting persons of Mexican heritage almost twice as often as non-Hispanic whites (NHW); with lower insulin sensitivity, rapid prediabetes/T2D onset, and severe outcomes. Ineffectively managed blood glucose (BG) risks serious complications, reduced life quality, and premature death. T2D is primarily self-managed; requiring BG control. HCPs teaching Mexican émigrés encounter culturally-steeped beliefs that affect decision-making, contradict the science model and are not understood by NHW-HCPs.

Methodology/Results: A purposive sample of 12 (10 women/2 men) were recruited in Los Angeles County. Each participated in a 1.5 – 4-hour semi-structured interview conducted mostly in English. A bilingual research assistant/participant-observer clarified questions/interpreted Spanish explanations. Participants were queried about what influenced DSM decisions, self-care and cultural aspects. Constructivist grounded theory informed data analysis through constant comparison; results were confirmed by co-analysis. Findings indicated that cultural requisites of *being proper* by practicing expected role/behavioral norms, eating hostess-prepared food, and *hiding* the socially-stigmatized diagnosis took precedence over positive DSM (+DSM). Food's smell/taste, had emotive meaning. Presence at frequent socially-required events and desire to "enjoy today" were powerful decisioning forces that interfered with *mastering* DSM. To meet social requisites and enjoy flavors gave short-term pleasure but raised BG. The progressive nature of T2D was feared; none understood the progressive loss of insulin production. *Motivation* of love of family/fear of dreaded outcomes significantly impacted decisions. *Accepting* the T2D diagnosis/responsibility for/outcomes of DSM were key to *being in the battle* daily toward +DSM. All were *Negotiating* between short-term pleasure and illusive, long-term BG effects.

Implications: HCPs may help patients understand cultural influences that interfere with/promote +DSM, helping identify ways to *negotiate* short-term cultural requisites/avoid long-term outcomes may result in safer DSM decision-making. The substantive theory:

Negotiating every-day diabetes self-management decisions about conflicts between culture, personal enjoyment, and long-term outcomes toward mastery of type 2 diabetes by Mexican-born adults.

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Dedication

This work is dedicated first to my parents, *Lloyd G. Hart* and *Patricia M. Bally Hart* who believed I could succeed at many things and supported all of my interests, spontaneous and passionate love for life and others, and sincere desire to make a difference. Their committed love for one another and our family has been a life-long mainstay of stability and perseverance. I miss you both deeply, and know you would be very proud of this day...

This is next dedicated to my beloved husband, *Bill Kepler*, and irreplaceable son, *Rémy AH Kepler*, for their love, forbearance and unending support. I treasure your love for me, regard for the mind, heart and spirit the Lord has given to me and years of prayer and sacrifices for this project. Never could life be as meaningful without you. Bill, I'm *so* grateful for you; your prayer has seen me to this end.

This work is also dedicated to the *participants* whose stories changed my practice and to *others of the same population* who will benefit from all that has been learned; of whom Dr. Instone once referred, "the salt of the earth." May these lessons benefit many more as others read of your *motivations* and *negotiations*.

In all, this work is fully dedicated to the *Lord Jesus Christ*, who inspired the question, called me back to research, provided unlimited perseverance, joy, meaning and deep satisfaction for this project that has been the most fulfilling of all of my professional endeavors. I love it to this late day. Lord, *You Alone* provided the vision, support, resources and endurance. That *You* have gifted *me* with this privilege has humbled me. You have molded me further.

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Chapter 1

Introduction

Background

Mexican-born immigrants bring to the clinical setting a unique mental model or explanatory model (Arcury, Skelly, Gesler, & Dougherty, 2004; Jezewski & Poss, 2002): patterns of thinking, perceiving (M. Z. Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Gaston-Johansson, Hill-Briggs, Oguntomilade, Bradley, & Mason, 2007; Weller et al., 1999), and responding to health, illness, and disease (Cabassa, Hansen, Palinkas, & Ell, 2008; Heuer & Lausch, 2006; Kleinman, 1980; López & Hill Golden, 2014; Luyas, 1991). This mental model affects how immigrants make decisions about the self-management, the different aspects of caring for their type 2 diabetes (T2D/DM2; Poss & Jezewski, 2002; Trief et al., 2013) within the U.S. health care system (Ashton et al., 2003; Simon, 2006). Immigrant clients are often not yet familiar with the Western biopsychosocial model (S. A. Brown et al., 2007) of the etiology and natural disease progression of diabetes (S. A. Brown, Upchurch, Garcia, Barton, & Hanis, 1998; Naidoo, Wing, & Rambiritch, 2016). Moreover, émigrés may not know other Latinos with diabetes who successfully manage daily blood glucose and practice preventative habits (Dlugasch & Ugarriza, 2014; Lorig, Ritter, & Gonzalez, 2003; X. Wang et al., 2016).

Explanatory model distinction. In addition to experiences with health and illness, many factors are known to contribute to a person's explanatory model, sometimes referred to as a *mental model* (Kleinman, Eisenberg, & Good, 1978; Redelmeier, Roszin, & Kahneman, 1993), in particular, culture, as well as language,

educational level (Applewhite, 1995; Fernandez et al., 2011; Simon, 2006; Swavely, Vorderstrasse, Maldonado, Eid, & Etchason, 2014; Yarcheski, Mahon, Yarcheski, & Cannella, 2004), and socioeconomics (Al-Ali & Haddad, 2004; McKinlay, Piccolo, & Marceau, 2013; Schneiderman et al., 2014). Both clients and health care providers (HCPs) hold their own unique explanatory models (Alcozer, 1998; Poss, Jezewski, & Stuart, 2003; Ramírez-Esparza, Chung, Sierra-Otero, & Pennebaker, 2011). Although people's beliefs and explanatory models generally become modified the longer they are in the health care system in the United States (Arcury et al., 2004; Schneiderman et al., 2014), HCPs encounter unique situations when teaching diabetes self-management (DSM) to émigrés of Mexican birth (Ağralı & Akyar, 2014; Vaccaro et al., 2012). Health care providers meet culturally-steeped beliefs about diabetes often related to experiences that not infrequently conflict with the HCP's commonly-held scientific model (Chesla, Skaff, Bartz, Mullan, & Fisher, 2000; Lemley & Spies, 2015; Pickett, 2016). This Western model held by HCPs is known to prevent disease and complications while reducing morbidity and mortality (Duggan et al., 2014; Sussman, Kent, Nelson, & Hayward, 2015). It is from this scientific model that diabetes education (DE) arises (Lorig, Ritter, & Jacquez, 2005; Rothschild et al., 2014; Swavely et al., 2014); however, it is not clear to the HCP what the immigrant understands about the biophysical model (Hatcher & Whittemore, 2007; Robertson, 2012). Differences between HCPs and patients may influence the optimal management of diabetes (Weller, Baer, Garcia de Alba Garcia, & Salcedo Rocha, 2012). One study on chronic kidney disease (CKD) identified actual differences in priorities between patients, their caregivers, and HCPs that complicated how the

three key factors understood “the notion of ‘living well’ with CKD” (Kang & Stenfors-Hayes, 2016, p. 1591).

Also lacking is the HCP’s knowledge of what factors or processes influence immigrant self-management decision-making. These are not documented.

Essentially, providers lack understanding (Brown & Hanis, 1999; Cusi & Ocampo, 2011; Garris, 2002) of immigrant decisional processes in relation to type 2 diabetes self-management.

Potential antecedent factor influence. Conceivably, antecedent factors affecting the choice to emigrate from Mexico have some bearing on decision-making once in the United States; however, the *if* and *how* is unknown. Multiple factors arising in Mexico are reported to contribute to emigration (Cano & DeLano, 2007; Stavenhagen, 1965). Previously identified influences include geo-political, economic, sociocultural-religious, and environmental-ecologic (Barkin & Ortiz, 1997; Buchenau, 2001; Carrera, 1998; De Genova, 2004; Diaz, 2000; R. H. Jackson, 2007; J. Ross, 1994). It is unknown how aspects of these factors, or factors not yet reported, might have influenced diabetes self-management decision-making in the past when living in Mexico, or more important to this study, once in the United States. This, too, is unreported to the HCP managing the health care of immigrants from Mexico with diabetes.

Statement of the Problem

While HCPs are acquiring more knowledge and understanding about Hispanic health beliefs (Barron, Hunter, Mayo, & Willoughby, 2004; Lemley & Spies, 2015; Schwab, Meyer, & Merrell, 1994), non-Hispanic providers are at times

underprepared or lack sufficient cultural understanding to ideally guide the health management of persons and families (Chesla et al., 2000) whose health beliefs and perceptions are not compatible with their own (Mayo, Sherrill, Sundareswaran, & Crew, 2007; Tovar & Clark, 2015). Communication between the provider and client plays an essential role in patient decision-making about succeeding health behaviors and interventions (Ashton et al., 2003; Caballero & Tenzer, 2007; Kirk et al., 2014). If a conflict or difference of understanding occurs between providers and clients, it can complicate adherence and/or impact the quality of health care delivery (Broome, 2012; Hagman, 2004). Moreover, Kim, Ford, Chiriboga, and Sorkin (2012) reported that poorer patient-provider communication has been asserted to contribute to health disparities in minority patients. Given the current rapidity and projected population growth of Hispanics in the United States, providers will increasingly interface with this expanding ethnic group (Strunk, Townsend-Rocchiccioli, & Sanford, 2013). According to the U.S. Census Bureau (2016), the Hispanic population increased to nearly 18% of the population in mid-2015 and is projected to have at least a 30% share of the total population by mid-century (Bernstein & Edwards, 2008).

The gap between the HCP's science-related explanatory paradigm and the immigrant's culturally-influenced model limits the ability of the HCP to initiate (Hatcher & Whittemore, 2007) diabetes education (DE) from the patient's reference point. If HCPs, particularly non-Hispanic HCPs, better understood the decision-making factors and processes related to the immigrant's diabetes self-management, providers would be better equipped to intervene in the decision-making process in

a more culturally-fit context. Understanding foundational, antecedent, and active processes, such as culturally-based influences, would presumably allow the HCP to better guide the immigrant toward preventative behavior (L. Chen et al., 2015; Creamer, Attridge, Ramsden, Cannings-John, & Hawthorne, 2016; McSweeney, Allan, & Mayo, 1997; Nath, 2007). In the meantime, the clinical expectation remains for the immigrant to locate him- or herself into the Western model and to accept the American cultural and health belief system. Thus, both a clinical-practice gap and a knowledge-literature gap exists between HCP knowledge and expectations in clinical practice, diabetes education, and how adult immigrants from Mexico make DSM decisions.

Purpose and Aims

The purpose of this study was to address yet unknown factors, dynamics, conditions, and processes utilized by immigrants of Mexican birth to make decisions about self-management of their type 2 diabetes. The specific study aims were:

Aim #1: Explore how the Mexican-born immigrant with type 2 diabetes makes decisions about diabetes self-management through identification and examination of:

Sub aim 1a: Factors, dynamics, and conditions that contribute to the decision-making process and the relative significance of each factor.

Sub aim 1b: Previous actions taken to address DSM when in Mexico and the United States, the rationale, and the outcomes; and,

Sub aim 1c: Processes of decision-making related to DSM.

Aim #2: Identify and explore antecedent factors in Mexico affecting emigration to the United States and whether those factors affect or have affected decision-making about DSM and, if so, how?

Research Question

How do Mexican-born immigrants make decisions about self-management of type 2 diabetes?

Significance

Mexico-born immigrants with diabetes are a fast-growing population at great risk for multiple morbidities and mortality (Centers for Disease Control and Prevention [CDC] 2016a). It is unknown how this population makes decisions about diabetes self-management, which is the foundation of diabetes care (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2016b). Without greater understanding of the factors that influence and the actual processes of decision-making in this ethnic group, many will eventually suffer significant complications, reduced quality of life, and increased risk of early death (Chamberlain, Rhinehart, Shaefer, & Neuman, 2016; Nalysnyk, Hernandez-Medina, & Krishnarajah, 2010). Diabetes education is successful with assisting diabetics in preventing untoward illness and events (Brown, Garcia, Kouzekanani, & Hanis, 2002), but programs are not always successful or sufficient to address Latino issues (Attridge, Creamer, Ramsden, Cannings-John, & Hawthorne, 2014); at times even those that are culturally designed for Latinos (S. A. Brown, Garcia, & Winchell, 2002; Lorig, Ritter, Villa, & Piette, 2008).

Learning about the process of and the factors that influence decision-making, in conjunction with known health beliefs (S. A. Brown et al., 2007; Lemley & Spies, 2015; Rogers, 2010), will facilitate the HCP in addressing the Mexican immigrant from his or her cultural reference point (i.e., explanatory model; Poss & Jezewski, 2002). This anticipated knowledge will serve to provide a bridge of understanding for the non-Hispanic HCP from the patient's reference point toward known scientific and biophysical knowledge models that prevent and delay the onset of disease and complications (Chamberlain et al., 2016). The theory derived from this study will serve as the framework for better understanding and improving the approach to diabetes care and teaching in the clinical setting. Additionally, what is revealed may contribute to instrument development in refining the design of a culturally, contextually-fit, diabetes education program. Ultimately, the triangulation of qualitative and quantitative data will further develop this needed body of evidence.

Type 2 diabetes.

Diabetes Mellitus 2 (DM2), also known as type 2 Diabetes (T2D), is a serious, chronic, progressive, multi-system, metabolic disorder characterized by persistent, recurring high blood glucose, otherwise known as hyperglycemia (CDC, 2014b; Naidoo et al., 2016; Rosenstock, 2007). The acronym T2D will be used throughout this paper except when referencing terminology used by other authors. The prevalence, or proportion, of persons with T2D, not only in the United States but worldwide, is increasing at an alarming rate and accounts for 85%-95% (Afable-Munsuz, Gregorich, Markides, & Pérez-Stable, 2013; Prevalence, 2012b) of all types of diabetes (World Health Organization [WHO], 2016b). Both *incidence* and

prevalence are used to describe the percentage of people with a disease, such as diabetes. The CDC clarifies the definitions as elucidated in Definition of Terms below. Essentially, prevalence denotes the proportion of persons “who have a condition at or during a particular time period” (Prevalence, 2012b, p. 4). Incidence, on the other hand, indicates the proportion or rate of persons who develop a condition during a particular time period” (Incidence, 2012a, p. 2) and represent new cases.

The root problem of diabetes is the gradual decline and often eventual loss of insulin excretion by the β -cells of the pancreas (Gastaldelli, Gaggini, & DeFronzo, 2017). Ultimately, peripheral resistance to insulin (Coleman, Lightell, Moss, Bates, Perrino & Woods, 2013) and insufficient insulin production render the hormone less effective or ineffective (NIDDK, 2016c). Diabetes 2 is primarily related to excess body weight and lack of physical activity facilitating complex, cellular changes in the body. Excess physical requirements for efficient insulin exceed the adequacy of insulin production and lead to hormone resistance in cells and peripheral vessels (Winnier et al., 2015).

Complications from the cumulative effects of hyperglycemia make diabetes the most-costly global, chronic condition (NIDDK, 2016b). High risk complications affect cardiovascular, cerebrovascular, renal, retinal, and neurologic systems; lead to reduced quality of life, injury, and disabilities (Pan American Health Organization [PAHO], 2017); and other potentially dangerous, complex outcomes including premature death (Berkowitz et al., 2015; Leung, Pollack, Colditz, & Chang, 2015).

For the vast majority of those affected, the disease does not need to progress to organ damage or mortality (National Diabetes Education Initiative [NDEI], 2017). Previously, the disease course of T2D was deemed difficult to alter (Gavin & al., 1997). However, research over the past two decades has demonstrated that for many persons, those who can modify their risk factors, including diet (American Diabetes Association [ADA], 2008b; WHO, 2016b), the disease can be avoided, slowed, or even reversed when consistent, aggressive efforts to control or avert hyperglycemia are made (Merlotti, Morabito, & Pontiroli, 2014; Phillips, Ratner, Buse, & Kahn, 2014). This is particularly true for those who control weight and maintain regular physical activity through lifestyle changes (Sussman et al., 2015; WHO, 2016c). Unfortunately, due to the insidious nature of T2D, persons are often unaware of how to interpret warning signs until a symptom or laboratory finding reveals the problem (Morbidity and Mortality Weekly Report [MMWR], 2013). Meanwhile, national and international organizations, governments, and programs support the prevention, delay of onset, and complications through behavioral changes (ADA, 2008b; NIDDK, 2016b; PAHO, 2012; WHO, 2014).

The Hispanic/Latino Influence

Hispanic/Latinos (H/L) have a disproportionate share (PAHO, 2004, 2017) of diabetes over non-Hispanic Whites (NHWs; ADA, 2007b, 2014a) and a 1.7 times higher likelihood of physician-diagnosed diabetes (CDC, 2016a). Geiss et al. (2014), examined data from the National Health Interview Survey (NHIS), for trends in incidence and prevalence of diabetes in nearly 665,000 persons in the United States between 1980 and 2012. Despite a gradual decline in the incidence of diabetes in

NHWs between 2008 – 2012, the incidence for H/L and non-Hispanic Blacks (NHBs) continued to increase significantly. While H/L in general have a higher likelihood of being affected by diabetes, persons of Mexican descent have the highest risk of all H/L ethnicities (ADA, 2014a). H/L have also been diagnosed at younger ages with less responsiveness to endogenous insulin (i.e., insulin resistance; CDC, 2008a; Cusi & Ocampo, 2011). This population develops more severe complications than NHWs, such as end-stage renal disease, and the overall death rate from diabetes is 40% higher (CDC, 2016a). While H/L have an overall lower death rate than NHWs, Mexicans and Puerto Ricans have an approximate 50% higher rate of diabetes-related deaths. In contrast, foreign-born Latinos are only half as likely to have heart disease. Diabetes is the seventh leading cause of death for NHWs in the US; however, it ranks fifth for H/L. In addition to a higher risk of diabetes, 23% more H/L are obese than NHWs, contributing to the diabetes risk (CDC, 2015a; MMWR, 2004).

Diabetes is essentially a self-managed disease (NDEP, 2008). Reducing avoidable risks through diabetes education and life-style changes has been well documented in substantially reducing complications (ADA, 2013; WHO, 2008). All persons with diabetes should receive culturally-accurate DE in order to self-manage effectively (S. A. Brown, 1999). DE is vital to develop healthy DSM practices; however, considerable evidence suggests that most DE programs lack adequate contextual fit for Latinos (Jack, Liburd, Spencer, & Airhihenbuwa, 2004; PAHO, 2012; Philis-Tsimikas et al., 2004; Weiler & Crist, 2009). Few DE programs are culturally geared; traditionally-designed programs applied to Latino groups are reportedly inadequate in reaching the population (S. M. Lee, 2005; Poss et al., 2003).

Diabetes education teaches persons with diabetes and their families about DSM, serving as the mainstay of diabetes care (NIDDK, 2016a).

Although H/L are more at-risk for diabetes and related complications, immigrants are considered a vulnerable population with less access to care, less quality of care, are often uninsured (Davidson et al., 2015; Hicks et al., 2006; Kollannoor-Samuel et al., 2011; National Center for Health Statistics, 2015; Vaughn, 2004), and lack English proficiency (Derose, Escarce, & Lurie, 2007; Environmental Change and Security Project, 1998; Frieden, 2015). Multiple external factors affect health care and one's access to care (Brown, 2008). These factors may affect decision-making about DSM. Decisions about diabetes may also be affected by the pre-emigration, antecedent factors in Mexico known to affect many Mexican citizens (Mechanic & Tanner, 2007). The socio-cultural-religious (Abalos, 2005; Rehm, 1999), geo-political (Cano & DeLano, 2007), environmental-ecological (Diaz, 2000; US Department of State [USDS], 1998), and economic (Garcia-Acevedo, 2003; McKinlay et al., 2013) realms historically influence emigration. How or whether these antecedents affect decision-making will be explored.

Data from a qualitative study that identifies the processes of decision-making, contextual conditions that affect choice, and how pre-immigration factors in Mexico influence decision-making about DSM will assist the non-Hispanic HCP who is working with H/L patients with diabetes. This understanding will enable HCPs to intervene more effectively in the decision process to provide better guidance for Mexican immigrants and their families toward more successful diabetes self-management behaviors and outcomes. Findings from this study have potential to

improve diabetes teaching in the clinical setting and the future development of culturally-embedded DSM education for this growing population. The primary purpose of this study is to identify the processes of decision-making and the factors that influence decisions about self-management of T2D by adult immigrants from Mexico.

Definition of Terms

Hispanic is an inclusive ethnic label describing people from all Spanish-speaking countries and does not provide distinctions among cultural beliefs, group values, socioeconomic status, education, degree of acculturation, or race (PAHO, 2016). H/L is understood to be a composite of many culture groups (CDC, 2006) born in and outside of the United States (López & Hill Golden, 2014). Although all H/L groups share aspects of common values and heritage (Thackeray, Merrill, & Neiger, 2004), such as language and an emphasis on extended family, H/L cultures vary significantly by country of origin (Hatcher & Whittemore; WHO, 2016b).

Latino is a more specific term representing persons of Latin American ancestry and incorporates individual cultures, beliefs, and languages. This distinction does not negate the importance of similarities in H/L cultures that may impact diabetes management behaviors (Weller et al, 1999). The U.S. Office of Management and Budget (OMB) and the CDC use the terms Hispanic and Latino interchangeably (PAHO, 2012; Thackeray et al.).

Mexican is a descriptive term used to describe Latino persons of Mexican heritage and culture. **Mexican-born** illustrates persons born in Mexico. Mexican

persons make up the largest and fastest growing H/L group in the United States, over 60% of this population (CDC, 2007c).

Emigrant or **Émigré** is defined as one who is “departing or having departed from a country to settle elsewhere” (Emigrant, 2016, p. 1). It is the individual who has left a country or region of the world to live elsewhere. He or she emigrated; left one place to go to another and the focus is on leaving as opposed to *coming to* or immigrating to a new place. The participants from Mexico left Mexico to live in the United States.

Immigrant has been defined by Kandula, Kersey, and Lurie (2004) as four principal categories of persons in the United States: (a) legal immigrants; (b) refugees, forced to flee one’s country due to persecution; (c) those seeking asylum (asylees also flee due to persecution, are not here legally, and must apply for refugee status); and, (d) undocumented. The former two are granted permission with proper papers to be stateside by the U.S. Immigration and Naturalization Service (INS). The latter two, here without legal documentation, are deportable or expendable (De Genova, 2004); may be deported. Immigrants are required to have vaccinations before arriving in the United States; refugees are not (CDC, 2015c). It is not the purpose of this paper to distinguish rank association, only to indicate that multiple categories fit this broader conceptual grouping.

Decision-making is a process in which one makes a choice for action or inaction. Various actors, conditions, or underlying motivational factors may influence how and what one elects to do. One may weigh the consequences of various options, consider health beliefs, role, social expectations, opinions of others,

what one has learned or seen modeled, or what action may have been successful, comfortable, unsuccessful, or uncomfortable in the past (Radina, Gibbons, & Lim, 2009). Often, decision-making is a type of problem solving; one usually considers context, and may or may not enfold beliefs, convictions, and expectations (Groff et al., 2000). Feelings and needs may drive choice, what one thinks, has analyzed, or reasoned. Choice is ultimately related to behavior, what one does or does not do; deciding not to choose an action or direction is a choice. Choosing can be a single momentary selection with eventual action or may be repetitious. Selecting may be individual, corporate, or interactional in nature (Strohschein, Bergman, Carnevale, & Loiselle, 2011). It is typically based on a problem, options, or regard for the consequences and/or living with one's choice. Preference may not be consistent or uniform between similar situations. Successful outcomes can strengthen confidence to choose; adherence can empower (Strohschein et al., 2011).

Prevalence is calculated as a rate using the number of people with the disease out of the total number in the patient sample or population (Prevalence, 2012b).

Incidence proportion . . . is a measure of the risk of disease or the probability of developing the disease during a specified period . . . it includes only new cases of disease in the numerator. The denominator is the number of persons in the population at the start of the observation period. Because all of the persons with new cases of disease (numerator) are also represented in the denominator, a risk is also a proportion. (Incidence, 2012a, p. 4).

Limitations and delimitations.

Due to the descriptive nature of this qualitative study, and small convenience-sample size, the findings from this study are not generalizable. This study was conducted primarily in English during the interview process, analysis, and methodological work with transcribed interviews in order for the doctoral-student/researcher to gain experience utilizing the constructivist methodology, which is inherently interactive in nature (K. Charmaz, 2008). It was anticipated that some Spanish would be employed for clarification of questions, brief responses, or for descriptive purposes by some participants. The intention was to have question-answer, concept, and construct-exploration dialogue in English. A future, funded study could examine bilingual transcripts of interviews by native Spanish-speaking participants to ascertain a more detailed, immigrant perspective on cultural factors or conditions in Mexico that may influence decision-making, allowing participants to explain contextual factors and processes in further detail.

Recent studies indicated that, while there are many similarities between Latino ethnic groups, more differences are being appreciated (Heiss et al., 2014; PAHO, 2012). There is a call to differentiate the unique features of distinctive H/L ethnic groups to gain a better understanding of diabetes, health beliefs, and statistics in specific groups (Chesla et al., 2000; López & Hill Golden, 2014). As the majority of Latino patients in Southern California where the study was done were from Mexico, this study examined the decision-making of Mexican-born immigrants only. Due to the complexity and compounding factors in insulin-dependent diabetes, also known as diabetes type 1 (Ku et al., 2016; van der Ven et al., 2003), and the

more prevalent form is T2D (PAHO, 2017), this study focused solely on T2D. Legal documentation status was not a relevant issue of this study and results of interviews with persons of either documented or undocumented status were essential to addressing the research question. Documentation status was neither questioned nor reported unless a participant voluntarily offered the information, indicating it was relevant to decision-making, or during the analysis process when it was found to impact decision-making for diabetes self-management in a Mexican-born immigrant with diabetes.

The following chapter will review the literature on the major aspects of the study, including T2D and prediabetes, diabetes self-management and pertinent aspects of diabetes education. Literature on the major factors that influence the Mexican immigrant and an extensive review of decision-making and decision-making by H/L will be reported.

Chapter 2

Review of the Literature

This chapter will review the literature on the major concepts of the research question: type 2 diabetes, diabetes self-management, Mexican-born immigrants, and decision-making. The four major content areas will be explored beginning with current, established content on diabetes, including rapidly progressing data on prediabetes; incidence and prevalence, diagnosis, insulin resistance, and disease progression; complications, including macro and microvascular, and related disease processes; risk factors; and the economic and personal costs of this global disease. Essential details and facts on Hispanic/Latinos (H/L) with diabetes, including the effects of an explanatory model and health beliefs, will complete the DSM section. The second section discusses the salient aspects of diabetes self-management, referred to as self-care in some instances, and diabetes education. Self-management of diabetes by H/L closes this section. The third section is a literature review on Mexican-born immigrants. This section reviews the influence of culture and ethnic identity, various aspects of vulnerable populations, and health disparities. Antecedent factors known to effect emigration from Mexico are briefly explained. The final section elucidates decision-making from the conceptual literature, including variables and conditions, and literature gaps. The final two decision-making segments include what has been reported on decision-making in diabetes and chronic disease, and decision-making in Hispanic/Latinos.

Diabetes. Type 2 Diabetes and prediabetes; Complications and consequences - Macro and Microvascular; Risk factors - Unmodifiable, Modifiable, and Economic and personal costs

Diabetes is a well-understood, major, multi-system disease capable of progressing with potentially dangerous outcomes (CDC, 2005a). According to the World Health Organization (WHO), diabetes is a cluster of diseases identified by high levels of blood glucose (BG)/hyperglycemia resulting from defects in insulin secretion and action, particularly insulin resistance (Lescheid, 2011). The incidence worldwide is burgeoning at an alarming rate (WHO, 2008, 2016b).

Type 2 diabetes and prediabetes: Incidence, and prevalence; Description and diagnosing; Importance of prediabetes; Insulin resistance and insufficiency; and Disease progression. The cluster of diseases known as diabetes mellitus includes type 1 diabetes (T1DM), often referred to as insulin dependent (IDDM); type 2 diabetes (T2D), which is the sole focus of this study; gestational or pregnancy-related diabetes (GDM); and less common forms of diabetes secondary to other causes, such as unusual genetic syndromes, diseases related to other pancreatic malfunction, drug- or chemically-induced, HIV/AIDS treatment, or following organ transplant (ADA, 2017b). The reasons for the growing concern over the expanding numbers of persons with T2D internationally and how and why this disease threatens both morbidity and mortality are important to grasp.

Incidence and prevalence. The CDC (2015b) recently reported that, between 1980 and 2014, the United States saw a fourfold increase in Americans being diagnosed with T2D, from 5.5 million to 22 million. Of serious concern, as of 2014,

one in four persons in the United States who had T2D was unaware of their diabetic status (NIDDK, 2016a). Data from NHANES 2011-2014 on almost 1,900 people found that over 34% of all ethnicities were unaware they had T2D and non-Mexican-Americans had an almost 70% odds of being unaware; Mexican-Americans were somewhat more aware. Persons 20-44 years and those over 64 years were more likely to be aware of their diagnosis than those 45-64 years (Menke, Casagrande, Avilés-Santa, & Cowie, 2017).

Type 2 diabetes is a growing international health problem of significant proportion involving all regions of the world, particularly low- and middle-income countries (Luk et al., 2008; WHO, 2016b). Of these same countries, only one in three reportedly have basic technologies to diagnose and manage T2D in primary care settings (WHO, 2016c). Globally, T2D has increased from 108 million persons in 1980 to 422 million in 2014, an adjusted increase from 4.7% to 8.5%, and reflects the universal increase in those who are overweight and obese (Afable-Munsuz et al., 2013) despite population growth (WHO, 2016c). Irrespective of the increase in diabetes education programs and general knowledge of risk factors, T2D continues to increase globally (Chatterjee, Khunti, & Davies, 2017) and is expected to double again, particularly in developing countries, in less than a decade (NIDDK, 2008; WHO, 2014). The WHO (2016c) reported that, in 2012, T2D was the known cause of death in 1.5 million persons; however, that same report indicated an estimated 3.7 million deaths were attributed to high BG, including the effects on cardiovascular diseases, chronic kidney disease (CKD), and tuberculosis; all related to recurrent,

above-normal BG. Most deaths were pre-mature, having occurred before age 70 (WHO, 2016b).

Further substantiating the salience of T2D-induced morbidity and mortality, a research project funded by the National Institutes of Health (NIH) recently released findings on the fraction or proportion of mortality attributable to T2D. Researchers utilized combined data from two national surveys, the National Health Interview Survey (NHIS) that ran from 1997 to 2009 ($N = 282,322$), and the National Health and Nutrition Examination Survey (NHANES) from 1999 to 2010 ($N = 21,814$). By design, the NHANES survey was “a stratified, multistage probability sample of the civilian, non-institutionalized U.S. population” (Vaccaro & Huffman, 2012, p. 391). Type 2 diabetes was self-reported in both surveys and the 3-month BG level, known as the hemoglobin A_{1c} (Hb A_{1c} or A_{1c}) or glycated A_{1c} was collected from NHANES data. Subjects were prospectively followed through 2011 for mortality status. The two studies reported the mortality proportion attributed to T2D was between 11.5% and 11.7%; the NHANES A_{1c} data attributed 11.8% deaths to T2D. Researchers were troubled to find that the actual proportion of deaths assigned on death certificates to T2D, as the underlying cause of death, was notably less at 3.3%-3.7%; this represents a sizable understatement of T2D-related deaths in the United States. The authors’ concern was that the underlying cause of death noted on death certificates was not a reliable marker for the actual contribution T2D played in mortality. They also asserted that, because T2D was frequently associated with other diseases (e.g., CVD, renal, peripheral arterial), other T2D-related or induced processes or complications were attributed as the underlying cause of

mortality when, in fact, the genesis of those disorders, at least in part, was the prolonged presence of T2D (Stokes & Preston, 2017). Considering the relationship of T2D to other serious disorders was important to comprehend more about T2D and how it has been identified as unique from other major medical problems.

Description and diagnosing. Type 2 diabetes was previously called non-insulin-dependent (NIDDM) or adult-onset diabetes (AODM; PAHO, 2017). The increasing incidence of T2D has been primarily related to lifestyle factors, chiefly poor diet and lack of exercise leading to excess body mass (WHO, 2008). Increases in T2D were linked to a greater incidence of obesity (Sellers & Goolsby, 2007).

Type 2 diabetes includes dysfunction in carbohydrate, lipid, and protein metabolism (ADA, 2008b). Because T2D is primarily an abnormal utilization of BG, also known as plasma glucose (PG), the threat of T2D is a continuum that extends from the high-normal BG level to prediabetes, an impaired glucose processing state, to diabetes (CDC, 2016c; Strauss et al., 2015). Prediabetes (Pre-T2D) is the endocrine state of those who are at increased risk of developing T2D (CDC, 2008b). Both high normal glucose tolerance (NGT), a fasting blood glucose (FBG) less than 100 milligrams per deciliter (mg/dL) with no caloric intake for 8 or more hours, and pre-T2D are hyperglycemic in nature, but below the threshold to diagnose T2D (Naidoo et al., 2016). Pre-T2D is determined by one of three mechanisms: (a) a FBG/fasting plasma glucose (FPG) level demonstrates impaired fasting glucose (IFG), between 100 and 125 mg/dL; (b) impaired glucose tolerance (IGT) is detected by a 2-hour plasma glucose level between 140 and 199 mg/dL, identified on an oral glucose tolerance test (OGTT; ADA, 2008b; Genuth, Palmer, & Nathan, 2016; Menke,

Casagrande, Geiss, & Cowie, 2015); or/and, (c) glycated hemoglobin A_{1c} test. The A_{1c} is a blood test routinely conducted about every 3 months as a point-of-care to evaluate the average level of glucose in one's blood (Balkau et al., 2015; Whitley, Hanson, & Parton, 2017). Glycation is the process of a glucose molecule bonding to a protein or lipid in the bloodstream (Dansinger, 2015). In this case, the glucose molecule attaches to hemoglobin, the protein in red blood cells (RBCs) that carry oxygen (NIDDK, 2014). Any given blood sample for A_{1c} allows a laboratory or in-office test to measure existing glycated hemoglobin on the red cells that are generated daily, circulate for an average of 3 months, then are reabsorbed within an average 90-day life-cycle. Every day, new RBCs are produced and others die. Thus, the A_{1c} is a reflection of one's average BG over the past 3 months and is reported as a percentage. About one-half of the glycated cells in an A_{1c} test are produced the previous month. An A_{1c} below 5.7% has been established as normal (Menke et al., 2015; NIDDK, 2014). A_{1c} is the test-of-choice for accuracy with the least variance within an individual and when compared to the other methods was significantly more favorable (Genuth et al., 2016; Whitley et al., 2017). In order for patients to understand their average BG, the A_{1c} can be correlated to the daily BG readings. For example, an A_{1c} of 6% is equivalent to an estimated average glucose (eAG) of 126. This is the lowest FBG reading to establish T2D, thus, an average indicates there are higher and lower readings within the 24-hour period. A reading of 9% is an eAG of 212 for the eAG reading and an A_{1c} of 12% is an eAG of nearly 300 (NIDDK, 2014). For example, daily ingested food/beverages would have actually contributed to

higher values than 300 on certain days because the FBG is typically higher after several hours of high caloric intake and has been averaged into the eAG.

In pre-T2D, the A_{1c} ranges from 5.7% – 6.4%, indicating *high risk* for developing T2D (Fox et al., 2015). Likewise, T2D is diagnosed utilizing the same testing methods.

Type 2 diabetes is confirmed with an A_{1c} over 6.5% (FBG/FPG \geq 126mg/dL or OGTT \geq 200mg/dL at 2-hours). Also, when a person has typical T2D symptoms of frequent thirst (polydipsia), urination (polyuria), hunger (polyphagia), fatigue, change in vision, and/or weight loss, T2D may also be diagnosed with a high random blood glucose (RBG \geq 200mg/dL) not related to a meal. Occasionally, a person does not experience notable symptoms and may be caught unaware of their diabetic status when undergoing routine blood testing (Genuth et al., 2016; Maty & Tippens, 2011).

The growing importance of pre-T2D. Previously, less attention was paid to the pre-diabetic state, referred to as *borderline* in the past (Gavin & al., 1997). This term, *borderline*, is still commonly used by Latinos; however, pre-T2D is now known to be present for approximately 10 years prior to reaching the threshold for T2D (Phillips et al., 2014). It is recognized as the period when one is able, in many cases, to avoid or delay the progression to T2D; the same is true for the high-normal range (Maty & Tippens, 2011). Like the actual disease, persons with pre-T2D are at significantly increased risk for heart and vascular diseases, stroke/cerebral vascular accident (CVA), and T2D (Cusi & Ocampo, 2011; Fox et al., 2015). As of 2012, over 35% of adults in the United States over the age of 20 and over one-half over 64 have prediabetes (CDC, 2016b). In 2016 that was 86 million Americans (Watson, 2017).

The CDC projects that, in lieu of lifestyle changes or other HC interventions, between

15% and 30% of the 86 million adults and adolescents in the United States with prediabetes will develop T2D within 5 years (CDC, 2016c). Due to the insidious, understated nature of the process, the transition from pre-T2D to T2D can be seamless, sometimes with symptom onset so subtle as to go unnoticed. Some may not know how to decipher the warning signs. Commonly, people misconstrue signs that forewarn of the presence of T2D. For the majority, it is difficult to identify without laboratory testing (Strauss et al., 2015; Zuniga, Drachman, & Paulino, 2004). The common symptoms of diabetes identified above, progress the longer one has the disease, usually hailing the disease's arrival (L. Chen et al., 2015; Genuth et al., 2016). The NHANES study reported that approximately one in ten persons with pre-T2D were aware they had the diagnosis (Morbidity and Mortality Weekly Report [MMWR], 2013). When one does not comprehend existence of a potential problem, then no action is voluntarily taken postponing diagnosis, intervention, and prevention; however, there are underlying and permanent changes well before the transition to the threshold of the diabetic state (Y. Li et al., 2016). Guidelines recommend screening for pre-T2D and T2D in children and adults at risk (Watson, 2017). A particular condition, insulin resistance, involves the insulin hormone itself, increasing the risk and progression of T2D.

Insulin resistance and insufficiency. Even prior to the diagnosis of T2D, cellular resistance to insulin gradually develops (Coleman et al., 2013) which hinders insulin from aiding glucose entry into body cells, as it is designed to do, and cells are unable to respond to the insulin (NIDDK, 2016c). The latter may be the result of a defect that develops in the insulin receptor signaling or through another

inadequate biochemical route or mechanism (Lescheid, 2011). This cellular-refusal to accept insulin is known as peripheral insulin resistance (IR; Gastaldelli et al., 2017). It is a condition in which whatever amount of insulin is produced, it is not used effectively by the body. The result is an accumulation of glucose in the blood rather than being properly absorbed by cells (NHLBI, 2011). The build-up results in pre-T2D and T2D; both of which lead to serious outcomes. With increasing cellular-insensitivity to the hormone, early-on, the elevated BG level continues to trigger pancreatic insulin release; this state is called hyperinsulinemia (Haffner, Mietinen, & Stern, 1996). However, over time the pancreas is unable to produce adequate insulin and excess glucose dominates (NHLBI, 2011). With excess caloric intake, and reduced physical activity in more people, the impaired caloric/energy overage contributes to "dysregulation" (Lescheid, 2011, p. 16) of insulin and leads to adipose deposition which contributes to IR.

Various studies have found that lipid metabolism plays a role in insulin resistance. In a recent publication, resistance to the "antilipolytic effect of insulin" (Gastaldelli et al., 2017, p. 1) was found to be higher across the age-continuum for persons who are obese and have a normal glucose tolerance, as well as persons with impaired glucose tolerance, or T2D, meaning that obesity, even in the person without diabetes, has similar effects as on those who have pre-T2D or T2D. Insulin resistance is more commonly seen in persons with excess body fat in the abdominal region (Winnier et al., 2015). A study conducted in South American identified that sleep deprivation of more than 8 hours per 24-hours reduced insulin sensitivity in

adolescents and was associated with central obesity (De Bernardi Rodrigues et al., 2016), indicating how early in life IR might occur.

Another factor that leads to reduced pancreatic β -cell function is the presence of systemic inflammation, even prior to T2D onset. Both IR and other intricate cellular functions are affected. When excess intake of nutrients results in the development of adipose tissue it also signals stress. Stress leads to recurrent activation of “proinflammatory kinase pathways” (Heiss et al., 2014, p. 2397) that cause the metabolic response to insulin to become desensitized. Even in dentistry there is growing evidence that when periodontal organisms enter the bloodstream, they release virulent factors that add to systemic inflammation, various biological interactions, and oxidative-stress-mediated pathways suggesting periodontitis factors effect T2D (Chapple, Genco, & workshop, 2013). The continuum from normo-vascular/normal glucose tolerance/pre-insulin resistance, to inflammatory and elevated glycemic-related changes mark generally-subtle disease progression. Other biochemical factors are found in association with the increased risk of T2D and pre-T2D; specifically, low magnesium levels. Magnesium-regulating genes are may increase risk through IR (Kieboom et al., 2017).

Disease progression. Because the pathophysiology of T2D is progressive in nature (Fleury-Milfort, 2008), there is a gradual, physiological dwindling of adequate, pancreatic β -cell-production of endogenous insulin, accompanied by advancing resistance to insulin (ADA, 2014c). The hormonal diminution of T2D eventually results in insufficient, and ineffective, endogenous insulin secretion and reduced function leading to hyperglycemia (ADA, 2017b). Although current

literature supports both genetic and environmental factors as the cause, the underlying pathophysiology of T2D continues to be studied; much more is understood about T1DM. Research is directed toward identifying specific phenotypes and genotypes so management might be more specifically-tailored (Chatterjee et al., 2017).

An aspect of prevention of the advancement of pre-T2D to T2D has been the use of metformin (MF), the first-line drug for the treatment of T2D. This drug is sometimes used to prevent or delay T2D onset in persons with pre-T2D (Qaseem, Barry, Humphrey, & Forciea, 2017) and offers other protective factors as well. Its primary function is to reduce insulin resistance, which facilitates glucose entry into cells and reduces hyperglycemia. Not all persons with pre-T2D apparently benefit from the use of MF. A recent study outcome indicated that only patients in the highest quartile risk to succumb to T2D were most likely to benefit from use of MF while in the pre-T2D stage (Sussman et al., 2015). The risk for progression, however, is not removed. If under these compromised conditions long enough, a person's pancreas will become incapable of producing effective insulin which leads to systemic and end-organ complications (NIDDK, 2016c). In cases in which T2D is poorly self-managed with inadequate BG control for an extended time, and/or insulin resistance is high, the individual's T2D must be treated with exogenous hormone (ADA, 2007a; Wick & Newlin, 2009). Likewise, even despite meticulous lifestyle practices and consistent use of oral and non-insulin injectable medications by some persons with T2D, when insulin presence is deficient and unsuccessful, the use of exogenous insulin becomes essential to maintain a euglycemic state

(Bahrman et al., 2014; Packer, 2007). Without it, hyperglycemia increases which leads to permanent alterations of the vascular system resulting in serious complications, or death (Fox et al., 2015).

Summary of T2D and pre-T2D. T2D is a major, endocrine system disease affecting most systems of the body. The disease is increasing at an explosive rate worldwide which parallels the increase in obesity and overweight; developing countries are at particular risk. T2D is progressive in nature and will calculably end in serious complications that eventually occur if BG is not managed correctly and consistently. Two primary malfunctions in insulin are the source of T2D-related issues. Over time, the β -cells of the pancreas increasingly lose the ability to produce the hormone insulin which is necessary to escort glucose into all body cells for energy. Nearly simultaneously, changes in the vasculature and cells throughout the body become resistant to the effects of insulin; together these lead to hyperglycemia. Numerous factors are being identified as contributing to the development of T2D, including cellular changes and thickening of vascular walls, pro-inflammatory factors, vitamin and mineral deficiencies, and others. Pre-T2D is the state of hyperglycemia lower than the T2D threshold, and above the normal glycemic range. Standards of measurement are universally accepted. During pre-T2D, some of the damage that arises to the vasculature and end-organs is already occurring; it will progress to T2D if not continually and adequately treated. The following segment discusses the vast, multi-system damage that occurs due to inadequately managed T2D.

Complications and consequences: Macrovascular - Heart and cerebral vascular effects; Microvascular – Eye, Kidney, Nerve and other complications.

The causes of T2D-related vascular alterations have been attributed to anatomic, structural, and functional modifications, all of which lead to injury that results in inadequate or failed function of multiple end-organs (Cade, 2008). Complications arise, in particular, due to recurrent hyperglycemia causing thickening of the vascular lining, reducing the blood flow to essential organs when damage occurs to the intima, or inner lining of the vessels. Researchers at Tulane University demonstrated that IR led to changes in insulin action which contributed to molecular modification in arterial cells which led to vessel wall thickening (CDC, 2014b). This process effected both large blood vessels, the arteries and veins, referred to as *macrovascular* (Cade), and small blood vessels, the capillaries, referred to as *microvascular* (The Emerging Risk Factors, 2010). Intimal thickening facilitates the development of atherosclerotic, plaque lesions (ADA, 2014c). Plaque lesions are formed of lipids, cholesterol, calcium, and other substances; together they narrow the vessel lumen. This abnormal hyperglycemic environment also facilitates clot formation, which further reduces patency. Clots may become embolic increasing the risk of life-threatening vascular events to the heart causing heart attack or to the brain, causing CVA (NHLBI, 2011). The outcome of changes involving the larger blood vessels lead to macrovascular complications.

Macrovascular complications. The effects of heart and cerebrovascular disease on diabetes. Macrovascular damage can lead to heart attack via coronary artery disease (CAD)/coronary heart disease (CHD), other cardiovascular disorders,

and cerebrovascular disease, or CVA. Together they are commonly termed cardiovascular disease (CVD; ADA, 2014c). Both heart attack, known as myocardial infarction (MI), and CVA, are the most serious complications to affect persons with T2D; they are life-threatening, macrovascular processes (CDC, 2005a). The ADA recently clarified the broader definition of atherosclerotic cardiovascular disease (ASCVD) as “acute coronary syndromes, a history of myocardial infarction (MI/heart attack), stable or unstable angina, CAD, coronary or other arterial revascularization, CVA, transient ischemic attack, or peripheral arterial disease presumed to be of atherosclerotic origin” (ADA, 2017i, pp. S-75). Atherosclerotic cardiovascular disease, often referred to simply as *heart disease* (HD), or *cardiovascular disease* (CVD), is ascribed to be the leading cause of both co-morbid conditions and death in persons with T2D. In fact, the risk that heart disease will cause heart attack or CVA that results in death is two- to four-fold higher in persons with T2D than without; independent of other risk factors (ADA, 2014c; The Emerging Risk Factors, 2010). It is equivalent to the risk of heart attack or death from heart disease in persons who have a history of having had a heart attack (NHLBI, 2011). This is why CVD is the primary risk factors for T2D today (Fox et al., 2015).

The NIH has defined *diabetic heart disease* (DHD) as the type of heart disease that occurs in persons with T2D. The risk for HD is higher, it can start younger, and become more severe. DHD sometimes includes CHD or heart failure (i.e., enlargement, reduced efficiency of the pumping function), known as cardiomyopathy. Myocardial weakness becomes insufficient to address normal body demands for circulating oxygen. When this occurs in a person with T2D, called

diabetic cardiomyopathy, the damage can result in heart failure and arrhythmias. Unfortunately, treatment interventions are often less successful which increases the risks for persons with DHD (NHLBI, 2011). In a large, international, multiethnic cohort, study which examined cardiovascular risk, researchers found that for each 1-mmol/L (18-mg/dL) *increase* in FBG there was a 17% predicted increase in future risk of cardiovascular events, or death. Following adjustment of CVD risk factors, an A_{1c} increase of a mere 1%, such as from 6.5 to 7.5 or 8 to 9, increased the risk of CVD events by 18%. The risk of MI, was almost one of five persons. The same 1% increase in A_{1c} was related to 12% to 14% all-cause mortality, which includes all causes of death (Fox et al., 2015). Likewise, a foundational study, conducted in the United Kingdom (UK) on the effects of oral diabetes medications, sulfonylureas class, or insulin on micro and macrovascular complications, researchers established that for each 1% *reduction* in A_{1c}, by either medication method, the risk of MI, CVA and heart failure diminished by 14%, 12% and 16% respectively (UK Prospective Diabetes Study [UKPDS], 1998a). A just-released study evaluated the effect of A_{1c} on older adults over age 65 using data from NHANES III, from 1999-2004, and Continuous NHANES, through 2011. Authors reported an A_{1c} >8% was related to increased risk of all-cause and cause-specific mortality. Since this data conflicted with some prior data they advised individualized BG targets which consider T2D longevity and comorbid conditions (Palta, Huang, Kalyani, Golden, & Yeh, 2017).

Another study reviewed literature on glycemic variations and chronic macro and microvascular complications. Researchers identified that nine of the ten studies found a significant, positive correlation between the variability of BG and disease

progression to cardiovascular events and death. Of significant concern was the finding that fairly brief, severe glucose elevations, commonly called “excursions”, (Fleury-Milfort, 2008; Nalysnyk et al., 2010, p. 288) such as occur following a large meal (postmeal) and during times of unmanaged BG while on a week-long vacation, were found to predict complications, even when the A_{1c} remained relatively stable. Beyond large vessel disease, there remains impaired circulation of small blood vessels that cause insult to other organs on the receiving end of small or microscopic vessels. The impairment of small vessel damage is termed microvascular disease. Interestingly, when assessing the correlation between hyperglycemia, and either micro- or macro-vascular disease, those organs affected by the microvasculature were found to be at higher risk, a 37% increased risk of retinopathy or renal failure (ADA, 2017j).

Microvascular disease: Retinopathy, nephropathy, neuropathy and other.

Diminished circulation of blood in small vessels leads to commonly-known end-organ damage. Most persons know that diabetes can result in damage to kidneys (nephropathy), eyes (retinopathy), nerves (neuropathy, which causes tingling, numbness and pain), and eventual amputation (ADA, 2013, 2017j), these can have devastating effects on life (Egan, 2017). Type 2 diabetes leads in causation of blindness, renal failure, and foot amputation (ADA, 2007a). These are more dreaded by many persons than macrovascular risks. Of significant concern is microvascular disease in younger T2D persons, those whose onset was before age 20, the prevalence of renal and retinal disease, and peripheral neuropathy was recently identified as significant despite A_{1c}, BMI, abdominal adiposity, or BP. This forewarns

of long-term complications in those who develop T2D early in life (Dabelea, Stafford, Mayer-Davis, & et al., 2017). Early screening is essential (Chatterjee et al., 2017; Pickett, 2016).

Diabetic retinopathy. Eye disease. Type 2 diabetes is the major source of blindness and visual impairment worldwide; the primary cause of the increasing incidence of blindness in adults in developing countries. It is a direct result of microvascular insult from persistent or recurrent hyperglycemia (PAHO, 2017). Diabetic retinopathy (DR) is a combined neuro-vascular complication directly associated with the extent of time one has T2D or T1DM, and the degree of hyperglycemic exposure and blood pressure (BP) control. Worldwide, DR affects 93 million. The ADA's 2017 updated position statement included a meta-analysis of 35 international studies conducted from 1980-2008 which examined prevalence of, and risk factors for, DR and vision-threatening DR. Pooled findings indicated the global prevalence of DR was over 35%; the more severe form, called proliferative DR was 7.5%. In developing countries, most new cases of blindness in persons 20-74 years were attributed to DR (Solomon et al., 2017; Yau et al., 2012). The WHO (2016a) reported that 7% of persons with T2D are at risk of blindness. Other eye disorders, such as glaucoma, cataracts, and ocular surface disease also develop, earlier and more often in the presence of T2D (ADA, 2017j; Threatt, Williamson, Huynh, & Davis, 2013).

Recent evidence indicated that persons with T2D who also had diabetic macular edema had significantly lower retinal blood flow than those persons who did not have DME. The reduced flow was independent of the presence of, or degree

of diabetic retinopathy (B. Lee et al., 2017). Other factors that increased the risk of retinopathy or were linked to it included protracted hyperglycemic states, BG excursions, HTN, nephropathy, and dyslipidemia (Do et al., 2015; Solomon et al., 2017). Aggressively and consistently addressing elevated BG to maintain a near-normal glycemic state, high BP by keeping it $\leq 130/$ and not $</60-70$ or $>/80$ and high cholesterol near-safe levels, have been shown to prevent and/or delay the onset and progression of DR (ADA, 2017j; Do et al., 2015). In some cases, control of these factors has improved visual function (ACCORD Study Group et al., 2010). Screening for the advanced retinal states of proliferative DR or macular edema, both of which may be silent and go unnoticed, was essential to prevent/reduce loss of vision and to intervene in a timely fashion to reverse the downward course (Writing Team for the DCCT/EDIC Research Group et al., 2016).

Nephropathy. Diabetic kidney disease. According to the ADA's (2017j) most recent update on microvascular complications, diabetic kidney disease, or CKD is attributed to T2D in 20-40% of persons with the disease, and is the primary cause of end-stage renal disease (ESRD). Current reports indicate that 10-20% of persons with diabetes die of kidney failure (PAHO, 2017). Unfortunately, due to the insidious nature of the disease process, renal disease may already be present by the time T2D is diagnosed. Of those persons over 65 years of age, 57% have not received adequate screening, although, rates of the disease have continued to decline (Carter & Lee, 2017; United States Renal Data System, 2016). CKD is staged according to the estimated glomerular filtration rate (eGFR) based on calculations of serum creatinine level. All five stages demonstrate some evidence of kidney damage, such

as protein in the urine, specifically, albuminuria. The stages range from Stage 1 which has normal or increased eGFR (≥ 90 ml/min/1.73 m²) to Stage 5 kidney failure (eGFR is < 15) or the individual is already on dialysis and there may be discussion about renal replacement. An eGFR < 60 is considered abnormal; only Stages 1 and 2 are not *abnormal* (ADA, 2017j). Late stage is highly dreaded, particularly by ethnic/racial groups who are more effected, such as H/L and NHBs (Bock, 2012). A urine test for microalbumin is usually obtained on an annual bases as an additional means of following renal changes (ADA, 2017s). Retinopathy is often associated with renal disease, although less in T2D than T1DM. But, it is on the rise; making it important to observe for retinal changes as renal changes occur (ADA, 2017j).

It is well-documented that tight glucose control can prevent or delay the onset and progression of renal disease. Some glucose-reducing medications have been helpful in lowering renal risk by effective glycemic control. However, the time from start of treatment to improved eGFR can be up to 2 years in T2D (ADA, 2017j; Andr sd ttir et al., 2014). Control of BP and high cholesterol are also known to delay renal disease progression; both help in reducing CVD events. Oral medications for both of these disorders can reduce CKD progression to ESRD. With anti-hypertensive medications, the challenge is to keep the systolic BP ≤ 130 while avoiding diastolic pressures $\leq 60-70$ or > 85 to preserve adequate glomerular circulation (ADA, 2017j; Grassi, Mancia, & Nilsson, 2016; Okada et al., 2013).

Diabetic neuropathy. Nerve damage. Diabetic neuropathies are a cluster of four unique neurologic disorders that are diagnosed by the exclusion of other neurologic syndromes. The two relevant to this study are: (a) peripheral

neuropathy, also referred to as distal symmetric polyneuropathy, which most commonly involves feet and legs (Pop-Busui et al., 2017); and (b) autonomic neuropathy, which is damage to the autonomic nervous system (ANS), affecting the heart, lungs, stomach, intestines, bladder, reproductive organs, and eyes (Mayo-Clinic, 2015a).

The serious consequence of diabetic peripheral neuropathies (DPN) is that about one-half of the time these neuropathies may not cause symptoms until advanced and damage to nerves is less treatable. This is particularly important for the most distal of the lower extremities, the feet. If neurologic changes are not recognized by HC providers (HCPs) and intentional foot care is not routinely performed by patients with diabetes, wounds to the under-sensitized limb can readily occur. Of those persons with DPN, one-half will suffer pain (Hershey, 2017). There are some treatments for DPN, but it is preferable to avoid any degree of damage (ADA, 2017j; Pop-Busui et al., 2017). Unlike management of other vascular complications that improve with tight BG control, a disadvantage of neuropathies in T2D is that glycemic control can only partially delay progression; however, loss of neuron function is *not* reversible. Early signs of pain, burning, and tingling, referred to as dysesthesias, involve smaller neuron fibers. Occasionally, sharp pains, cramps, or even hypersensitivity to any form of touch occurs. Once larger nerve fibers are involved, one can experience numbness and loss of protective sensation (LOPS). Weakness, loss of reflexes, balance and coordination may ensue. When the latter nerves are damaged, there is risk of diabetic foot ulcers which are slow healing and can eventually lead to amputation (ADA, 2013; Cousart & Handley, 2017; Mayo-

Clinic, 2015b). At least 15% of persons with diabetes suffer a foot ulcer at least once in their life with diabetes. Some persons are affected in the upper extremities as well (L. Wu, Norman, Dumville, O'Meara, & Bell-Syer, 2015).

Autonomic Nervous System neuropathy results when nerves that control involuntary functions of the body become damaged. In this discussion, it is due to high glycemic levels; however, other causes, including infection or some medications, may be the source. Damaged nerves interfere with neurotransmission between the brain and organs, which are dependent upon the ANS for proper function (Mayo-Clinic, 2015a). Malfunction may include erratic BP, including orthostatic hypotension, decreased (an early symptom) or rapid heart rate (a late symptom) and/or inability of heart rate and blood vessel regulation to compensate for BP irregularities. Evidence is growing that associates low Vitamin B12 levels to cardiovascular autonomic neuropathy; no causal relationship has been established. But, persons with diabetes who routinely take MF for BG control and proton pump inhibitors, such as omeprazole or pantoprazole to reduce gastric acidity, are more likely to have lower serum Vitamin B₁₂ levels (C. S. Hansen et al., 2017b). In contrast, both low and high levels of Vitamin D, called dysvitaminosis, have been associated with CAN. More study is recommended for both vitamin effects in diabetes (C. S. Hansen et al., 2017a). ANS neuropathy sometimes includes dysfunction of sweat glands (excessive sweating) and/or disturbances in internal temperature regulation. Too, any portion of the gastrointestinal (GI) track may be involved, including problems with motility such as ineffective esophageal or stomach contraction in which food does not move along the track, termed gastroparesis. In the lower GI

track, intestinal motility may lack regularity with bouts of constipation, diarrhea, or even loss of control resulting in fecal incontinence. Genitourinary neuropathies can lead to sexual dysfunction in both men and women ranging from reduced libido, to erectile dysfunction, to arousal or pain issues during intimacy (Ma et al., 2008). Urinary bladder inconsistencies can cause urinary malfunction, such as incontinence, urgency, weak stream, or other personally and socially-troubling symptoms (Mayo-Clinic, 2015a). Similar to other micro and macrovascular complications, when autonomic neuropathies are identified and treated, there is an opportunity to reduce symptoms and lessen sequelae; but, reversal is not possible (ADA, 2017j).

Another aspect of nerve injury results in neuropathic pain syndromes that may be caused by disorders that affect the brain or spinal cord, the central nervous system, as well as the peripheral nervous system. Injury can occur with recurrent hyperglycemia, cancer, and other nerve-damaging disorders. Pain due to nerve damage is called neuropathic pain, meaning there is pathology with nerve function and transmission (Beutler, Banck, Walsh, & Milligan, 2005). When nerve endings sustain damage, they do not stop sending pain impulses, even though there is no reason to continue; nothing is actually stimulating the pain reflex. Both spinal cord and brain pain-pathways enlarge and become more active which causes considerable, and difficult-to-manage, pain (Smith & Loprinzi, 2016). Because this pain can be severe it often impacts one's mobility and can lead to isolation or social dysfunction, all of which lead to reduced quality of life (ADA, 2017j).

Other complications. Alongside diminished neurologic function, particularly diabetic neuropathy with LOPS, is reduced vascular flow to extremities due to peripheral arterial disease, vessel damage via a recurring hyperglycemic state. Reduced, distal arterial flow eventually leads to foot ulcers and can result in infection that usually requires antibiotic treatment. If prolonged or severe, the result is loss of survivable distal tissues. Both nerve and tissue damage result in forfeiture of viable lower limb tissues (Mohammedi et al., 2016; WHO, 2016a) that requires amputation, from distal to proximal in many cases. This is one of the most dreaded complications, particularly for H/L and NHBs. In addition to poor glycemic control, peripheral arterial disease, and diabetic peripheral neuropathy with LOPS, other factors that contribute to an increased risk of amputation include cigarette smoking, foot deformities, a callous or corn in a pre-ulcerative condition, or history of foot ulcer, or amputation; also, visual deficiency and diabetic nephropathy demonstrate significant risk (ADA, 2017j).

In addition to increased susceptibility to acquired communicable illnesses, such as pneumonia and influenza (ADA, 2007a), persons with diabetes are at a significantly higher risk of morbidity and mortality than non-diabetics. This vulnerability also includes generally poor or delayed wound healing, dental disease (Chapple et al., 2013; Teeuw, Kosho, Poland, Gerdes, & Loos, 2017), and problems in pregnancy, including an increased risk of fetal death (Thackeray et al., 2004). These are particularly common in poorly controlled or extended diabetes. Even the incidence of depression is higher in those with diabetes and has been found to increase overall morbidity and mortality risk. This is more true in younger persons

with diabetes, those who use insulin, are overweight or obese, have a higher A_{1c}, have neuropathy, and/or are from an ethnic minority (WHO, 2016c). Both depression and anxiety have been found to increase the mortality risk in persons with T2D; independent of one another, and interfere with metabolic regulation (Naicker et al., 2017; Skinner, 2004).

In cases of uncontrolled diabetes, biochemical imbalances, and events such as acute, diabetic ketoacidosis and hyperosmolar (nonketotic) coma (CDC, 2007c) can occur. All these conditions can threaten health and/or quality of life and may further complicate one's self-care (CDC, 2011). As shown, research is underway to identify specific genes as the cause of and solution to T2D (Haverdink, 2006). However, until much more is understood about genetic etiology, prevention remains essential to address known risk factors (ADA, 2017e; Sellers & Goolsby, 2007).

Summary of complications and outcomes. Complications of T2D are secondary to the effects of hyperglycemia that result from progressive decrease of adequate endogenous insulin secretion intertwined with increased cellular insulin resistance. Complications fall into two primary categories. Macrovascular damage is the result of insult to and cellular changes and thickening of the larger blood vessels that predominantly place the heart and brain at risk. Damage to very small vessels and capillaries results in microvascular changes with impairment to the end organs: the eyes, kidneys, and nerves of the peripheral and the autonomic nervous systems. Blindness, decreased function of and renal failure are major functional risks. Loss of lower extremity function, sensation, balance, and risk of infection or amputation results from nerve and microvascular damage. Other potential complications

include infection, slow healing wound, dental issues, pregnancy complications, and depression and anxiety.

Left untreated or ineffectively managed these results are definitive. Persons with diabetes do not need to suffer disease progression and complications because research strongly suggests lifestyle interventions can change predicted outcomes (ADA, 2017d; Colagiuri, Colagiuri, Yach, & Pramming, 2006; National Diabetes Education Initiative, 2017; Phillips et al., 2014). The WHO (2008, 2016b) cited multiple studies that have demonstrated reasonable lifestyle modifications can prevent T2D onset in high risk persons; or delay onset. These behavior adaptations (PAHO, 2017) are specifically geared toward tight BG control to reduce rapidity of the disease process and prevent or delay onset of complications (ADA, 2017e; National Diabetes Education Initiative, 2017; NIDDK, 2016b; OMHD-CDC, 2008; Whittemore et al., 2009).

Risk factors: Unmodifiable, Modifiable, Economic and personal costs.

The risk of T2D is associated with factors that are both modifiable, meaning they can be changed or minimized by the individual; and non-modifiable, they cannot be altered. Experts and providers recommend that the at-risk individual attempt to control and reduce the potential for those risk factors that lead to T2D, recurrent hyperglycemia, or worsen related disorders known to promote the transition of pre-T2D to T2D, from the presence of no known vascular problems to serious macro and microvascular disease processes. In addition to hyperglycemia, those RF that are modifiable need to be controlled or kept in balance with physical activity, dietary

constraint, and medication (WHO, 2016b). Hypertension, dyslipidemia, obesity and stress are particularly problematic.

Unmodifiable risk factors. Five life factors that predispose an individual to an increased risk of T2D that cannot be modified include: (a) age over 45 years; (b) a genetic predisposition toward T2D, that is, having a parent or sibling with T2D (ADA, 2014c), as is very common in Hispanics (CDC, 2016a; Hartweg & Issabelli-Garcia, 2007); (c) one's ethnicity, that is why Hispanics have a higher prevalence (PAHO, 2012); (d) a history of gestational diabetes; and/or, (e) having delivered a baby greater than 9 pounds (CDC, 2016c). Because these life factors cannot be altered, those environmental and behavioral factors that the individual has some ability to control, such as dietary intake, need to be the focal point of reducing risk of chronically elevated BG levels (WHO, 2016c).

Modifiable risk factors: Obesity, HTN and dyslipidemia, Stress, and Cardiometabolic abnormalities. Those risk factors that can be modified include excess body weight in the form of overweight or obesity; insufficient physical activity, that is less than 3x/week; an unhealthy diet; and smoking. Other modifiable risk factors include controlling HTN; making improvements in IR, through glycemic control; and reducing abnormal lipid metabolism, that is often related to excess weight (ADA, 2015). Through one's behavior and environment one can make changes to prevent or reduce one's risk of developing T2D (WHO, 2016b). The ADA (2014a) reported that job strain was also a risk factor for developing T2D. They cited a European study of 125,000 subjects in whom job strain was of equal risk for men and women, as an independent risk factor, not related to unhealthy life-style

factors. Since there is a significantly higher risk of CVD in persons with elevated BG the international recommendations are to target environmental factors. But, the most essential effort is to reduce risk through prevention and reduction of overweight and obesity, including in children, through diet and adequate physical activity (Stern & Haffner, 1990; WHO, 2016c). Weight loss is the most cost-efficient way to prevent T2D and resultant complications; prevention of CVD is essential (Cusi & Ocampo, 2011).

Obesity. Obesity is recognized as a chronic disease, a major healthcare challenge both in the United States and around the world, and is a significant contributor to both morbidity and mortality (Heymsfield & Wadden, 2017; Soleymani, Daniel, & Garvey, 2016). The disease is clinically defined as a Body Mass Index (BMI) equal to or greater than 30 and overweight is a BMI between 25 and 29.9. The normal BMI range is 20-24.9. BMI is calculated as weight in kilograms divided by height in meters squared (kilograms /meters² [kg/m²]; Menke et al., 2015) and is most accurate when height and weight are measured and calculated rather than self-reported. Obesity is graded in three ascending weight levels; American's use Arabic numerals and international agencies use Roman numerals. Grade 1/I obesity is a BMI of 30.0–34.9. Those with Grade 2/II obesity have a BMI of 35.0–39.9, and Grade 3/III obesity is recorded as a BMI of 40 or higher (National Center for Health Statistics [NCHS], 2015). A recent study examined the association of BMI to a “healthy and chronic disease-free life expectancy” (Stenholm et al., 2017, p. 1) in European and Scandinavian subjects. Researchers identified an increased number of years without chronic disease (9 years for men and 7 years for women)

for persons of normal weight over those in class II obesity. Study authors suggested that the sooner obesity is reduced the greater the length of time expected for chronic disease-free years. Surveys have provided evidence that both overweight and obesity (O/O) are increasing in all age groups worldwide (PAHO, 2012). Between the years of 1999-2002, and 2011-2014, the prevalence of persons with Grade 1 obesity increased from almost 18% to almost 21%. Grade 2 prevalence increased from 7.6% to 8.8%, and Grade 3 increased from almost 5% to almost 7%. Also, of growing concern, is the prevalence of obese children. Between 2011-2014, nearly one of every 10 pre-school-aged children (2-5 years) were obese. Similarly, just under 20% of school-aged (6-11 years) children, and adolescents were obese, both in the United States (NCHS, 2015), and throughout the Americas (ADA, 2015; PAHO, 2012). Recent longitudinal evidence indicated that the long-term effects of childhood obesity, that is, a higher BMI and larger waist circumference in childhood were associated with long-term left-ventricular cardiac structural changes and another study found childhood obesity-based T2D in combination with heart disease significantly reduced quality of life and longevity (Wooton & Melchior, 2017; H. Yang, Huynh, Venn, Dwyer, & Marwick, 2017). A recently released observational study, using genome data from the U.K. Biobank found that those persons genetically-predisposed to a higher waist-to-hip ratio, once adjusted for BMI, were at increased risk of both T2D and CHD (Emdin et al., 2017). For adults in the Americas, nearly six of every 10 is obese or overweight. This has strong repercussions for the incidence and prevalence of T2D in these same continental

sectors, and around the globe, since excess weight most often precedes the diabetic continuum (NCHS, 2015).

Akresh (2007) pointed out that the BMI does not have a linear relationship with any particular objective health measures. For example, some persons with a very high BMI do not develop T2D, although they are at a significantly higher risk as reported. Also, because BMI does not account for muscle mass - muscle weighs more than adipose tissue. Because men have a higher percentage of body muscle, their BMI is higher per an equivalent height to women.

While obesity is not related in a linear fashion to T2D, it *is* strongly linked to O/O. According to the WHO (2016b), both O/O are the most influential risk factors for T2D. Worldwide, O/O together with limited physical activity are thought to be the most significant contributors to the diabetic burden. Evidence of a high proportion of physical inactivity and O/O have been provided by national population-based surveys from many countries over the past decade (WHO, 2016c). A Finnish study, likewise, asserted that the increase in T2D prevalence was due to sedentary lifestyle and obesity (Tuomilehto et al., 2001). The NHANES trial from 2005-2010 found that when both general obesity (BMI>30) and abdominal obesity, per specific US parameters, were compared in those persons with and without T2D, both measurements were higher in those with T2D than those with normal glucose control (Menke, Knowler, & Cowie, 2016). Another study examined both the effects of lifestyle and genetics on predicting obesity and T2D. They found that each, separately, had predictive accuracy to point toward T2D (Poveda et al., 2015). A contemporary research project that examined the genetic predisposition of a higher

waist-to-hip ratio found an increased risk of both T2D and CHD; authors asserted a causal relationship between excess abdominal adipose tissue and these undesirable outcomes (Emdin et al., 2017). Adding complexity, insulin resistance has also been found to be associated with obesity, a sedentary lifestyle, and advanced age (Genuth et al., 2016). In a recently published study, researchers of NIH-grant-funded research on T2D utilized the NHIS and NHANES data from late 1990's through 2011 to examine subgroups for causes of mortality. Of import to the current study on immigrants from Mexico with T2D, the NIH-funded researchers found that the fraction of deaths in obese persons reached almost 20%, nearly twice the number for non-obese person with T2D, which has ranged from <11.5-11.8% (Stokes & Preston, 2017). Evidence gleaned from the Women's Health Initiative (WHI) of postmenopausal women from different ethnic backgrounds indicated that the higher the degree of central obesity, using waist circumference, the higher the mortality level was in all ethnic groups (Z. Chen et al., 2017). In addition to higher morbidity and mortality rates, obesity increases HC costs consistently. During the first 5 years of the new millennium, between 15%-20% of all HC costs were obesity-related (Cusi & Ocampo, 2011). Contrary to the need for more weight loss in more individuals of all ethnicities, a disturbing new report discussed the trend in the change of attitudes and increased tolerance of the public toward O/O between 1988 and 2014. Using NHANES data, investigators found persons with excess weight were content with their weight and fewer were motivated to lose excess (Snook et al., 2017). Another report found that H/L and NHBs were less likely than NHWs to self-report their obesity status or acknowledge associated health risks. H/L in particular

were also less likely to identify the connection between obesity and T2D, HTN, and heart disease (Sivalingam et al., 2011).

In the effort to manage glucose levels in T2D through weight loss, persons are most successful early in the T2D process when insulin resistance, that is obesity-related, has resulted in "reversible β -cell dysfunction" (ADA, 2017g, pp. S-57; Corwin, 2017) while the ability to secrete insulin has remained fairly stable. There are various means of attaining necessary weight loss; most of which were not the purpose of this study. Lifestyle adjustments are appropriate for nearly every person with T2D, some though, will require, and benefit from, pharmacologic remedy (Heymsfield & Wadden, 2017), others from surgical intervention. The latter is being utilized more often than in the past; and quite successfully for many obese persons with T2D (Ikramuddin et al., 2016; Schauer et al., 2017; Steven et al., 2016).

In any case, maintaining weight is a challenge over the lifetime, particularly for those who already suffer with obesity. Evidence shows that for those who can achieve and maintain a 5%-10% weight loss for over 1-year several comorbid conditions improve. Although it is difficult to maintain weight loss through lifestyle adjustments, when provided with support for a healthy diet, consistent physical activity, and reinforced behavior changes, it is possible (Soleymani et al., 2016). In further support, recently published standards from the 2016 European Guidelines on CVD prevention in clinical practice, found that physical activity is associated with a reduced CVD risk despite a person's age or weight, as shown in the Rotterdam Study from 1997-2012 (Koolhaas, Dhana, Schoufour, & al., 2017). Fortunately, weight maintenance also can significantly reduce the development of and damaging

effects of HTN and high cholesterol. Since dietary control is an important aspect of weight control, both cholesterol and BP control are a benefit. The risks of not controlling both of these, especially in the presence of vascular changes of diabetes, can lead to dangerous outcomes (ADA, 2017i).

Hypertension and dyslipidemia. Macrovascular changes also contributed to hypertension (CDC, 2011). Elevated BP has been proven to be a primary factor to increase the risk of CVD events in persons with diabetes. HTN has been defined as a sustained, or recurring systolic BP of ≥ 140 / and/or a diastolic BP of ≥ 90 (Joint National Commission on High Blood Pressure - 7 [JNC7]; 2004). About three-quarters of persons with T2D have HTN; for the American public at large, close to one in every three had high BP (ADA, 2015). When HTN was present with diabetes, the risk of MI, CVA, and all-cause mortality increased. The Fox et al (2015) updated report on the prevention of CVD in adults with T2D asserted that when HTN and T2D are co-morbid conditions, the risk of developing heart failure, kidney disease, and other vascular events increased. Conversely, a study of over 11,000 in the Action in Diabetes and Vascular Disease (ADVANCE) trial assessed the long-term effects of lowering BP and intensive glucose control in persons with an extended T2D history. They found that the additive effects of control, reduced micro and macrovascular renal damage, delayed the onset of renal damage, and reduced all-cause mortality. Authors concluded that reducing BP and keeping tight BG control had important clinical outcomes (Zoungas et al., 2009). Newly released meta-analyses results of the 4 major studies (ACCORD, ADVANCE, UKPDS and Veterans Affairs Diabetes Trial [VADT]) revealed that intensive BG control over 5 years

decreased renal and retinal microvascular events and complications; but neuropathic events were not reduced (Zoungas et al., 2017). More specifically, a literature review of the influence of HTN on diabetic retinopathy (DR) provided evidence that DR could be prevented up to 4-5 years with safe BP maintenance. Although they found evidence of delay to DR disease, they did not find that BP controlled the progression of DR or that BP maintenance alone could prevent the occurrence of DR (Do et al., 2015). In summary, reducing BP to the 130-systolic range led to risk reduction of CVD in persons with T2D (ADA, 2015; Sarafidis, Lazaridis, Ruiz-Hurtado, & Ruilope, 2017) and could delay the onset of diabetic retinal disease (Do et al., 2015).

Another commonly associated factor known to further increase the risk of CVD is hyperlipidemia; the presence of excessive and unhealthy lipids/cholesterol. It is a major comorbidity often referred to as hypercholesterolemia or dyslipidemia. Although worse than the prevalence of HTN, the ADA reported that almost one-half of Americans had high cholesterol (ADA, 2015), but persons with T2D had a higher prevalence that contributed to the higher risk of ASCVD. Controlling BG levels has been thought to protectively modify plasma lipid levels, particularly in patients with very high triglycerides and an inadequately-controlled glycemic status (ADA, 2017i). However, there were successful ways to reduce this risk. Numerous randomized, controlled clinical trials (RCT) have given evidence to the benefits of pharmacologic interventions, particularly with the use of statins and other new drug classes, on outcomes of ASCVD, for both those with and without CHD (ADA, 2017i). A much more recently reported risk factor for adults under 50 years (ages 32-46) was the

presence of coronary artery calcium, identified on computerized tomography (CT) scan. Both NHW and NHB coronary artery calcium-affected young adults were found to have an increased risk of nonfatal CHD and CVD, and fatal CHD upon 12.5-year follow-up (Carr et al., 2017).

Conversely, results of a recently-released meta-analysis warned of the increased risk of the onset of T2D for those persons who used statins, the antilipemic class of medications to lower cholesterol, chiefly those persons in the pre-T2D range or with T2D risk factors. In trial meta-analysis, the incidence of new-onset T2D increased by 9%-13% in association with the use of all statins. However, in the observational studies, the increased risk was 44%. Authors recommended scrupulous monitoring in non-diabetic persons using statins (Casula et al., in press). Offering additional encouragement about the potential benefits of long-term lifestyle modifications on cholesterol esters and phospholipids, both precursors to high cholesterol, a timely Finnish study evaluated the effects of a controlled diet and exercise study on children 6-8 years. The intervention benefitted the composition of plasma fatty acids in the sample of over 500 children; investigators suggested the value starting dietary and physical activity in youth (Venäläinen et al., 2016).

In addition to efforts to modify weight and reduce incidence and progression of HTN and dyslipidemia, another lifestyle-related modifiable risk factor has been stress. All forms of stress, psychologically and physiologically-based have been found to affect the health outcomes of person with T2D (Chatterjee et al., 2017).

Stress. The literature links both psychological and physiological stress to T2D. Psychological stress may be related to the issues of life, such as work, finances,

family needs, relational and role requirements, or the actual stress of diabetes self-management, dealing with the worries, burdens, needs, management failures, and potential poor outcomes of T2D, sometimes referred to as diabetes distress.

Physiological stress involves numerous inflammatory markers and non-insulin hormonal influences, most of which were not addressed in this study. The two dynamics are closely intertwined as psychological stress is a frequent stimulant of, or foundation, to physiological reactions (R.-H. Wang et al., 2016).

Chronic psychologically-generated stress, due to life and work stressors, has been reported to influence one's metabolic mechanisms and add to insulin resistance (CDC, 2011) and the metabolic syndrome discussed below. A recent study found that chronic stress led to extended exposure to high cortisol levels, that were related to adiposity markers that persisted long term (S. E. Jackson, Kirschbaum, & Steptoe, 2017). Moderate and high degrees of chronic stress have been found to be related to higher FBG, post-meal BG, and A_{1c} levels. While the processes of how chronic stress interacts with glycemic metabolism or IR are still under investigation, it is likely to be complex in nature. Both behavioral aspects, including a diet high in fat and sugar, sedentary lifestyle, alcohol use, and smoking; as well as negative emotions, particularly anxiety and depression, are suspected contributors to the development and progression of T2D (McCurley et al., 2015). Cited earlier, job strain was found to be an independent risk factor for T2D in both genders (ADA, 2014a). Also, both stress and depression have been correlated to a higher incidence of CV mortality (Cummings et al., 2016). A report from Quebec evaluated the non-adherence to anti-depressant medication(s) (AD) in those with T2D and depression.

Non-adherence was defined as $\leq 90\%$ of days covered by one or more AD in the year (Lunghi, Zongo, Moisan, Grégoire, & Guénette, *in press*) following the diagnosis of depression. Authors found that 52% were non-adherent; they expressed concern that depression that is not managed is associated with poor glycemic control. Those who were younger, had an additional medication added, multiple HCPs, more than four pharmacy claims, higher SES, fewer diabetes complications, and were non-adherent at baseline were more likely to be non-adherent.

Some research has linked psychological stress with elevated proinflammatory factors, such as C-reactive protein (CRP), interleukin-6 (IL-6) and other cytokines, to an increased risk of T2D. A meta-analysis of over 30 studies that involved over 60,000 subjects concluded that elevated inflammatory factors were significantly associated with an increased risk of T2D development (X. Wang et al., 2013). McCurley et al. (2015) suggested these findings supported the premise that psychological stress might indirectly influence inflammatory processes that modify glycemic control.

Correspondingly, a psychologically-founded stress directly linked to T2D is called diabetes-related distress. It has been outlined as an emotional burden related to DSM, access-to-care, and support issues. When persons with T2D experience loss of control of their T2D through poor self-care and/or medication management, a sense of failure about poor BG control, or diminished self-efficacy in which one doubts whether (s)he can be consistent in DSM, the person is said to have an increase in diabetes distress. Although, diabetes-related distress appears similar to depression, discerning between the two is necessary as the approach to treatment is

different (Sweatman, Lauerer, Pruitt, & Drayton, 2017). In addition, sometimes illness, such as complications or disability, forces lifestyle change. Distress likely varies over time depending upon how well one adapts to T2D, the rapidity of disease progression, evolution of complications, and complexity of management and treatment (Burns, Deschênes, & Schmitz, 2015; Ehrmann, Kulzer, Haak, & Hermanns, 2015). Factors known to increase diabetes distress risk include having T2D at a younger age, low education level, poor diet, running a high BMI or A_{1c} level, using insulin, and/or being female. Specifically, there is a marked association between the length one has T2D and diabetes distress. The physiological stress of microvascular complications and insulin use, seen in those with extended T2D treatment, have been observed more often to have a higher degree of diabetes-related distress but not related to duration of disease (Kasteleyn et al., 2015).

Other hormone-secreting organs are also involved in stress reactions. The hypothalamic-pituitary-adrenal axis and the sympathetic-adrenal-medullary axis are activated during stress. While the acute response has normo-adaptive response, when either axis is stimulated for a prolonged period the result can be adverse and can increase the risk of metabolic syndrome (McCurley et al., 2015). Further exposures, such as periodontal disease and other infectious processes, have adversely affected glycemic regulation in both diabetic and non-diabetic individuals. In fact, the higher the number of microvascular complications and A_{1c} level in a person with T2D, the higher the risk for periodontitis infection (Nitta et al., 2017). The relationship severity to any of these infections has been directly dose-related; the more severe the infection, the worse the diabetes complications (Chapple et al.,

2013). In fact, periodontitis may actually herald the presence of and serve as a risk indicator of T2D. A recent European study found numerous dental patients who had periodontitis in the pre-T2D stage actually had T2D (Teeuw et al., 2017).

Of equal concern to chronic stress' contribution to the development of T2D is the strong relationship of chronic stress to the prevalence of CVD, CVA and related CVD risk factors such as HTN and dyslipidemia. The importance of stress' impact on CVD has been compared to that of dyslipidemia as a biological matter and smoking as a behavioral practice; both weigh heavily on cardiovascular outcomes (Gallo et al., 2015; McCurley et al., 2015). Kiecolt-Glaser et al (2016) found that women with a history of major depressive disorder who experienced a recent stressful situation, the stress affected the metabolic mechanism that promotes inflammatory (including CRP) and atherogenic responses. As has been demonstrated, various types of stress effect both diabetes-generated and cardiovascular-generated, maladaptive responses in macro and micro vasculature. They are intertwined and pose mutual, adverse risks to all levels of health.

Cardiometabolic abnormalities and metabolic syndrome. Cardiometabolic disease, as the name implies, is a cluster of cardiovascular diseases, including CVD risk, HTN, and dyslipidemia, along with metabolically-based diseases or disorders, particularly T2D and pre-T2D, metabolic syndrome (MetS), and non-alcoholic fatty liver disease (NAFLD; Soleymani et al., 2016). In the United States, approximately one-third of adults are thought to have MetS; the highest prevalence is in H/L. Often, cardiometabolic abnormalities (CMAs; Heiss et al., 2014, p. 2393) are referred to as components of the MetS. The MetS is an assemblage of risk factors that occur more

often together than alone, and lead to the development of CVD and T2D. For many years the presence of MetS has been observed and explored internationally.

The United States, through the National Cholesterol Education Program (NCEP of the NIH) has established the American criteria for the syndrome using ethnically-based research. The international community, through the International Diabetes Federation, has done the same by establishing thresholds for various race and ethnicities that are lower than NCEP criteria for waist circumference. Overall, there are strong consistencies for inclusion of CMAs. The variance between health agencies is related to waist circumference (Heiss et al., 2014; PAHO, 2017) as numerous people groups around the world are at risk for CVD and T2D when their waist circumference is less than American standards, such as Asians and Polynesians. The Endocrine Society has advised that “cut points for central obesity” (Heiss et al., 2014, p. 2395) be ethnicity-specific in order to avoid under or over-classification for the purpose of accurate risk management.

Nearly a decade ago, international efforts were made to come to a more consistent definition with uniformity of inclusion factors since it is a syndrome of various signs and symptoms. The “harmonized” (Alberti et al., 2009, p. 1640) risk factors include: (a) high BP ($\geq 130/$ and/or ≥ 85); (b) dyslipidemia, specifically, high triglycerides (≥ 150 mg/dL) with low high-density lipoprotein (HDL), termed *good* cholesterol (< 40 mg/dL) levels; (c) elevated FBG levels ≥ 100 mg/dL; and, (d) central/abdominal obesity. As suggested, the latter is ethnicity- and gender-ethnicity specific. The international community allows for obesity as a MetS factor, with waist circumference requiring further definition due to ethnic group variances.

These four factors are in the company of insulin resistance. The presence of three of the five factors in an individual qualifies them for a diagnosis of MetS (Cusi & Ocampo, 2011). Research continues, but it is understood that MetS, along with O/O or T2D, interact and lead to cardio and vascular damage (NHLBI, 2011). In fact, T2D-based MetS is an independent predictor to new onset CKD (Luk et al., 2008).

While MetS is often found as a RF for T2D or CVD as a syndrome, it has not been found to be of higher risk than the five individual RF that make up the syndrome; no consensus exists on using it as the screening tool to predict future T2D risk (Heiss et al., 2014). MetS continues to be reported in the literature as a risk factor for T2D and CVD and research continues. Thus, MetS is included in this paper in the discussion on T2D. As more models for causation are identified, there may be more links identified as it is an internationally-recognized phenomenon.

Factors thought to contribute to the MetS include physiologically-founded and behaviorally-based components. Excess food consumption is likely the most commonly-cited cause, in conjunction with a lack of adequate or absence of physical activity. Since excess nutrient intake precedes the development of adipose tissue and stress signals the release of proinflammatory factors that contribute to insulin resistance, then the intake of diets high in saturated-fats generate metabolic disease. Intestinal microflora are thought to promote CMAs by increasing the host's capacity to derive additional energy from digested food passing through the gut. These same organisms are thought to interact with the immune system through regulation of inflammatory signals. The latter may desensitize insulin receptor signals that may induce additional calorie ingestion (Heiss et al., 2014). More study is needed.

On the behavioral side, similar to obesity, a sedentary lifestyle has been linked to the effects of glucose metabolism and the MetS. In fact, a very recent publication from the United Kingdom, linked MetS to a sedentary life-style with fewer and shorter steps/day and more than 7 hours/day of sitting. Of importance was that a sedentary posture of sitting was significantly associated with a higher risk for CHD and increased waist circumference (Tigbe, Granat, Sattar, & Lean, 2017). Likewise, the Maastricht study (Berg et al., 2016), done in the Netherlands in collaboration with the European Association for the Study of Diabetes, found that a single extra hour of sedentary time was linked to higher odds (22%) of developing T2D, and an almost 40% increased odds risk for the MetS. While the links were not strong, researchers recommended further, longitudinal studies to determine if a sedentary lifestyle contributes to T2D and may be modified to reduce the risk of T2D and MetS. Due to concern about exacerbation of postprandial dysmetabolism in T2D, investigators of another recently released study evaluated the effects of different levels of activity on the numerous lipids. Activity levels ranged from sedentary to light activity of breaking up periods of sitting to simple activities utilizing resistance. Authors concluded that intentional interference in extended times of sitting may benefit post-meal plasma lipid-triggering inflammatory processes and/or oxidative stress effects (Grace et al., 2017). To emphasize the risk of a sedentary lifestyle, a recent study examined the relationship between infrequent physical activity of more than 30 minutes/week and the risk of elevated BG, as either pre-T2D or T2D not-yet-diagnosed in persons of normal weight/BMI. Researchers used existing data from the 2014 Health Survey for England. They

found that healthy-weight adults with low physical activity had abnormal glucose levels; some had undiagnosed T2D. Their healthy-weight counterparts, who had a higher level of physical activity, were less likely to have abnormal BG (Mainous, Tanner, Anton, Jo, & Luetke, 2017).

As the prevalence of T2D increases internationally, numerous elements, outside of diet and exercise, are being examined as contributing forces. Beyond complex science-based genetic and physiological factors, and psychological and relational influences within a person, causes, outside of the individual, such as socio-economics and political conditions, may mediate. The effects of urbanization, immigration, dietary changes in a new culture, and cultural beliefs in the context of globalization are all conditions that are thought to exert an effect on health in the formation of the MetS (Candib, 2007; Kodavanti, 2015). Not surprisingly, the annual cost of treatment for MetS is 1.6 times higher than those who do not have the syndrome (Cusi & Ocampo, 2011).

Economic and personal costs of T2D. The cumulative effects of hyperglycemia are the source of diabetic complications making the disease the most costly, chronic disorder worldwide (PAHO, 2017; Rizvi & Sanders, 2006; WHO, 2016b), including both direct and indirect costs (ADA, 2017i). Leung et al (2015) analyzed expenditures for lifetime HC and number of years of life lost in association with T2D. They reported a decrease in life expectancy ranged from 3.3 to 18.7 years and the increased lifetime expenditures for HC ranged from almost \$9,000 to almost \$160,000, depending upon the age, race, gender, and BMI of those studied. While the data was from the turn of the millennium, it was substantial in importance because

costs and the prevalence of T2D since have only increased. In 2007, indirect costs from absenteeism of 15 million work days reduced work productivity by 120 million work days, led to T2D-related unemployment disability (445,000 unemployment cases), and lost productivity nearing \$27 billion from mortality; these factors cost the United States \$58 billion. This represented a 32% rise of \$8 billion annually since 2002 (ADA, 2008a). As of 2012, statistics indicated that the annual medical costs of Americans with T2D were almost \$8,000, more than twice as high than for those who did not have T2D. The cost of diagnosed T2D included \$176 billion in direct health costs, plus almost \$70 billion attributed to decreased productivity, for a total of \$245 billion. In all, it was a further increase of over 40% in only 5 additional years (NIDDK, 2016b). The indirect productivity expenses are even higher in Latin American countries than direct costs (Barcelo', Aedo, Rajpathak, & Robles, 2003). Ironically, most national T2D-related costs incurred are related to unnecessary and preventable complications, physical complications that lead to disabilities, soaring economic costs, and many other expenditures, such as caregiver lost wages, that are not accounted for here (ADA, 2008a). Large portions of family income can be dedicated to T2D care (WHO, 2008).

The lifetime cost of T2D to the individual as a whole cannot be measured by dollars. Untold social and family suffering and personal expenses place a heavy encumbrance upon the person with diabetes, their family, and communities (Jack, Narayan, Satterfield, & Lanza, 2003). Recently, family members in an international study reported that supporting a person with T2D family member was "a burden" with an average of two of every three members reported having "distress" (Kovacs

Burns et al., 2013, p. 778) about the needs of their diabetic family member. For persons with T2D, psychological aspects can involve fear and anxiety, lower self-esteem and a sense of uncertainty as discussed in the Stress section above.

Relationships can suffer, comprising social, familial, and marital, including sexual relations (Callaghan & Williams, 1994). Risks of complications and effects on quality of life increase as time passes, the pancreas progressively fails, insulin resistance persists, and vascular changes with end-organ damage results (ADA, 2014c). These give way to potential disabilities (NIDDK, 2016b) and serious, enduring and compound complications (Berkowitz et al., 2015; Leung et al., 2015). Additionally, monies spent on HC management and complications, lost work days, societal burden, and other population-based expenses and losses, particularly for poorer societies, solidify T2D as the overall, most costly health condition in the world (WHO, 2016b). Diabetes is very complex for the individual and family; this calls for broad governmental and non-governmental commitments to address social, physical, and environmental issues that help to reduce the prevalence, and/or interfere with prevention of T2D (Chatterjee et al., 2017; Colagiuri et al., 2006).

Summary of risk factors. Risk factors for T2D fall into two primary categories. The first are unmodifiable because they are fundamental to a person's life that cannot be changed. A person over 45 years of age, or who has a parent and/or sibling with T2D, and, one's ethnicity, particularly Hispanic/Latino, cannot be changed. Neither can a pregnant woman who developed gestational diabetes nor delivered a child over 9 pounds modify those life facts; they are unmodifiable risk factors for T2D. However, there are numerous RF that are modifiable. International

agencies and state-sponsored reports point to the continual and worsening rate of obesity and overweight as the most potent contributor to the expansion of T2D as the latter follows the global pattern of weight gain. Abdominal adiposity carries the most risk for O/O. The partner to excess weight is the reduction in physical activity in persons worldwide. Both HTN and dyslipidemia are often found alongside obesity and both contribute to CVD that worsens and contributes to the complications of T2D. Managing both HTN and cholesterol within safe established ranges are known to reduce all associated disorders of ASCVD and T2D. Reduction in body weight decreases all of these risks. Psychological and physiological stress, depression, and anxiety contribute to pro-inflammatory and other biochemical factors that exacerbate all of the above, particularly in the chronic, high stress state. All of the CVD-related factors, hyperglycemic states, increased waist-to-hip ratio, and insulin resistance are cardiometabolic factors. Gaining control of each of these reduces long-term risks. As the most, costly disease, economically and personally/family-wise worldwide, T2D and related disorders require daily attention to bring them under control in order to avert, delay, and/or reduce untoward and often irreversible diabetes-related complications.

Summary of T2D. Type 2 diabetes is the most prevalent form of diabetes worldwide and is growing rapidly in all geographic regions of the world. Poorer societies are at particular risk and have the fewest resources to counter T2D. The increase in T2D parallels the rapid global rise of O/O, alongside reduced physical activity. Reduction in the production and effective utilization of insulin, frequently in the presence of excess weight, are major contributing factors. T2D-related problems

and physiological changes are a continuum identified through established global testing methods. Pre-T2D has become respected as an extended decade when vascular changes actively occur in the presence of hyperglycemia in advance of the diagnostic threshold. It is an ideal time for the persons to modify their lifestyle to prevent or delay the onset of T2D and curtail progressive, predictable injury. Most persons with impaired glucose tolerance are unaware and many reach T2D without recognition of their high BG.

Pancreatic-related factors include a diminution of β -cell production of insulin with systemic, cellular-resistance/desensitization to the effects of endogenous insulin. The hyperglycemic state provokes insulin excretion that promotes insulin resistance and contributes to damaging, macro and microvascular vascular morphology changes. Pro-inflammatory, and other physiological and metabolic factors affect lipids and proteins in changing the vascular environment. Due to the progressive nature of this multi-system disease, if consistent efforts are not taken to reduce hyperglycemia, complications will occur; some are not reversible.

Macrovascular changes affecting the heart (e.g., CAD, CHD, DHD, MI), cerebral vasculature (CVA), and cause other arterial-damaging complications. ASCVD is the leading cause of death in persons with T2D. Microvascular damage leads to retinal vasculature changes that lead to serious complications and blindness. Maintaining a healthy BP is critical; screening for insidious retinal changes is essential. Renal disease affects nearly two of every five persons with diabetes. Due to its stealthy nature, kidney damage may have occurred by the time of T2D diagnosis. In the late stage, many persons require dialysis; a treatment highly-dreaded by H/L. Consistent

BG control can improve both renal and retinal health; BP control is also essential. Neuropathy, on-the-other-hand, does not improve once damage has occurred. Both the peripheral and the ANS can become involved with damage to small peripheral nerves causing distal tingling, and numbness in larger distal nerves; eventually weakness or instability can occur. Due to loss of nerve sensation from hyperglycemia delayed wound healing with foot ulcers occur can foreshadow the eventual amputation of dying extremity tissues. Damage to the ANS affects dysregulation of heart rate and BP, GI peristalsis, genital and urinary function, and occurs after long or frequent periods of BG excursions. In some persons, injury to pain pathways occurs causing individuals to suffer burning, ineffective, ongoing pain that is difficult treat. Nearly one-half of diabetes-generated neurologic damage, including LOPS, goes unnoticed until advanced, and is irreparable. Diabetes also predisposes one to higher infection risk, biochemical imbalances a higher incidence of depression, and other vulnerabilities. All of these increase mortality risk.

Risk factors for T2D are both modifiable and unmodifiable. Modifiable risk factors include the major culprit of T2D, obesity and overweight. HTN and dyslipidemia worsen the vasculature and are higher risks in T2D. Psychological and physiological stress can increase BG and contribute to HTN and lipid function. The MetS is a RF, but not more predictive than individual modifiable RF; it continues under investigation. For most persons, T2D is preventable, or its onset and complications can be delayed and/or reduced through aggressive weight and BG control. Consistent maintenance of one's BG in the normal range, with a minimal

number of excursions, and regular physical activity to avoid a sedentary lifestyle are universally-recommended approaches to prevent complications and reduce RFs. Finally, the economic and personal/interpersonal costs to the person with T2D, their family, community, regional and national entities, the HC system in the United States, as well as, employment sectors, measures in the billions annually; they are the highest for any disease in the world. The ramifications for H/L with T2D is generally higher, sooner, and more significant than for other ethnic groups, particularly in the United States. The following section will discuss the factors in T2D as relates to the population under study.

Hispanics with T2D: Incidence and prevalence; The science, Vascular changes – CMA, stress, depression and anxiety; Explanatory model – Health beliefs and Fear of Insulin

Incidence and prevalence. Hispanic/Latinos, the largest U.S. minority group, with over 50 million living in the United States, make up 16-18% of the population (ADA, 2014a; Gallo et al., 2014). In a recent, prospective, multicenter study supported by the National Heart, Lung and Blood Institute (NHLBI), conducted in four U.S. metropolitan areas, the Hispanic Community Health Study/Study of Latinos (HCHS/SOL) extended from 2008 to 2011, included over 16,000 H/L ages 18–74-years. While the overall prevalence rate was 18.3%, it increased with age to reached over 50% for Latinas and over 44% for Latinos over 70 years. The risk to develop T2D also increases through the generations in Spanish-speaking immigrants; from first or second generation to third generation immigrant. Findings are from the Hispanic Established Population for the

Epidemiologic Study of the Elderly (HEPESE), a longitudinal cohort study of over 3000 Mexican Americans ≥ 65 years from five states in the American Southwest (Afaible-Munsuz et al., 2013). Current guidelines from the ADA and American Association of Clinical Endocrinologists specifically identify H/L ethnicity as a risk factor for both pre-T2D and T2D (Cusi & Ocampo, 2011).

The prevalence of obesity, smoking, heart disease, hypertension, asthma, cancer and T2D is higher in Hispanics born in the United States than those who are foreign-born (Frieden, 2015; Huh, Prause, & Dooley, 2008). Another set of indicators was the education and income levels of subjects. The higher these two factors, the lower the T2D risk. The Principle Investigator (PI) of the HCHS/SOL summarized that the population had a very high risk for diabetes-related complications from poor glycemic control. A troubling fact was that the longer one lived in the United States, the higher the likelihood that they would develop T2D (ADA, 2014a; Schneiderman et al., 2014). Similar findings were identified in a rural-setting study in which a higher level of acculturation corresponded slightly more to a higher prevalence of T2D than did a lower acculturation level (Coronado, Thompson, Tejada, Godina, & Chen, 2007). Acculturation meant the individual had adjusted to and taken on some of the dominant-culture's features and practices (Rodríguez-Reimann, Nicassio, Reimann, Gallegos, & Olmedo, 2004). A further study supported this data (Gorman, Read, & Krueger, 2010) while another study offered conflicting data (S. E. Ross, Franks, Hall, Young, & Cardarelli, 2011). Interestingly, the New Immigrant Survey found that the length of time in the United States was the most potent acculturation predictor of BMI; however, for those who did not make a

significant dietary adaptation in the United States after a number of years, the length of time here did not equate to further years of adaptation (Akresh, 2007).

Adding to the Hispanic disparity, as well as being diagnosed at younger ages, complications are more serious and occur earlier (CDC, 2008a). Compared to NHWs, in 2010, Hispanics were three-times more likely to need to be treated for ESRD (CDC, 2016a). Morbidity risk is increased due to higher rates of physical inactivity, mid-abdominal body fat, obesity in females, and high BP incidence (Heiss et al., 2014). Also, H/L are less sensitive to the effects of insulin, developing insulin resistance earlier than NHWs. While environmental and genetic factors contribute to IR in this population, the ethnic group as a whole is known to have a higher level of IR than NHWs, independent of other correlates. A foundational investigation, the Insulin Resistance and Atherosclerosis Study, referred to as the IRAS, provided strong predictive evidence that persons from all ethnic/racial groups who had both IR and β -cell dysfunction would develop T2D. In spite of this common factor, H/L convert more quickly from pre-T2D to T2D. Americans as a whole convert from pre-T2D to T2D at a 5%-10% rate annually, but the rate for H/L conversion has reached 15% (Cusi & Ocampo, 2011). Data from the NHANES study from 2009-2010 on almost 1,500 Hispanic women in the United States revealed that approximately 37% had FBG that ranged from pre-T2D to T2D. Through further analysis, researchers asserted that of the up to 5.5 million Hispanic women in the United States who have T2D, approximately 4 million had never been told by a HCP about their personal risk for either condition; nor were they informed of being *borderline* for T2D (Strauss, 2014). Borderline is the commonly used term within H/L communities; although, it

is based on outdated standards (Gavin & al., 1997). Approximately one-quarter of those women had no idea their FBG was elevated, or that they had T2D, and had not been for a HC visit for over one year. This was a lower percentage than for NHWs and NHBs. Authors suggested finding ways for Latinas to obtain health services and diabetes screening (Strauss, 2014). In 2010, according to the CDC (2016a), the mortality rate from T2D for H/L women was 1 1/2 times that of NHW women. The HCHS/SOL also found that over 40% of H/L were not aware of their T2D; the older the person, the less likely they were to be aware of their diseased state. Likewise, over one-half lacked sound glycemetic control (Schneiderman et al., 2014). Also troubling, national statistics from 2011-2014 identified H/L children ages 2-19 as having the highest rates of obesity of all youth in the United States, at about 22%; more than one of every five children (NCHS, 2015).

While the genetics of T2D are still not well understood (Skyler et al., 2017), there is strong agreement, across the international spectrum, that management of environmental factors, specifically obesity, is both the most effective, and least costly means to address the issues. Obesity and smoking are the two top risk factors for Hispanics (CDC, 2015a). Other factors known to affect the development of obesity in Hispanics are urbanization, mechanization, changes in nutrition, reduced physical activity, as well as other less clearly identified influences (Cusi & Ocampo, 2011; PAHO, 2017). Biophysical-based discrepancies also apply to H/L. In many of the complications, H/L face a higher incidence and often, earlier onset.

The science. Vascular changes: Cardiometabolic abnormalities, and the Influence of stress, depression and anxiety. There is a known, higher risk of

microvascular complications in H/L. Retinopathy was found to be almost twice as common in this population than NHWs and ESRD was 40% higher. Occasionally, a study differed with these results that led researchers to believe that differences were ethnic-group-specific; some H/L groups do have a lower T2D incidence, such as South Americans. According to the NHANES survey of 2003-2006, the prevalence of dyslipidemia was increased for Mexican-American persons compared to NHWs and NHBs. Specifically, triglycerides were often found to be higher; possibly genetically-based (Cusi & Ocampo, 2011).

Cardiometabolic abnormalities. From the cardiometabolic abnormalities purview and due to the epidemic of obesity in the Hi/L population, there is added concern about the risk that the MetS places on conversion to T2D, cardiovascular outcomes, and loss of life. Using the harmonized definition of MetS discussed above, the prevalence ranges from 34%-39% depending upon abdominal girth, with the highest rates in Mexican-Americans (M-As) according to NHANES (Heiss et al., 2014). An important finding from the HCHS/SOL was that 96% of women and 73% of men with the MetS had abdominal obesity using American standards. Thirty-six percent of Latinas and 34% of Latinos had three or more of the five CMA factors. Researchers concluded that CMAs that are known to be MetS factors, are high in H/L, although vary by gender and ethnic background. In women, abdominal adiposity is dominant and a mixture of CMA, such as high BP or deficient function in lipid or glucose metabolism, are more characteristic in men (ADA, 2014a).

Preventing metabolic aberrancies is important; so is understanding that CMA manifestations differ between genders and ethnicities (Heiss et al., 2014). A recent study that utilized data from the Women's Health Initiative looked at the relationship between waist circumference and BMI in postmenopausal women ages 50-79 of varying ethnic groups. They found that while overweight or mild obesity did not present as a mortality RF for most ethnic groups, they were risk factors for Latinas in category 1 obesity with a BMI 30-34.9 (Z. Chen et al., 2017). In recent years, psychological and physiological stress, depression, and anxiety have been identified as risk factors for T2D in vulnerable populations, such as H/L, and have important ramifications for the development and progression of T2D (Candib, 2007; Cusi & Ocampo, 2011; Wassertheil-Smoller et al., 2014).

The influence of stress, depression, and anxiety. Stress has been demonstrated to play an important role in T2D, insulin resistance, and metabolic syndrome (ADA, 2014a; Kiecolt-Glaser et al., 2016). It was not surprising then, that a multisite study by Gallo et al. (2014), the Hispanic Community Health Study/Study of Latinos Sociocultural Ancillary Study (2010Y2011) found that various indicators of chronic stress, both perceived, and traumatic, were related to CVD prevalence and risk factors, meaning more frequent cases of CHD and CVA in H/L. A rate of 38% of Mexican and Puerto Ricans with T2D were found to have a high level of depressive symptoms; other H/L ethnic groups had lower levels (Wassertheil-Smoller et al., 2014).

Stress was also linked to a higher frequency of T2D and HTN in almost 5,000 Hispanics who did not have CVD. Both perceived and traumatic stress were related

to a higher frequency of smoking. Chronic stress was related to less well-regulated glucose in Hispanics, even before the onset of T2D. In both medical anthropology and public health literature, several studies reported that H/L attributed stress and emotional distress as the cause of their T2D (Hunt, Valenzuela, & Pugh, 1998; Jezewski & Poss, 2002; Mendenhall, Seligman, Fernandez, & Jacobs, 2010; Weller et al., 1999). The HCHS/SOL did not find results to dispute the effects of stress on inflammation. Instead, findings suggested that in higher levels of chronic stress, glucose regulation in the pre-diagnosis period was less effective in Hispanics. Thus, it has been recommended that chronic stress be assessed as an aspect of cardiometabolic risk and that interventions targeting stress be implemented in T2D care of Hispanics (McCurley et al., 2015).

Previously, unity within the family has been documented to reduce psychologically-induced distress in Hispanic families. The family unit has arisen as the primary influencing force to promote enduring, emotional stability and well-being. This influence motivates harmonious, interpersonal relationships (Hernandez et al., 2016). Nevertheless, even a family with strong support can sometimes find an uncomfortable reversal of roles such as when children are reminding their parents what they should eat or not eat (Hatcher & Whittemore, 2007). A qualitative study that explored the effects of post-immigration on *familismo*, that is, the family as central to Hispanic life, reported that continuous social stressors tended to undermine the integrity of the Hispanic, immigrant-family health. Post-immigration demands stressed family roles and modified responsibilities as families navigated new social, work, and environmental terrain in their efforts to have a better life in

the United States (Rojas, Grzywacz, Zapata Roblyer, Crain, & Cervantes, 2016). At times, these situations resulted in anxiety or depression.

Priest and Denton (2012) found that various ethnic groups tended to be affected in different ways when evaluated for various anxiety syndromes. Both family cohesiveness and family discord related to a sundry of anxiety disorders in persons in Mexican families. The authors suggested that family structure, if too rigid, might foster task-performance expectations that promote negative patterns. More flexible family structures may facilitate healthier stress management. In a study by Cabassa, Hansen, Palinkas, & Ell (2008), Hispanics identified depression as an accumulation of multiple social stressors and reported that both somatic and anxious feelings were related to the Hispanic perception of depression, that they call *nervios*. In fact, the authors identified a reciprocal relationship between T2D and depression. Due to how both disease processes impact each other, the researchers recommended that integrated therapies be used in depressed Hispanics with T2D. Similarly, they urged HCPs to recognize *nervios* as the explanatory model of depression in low-income Hispanics.

Explanatory model: Health Beliefs and Fear of insulin. Alcozer (1998) explored the lived experiences of 20 M-A women (10 working class and 10 middle class) with T2D. She inquired about the experience of living with T2D, within the context of their family and generated an explanatory model of T2D. Upon reaching saturation, the study results suggested that with a family history of T2D, the diagnosis of T2D was a predictable trauma of perceived threat to one's life, self, and family. Themes also included coping with the incurable disease in order to control

fear as well as the struggle and processes of living with T2D in the presence of family. Distilling the threat and integrating diabetes into life were influenced by their explanatory model, family context, and by HCP response.

A literature review written by Hatcher and Whittemore (2007) concentrated on the beliefs about T2D of H/L adults. Consistent with other areas of the literature, they found subgroup variance; however, there were numerous, generally-held beliefs. Hispanic/Latinos understood the etiology of T2D included both biomedical causes, specifically heredity, and more traditional, folk beliefs, such as *susto*. *Susto* was the concept of having strong emotions, often related to fright or being scared. Mendenhall et al. (2010) asserted that those patients who were less well-acquainted with the biomedical model held by HCPs were more likely to attribute their T2D to stress and emotional distress. Hatcher and Whittemore (2007) found that Mexican persons more commonly reported a cultural etiology of their disease, of importance to this study. It is notable that three essential contributing factors now known to contribute to the risk of, or prevention of T2D, were unknown at that time (Heymsfield & Wadden, 2017; Soleymani et al., 2016). First, overweight was not thought to be a causation factor of T2D. Secondly, H/L did not believe that T2D could be prevented because T2D was/is known to be hereditary. That is, if one has the genes, one is destined to have T2D. Thirdly, diet and exercise were not consistently seen as helpful. D'Alonzo and Fischetti (2008) found that Latinas perceived vigorous exercise as being “unfeminine” (p. 175) and claimed that responsibilities to their families were more important and interfered with exercise.

Traditional Hispanic foods were seen as barriers to healthy eating, especially at family gatherings.

In various studies, participants saw T2D as a serious illness that caused many identifiable symptoms. In general, participants knew that treatment of T2D was done through biomedical and herbal therapies. In some studies, participants used herbal treatments but did not know what the herbs were supposed to do. In one study, M-As used herbs to treat T2D that were not indicated for T2D (Poss et al., 2003). Their T2D explanatory model also included religious beliefs. A negative attitude about insulin was also a common finding (Hatcher & Whittemore, 2007). In a complimentary study, the beliefs about T2D in non-diabetic H/L were explored. Consistent with the explanatory model of H/L person with T2D, the disease was seen as a serious, inherited disease that could result from strong emotion (*susto*), or lifestyle factors, such as poor self-care or diet; and weight loss was a worrisome outcome (Arcury et al., 2004).

Garcia (2002) found similar results, but added that symptoms appeared to have different meanings to different persons and sometimes varied within the same individual. An additional factor, when comparing the explanatory models of patients and HCPs, was that M-A patients tended to associate and elaborate the cause of health issues as arising from their social environment. They “narrate distressing tales about how their illness has affected their lives” (M. Z. Cohen et al., 1994; Mendenhall et al., 2010, p. 223). Hispanic adults did believe that T2D was a serious, silent, life-threatening disease about which one lives in fear, and it sets the person with T2D apart from other persons. In all, authors found a “fairly cohesive” (Hatcher

& Whittemore, 2007, p. 536) explanatory model of T2D. They recommended HCPs use this model as a point of initiation in discussing individual patients' explanatory model of illness, to clarify misconceptions, and develop an individualized plan of care.

Finally, in a study of migrant farmworkers, that looked at their perceptions of living with T2D, six themes were identified: (a) commonness or usualness of diabetes; (b) causes of diabetes; (c) symptoms that occur during the time before diabetes is diagnosed; (d) bearing and implications that diabetes has on daily life; (e) fear of long-term complications due to diabetes; and, (f) understanding the chronicity of diabetes. It is unknown if the latter included understanding of the progressive nature of T2D. These findings were aspects of individual perceptions and cultural beliefs (Heuer & Lausch, 2006). Understanding linkages between beliefs and actions can facilitate improved care (McSweeney et al., 1997).

Health Beliefs. Health beliefs are core attributes of one's explanatory model and are foundational to the decision-making process (Bade, Murphy, & Sullivan, 1999). There is a need for non-Hispanic HCPs (N-HHCPs) to understand factors that influence the beliefs, values, and perspectives of H/L patients, in order to understand their health behavior choices. When information gained by N-HHCPs is used to facilitate patient understanding of how to more successfully participate in their own health practices, DSM is improved (S. A. Brown et al., 2007). All HCPs should appreciate the influence that personal habits, the family, important others (Chesla et al., 2003; Gallo et al., 2015; Priest & Denton, 2012), and culture likely has upon the person with T2D (Applewhite, 1995; Robinson et al., 2016; Schwab et al.,

1994). Cultural variances are generously noted in the literature. For instance, Jayne and Rankin (2001) reported beliefs of Chinese study subjects with diabetes did not correlate with the biomedical model perspective. Japanese women with breast cancer needed different forms of social support than would be offered in other cultures (Makabe & Hull, 2000) and culturally-based barriers to pap smears were identified in some Thai women (Jirojwong, MacLennan, & Manderson, 2001). These subjectively-based views often do not align with the biophysical model held by HCPs (Kleinman et al., 1978; Taft, Riehl, Dowjotas, & Keefer, 2014).

Typically, the health-science model views biophysical causality of disease and illness as superior to the non-science/non-biophysical model and may inherently consider characteristics of other cultures as inferior, or persons of the science perspective may believe persons of various ethnic backgrounds utilize cultural traditions to make meaning out of events that affect health and life, rather than use science-based rationale. Some N-HHCPs who hold a biophysical health perspective tend to believe that non-Western cultures have “magical thinking” (Thorne, 1993, p. 1938). Ironically, the Western view fails to see the contradiction that rituals, myths and symbolism are present in, or rationalized by, allopathic medicine also, such as the value of a white lab coat, having a waiting room full of people needing assistance, and use of titles. Failure to understand other cultural belief systems and how these contribute to decision-making can interfere with HC delivery (Hartweg & Issabelli-Garcia, 2007; Mayo et al., 2007).

Hatcher and Whitemore’s (2007) integrative literature review also found that, in general, Hispanic adults understood the source of diabetes was an

integration of biophysical etiology and traditional-folk beliefs, such as *susto* and religious beliefs. The latter trend contrasted fatalism with faith in God as a support system through whom strength and hope were gained. Similarly, Larkey, Hecht, Miller, and Alatorre (2001) found faith in God to be important to the success of health for Latinos. Hernandez et al. (2016) identified faith and religious beliefs as prominent factors of well-being. Participants expressed that without faith, they could not achieve a state of well-being. Faith in God helped them to view problems as a means for personal growth and suffering as a road toward a satisfying life.

Susto was also an important factor in several studies. In the Jezewski and Poss (2002), the Arcury et al. (2004), Sullivan, Hicks, Salazar, and Robinson (2010), and Garcia (2002) investigations, *susto* was considered a primary cause of diabetes. In a more in-depth look at this phenomenon, *susto* was defined as “an event that could change the bodily state, causing a susceptible person to be more vulnerable to the onset of T2D after some unspecified time” (Poss & Jezewski, 2002, p. 360) to which some were believed to be more susceptible. Lemley and Spies referred to it as “severe fright” (2015, p. 185) and reported that Mexican immigrants had a variety of views on the relationship of *susto* to diabetes, such as its connection to depression.

Integrative treatments from both biophysical-Western medications and traditional folk-herbal sources have been recognized, and mixing the two has been a common behavior (Manderson & Canaway, 2013). Those who use both, report that they trust, are knowledgeable about, and comfortable with the use of traditional folk methods, and also have confidence in allopathic/Western care. It is typical for family

and friends, neighbors and coworkers to offer guidance on the use of herbals (Hatcher & Whittemore, 2007; Poss et al., 2003).

Complementary and alternative medicine (CAM) is often referred to in Western HC as *herbal medicine*, which also includes teas and sometimes the use of curanderas, cultural medicine healers (Rogers, 2010). A literature review of 42 studies between 1980 and 2007 on the use of CAM found that 50%-90% of Hispanics used some CAM substance. Researchers were surprised to find that several likely-unfamiliar-to-HCPs substances, such as linden, sapodilla, and star anise were routinely found in various studies (Ortiz, Shields, Clauson, & Clay, 2007). Examples of other herbal substances included sabila (aloe vera) and nopal (prickly pear cactus), that have broad and decades-old use in treating depression and other maladies. Nopal is also used for BG regulation. While some evidence in the literature, even if insufficient, upholds the effectiveness of their use, they lack Food and Drug Administration regulation, in part because of the risk of side effects. However, these factors do not dissuade their cultural use (Lemley & Spies, 2015; Sullivan et al., 2010). Similarly, it was common for migrant farm workers to use herbal remedies because they felt that herbs and other natural substances were more trustworthy than Western medications. Another factor was that remedies had been passed down through the generations, often by mothers. The majority reported no adverse reactions although the literature cited various untoward drug-herb interactions that ranged from gastrointestinal upset to renal toxicity and hypoglycemia. Also, not uncommon, they did not mention herbal use to HCPs (Poss, Pierce, & Prieto, 2005). However, in a multi-ethnic study, elders did report use of

CAM alongside conventional medicines. In all, authors found that CAM did not replace biomedical use, especially for conditions that were considered “too serious” (Manderson & Canaway, 2013, p. 1638; Schoenberg, Stoller, Kart, Perzynski, & Chapleski, 2004) such as CVD.

Therefore, respectful awareness of herbal remedy/CAM use, susto beliefs, and other culturally-based effects, such as trust first in the advice of family members, are essential factors for HCPs to consider. Assessing these influences and utilizing communication skills that are sensitive to cultural factors is important to success of the N-HHCP to effectively provide supportive care and to intervene in a constructive fashion (Lemley & Spies, 2015). Despite the mutual comfort with the effectiveness of Western HC, strong, negative attitudes toward use of exogenous insulin prevailed, fearing it was dangerous or resulted in untoward outcomes or death (Hatcher & Whittemore, 2007).

Fear of insulin. In spite of a cultural apprehension to use exogenous insulin, an increasing number of persons with T2D use it to help maintain BG control, often while continuing to take oral agents and practicing diet and exercise (ADA, 2005). However, many who would benefit from exogenous insulin are hesitant to use it, even when they know they no longer benefit from oral agents (Bahrman et al., 2014; Nam, Nam, & Song, 2014). These fears may be due to negative preconceptions, especially for insulin-naïve older patients. One author quoted participants as saying, “I think the drug itself is like cancer. You know, the chemotherapy kills, and I think the insulin does more harm than good,” and another said, “I feel like I was kind of a failure in doing my part and taking care of myself” (Miller & Powell, p. 1).

Geriatric patients who are insulin-naïve have had a markedly stronger negative attitude about insulin therapy over patients who already used insulin. Some studies report a stigmatization of insulin injections (Bahrmann et al., 2014; Davies et al., 2013; Skinner, 2004). These apprehensions are common in the Hispanic population and other cultural and ethnic groups (Bock, 2012; Miller & Powell, 2014). Nevertheless, in the absence of effectual insulin, whether endogenous or exogenous, complications of hyperglycemia do occur (ADA, 2014c). All of the above factors and conditions influence DSM in H/L (Kale et al., 2015).

Summary of T2D in Hispanic Latinos. Type 2 diabetes disproportionately affects H/L more than other minorities. They possess more risk factors and suffer a greater burden of T2D with a higher incidence, more severe disease. Over 18% of Mexican persons have T2D. The prevalence is nearly twice that of NHWs and increases significantly with age.

The longer the Mexican immigrant is exposed to the dominant culture in the United States, the more likely s/he will develop T2D. Having a higher education and income level does reduce the risk. Hispanic/Latinos are diagnosed when younger, and are predisposed to more significant and earlier disease-related complications. Insulin resistance develops sooner and progresses more quickly from pre-T2D to T2D, and the rate of conversion to T2D is higher.

Some studies have shown that two of every five H/L are unaware of his or her diabetic status; this is more common in elders. Additionally, Hispanic women are often not informed of their risk of pre-T2D or T2D, and have less frequent HC visits and screening. Hispanic/Latinos children and youth have the highest obesity

rate (22%) of all ethnic groups. In addition to the genetic predisposition, T2D generally results from poor life-style practices. In, particular, O/O are worsened by nutritional changes while living in the United States, and insufficient physical activity are important contributing factors. Other environmental, urbanization, and pro-inflammatory factors also impact the development and progression of T2D.

Hispanic/Latinos experience complications that affect the cardiovascular system and microvascular retinal, nephritic and neurologic structures. Each cardiometabolic abnormality, meaning HTN, dyslipidemia, hyperglycemia, and insulin resistance, is common in the population. The issue of increased, unsafe, abdominal adiposity is a major contributing factor, especially for Latinas, whereas lipid and glucose metabolism are more common in Latino men. Psychological and physiological stress, depression, anxiety, and perceived traumas are recognized as having an impact on development of T2D in H/L which increases the progression of the disease. Biochemically, chronic stress worsens insulin resistance, a major contributor to MetS, and interferes with glucose metabolism. Chronic stress also promotes HTN and macrovascular changes. The effects of post-immigration life on H/L families has placed significant stress on some family units as they attempt to adjust to life in a new culture that tends to modify family structure and roles; this adds to chronic stress. In other cases, family structure and expectations may increase stress and promote anxiety or depression. Depression can also be seen by the H/L as being the result of accumulated stresses. Some family units adjust more effectively and provide adequate support.

Over the past two decades, an H/L explanatory model of T2D has been described. In all, T2D has been understood to be both genetically-tied and environmentally-related through lifestyle factors, especially overweight, obesity, poor self-care, and psychological stress, in particular, *susto*, the experience of strong emotions, shock, or fright. Those less influenced by the biophysical model more commonly ascribe the genesis of T2D to emotional distress. Hispanic/Latinos recognize that T2D is treated by biomedical means, particularly medications, and through herbal approaches; although, they do not always know what a particular herb does for their T2D. Dietary management is commonly understood. Wariness about exogenous insulin is common. In general, T2D has been seen as a very serious, potentially life-threatening disease that leads to multiple, serious complications. The meaning of various symptoms differs between individuals and sometimes the same person. Symptoms tend to be central to interpreting meaning and the impact of T2D on life. The H/L understands that T2D is common in their culture, symptoms come before the diagnosis, and T2D has burdensome consequences for everyday life as chronicity wears on each Latino person with T2D. The fear of long-term complications of the disease is never far from their minds.

Health beliefs are a salient aspect of one's culture and help to form one's mental model. Religious beliefs are an integral part of the H/L belief system. Patients and HCPs alike have an explanatory model of health, illness, disease, and experience all contributing to that mental model. These models help one to understand a particular disease, such as T2D. Latinos reportedly have a combined perspective about T2D conjoined of traditional-folk beliefs and biopsychophysical

(Western) components with a possible fluidity between the two perspectives. T2D is seen as a serious, hereditary and life-threatening disease that cannot necessarily be prevented. Insulin continues to be avoided as a method of T2D management; however, for those who use exogenous insulin, the PIR is less significant. Other barriers to self-care and T2D improvement exist in one's everyday life.

Having now a thorough perspective on the prevalence, incidence, causes, complications, and risk factors of T2D and pre-T2D, including the uniqueness to the H/L and Mexican person with T2D, the following section will discuss diabetes self-management in general. Those factors that influence DSM and life-style modifications that control BG are discussed. Since DSM is founded on education about DSM, those conditions and factors that influence the learning of DSM will be elucidated and include the importance of English language comprehension and proficiency, the necessity of culturally-architected DSM education for successful DSM, and the critical HCP factor that influences aspects of DSM will be reviewed.

Diabetes Self-Management: Influencing aspects, Life-style modifications, Education, Diabetes Self-Management by Hispanic/Latinos

The majority of T2D HC is self-managed (NDEP, 2008), hence, self-care is termed diabetes self-management (DSM). Self-managed means the individual who has the chronic illness actively addresses the various facets of their own care, in concert with their family, and guidance by their HCPs (Schulman-Green, Jaser, Park, & Whittemore, 2016). When first diagnosed, persons with T2D have to adjust their own daily activities, and often that of their family, so as to incorporate T2D self-care activities, behaviors, and goals into their daily lives. Typically, this is done close to

the time of diagnosis when the new person with T2D has learned of the diagnosis and the myriad steps that need to take place in order to practice effective DSM.

A recent study conducted by researchers at the National Institute of Nursing Research (NINR), examined literature in self-management to identify common data elements (CDEs) of SM including theoretical, conceptual, and definitions with the intent to propose a set of CDE to be developed for research in SM. They identified three initial, working, common, self-management processes that were pertinent to individuals who practice DSM. These included (a) activation/getting started, (b) self-regulation/self-control, and (c) self-efficacy/becoming skilled and confident to manage chronic conditions (Moore et al., 2016). Previous to that, a meta-synthesis of 101 studies published from 2000-2011 explained SM processes in various chronic disorders. They, too, found three similar processes: (a) focusing on illness needs; (b) activating one's resources; and, (c) living with chronic illness. Authors noted the importance of SM processes varied over time as well as between and within persons. They called on HCPs to build SM plans around the needs and process of the patient through interactive communication (Schulman-Green et al., 2012). As DSM is an ongoing process, the challenge is for the HCP to assist or facilitate the integration of DSM into people's lives, based on their phase in the DSM process, life context, and capabilities; adequate support is essential (Auduly, Asplund, & Norbergh, 2012).

Currently, effective DSM is documented to improve serum BG, lower quarterly A_{1c}, improve dietary and physical activity practices, reduce obesity and overweight, and decrease the risk of having macro and microvascular complications. Prudent life-style modifications have been demonstrated to reduce and prevent the

progression from the pre-T2D state to T2D (ADA, 2014b). A “multifactorial treatment approach” (Chesla et al., 2003, p. 375) of daily and/or routine DSM includes: diet; exercise, the use of medication; tracking daily SMBG; routine laboratory testing for A_{1c} and FBG levels; periodic HC visits, diabetes education in class settings and with the HCP, treatment and management of co-morbid conditions and risk factors and awareness of signs of abnormal BG levels or disease complications; keeping track of these can be a very time consuming process. These aspects of DSM have been well-established in clinical practice and scientific literature for many years and were recently updated (ADA, 2017s; CDC, 2005a). Thus, they are the guidelines for person with T2D to follow. For adults, it is the individual’s responsibility to attend to all of these matters daily, or quarterly, as appropriate. Annual evaluations for retinopathy, nephropathy, and neuropathy are important. For some, a constant vigilance is needed to prevent the creeping threat of physical impediment from complications. Long-term lifestyle management is required. The reward of tight glycemic control has reduced the risk of macro and microvascular disease and HC costs (Banister, Jastrow, Hodges, Loop, & Gillham, 2004; CDC, 2011; Rizvi & Sanders).

It is important to note that changes that occur in knowledge and attitude, through instruction and information alone, are generally not sufficient to change the desired self-care activity and do not predict control. “Knowledge does not always translate into positive behavior changes...” (Benoit, Fleming, Philis-Tsimikas, & Ming, 2005; S. A. Brown et al., 1998, p. 331; van der Bijl, van Poelgeest-Eeltink, &

Shortridge-Baggett, 1999). However, as will be demonstrated, education in many cases has the power to positively benefit and transform health outcomes.

Influencing diabetes self-management aspects. Numerous factors have been identified that impact DSM; these are different than processes of SM. In a literature review on issues that affect DSM in rural studies, three themes emerged that are consistent with findings in many non-rural studies. They found that rural patients with T2D were impacted negatively and positively by (a) barriers to DSM; (b) provider contributions, tools and education that enrich and augment DSM; and (c) recommendations and guidelines to improve the efficacy of DSM (S. Ross, Benavides-Vaello, Schumann, & Haberman, 2015).

Patient self-assessments of DSM have been shown to correlate with glycemic control and key aspects of high-quality diabetes care. For instance, patients with a higher level of personal motivation have reported more routine practice of healthy dietary choices and SBGM (Shigaki et al., 2010). A nationwide sample of patients in 21 Veteran's Affairs (VA) facilities was assessed for glucose control via A_{1c} and *processes of care*; these are standard measures of quality diabetes care (Mainous, Diaz, Koopman, & Everett, 2007) that included receipt of A_{1c} testing, eye exams, and nephropathy screening. These are usually done on an annual basis (ADA, 2017s; Chamberlain et al., 2016). Medical records of over 1,000 patients with T2D in the VA system who had completed the Diabetes Quality Improvement Program survey were included. Multivariate regression was used to explain the variation in A_{1c} level and receipt of diabetes processes of care. Patients with higher DSM self-evaluations and diabetic services had lower A_{1c} levels. Authors asserted that benefits of patient

self-evaluation reinforced DSM understanding, improved glycemic control, and proposed that patients who have a higher level of engagement in DSM might have a higher likelihood of receiving necessary services (Heisler, Smith, Hayward, Krein, & Kerr, 2003). Possibly those who scored lower also had a lower level of acceptance of T2D.

In females over 70 years of age who required DSM training, their negative health beliefs interfered with treatment adherence and they were found to be at higher risk for sequelae. When subjects perceived they had barriers to completing DSM behaviors, they tended to have less-healthy diets and did less exercise (Ağralı & Akyar, 2014). It has also been documented that one's educational level affects how closely persons with T2D followed DSM recommendations. Persons of lower educational and economic status were less likely to adhere to treatment or dietary recommendations whereas those who were more highly educated, with stronger cognition skills, reportedly followed guidelines better (McWilliams, Meara, Zaslavsky, & Ayanian, 2009). The higher the level of self-efficacy and the confidence that they could complete DSM tasks successfully, the more often they performed SBGM and adhered to a healthier diet. They also were less likely to skip medications or to binge eat (Aljaseem, Peyrot, Wissow, & Rubin, 2001). Social support, too, has been shown to provide significant benefit by lending confidence to the person with T2D, that (s)he would be able to complete DSM. A study conducted in Portugal found that when the person with T2D perceived partner support and had the intention to perform SBGM, together these factors predicted completion of SBGM.

Positive support led to better metabolic control and more frequent SBGM; negative support led to poorer control and self-practice (Costa, Pereira, & Pedras, 2012).

Life-style modifications. Over the past decade, T2D care has evolved from provider-focus, telling patients what to do, to a more patient-centered approach that supports T2D as a day-to-day, self-managed disease. The patient and his or her family or support network are central to DSM, in cooperation with HCPs. In order to prevent complications, lifestyle goals of persons with T2D should include attaining and maintaining a healthy body weight/BMI. Generally, this is done, in part, through a minimum of 30 minutes of moderate-intensity activity on most days of the week; more is required if one is overweight. This type of exercise, alone, reduces one's risk of developing T2D by a substantial 40% (ADA, 2017d). To this point, two studies evaluated the benefits of intense lifestyle interventions (ILI). The first compared the efficacy of ILI to MF 850mg twice daily, and standard care, in prevention of T2D in prediabetic Latinas who had pre-T2D. The 12-month, 24-session program used community health workers (CHWs) who were Latin community members trained as peer leaders, to teach self-management skills, often referred to as "promotores" (Shepherd-Banigan et al., 2014, p. 507). Not unexpected, the ILI group had a significantly larger mean loss of weight and greater waist circumference reduction, but only minimal A_{1c} decrease compared to MF and standard care (O'Brien et al., in press). The second study did an ILI intervention for 8 weeks and one for 16 weeks against standard care as control. Both interventions yielded significantly better results than standard care (McInnes et al., in press) and asserted that ILI can significantly benefit weight loss and lower A_{1c} to some degree; remission was

possible. The other most essential component of lifestyle reform was a healthy, daily diet. Learning the art of SMBG was an important step in developing self-efficacy in DSM, particularly because it was physically uncomfortable and required daily attention. Participants of one study who self-reported progress in learning the technique found that they had normalized the behavior when they became accustomed to doing SMBG (Tanenbaum et al., 2015). Avoiding tobacco use via smoking cessation and avoidance of second-hand smoke reduces CVD risks (ADA, 2017d; PAHO, 2012). An important meta-analysis of lifestyle interventions revealed a significant association with reduced CVD development in persons with T2D who practiced healthy lifestyle behaviors (L. Chen et al., 2015). A further aspect of DSM is use of medications to manage T2D and ASCVD for patients of all ages with T2D (ADA, 2017i). Receiving care for psychological issues, including depression and anxiety, is important. HCPs are advised to assess the degree of burden to the person with T2D and her/his family, their ability to complete aspects of DSM, including their level of self-efficacy and social and family support (ADA, 2017d; PAHO, 2012).

Diabetes self-management education: Language comprehension and Health literacy, Culturally-sensitive education, and Health care provider factors. Before the person with T2D is able to perform the many facets of DSM, the individual, and often family members, must learn the various aspects and how to complete them. For example, one must learn how and when to perform SBGM, to keep record of BG readings, and begin to correlate those readings to signs and symptoms of hypo or hyperglycemic variations. This education is called diabetes self-management education (DSME) and diabetes education (DE). Behavior change

is the essential outcome measurement in DSME (Peeples, Mulcahy, Tomky, & Weaver, 2001). Mulcahy (2003) summarized the goals of DE is to improve overall health, empower patients and families to obtain knowledge, acquire skill, develop self-confidence and enhance motivation, expand problem-solving and coping methods, and overcome barriers to successful self-care. According to statistics from the CDC very few patients actually receive formal DE. In 2015 <7% of those surveyed had participated in DSME in the past 12 months (Cordisco & Broccoli, 2015). Modifying lifestyle is "notoriously difficult to maintain" (Rosenstock, 2007, p. 3). Numerous studies have found the benefits of DSME to include improved T2D knowledge and appropriate DSM behaviors, A_{1c}'s are typically lower, weight is reported to be decreasing, all of which lead to better quality of life and ability to cope with life struggles. HC costs also improve (ADA, 2017d; R. Chen, Cheadle, Johnson, & Duran, 2014; Chrvala, Sherr, & Lipman, 2016; Haas et al., 2014); although increased knowledge has not always led to improvements. Unexpected findings came from a NIH-supported study that evaluated trends in T2D-related knowledge as well as perceptions and behaviors about T2D risk. The study utilized population-based surveys from 2006, 2008, and 2011 by the National Diabetes Education Program (NDEP). It included persons with and without a T2D diagnosis. Findings revealed that since 2006, there had been a salient improvement in knowledge/awareness of both T2D and pre-T2D; however, for those people with pre-T2D (PWP), their personal perceived risk for T2D did not increase. Researchers surmised that PWP did not apply knowledge of perceived risk to themselves; also,

the importance of having a family history of T2D decreased amongst H/L and PWP (Piccinino, Griffey, Gallivan, Lotenberg, & Tuncer, 2015).

An important aspect of DSME is that skills are usually gained in a group setting where patients learn to make informed choices which is empowering (Murphy, Casey, Dinneen, Lawton, & Brown, 2011). Another suggested aspect of DSME is inclusion of DSM support when first diagnosed to assist the person with T2D in their transition process of learning and gaining DSM skills (ADA, 2014b). Since it has been determined that the first 10-years of the natural history of T2D development, the period of pre-T2D when a person might be treated for hyperglycemia, is usually squandered from treatment, recommendations are to test for and find pre-T2D and T2D as there is strong evidence that if located early it is possible to prevent or delay the development of complications (Phillips et al., 2014).

Finally, a recently released meta-analysis of 47 studies reviewed the effectiveness of group-based interventions in comparison to individual mediation or usual care. They evaluated benefits in clinical factors, lifestyle behaviors, and psychosocial outcomes of participants for a minimum of 6 months. Researchers found there were larger reductions in A_{1c} in group-based DSME than in controls at most time points for up to 36-48 months. Other group-based favorable comparisons included FBS, weight, waist circumference, triglyceride levels, and T2D knowledge (Odgers-Jewell et al., in press). Authors concluded that group-based DSME intervention was more effective than usual care or individual education to better the outcomes of clinical, lifestyle, and psychosocial factors. Consideration of language

issues and the ability of a patient to understand T2D information is of great importance and must be taken into account in the design and delivery of DSME.

The importance of English language comprehension and health literacy.

One recurring problem in standard DE is language comprehension of concepts being taught. In addition to having to learn about a new culture, customs, and insurance plans, not knowing a language is a barrier to HC for immigrants who often have significant language and health literacy (HL) difficulties (Cusi & Ocampo, 2011; Eamranond, Patel, Legedza, Marcantonio, & Leveille, 2007).

English language proficiency. Lack of proficiency in English has been identified as a major barrier for study subjects who try to read health education materials or surveys even when they had been translated to the mother tongue (S. A. Brown, Becker, Garcia, Barton, & Hanis, 2002). English-speaking patients and those persons in higher SES were more likely to have better relations with providers and to use the HC system more often and effectively (Barron et al., 2004), were chiefly third-generation immigrants, who had English language acculturation versus first generation H/L (Afable-Munsuz et al., 2013). SES was linked as a barrier with language deficiencies and lower education. Cultural barriers and economic challenges have been known to exacerbate comprehension problems by interfering with access to and the ability to make sense of relevant health information (Kreps & Sparks, 2008). A branch of the ENDOW study examined the relationship between English language use and preferences for involvement in medical care by women of Mexican heritage. Reduced English language use had a lower association for wanting to be involved with making medical care decisions and information seeking

(Tortolero-Luna et al., 2006). In the case of the use of mass media, when Spanish was used more readily than English, there was a significant association between undiagnosed HTN and Spanish language (Eamranond et al., 2007). The same could be true of T2D. This has an unfavorable effect on HL.

Health literacy. Research indicates that HL affects how one understands what one is taught, reads, and effects how one grasps health information. Health literacy involves being able to follow through by completing responsibilities related to the health issue; in this case, HL is the ability to accurately obtain, read, comprehend, and complete crucial DSM tasks (Kutner, Greenberg, Jin, & Paulsen, 2003). Low HL has been found to be more common in those with less education, being older and an ethnic minority, and in whom English is a second language; all are related to untoward outcomes of T2D (Cajita, Cajita, & Han, 2016; Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Low HL has affected the outcomes of numerous disorders. In asthma self-care, elders showed poor adherence to medications and inhaler use technique was worse in persons with lower HL (Federman et al., 2014). Decreased adherence to medication use was predicted in elders with chronic obstructive pulmonary disease (COPD) who had low HL in union with illness beliefs (Kale et al., 2015). Specific to DSM, low HL in African Americans led to underuse of medication (Aikens & Piette, 2008).

Specific to H/L, an important study evaluated self-report by various English and Spanish-speaking ethnic groups related to questions about HL. Using a 5-point Likert scale, people answered, "How confident are you filling out medical forms?" (Sarkar, Schillinger, López, & Sudore, 2011, p. 265). Almost half of the subjects were

Spanish-speaking; 47% and 12% had inadequate or marginal HL, respectively. The Swavely et al. (2014) study of various ethnic groups found persons of low HL had improvement in DSM when they participated in a culturally-sensitive DSME program. Finally, a study evaluated the benefits of an intervention to address HL and personal learning styles in English and Spanish-speaking persons. Using materials that specifically targeted their HL level and LS, the participants' T2D knowledge increased substantially (Koonce, Giuse, Kusnoor, Hurley, & Fei, 2015).

Culturally-sensitive diabetes self-management education. Multiple reports over a number of years have recommended that DSME should be tailored to cultural needs, practices, and perspectives. Inclusion of cultural elements, language, religious/spiritual aspects, and HL have a beneficial impact. Culturally-sensitive programs have resulted in improved results in H/L (S. A. Brown, 1999; Cusi & Ocampo, 2011; Zeh, Sandhu, Cannaby, & Sturt, 2012). Consideration of the individual's personal and cultural preferences, values, and needs equips the person with T2D to make healthy, informed choices (ADA, 2014b). Providing culturally-based DE from the beginning of one's diagnosis has been strongly recommended (Lorig, Gonzalez, & Ritter, 1999; Lorig, Ritter, Dost, et al., 2008; Lorig et al., 2003; Tanenbaum et al., 2015; Zeh et al., 2012). A recent RCT identified that H/L who received DE soon after diagnosis, had lower A_{1c} than participants whose DE intervention was delayed. This was thought to be, in part, because those with early intervention tended to practice more moderate to vigorous physical activity than the group who received delayed DE (Duggan et al., 2014).

The development of effective DSM has been shown to relate to appropriate DE that requires HCPs to understand aspects of what a person from a different culture believes, so as to beneficially affect their health (S. A. Brown, Garcia, & Winchell, 2002; Hendrickson, 2003). Nevertheless, understanding cultural variance in order to design DE around a culture can be an arduous task due to the challenges of understanding the specific culture. Conventional interventions with Hispanic groups have been shown to be less effective or insufficient (Brown, Garcia, et al, 2002; Poss et al., 2003). Contextually-fit T2D intervention programs have been developed and shown to be effective in improving health behaviors, HC status, and HC use (Brown, Garcia, Kouzekanani, & Hanis, 2002; Zunker, Rutt, & Meza, 2005). Tovar and Clark (2015) found that H/L and persons with lower education level specifically require DSME that fits both their education-literacy level and cultural aspects. When HL was core to a culturally-fit DE program for lower SES H/L with T2D, significant growth in knowledge about T2D translated to sizable improvement in diet, foot care, exercise, and A_{1c} levels (Swavely et al., 2014). When patients understood terms, questions, explanations and instructions, they were more receptive to learn. Numerous studies support the benefits of culturally-sensitive DSME; some include same-culture Community Health Workers (CHWs) who teach SM skills exclusively in Spanish in community settings and often include family and friends. Longitudinal studies have reported improved health behaviors, health status, and self-efficacy that have remained at the 1-year follow-up (Castillo et al., 2010; Feathers et al., 2005; Lorig, Hurwicz, Sobel, Hobbs, & Ritter, 2005; Lorig et al., 2003; Lorig, Ritter, et al., 2005; Mauldon, Melkus, & Cagganello, 2006).

Two studies conducted in Southern California evaluated the effects of comprehensive DE on diabetes-related health indicators. The first demonstrated, significant improvements in A_{1c}, FBG, cholesterol/high density lipoprotein (HDL) ratio, HDL levels, reductions in weight, fat (total, percent and truncal), and waist-to-hip ratio at three months post-DE. (Metghalchi et al., 2008). The second study enlisted 153 high-risk, underserved and underinsured H/L persons with T2D to participate in a nurse-case management and peer education-empowerment group. The aim was to improve T2D clinical care, patient knowledge, treatment satisfaction and to reduce negative, culture-based, health beliefs. Following 1-year in Project Dulce, the intervention group had statistically significant improvement in A_{1c} (from 12% down to 8.3%), cholesterol, and diastolic BP. All aims improved in comparison to the 76 in the control group (Philis-Tsimikas et al., 2004). Both studies supported the design and success of culturally-sensitive DE programs. The Starr County Texas group on the Mexican border compared two DSM interventions designed for Mexican Americans; an extended and a compressed version of the same content. Both were culturally competent in language, diet, family participation, social emphasis, and the inclusion of cultural beliefs. Both promoted better metabolic control and T2D knowledge; however, those who attended the extended version had larger A_{1c} reductions. Other group studies have shown successful results also (S. A. Brown, 1992; S. A. Brown, Becker, et al., 2002; S. A. Brown, Garcia, Kouzekanani, et al., 2002; S. A. Brown & Hanis, 1999).

The health care provider factor: Relationship and barriers. Although DSM continues daily, patients only attend DSME on a rare basis. Standard of care places

the responsibility of providing HC advice in the hands of the HCP at routine visits. (S)he is expected to periodically review the facets of DSM and T2D with the patient and often the family (S.-F. V. Wu et al., 2011). Two primary conditions have been identified that impact the HCP's success in fulfilling this responsibility: the relationship with patients, including time limitations and differences in expectations; and language and educational barriers.

Type of relationship. Falke and Lawson (2015) examined the sort of relationship qualities that patients with T2D and their spouses want with their HCP. Through grounded theory, they found two primary dimensions: decision-making and caregiving. Eight of 18 couples preferred that HCPs work collaboratively with them but, of surprise to investigators, the other 10 preferred the HCP make the decisions. One-half wanted emotional support, the other half wanted the HCP to act instrumentally in giving care. Likewise, a review of five RCTs found psychological and emotional advantages to shared decision-making because diabetes patients felt respected by HCP (Vivian, 2016). In a multi-ethnic investigation that evaluated patient satisfaction, when the decision-making process was shared with physicians, the satisfaction level was higher (Nápoles, Gregorich, Santoyo-Olsson, O'Brien, & Stewart, 2009). A dual-site study conducted on the Texas-Mexico border and in Guadalajara, Mexico was to determine unique concepts about T2D between physicians, patients with T2D, and persons in the community. While the differences were found to sometimes affect ideal T2D care, authors identified that language and culture were not the primary factor because differences were greater in Mexico. They suggested that educational level and differences in class might contribute

more to the provider-patient gap (Weller et al., 2012). Regarding the time-with-patients factor, a cohort Canadian study explored the relationship between primary care physician's overall volume of patients, the time available to treat T2D patients, and the quality of care received. HCPs with higher volume of T2D-specific patients provided better quality of care per several indicators (Cheung et al., 2017).

Language barriers and patient education. A literature review summarized attitudes and perceptions of HCPs and H/L patients regarding treatment of H/L patients. Twenty articles were examined for recurring themes of HCPs perceptions and 29 articles were reviewed for H/L patients. HCPs experienced limitations in communication due to language, cultural, and institutional barriers. Experienced HCPs grew more culturally astute and confident the longer in practice; however, lack of understanding about the different culture impacted their attitudes. Initially, inexperienced providers perceived disparities for patients, less so as they became acculturated to the HC system. When they had to depend upon family for interpreting communication was complicated; HCPs preferred professional interpreters. While HCPs appreciated the differentness of cultures, they knew they were underprepared; however, lack of time was a larger barrier than was lack of skill or interest. The H/L patients also had communication issues, often related to limited Spanish by HCPs who could not elicit patient concerns, even with qualified interpreters. Contrary to HCPs, patients preferred to have family or friends interpret because they worried whether professional interpreters were accurate and thorough. Issues for interpreters were length of physicians' sentences, limited experience working with interpreters and patient-family culture, and the

interpreter's familiarity with medical terminology. Patients' perceptions of care included feeling rushed, getting incomplete information, and lack of respect by staff. Assumption and expectation gaps included HCPs' lack of understanding of the demands of female patients' roles and importance of the family. Spanish-only patients were less satisfied with care than bilingual patients. H/L depended upon guidance from family and friends about HCP; they preferred same-culture providers, but generally, avoided going for care visits. In sum, the attitudes and perceptions of HCPs did affect the quality of care for many patients (Mayo et al., 2007).

While language barriers are commonly found to contribute to less adherence to DSM, Fernandez et al. (2017) evaluated H/L medication-adherence and language, to HCP Spanish-fluency. They found that it was not the level of Spanish proficiency in HCPs that affected adherence, rather the limited English proficiency of the patient, the lower the compliance irrespective of HCP fluency. In another study, Latinas who had better English-language proficiency reported being more effective in communication that was related to higher levels of treatment satisfaction (Yanez, Stanton, & Maly, 2012). Other studies have demonstrated dissatisfaction among Spanish-speaking H/L when communication with physicians was unclear (Nápoles et al., 2009). One issue of concern has been the lack of consistent attention by HCPs to prevent advancement of pre-T2D to T2D. For many providers, consistent attention by HCPs has not been a strength. Data from the 2012 National Ambulatory Medical Care Survey were examined in adults 45 years and older without diagnosis of T2D. Of over 11.1 million visits reviewed, over one-third had an A_{1c} in the pre-T2D range; however, review of records indicated that only 23% of those with

diagnosed or undiagnosed pre-T2D received either lifestyle modification counseling and/or a prescription for MF (Mainous, Tanner, & Baker, 2016).

It has been common for patients to report they received no nutritional-dietary, weight management, or physical activity guidance at HCP visits, yet those who did receive specific guidance reported a notably higher frequency of performing those behaviors, regardless of ethnicity (Vaccaro et al., 2012).

Specifically, HCPs tended not to address obesity as a specific issue; the topic was inserted or hidden in the broader range of topics discussed in primary care. For the 99% of self-identified obese patients who wanted to reduce weight, less than two of every three were offered guidance from their HCP (Asselin, Osunlana, Ogunleye, Sharma, & Campbell-Scherer, 2015; Sivalingam et al., 2011).

Summary of diabetes self-management and diabetes education. Type 2 diabetes is a chronic disease primarily managed by self-care. DSM is the cornerstone of T2D care and multi-faceted. The patient is responsible to focus on the disorder, to practice self-control, to utilize one's resources from within and outside of one's self, and gain self-efficacy/confidence to carry out activities of DSM over time. When practiced consistently, multi-system complications may be prevented. Research demonstrates that physiological markers such as HgA_{1c} and BMI can be better controlled with daily attention to self-management of the disease.

Well-established guidelines for daily care include dietary practices with consistent restrictions on types and amounts of food that increase BG; physical activity; SMBG to track BG levels; consistent use of medications with observation for high or low BG symptoms; and management and prevention of co-morbid

conditions, risk factors, and disease complications. On a quarterly basis, routine lab tests to monitor A_{1c} and FBG along with follow-up visits with the HCP, and DE and annual processes of care. DE in a group DSME setting is recommended soon after diagnosis so that life-style changes happen more quickly. Lifestyle adjustments are difficult and require support. Observation for macrovascular, ASCVD, and MetS are ongoing. There is strong evidence that T2D can be kept in control and that complications can be avoided or delayed for extended periods by meticulous management of daily BG; and the incidence of morbidity and mortality can be reduce through DSM. Outcome results in physiological measurements, improved DSM behaviors, knowledge and beliefs, patient-treatment satisfaction, and cost benefit are evident.

Factors that influence DSM include SMBG as those persons who are more aware of their ongoing BG status and accept their T2D status, have higher self-efficacy, tend to have better control, and lower A_{1c} levels. Lower SES and education levels are correlated to less successful BG control. Social support has been shown to make a substantial difference in DSM practice consistency, particularly exercise and diet. Intensive lifestyle interventions have been effective in reducing the risk of T2D and undesirable outcomes. Avoidance of smoking, smoke exposure, and alcohol use reduce the risk of associated CVD. Medications for co-morbid conditions may benefit both CVD and T2D co-risks.

Diabetes self-management education show benefits to those who attend including improved quality of life, fewer complications, higher levels of T2D knowledge that translates into improved glycemic control/lower A_{1c}, BP, waist

circumference, and cholesterol. Dealing with psychosocial issues is also helpful. Unfortunately, some persons who are at risk of T2D or have more severe disease have lacked self-perception of their risks, leading to undesirable outcomes. Lower English-language comprehension and proficiency are known barriers to effective DSM. SES, income, and educational levels contribute to DSM proficiency. The better the English, the more successful the DSM. Similarly, poorer HL is correlated with lower education, SES, ethnic minorities, elders, English as a second language, and worse T2D outcomes; H/L continue to have low HL skills. Culturally-designed DSME for the H/L has been found to meet more needs. Traditional DSME have not been successful with H/L. When cultural elements, Spanish language, religious aspects, and HL have been enfolded into DSME, T2D results have been more successful, knowledge has improved, and commitments to DSM have been higher and more consistent. Because many H/L have a lower educational attainment and HL, enfolded cultural components has been beneficial. Many successful programs now exist. As more culturally contextual programs are devised better outcomes can be expected. Studies on program failure or equivocal results were not located. It is unknown if unsuccessful results were not published or if no program failure exists.

Finally, the HCP factor includes the relationship with the patient and family. Patient preference for the type of relationship with the provider varies from caregiving to decision-making. Language and understanding of the provider impacts the relationship; however, it is not only the commonness of language and culture but extends to role and class also. The HCP may know there is a need and wants to assist, but lacks the time, resources, or referrals interfere.

Diabetes self-management by Hispanic/Latinos: Barriers and Social

support. The adjustment to the diagnosis of T2D can be very challenging in particular for persons of strong family orientation as is seen in the H/L culture (Costa et al., 2012). Generally, H/L are slow to make effective life-style changes. The literature indicates this population does not control BG, BP, cholesterol, or abdominal obesity well (Cusi & Ocampo, 2011). All four of the cardiometabolic abnormalities of the MetS are modifiable risks factors for T2D and CVD (Berg et al., 2016; G. Kim et al., 2012; PAHO, 2017). For many years, only a small percentage of Mexican-born diabetics had been known to control their blood sugars and go for regular HC. They were found to be less adherent to DSM, including medication use, than NHWs. Their diet and exercise habits have been markedly lower and they have gone for annual eye exams less commonly (Coronado et al., 2007; J. B. Hunter, Guernsey de Zapien, Denman, & Moncada, 2003; Trief et al., 2013). Even those H/L who were English-proficient participated less in moderate physical activity in comparison to NHWs (August & Sorkin, 2011a). As recently as 2014, up to 52% had poor BG control (ADA, 2014a). One non-adherence factor was avoidance of using newly prescribed diabetes medications or stopping use early in the first two years of a prescription. The less English proficient, the less the medication adherent. This was true even when the HCP was fluent in Spanish. Fernandez et al. (2017) advised that it will require more than same-language HCPs or interpreters to improve medication adherence. However, literature review of 52 studies on T2D medication-adherence of H/L by Sapkota, Brien, Greenfield, and Aslani (2015) found that most of the interventions showed some success and benefitted Latino subjects.

In a study to identify factors that influence H/L DSM, four themes emerged that either enhanced or hindered DSM practices: (a) access to resources, (b) struggle with diet, (c) self-efficacy, and (d) social support. Having access to services, supplies, and other resources was beneficial, but lack thereof was a hindrance. The universal struggle with diet was a common limitation to DSM. Once self-efficacy was gained, DSM felt less defeating; until then the struggle was difficult. Those with beneficial social support were more successful than those without it or who faced conflict from family or friends. Not surprisingly, the family's role in determining the success of DSM was a sub-theme to all four major themes. Authors stressed the significance of the Latino family's influence in DSM (Ramal, Petersen, Ingram, & Champlin, 2012). Each of these themes was a potential barrier to successful DSM.

Barriers. A variety of factors have been identified as obstacles that make DSM difficult and/or barriers that actually obstruct or are perceived to obstruct DSM activities. Findings in a doctoral study suggested that when interventions were undertaken to address Latinos' perceived barriers to DSM, such as interference with diet, exercise, and medication management, negative impacts on life were reduced (Flores, 2004). A second study evaluated perceived barriers to DSM by H/L and their families. Three primary themes emerged: they experienced suffering from T2D, difficulties in the daily DSM, and a lack of resources and support. Family themes included that they had confidence they would provide support, but lacked knowledge on how to do so; researchers recommended inclusion of family support (Hu, Amirehsani, Wallace, & Letvak, 2013). A literature review of eight studies of H/L cited lack of access to care, low literacy levels, and difficulties with cultural

differences between patients and providers as DSM barriers. Consistent with discussions above on HL and educational level, due to overall, lower educational levels, H/L have followed recommendations less well (Gonzalez, Berry, & Davison, 2013; McWilliams et al., 2009; Sloan, Padrón, & Platt, 2009). In examining NHANES data, Cusi and Ocampo (2011) identified barriers to treatment goals including SES conditions, language, and cost of /access to goods and services. In one study of over 20,000 persons, of which about 10% were H/L, the latter generally received less appropriate and quality care affecting their ability to oversee their disease. They lacked sufficient A_{1c} monitoring, routine eye and foot exams, vaccinations, DSME, and daily BG and self-foot exams (NHS England and Public Health England, 2015).

Another factor that contributed to immigrants not seeking care and not practicing adequate DSM has been misinformation about the disease. One study identified that, of minority persons, 58% were Latinos who had misconceptions about T2D. This included believing it was possible to cure T2D (Mann, Ponieman, Leventhal, & Halm, 2009). While this is not entirely inaccurate, it is only through very aggressive and persistent management that this is possible (Phillips et al., 2014). M-A person with T2D have been reported to believe that BG levels of 200 mg/dL or less are normal; twice the current FBG level. This too, is an outdated standard (Gavin & al., 1997). Patients in rural Washington reported concern about lack of T2D knowledge and how to obtain it. Their personal lack of responsibility for DSM was also a barrier (Livaudais et al., 2010).

Social support. Just as the degree of accurate information about T2D varies between individuals and families, so does the level of support and involvement

(Hornsten, Sandstrom, & Lundman, 2004; Makabe & Hull, 2000). The benefits of social support in Latino families and communities have been documented to improve weight loss through mutual participation in physical activity. Latinos were more likely to adhere to physical activity and achieve weight loss when family members participated in social support activities (Marquez et al., 2016). The more social support is provided, the lower the prevalence of T2D and A_{1c} in this population (Banister et al., 2004; Gallo et al., 2015). Further evidence was found in an 8-week, Spanish-taught, Hispanic family-based, DE-intervention-program. At the 1-month follow-up, significant improvements had occurred including a profound average decrease in A_{1c} by almost 5%, lowered systolic BP, corrected inaccurate knowledge and understanding of T2D, better sense of self-efficacy of being able to perform DSM, enhanced quality-of-life, and a sense of well-being. Improved dietary intake, frequency of SMBG, and foot inspections were also reported. All family members had significant improvements in BMI and knowledge of T2D and DSM (Hu, Wallace, McCoy, & Amirehsani, 2014; Shepherd-Banigan et al., 2014). Fortunately, a social network does not have to be family exclusively. For example, screening for cholesterol, BP and BG have increased when someone from an older H/L generation encouraged a younger person to do screening (Ashida, Wilkinson, & Koehly, 2010).

Summary of diabetes self-management in Hispanic/Latinos. The life alterations to achieve DSM are challenging. In general, the H/L population does not make adequate changes; control BG, BP, cholesterol, or personal weight; and many are not physically active. The obstacles and barriers for the culture are multi-faceted. Learning about one's diagnosis of T2D tends to trigger many negative

feelings and worries. Family influence is important and support varies between families. It is common for Hispanics to not understand the disease process and to have misinformation about how one develops T2D or how to prevent it. Oftentimes, Hispanics do not understand the Western approach to management that promotes improved lifestyle interventions and better glycemic control. Nonetheless, when provided with culturally-appropriate DSME and support, there are consistent improvements in BG control. Learning the skills and importance of DSM is essential to diabetic health.

One missing piece of information about DSM by H/L continues to be the lack of understanding of the decision-making process. There is a clinical need for culturally-relevant DE programs that requires understanding aspects of what another believes in order to design these programs (Hendrickson, 2003; Kemp, 2005). Decision-making will be discussed in the final section, following the next section on the Mexican-born immigrant. This next section on Mexican-born immigrants will discuss four relevant rubrics. The first will be an outlay of the socio-economic and educational factors of Mexican immigrants in the United States. The influence of culture, cultural, and ethnic identity, and importance of language to the culture will be followed by a segment on vulnerable populations, including health disparities, economics, insurance status, and access to care. The final segment will frame the antecedent factors known to effect reasons for emigration from Mexico.

Mexican-born Immigrants: Socio-economics, education; Cultural influences, identity and language; Vulnerable population, disparities, insurance, access; and Antecedent factors

In multi-cultural societies, HC contact with immigrants who have T2D continues to climb (Hjelm, Nyberg, Isacson, & Apelqvist, 1999; PAHO, 2012). In the United States, persons of Mexican-decent form the predominance of the H/L population (ADA, 2014a; Zunker et al., 2005).

Socio-economic factors and education levels. The likelihood of poverty has been higher for Mexican-born immigrants at 28% compared to 18% of all immigrant families and only one in 10 native-born families. English proficiency was lower in Mexican immigrants than for overall foreign-born immigrants. Likewise, Mexican immigrants had a lower education level when compared to other foreign-born immigrants (Zong & Batalova, 2016).

Influence of culture. Cultural and ethnic identity and language. A quintessential component of an individual's persona is their culture. Culture plays a critical role in the development of each person (Kleinman, 1980). The individual's culture, ethnicity, family, gender, age, personality, lived experience, as well as roles within family, community, and larger society (Chang, 2015; Chesla et al., 2003; Jack et al., 2003; Weiler & Crist, 2009), along with other environmental factors and overall context (Kleinman et al., 1978) shape personal formation (Weller et al., 1999). Culture is the unifying structure of behaviors, ideas, attitudes, values, habits, beliefs, customs, language, rituals, ceremonies, and practices to a particular group of

people. This structure provides the group with a general and coherent design for living and patterns for interpreting reality. (Jack et al., 2004, p. 966)

Generally, the Mexican and H/L cultures are more community- and collective-oriented than the individualistic, American culture (Ruby, Falk, Heine, Villa, & Silberstein, 2012). In the Mexican and H/L cultures it is the welfare and opinion of the community and family, the collective-other, that carries more import than the individual (Shkodriani & Gibbons). Chang (2015) described collectivism as a person prioritizing the “interrelatedness of the self to others and the primacy of group goals and social obligations” (p. 4). She compared how Latino American (L-A) and Asian American college students, each from unique collectivist cultures, underutilized social support as opposed to groups from more individualistic cultures who made personal needs a priority. She found that L-A were more uneasy about maintaining group harmony, felt that they would disrupted group unity, and were afraid of being judged if they made their needs known (Chang, 2015). They had been raised with this group identity. Indeed, there is variance of personality, family influence, beliefs, values, and experiences between H/L ethnic groups. Two key factors identified in the literature as fundamental cultural components are ethnic cultural group identity and shared language (Afable-Munsuz et al., 2013; Schwab et al., 1994).

An essential aspect of the community-oriented society is the cultural identity. The most central, relevant ideas within cultural identity are a sense of belonging to a group, sharing companionship in various aspects of life, societal norms, common values, beliefs, traditions, social expectations, rules and etiquette, religious-spiritual

coping (Alamilla, Scott, & Hughes, 2016), language(s), the population's basic principles and goals of living, and often are related to race. These elements are generally passed down through time, serving as the heritage from which one derives his or her sense of personhood and sense of self, one's identity. Cultural identity is the foundational fabric of a people contributing significantly to how each one sees him or herself and affecting choices and resultant behavior. An important aspect of one's cultural and ethnic identity is how one appears to others. One typically feels safe within the group (Bravo, Umaña-Taylor, Guimond, Updegraff, & Jahromi, 2014). Cultural - ethnic identity is related to more stable mental health (Burrow-Sánchez, Meyers, Corrales, & Ortiz-Jensen, 2015).

The importance of English-language proficiency, understanding and comprehending what is said, and the undesirable effects of low HL have been discussed. Low language proficiency and HL have been shown to place a person in a less-than-ideal position when seeking HC in the American HC setting or for successful DSM. The importance of language to a culture is of equal magnitude in importance. Language has a very, powerful influence on culture. Language of a people group is a profoundly salient, distinguishing feature of culture (Barron et al., 2004), is unique to each people group, and helps to define a culture. Domian (2001) asserted that language is such an intricate and core part of a culture that when one has the language of a culture, one in fact, has the culture. The vernacular communicates beliefs and cultural concepts, feelings, thoughts, values, and more. When the overall culture, language, and form of expression are unfamiliar to another individual, the likelihood of misunderstanding increases (Davidson et al.,

2015) as is the case between N-HHCPs and Mexican immigrants (Choi, 2001). These differences may be subtle and appear superficial or seemingly insignificant (Hjelm, Bard, Nyberg, & Apelqvist, 2007). They may lead to confusion and lack of understanding between well-meaning persons.

Vulnerable population: Disparities; Economics, Insurance and Access.

Immigrants are identified as a vulnerable population (VP; Derose et al., 2007; Shepherd-Banigan et al., 2014). Vulnerability is defined as

The susceptibility to harm, results from an interaction between the resources available to individuals and communities and the life challenges they face.

Vulnerability results from developmental problems, personal incapacities, disadvantaged social status, inadequacy of interpersonal networks and supports, degraded neighborhoods and environments, and the complex interactions of these factors over the life course. (Mechanic & Tanner, 2007, p. 1220).

For the H/L immigrant, many factors, particularly social, contribute to vulnerability: immigration status, lower SES background, many living below the poverty line, insufficient English proficiency, lower educational level, lack of insurance, various governmental policies on access to care, location of residence, presence of stigma, and/or being marginalized (Derose et al., 2007; Frieden, 2015). Many VPs, including immigrants from Mexico, have compounded vulnerability (i.e., more than one VP characteristic), such as being a racial minority, working poor, and under or uninsured (Van Zandt, Sloand, & Wilkins, 2008). These vulnerabilities commonly lead to disparities in health and HC (Babamoto et al., 2009).

Health disparities. Poverty is the greatest predictor of vulnerability of health (Vladeck, 2007). Generally, those more vulnerable to health problems are less likely to obtain HC and, more likely, to lack culturally-competent HC, education, advocacy, and support for health issues (Vasas, 2005). Disparities in HC are commonly reported about ethnic minorities, including immigrants and those in lower SES groups (Flaskerud et al., 2002). Émigrés generally have less health insurance, limited access to local care, use less HC, and are recipients of lesser quality of HC than U.S.-born populations; with variances between subgroups (Derose et al.; Van Zandt et al., 2008). Using data from the 2005-2006 Diabetes Study of Northern California (DISTANCE), researchers sought to understand the association between H/L with limited English proficiency, glycemic control, and same-language HCP. Language barriers were found to add to higher BG levels and health disparities (Fernandez et al., 2011). Even when exercise habits for H/L improved significantly across reviewed studies, they were less likely than NHW to receive care standards or to engage in most care offered. Reviewers were concerned that H/L had the lowest rating on most health measures (R. Chen et al., 2014). Of all groups in the national health statistics of 2015, H/L were most likely to be without dental care due to cost (National Center for Health Statistics, 2015). An important aspect of HC delivery and receipt is one's insurance status.

Economics and insurance status. The uninsured status is a more powerful predictor of a HC barrier than is ethnicity (Pauly & Pagan, 2007). Those in the lower class and the uninsured have the greatest risk of having insufficient or to lack preventive care, irrespective of ethnicity (Oladele & Barnett, 2006). Sadly, for

insured persons in the community, the presence of a higher percent of uninsured adversely affects the quality of HC for those who are insured (Pauly & Pagan, 2007). McWilliams et al. (2009) reported improved BP, BG, and cholesterol levels since 1999 in adults with T2D and CVD, but lamented that racial, ethnic, and SES disparities have not decreased at the same pace. They did note that Medicare for persons over 65 years have led to less distinction.

A study by Vaughn (2004) utilized data from the 1998 Medical Expenditure Panel Survey, a sample representative of civilians in the United States. She compared insurance status on HC utilization and the quality of DSM in H/L between NHBs minorities and NHWs. She cited that income level was key to both the frequency and type of care, despite insurance, and that persons with insurance had better health outcomes than the uninsured. Insurance coverage alone was found not to be sufficient to benefit low-income persons who had switched to a high-deductible insurance. A controlled interrupted-time-series study of over 24,000 patients with T2D found that disease monitoring and routine outpatient visits did not improve for those with a high-deductible but led to significantly increased risk of T2D complications. Emergency department visits were appreciably increased for acute, T2D-related complications that could have been preventable through routine HC visits (Wharam et al., 2017). Likewise, due to financial reasons, H/L reportedly did not routinely practice SMBG (López & Hill Golden, 2014). The HCHS/SOL found that while there was a high level of H/L with T2D in low-income and lower-education households, there was improved awareness of T2D, which suggested that to increase the volume of insured may reduce the SES to T2D link. Increased

awareness was related to improved glycemic control among those with insurance while those with poor BG control were uninsured (ADA, 2014a; Schneiderman et al., 2014). The benefits of insurance for H/L include higher level of health services usage, self-reports of improved HC outcomes and disease management, and long-term survival (McWilliams et al., 2009).

Access to care. Ultimately, access to care is a critical factor for HC benefits. People must be able to access HC to receive the benefits of education, insurance, disease monitoring and preventive services. A study on the association between health status and behaviors, care access, and use of preventive health services by H/L in the United States, and disparities related to language issues found that despite SES, Spanish-speaking H/L were disadvantaged compared to NHWs. Authors warned that language was the mark of a VP (DuBard & Gizlice, 2008). Cusi and Ocampo (2011) called for attention to socioeconomic and cultural barriers, including language, HC costs, and various types of access to supplies, and HC access if the care of high risk groups with T2D is to improve. According to Mann et al (2009) knowledge about T2D may be lacking more in persons of lower SES and minority status who have less access to HC and DE. Such is the case of many Mexican immigrants. In the past, of all H/L groups in the United States, M-As had the highest number of barriers to both access to and utilization of HC services (J. B. Hunter, et al., 2003). When both M-As and Vietnamese of low-income status reported use of HC services, M-As perceived that the financial burden related to their T2D was a greater barrier than did their Vietnamese counterparts or NHWs (Ngo-Metzger, Sorkin, Billimek, Greenfield, & Kaplan, 2012). Community health center (CHC) medical

directors were surveyed about access to specialty health services for low-income patients receiving HC in all federally qualified CHCs in the United States. Not unexpectedly, uninsured persons had more difficulty obtaining access to off-site specialty services such as clinic referrals and diagnostic testing, than did patients with insurance (Cook et al., 2007).

Summary of vulnerable populations. Poverty is the greatest predictor of vulnerability of health. Persons with higher levels of vulnerability have less likelihood of acquiring HC, education, or to have adequate advocacy and support. Language obstacles are often a major disadvantage. Immigrants are a VP, at greater risk for injury, illness, prejudiced treatment, and of being exploited. Mexican immigrants are victims of compounded vulnerability. Persons of lower SES and minority status who have less access to HC may lack adequate knowledge about T2D. Ironically, those who are more vulnerable to health problems are also less apt to go for HC and commonly receive less culturally-competent HC, education, and advocacy. Even those persons with T2D of lower income who have insurance tend to underutilize HC. Communities that have a high percent of uninsured tend to have lesser quality HC for the insured, also. Insurance with high deductibles can lead to poor outcomes. There is more difficulty obtaining access to off-site specialty services and referrals for the uninsured.

Antecedent factors known to effect emigration from Mexico: Socio-cultural, Geopolitical, Economic, Environmental and ecological. In reviewing the literature, it was noted that reasons for emigration from Mexico may have had some bearing on the factors and processes of decision-making about DSM and

thereby lent perspective to the research question. The literature gives many *raison d'être* for people groups or individuals and families to emigrate from their homelands to an unfamiliar location, in search of a better life, a more secure setting, or promising future (Buchenau, 2001; Zuniga et al., 2004). Around the globe, the reasons are multi-factorial. In the socio-cultural arenas, persons move to make a new home or to attend to unmet needs. Others shift to be with loved ones or to receive education (Flaskerud et al., 2002; Marshall, Urrutia-Rojas, Mas, & Coggin, 2005; McCauley, 2005; Mechanic & Tanner, 2007). Others go in hopes of better HC (Derose et al., 2007; Frye, 1991; Jirojwong & Manderson, 2002). Countless leave for economic incentives to forge a better life or, in contrast, to escape exploitive or repressive poverty conditions. Economics are the most commonly reported reason that persons leave Mexico to immigrate to the United States without regard to documentation status (Marshall et al., 2005; Mechanic & Tanner, 2007). Geopolitical conflicts, wars, racial discord, or tyrannical political conditions force others to take flight of their homelands (Sahay, 2006). Finally, some go in quest of adventure or as a rite-of-passage (J. Ross, 1994). Transnational migration, on the rapid rise worldwide, adds complexity to the issue. McGuire (2001) advocated pre-migration conditions might be more important factors driving people to emigrate, over those features that draw people to immigrate to a new situation. Both pre- and post-immigration deserve evaluation.

Multi-factorial, complex issues have accumulated over a 500-year history since the Spanish invasion in the early 1520s (J. Ross, 1994). These irreversibly and radically changed the life of native peoples of the region now called Mexico (Diaz,

1999). Over a few short decades, rapid destruction of the pre-invasion world occurred (Olivares, 2004b). Through an extensive literature search on emigration from Mexico, four primary conceptual rubrics were identified. This section addresses the four themes: (a) socio-cultural and religious realms; (b) geopolitical dominance; (c) economic issues; and, (d) environmental-ecological domain.

Socio-cultural religious realm. A major force in the socio-cultural-religious sphere has been the institutionalization of a dualistic societal paradigm. Essentially, Mexico is said to have two primary social classes. The minority, less than 10%, are the ruling, upper *society* made up of lighter skinned persons from Spanish-European roots (Statistical Information for the Country of Mexico [SICM], 2007; J. Ross, 1994). The majority is the lower class, called the *populace*, and is comprised of full- or mixed Indigenous backgrounds (Rodriguez & Gonzales, 1996). The division is founded on the Eurocentric orientation that light skin is normal; thus, superior (Buchenau, 2001). Socio-cultural class factors place the indigenous or Native peoples, known as *indio* (R. H. Jackson, 2007), lowest within the populace (Rodriguez & Gonzales). A multiplicity of factors has retained the lower class, forming a racial disparity or social racism for centuries as an ethnic discrimination (Redfield, 1929). To this day, those of darker skin color have lower “occupational prestige scores” (Espino & Franz, 2002, p. 612) than co-workers of lighter skin-tone.

The populace is disadvantaged, impoverished, disrespected, and lacks potency to change age-old values. They are socially eclipsed (McGuire, 2001). Five centuries ago, the conjoining of Spaniards and Natives in the 16th and 17th centuries resulted in a new mixed ethnic group, the *mestizo* (Diaz, 1999) or *Mexican*

as known today (Lenchec, 2002). Research on the gene pool of 1,000 M-As in Texas found that of those tested, 31% of the genetic pool was Native American, 61% and 8% were Spanish and African, respectively; Puerto Rican and Cuban percentages differed. Due to the high degree of Native American genome present, it was thought in part to be why T2D was higher in the Mexican ethnic group (Hanis, Hewett-Emmett, Bertin, & Schull, 1991). Today there is virtually no middle class in Mexico, it has been said that socially, there is little room for one (Rodriguez & Gonzales).

The ruling class values wealth, property, prestige and individual success (R. H. Jackson, 2007); they have an individualistic worldview (Shkodriani & Gibbons, 1995). These ideals are antithetic to the native's collective perspective. Features that distinguish the native ethic are identification with the land, shared property, tribal uniqueness, industrious and creative work (Berlinguer, 1992), and being spiritual in nature and practice (Olivares, 2004b; Schmal, 2004). The ruling class has far too much to lose in social, cultural, economic and political base to effectively facilitate true reforms necessary to produce a more equitable society (R. H. Jackson).

Geopolitical dominance. Geopolitically, since the Spanish invasion in the early 1500s, the operating political system has been a *one-man* or *one-party* Eurocentric-type rule (J. Ross, 1994). In the following three centuries, a series of complex laws, prohibitions, and rules mounted in favor of the settler, maintaining the Indio inferiority with limited power and voice (Diaz, 2000). Dominance over the common person allowed the ruling elite continued authoritarian governance. Domination reportedly has been accomplished through ruthless and dishonest

manipulation of the political system (Lenchec, 2002). As is the case socially, there is no motivation for the ruling political class to modify its practices.

Issues surrounding the US-Mexican border have been a lightning-rod for discussion and dispute. Border history outcomes are salient to the current research. Historically, the border to the United States was non-existent (Nostrand, 1975) until the war with Mexico in the mid-1800s. In 1848, over one-half of the Mexican territory, in what is now the southwestern United States, became property of the United States and a significant number of its citizens were suddenly living in the United States, not Mexico. Still the border remained open for easy bi-directional passage until the last half-century when significant changes occurred politically on the American side. Prior, the demand for “cheap Mexican” labor (De Genova, 2004, p. 165) in the United States and the need for income by an able, willing working class of citizens of Mexico were a complimentary fit. The numbers of immigrants from Mexico annually exceeded 1 million. By 1976, that number had been reduced by 99% to near 18,000. Over the course of 3 years, changes in American law transformed the status of the once-legal, welcome migrant into an illegal immigrant. Also, remittance funds that were sent home to impoverished Mexican families were lost (Delgado-Wise & Márquez Covarrubias, 2007; SourceMex, 2005). This resulted in a more threatened and vulnerable Mexican state (U.S. Department of State [USDS], 1998). These rapid, radical changes had a “distinctive and disproportionate impact upon Mexicans” (De Genova, p. 160).

On the economic front. Since the Spanish invasion, the most easy-to-farm, fertile lands early belonged to wealthy, foreign land owners. Communal lands

tended by Natives were taken for private property, kept in elite families for generations until being sold to agribusiness in the 1990s (Barkin & Ortiz, 1997). Consequently, Native Mexicans were consistently forced further from self-sufficiency with progressively less arable land (Buchenau, 2001; Diaz, 2000). The impact has been severe as the majority of Mexicans are and have been people of the land for millennia (Schmal, 2003). In more recent decades, globalization has had a principle impact on arenas of life in most nations and peoples of the world, even if only indirectly. To globalize is “to make worldwide in scope or application” (Globalization, 2009, p. 1). In particular, it is an increasingly integrated global market economy with the underlying goal of free trade, free flow of capital-monies, and often accessing cheaper labor forces in foreign sites.

The tapping of cheap labor has continued to occur in Mexico. Predominantly built on economic growth, little is considered for the populace. With international agreements, investment and trade was opened (Barkin & Ortiz, 1997); particularly through the North American Free Trade Agreement (NAFTA). These agreements benefitted the governments of Mexico and the United States and the Mexican ruling class with crushing results for the majority of Mexican people (Carrera, 1998; Heredia, 1996). Many Mexican workers were released from their places of employment increasing domestic consumer debt; this led to bank-system failure and devaluation of the peso. In order to compete in the world market, wages were decreased. Also, due to the rise in inflation, “buying power” (Kemp, 2005, p. 2) declined significantly. The unemployment rate increased, resulting in the collapse of more families below the poverty level (Barkin & Ortiz). The outcome has been the

displacement of countless Mexican nationals who struggle to prevent further demise. Even before globalization, Mexico had an economy of partial dependency upon the United States. Economic changes in the United States have continued to affect Mexico, its commodities, and ability to provide products (D. Cohen, 2001).

Environmental and ecological sphere. The final domain integrates aspects of the previous three. Specifically, devastation in the environmental and ecological sphere over centuries has profoundly affected the peoples and land of Mexico. Indigena are people of the land (Diaz, 1999), are dependent upon it, care for it, and culturally identify with it (J. Ross, 1997). For myriad reasons, the land has been exploited, systematically siphoned, and irreversibly damaged (J. Ross, 1994). Three forms of destruction are found to have transpired in relation to poor land management. Foremost is the physical damage via soil erosion, in part due to the loss of successful native erosion-resistant agriculture techniques aborted for European-forced practices; deforestation and denuding of ecosystems (Diaz, 1999; J. Ross, 1997; Schmal, 2005; Stavenhagen, 1965); severe overgrazing by imported, non-native livestock (Minnesota State University eMuseum [MNSU], 2007); water and air pollution with toxic chemicals and heavy metals found in the water and soil; and desertification (Candiani, 2012). Poorer soil impedes useful farming that leads to insufficient productivity to meet community needs. Ironically, two decades ago, a U.S. Congressional report on the environment in and migration from Mexico deemed “rural land degradation or desertification” as the “root cause of Mexican migration” (Environmental Change and Security Project, 1998, p. 61; Stavenhagen, 1965).

The second destruction is loss of territorial land through apprehension of communal properties, as previously discussed. Finally, the lasting psychological-emotional dejection (Berlinguer, 1992) in those who believe the land is an extension of themselves and facilitates cultural expression. Loss of the native's identification with the land adds to social disparity by fueling the societal belief that indios are disposable and exploitable (Stavenhagen, 1965). More recently, 11% proposed reduction in agricultural subsidies left the Mexican farmer further vulnerable to competition by foreign companies. It eliminated over a dozen programs directly tied to rural farming needs: electrical support, fertilizers, and product export assistance, harming *campesino* (farmer) productivity and livelihood (SourceMex, 2007b). Environmental laws are weak and favor the privileged, including international entities doing business in Mexico, or laws are ignored through illegal permits to the advantaged and harsh enforcement has been toward natives (J. Ross, 1997).

In sum, two significant reasons for emigration were identified in this section. Per the literature, economic issues are the most influential factors in why people emigrate from Mexico to the United States. Also, according to the U.S. study, the root cause of Mexican emigration is degradation or desertification of rural lands. Whether or not any of these pre-emigration factors will have been reported as an influence to decision-making for DSM in Mexican immigrants will be discussed.

Without more data to identify the immigrant's viewpoint and process of decision-making, HCPs lack an important tool to link effective interventions (Chan, Haynes, O'Donnell, Bachino, & Vernon, 2003) and culturally-meaningful information

to the client's frame of reference to assist them to improved DSM. Meanwhile, HCPs need to identify cultural divergence, in order to respond adequately (Poss, 1999).

Decision-Making: Conceptual literature, Decision-making process, Contributing influences; Decision-making in T2D and chronic illness, How patients have decided

The current literature on diabetes, pre-T2D, and DSM by Mexican-born immigrants has been discussed. Discourse now turns to the primary focus of the study, the factors and processes of decision-making by this largest ethnic group in the United States. First, the conceptual literature will be examined, then the factors, conditions, and variables that have been heretofore identified. Current findings relevant to the research question, decision-making in H/L, and gaps in the literature will complete the deliberation.

Conceptual literature: Rubrics and Concept of patient decision-making.

Multiple discipline-based theories and models exist in the decision-making literature; the majority are not suited to health-based discussions or to qualitative research. The foci of health-related decision-making literature is: (a) patient decision-making; (b) clinician-based/clinical decision-making that focuses exclusively on a clinician making a medical/treatment decision; and (c) shared decision-making (SDM) as a mutual activity that occurs between the patient and the provider as the HCP engages the patient in the process. The focus of this section is patient decision-making. Periodically, in relation to patient decision-making, SDM, or clinical decision-making will be referenced.

Conceptual rubrics: Normative, Descriptive/ heuristics and prescriptive.

Beginning in the mid-twentieth century, decision-making theory took root in mathematical, decisional-statistics, economic utility arenas, political science, cognitive and behavioral disciplines, decisional conflict theory, and transactional theories, amongst other decision theories (Edwards, 1954; Noone, 2002; Tversky & Kahneman, 1974). Decisional theories fall under various rubrics of function. Much of the literature clusters around theories and descriptions under two common rubrics, based on cognitive and rational thought versus intuitive response; however, some literature also describes a third rubric. The rubrics are: (a) normative theories that describe what people should do in decision-making; (b) descriptive theories that explain how an individual actually does go through the process of decision-making, that is, how one does choose (Garro, 1998); and (c) prescriptive theories wherein aids are developed for decision support. The latter assumes people may be poor decision-makers and require assistance (Bekker et al., 1999), or in the case of shared care, due to the patient complexity of overlapping issues those involved may benefit from a decision-aid.

Normative theories. Normative theories are statistically or mathematically-founded and quantify the decision-making process in a rational and analytic fashion; they are based on utility. Classically, these theories are about how persons *should* choose, assume that people are fully informed to make the best decisions, and *do* take the best action. They also include risk assessment (Edwards, 1954; Garro, 1998; Pierce, 1993; Strohschein et al., 2011). This perspective lacks relevance to this study in three ways. First, the assumption that persons are fully knowledgeable,

informed of options and alternatives, and make the best choice is contrary to the facts about the population under study. Secondly, people often do not estimate the likelihood or probability that something will or will not occur. Third, factors in the individual's life (e.g., real world, their inclinations, the affective aspect of an individual's reasoning) are excluded from the utilitarian function; thus, these models fail to capture and include the meaning of a decision. The deliberative aspect may decline with age (Bekker et al., 1999; Montbriand, 1995). Ironically, however, a format often used in DE is founded on the normative ideal to dictate to immigrants what they *should* do in making decisions. Background of the current study indicated that common DE formats often fail to reach the intended immigrant population. Also, HCPs often presume that patients understand all that is said to them, and in detail, when first taught a new principle or given options or descriptions; an unreasonable expectation (S. A. Brown, Garcia, & Winchell, 2002).

Descriptive theories and heuristics. Descriptive theory resulted from the understanding that normative theory is generally not realistic and does not consider the complexities or uncertainties of patient decision-making (Bucknall, 2007). Rather, people have limitations in their ability to process information and tend to be more "naturalistic" (Bekker et al., 1999; Strohschein et al., 2011, p. 915) in problem solving. Descriptive theories are instead about how people do choose, attend to the reasoning process rather than how they should choose. People often employ an intuitive-type of decision-making by resorting to automatic responses, they *get back to the simple bottom line* that may or may not result in reasonable choices. In this

mechanism, one is often dependent upon what one sees or senses; it requires minimal effort and is enhanced through life experiences.

Decision-making is often assisted by simplifying procedures or using simplistic rationalization, called heuristics. Heuristics are a means of discovery (the Latin root means “to discover”; Garro, 1998; Heuristics, 2017, p. 1) that help a person to understand how to approach or solve problems. One then develops a “rule of thumb” or set of “rules” (Bucknall, 2007; Fischer & De Vries, 2008, p. 388) that guide in decision-making. In some instances, intuition can direct patients to choices that do not serve their best interests. For example, a man with T2D may determine that while drinking one beer increases his BG, it does not excessively increase it. He notes, however, that a second beer will increase his BG above the level he can control that day. He sets a rule that, “It is ok to have one beer, but, I shouldn’t have two.” The problem is that his diabetic state does not adequately process even one beer and results in his BG increasing with each beer; only less excessively with one than two. Over time, this is a simple rule for him to follow in a social setting when he might feel pressured to drink beer as others are doing as it removes the necessity to think or struggle with the decision or outcome. His BG excursion is damaging to his vasculature and end organs in the long-term each time he resorts to this simple rule.

Other times, in using a heuristic approach, a person relies on the expertise and/or experience of another: family member, HCP, another person with T2D, expert roofer, or auto mechanic. In other situations, there is too much information or facts to gather and/or too little time to sort it and/or uncertainty whether the information is adequate or will change the outcome. In still other circumstances, one

resorts to emotions to compare options and potential outcomes. Namely, a positive-emotion dictates that the situation is adequate and there are few or no perceived high-risks, thus one can continue in the same vein. However, a negative emotion indicates something is not right and the risk is higher with fewer perceived benefits; thus, one should not continue (Fischer & De Vries, 2008; McCaul, Peters, Nelson, & Stefanek, 2005; Strohschein et al., 2011). Patients sometimes address both safety and danger categorically, meaning they undervalue how important "partial risk reduction" (Redelmeier et al., 1993, p. 72) is and can be influenced by the way they understand a problem is framed. Fischer and De Vries (2008) describe the process as being an integrated one in which, based on the evaluation of previous behaviors, the person uses the past to predict the future, including behavior. This makes decision-making a limited effort that can lead to inaccurate evaluation of an action and the outcomes.

The literature has shown that people often resort to the common, less complicated, more simple or familiar choice; that is, how they felt or perceived a situation or deferred to others to make their decisions. They do not always consider more complex factors or influences. This principle of descriptive theory is consistent with intrinsic assumptions about this study, that limitations and barriers may exist in this population and they sometimes resort to simple choices; at times, the DSM decision-making results were less-than-ideal.

Prescriptive theories and the need for more clarity. Prescriptive theories, on the other hand, are founded on the postulation of poor decision-making; people need assistance with making decisions. These theories were initially a subset of

normative theories but included values-based and attitude-inclusive features (Bekker et al., 1999) that enabled assistance in the form of decisional aides. It should be clarified that some literature has described normative models as prescriptive because they prescribed or dictated how one was to choose (Garro, 1998). However, the rubric of prescriptive theories relates to the need for assistive tools; the assumption that one cannot make an effective decision without assistance. Prescriptive theories also include some cases of shared care. In the case of complex overlapping or conflicting medical/ health care priorities for the patient, HCP and patient/family may benefit from a tool to help guide them through the intricacies and demands of multisystem illnesses such as diabetes (Yu et al., 2014). Although available, decisional aides may not be used (Hill et al., 2009).

This current study asserted that, rather than poor decision-making by the immigrant, the client might not have been adequately informed and/or approached by the HCP in a culturally-knowledgeable manner that was understood by the émigré. Moreover, underlying cultural dimensions that effected, influenced, and motivated decisions needed to be discovered. Therefore, this qualitative study was not based on a theoretical framework, but rather on conceptual inquiry because none of the theory rubrics adequately addressed the problem statement.

Other investigators have had similar issues with existing frameworks. For example, McCaul et al. (2005) expressed concern that traditional (normative) decision-making theories have failed to capture the effect of real-life decisions because they have not included the influence of affect. They argued for the inclusion of patient affect and beliefs in SDM for cancer patients. Citing studies that had

included the affect aspect of patient decision-making that had improved the decision process, they also acknowledged there was potential for harm. In all, they asserted that the existing motivational–emotional state of the patient can influence decisions as well as their self-concept. While their report had a different chronic care focus, the finding that motivation and affect influenced decisions was consistent with the literature on the importance of affect and beliefs to Mexican immigrants. The current study began to address the gap about DSM decision-making processes by Mexican immigrants including factors that influence those processes. But, first, a description of patient decision-making.

Concept of patient decision-making: Concept, Decision-maker, Decisional conflict, and Informed decision. The concept of “patient decision-making” (PDM) has its roots in clinical-medical decision-making because for many years the focus of decision-making was on the clinician rather than inclusion of and/or release of decision-making to the patient. Much of the transition from clinician-focus to patient-focus has been found in the SDM literature, as it is currently. However, prior to the patient making a decision about a health issue, there must be a *decision problem*. Research pioneers in decision-making defined a decision problem as “the acts or options among which one must choose, the possible outcomes or consequences of these acts, and the contingencies or conditional probabilities that relate outcomes to acts” (Tversky & Kahneman, 1981, p. 453).

Four elemental aspects to a decision have been identified. A decision includes: (a) initial options, alternatives or choices; (b) values, what something might be worth, its utility, and/or desirability; (c) uncertainties or probabilities,

analytic or believed; and (d) potential outcomes or consequences. The difficulty, however, lies in the fact that patients might not have the capacity, knowledge, or experience to weigh all of the facets of the problem or the alternatives (Pierce & Hicks, 2001). If patients reframed the decision problem into their own terms as they understood it, they might add other options than those that had been offered or discussed or might discard one quickly without reflection (Pierce, 1993). The person with T2D who had decided in the past they would never use insulin might discount that option without regard of the current situation.

Important work by Strohschein et al. (2011) analyzed the concept of “patient decision-making”. Utilizing an extensive literature review on decision-making by older persons with cancer, researchers sought to identify a consistent, “mature,” (p. 905) working definition of the concept. Due to numerous, inherent inconsistencies and frequent lack of an actual definition of the concept, they found weaknesses in concept definition and usage. Numerous articles have not defined the term and those that did were inconsistent, including a concept analysis of decision-making by Noone (2002) that used a dictionary definition that was modified throughout the concept analysis; it was not specific to PDM. Strohschein et al. found that it was common for clinical decision-making to overlap with PDM and not all of the standard features expected of a concept analysis were met in the literature review. For example, preconditions, such as the presence of both a decisional problem and choice, had varied conceptualizations. Outcomes have been a core component of concept analysis as they link a concept to the existing context. Rather than descriptions of outcomes, however, they found opinions, where values were

attached to outcomes. Specifically, a *good decision* was equated with compliance with HC recommendations rather than considered a *reasonable choice* according to the criteria of the patient. However, patients more often make choices founded on their values and what they thought was important for themselves and those important to them. They found that the literature had no consensus on what might designate a good decision: was it the process of decision making and the criteria to judge it? how well the choice fit the patient's criteria? how comfortably one could live with one's decision? or should the assessment of the post-decisional appraisal determine whether the decision was a good one? At times, simply making a decision was found to empower the decision-maker. One might reaffirm, reverse, or restrain the planned choice of action; or the current choice might direct or redirect subsequent choices, especially if they were similar or regarded the same issues (Pierce & Hicks, 2001; Strohschein et al., 2011). Noone (2002) described it as either accepting or reevaluating one's choice.

Other aspects of concept analysis included the conceptual distinction from other closely-related concepts; this clarity was also lacking in the literature. Regarding the timing of PDM, authors found some literature described PDM as a distinct event (Redelmeier et al., 1993) while others described it as a process; still others observed changes over time. From this, authors derived that PDM has a temporal quality. Some literature described the concept as individually-based decision-making and others found it to be interactional with family and important others as well as HCPs. The interaction with HCPs was identified as having had a critical impact on PDM in numerous studies. As clinical decision-making has had an

inherently rational dimension, some studies expected PDM to follow suit. This led to the view by some authors that patients were irrational in PSM, rather than that they might use different criteria for making decisions (Strohschein et al., 2011).

In 2000, Broadstock and Michie (2000) proposed that PDM might be an integrated concept that is both normative (i.e., rational and analytic) and intuitive in nature. They suggested patients might try to keep their efforts at decision-making simple while they try to make an accurate and thoughtful decision. In the end, Strohschein et al. did identify the concept of PDM as an ongoing process with temporal features that change with time and reflect individual and relational components as well as analytic and affective dimensions. PDM was also found to be a process that linked one's health beliefs to their behaviors. The working definition, a compilation of Noone (2002) and Pierce and Hicks (2001) was,

Patient decision-making refers to an ongoing process comprising complex cognitive, perceptual, affective, behavioral, and relational components by which individuals select an acceptable solution or a salient alternative concerning a health-related issue, influenced by interactions among individual and contextual factors, culminating in decisional consequences and post-decisional appraisal. (Strohschein et al., 2011, p. 919)

Finally, the concept analysis by Strohschein et al. (2011) distinguished PDM as unique from shared- and clinical-medical-decision-making and validated that the concept had a dynamic component that changed over time, had characteristics of the individual and at times, relational, emotional and analytic.

The decision maker. The decision maker is the person who reaches the final decision about an act, behavior, plan, action, or to refrain from action related to what is chosen or decided upon. Generally, emotions, mental considerations, needs, experience, history, preferences, beliefs, values, expectations, and roles along with interpersonal, financial, and physiological factors impact the decision process, as may heuristics. Risk appraisal/perception about the impact of one decision or another has its foundation in the culture from where the individual derives his or her identity and sense of self. Context of the decision and one's life circumstances always impact the decision-maker, sometimes more than others. Once the decider reaches their choice and some behavior does or does not transpire, the decider often moves into a post-decision evaluation (Mellers, Schwartz, & Cooke, 1998).

Decisional conflict. Prior to a decision being reached, a *decisional conflict* may arise in which there is a disconnect between the patient's values or wishes and the alternatives that are offered, competing options with risks or uncertainties, equally poor or competitive alternatives, or the person deciding (the decider) may foresee that they might have regret in not having chosen a beneficial option. Finally, the outcome or consequences may not be clear or certain. Also, some patients do not want to be involved in decision-making for various reasons (Pierce & Hicks, 2001).

An informed decision. A final clarification from the conceptual literature is the salience of the informed decision. Informed decision-making has both ethical and legal dimensions. An informed decision implies that a patient has been provided sufficient information necessary to comprehend the options that may be available and the projected, presumed, or hoped-for outcomes or consequences in order to

make an informed choice. When a person consents to a procedure, intervention or other health-related activity including taking medication or having a blood specimen drawn for an A_{1c} test, (s)he should be given the opportunity to choose a course of action.

Informed consent is a legal and ethical protection afforded to all patients of all backgrounds and ages. While portions of those legalities are outside the realm of this study, the standards for presenting information to the patient to make an informed decision do apply. There are three legal standards: (a) *professional practice standard* in which “the disclosure is consistent with the standards of the (health care) profession” (Burkhardt & Nathaniel, 2014, p. 274). This is required for consent for surgical and invasive interventions, but is rarely readily understood by non-professionals; (b) *reasonable person standard*, also known as the *prudent patient standard*, is the information that is presented is comparable to what “a reasonable person in similar circumstances would need in order to make an informed decision” (p. 274). It includes the risks a *reasonable person* considers when making a decision regarding whether to undergo treatment. This is the legal and medical language broken down into what the average individual would need to know. What information would the average person with T2D need in order to understand the test or procedure? The last standard, (c) *subjective standard* is “what the particular person wants or needs to know” (p. 274). The person may choose to have very little information provided and agree to whatever is recommended by the HCP or family, or the person may need more than the average person and require numerous *What if...* questions to be addressed; it is individual-dependent.

Informed decision-making, based on informed consent, provides legal protection of a patient's right to personal autonomy. It gives the patient an opportunity to self-determine, to choose a course of action in regard to plans for health care. Information includes both disclosure and understanding of the essential information. Consent implies the freedom to accept or reject something. It is the role of nurses and other HCPs to assure these national standards and ethical guidelines are kept, including attention to language barriers, cultural differences, and possible conflicting values and goals between patients and providers (Barnes, Davis, Moran, Portillo, & Koenig, 1998; Burkhardt & Nathaniel, 2014; Dandry Aiken, 2004; Kaufmann, 1983; Pirbhai, 2003).

The decision-making process. When the literature was searched for content on the *process* of decision-making, that is, the steps one takes to progress from being aware of a decision problem, that there is an opportunity or need to make a choice, through the considerations necessary to arrive at a health decision, very few references were located. The majority of the literature that mentioned or focused on the process of decision-making generally discussed factors that *influence* choice or different *types* of choice. Very little material was located about the actual steps, categories, or stages through which one passes in the PDM process.

Probably the most important work on the decision-making process was done by the Thorne-Paterson group. They evaluated factors, characteristics, and processes, and of patient decision-making in chronic disease in several qualitative investigations. In 2003, the Thorne-Paterson group investigated the everyday self-care decision-making by persons with expertise in self-care management of T2D,

HIV/AIDS, and multiple sclerosis. Utilizing secondary analysis of two similar studies, the majority of whom had DM, they constructed an account of how these persons made their decisions. This investigation was more process-oriented than the majority of the literature that looked at factors influencing decision-making. Major themes included: (a) learning about the disease and deciding to take control; (b) fine-tuning the disease-specific self-care, specifically experiencing the disease, managing social context, lifestyle, treatment, HC, and considering the future; (c) evaluating measures taken, such as utilizing expert resources and attending to biomarkers, developing one's own standards, and taking complexities consideration. Authors concluded that the concept of self-care decision-making was more complex than simply learning about a disease and complying with therapeutic actions. More studies like this are needed to identify the decision-making process for DSM.

In another study, Paterson, Russell, and Thorne (2001) sought to identify traditional assumptions about every-day self-care decision-making in chronic care and to contrast those with relevant research. Prior to their work, decision-making information was often derived from single-incident choices or superficially related contexts that did not reflect the complexity and real-life challenges of living with a chronic disease. In fact, they asserted that the literature that focused on adherence issues had made the subject murky. They suggested Garro's understanding of decision-making was grounded in the context of people's personal and social lives. Garro (1998) conceptualized decision-making to include four essential components: inclusion of the many and frequent goals and expectations that faced decision-makers; the way that one framed or represented their decision; the socio-cultural

context; and the complicated and multifaceted psychological processes that contributed to the construction of a decision regarding chronic disease self-care. From findings in a similar study, Thorne et al. (2003) concluded with this recommendation,

Practitioners can address these criteria by conceptualizing everyday self-care decision-making as personally constructed, changing over time and in various situations, entailing a complex interplay of mediating and contextual influences, and arising from an authoritative knowledge that evolves in living with the disease over time. (p. 1350)

A study in Korea more closely approximated the concept of the decision-making *process* than most authors who use this term. The author inquired about the experience of deciding to donate a kidney. The core category was identified as “wishing to give (a kidney)” (Yi, 2003, p. 65); there were six sub-categories of influence: motives, intervening conditions, inhibiting factors, facilitating factors, donor characteristics, and consequences. Two phases in decision-making were identified; the deliberation phase and the execution phase. During deliberation, a phase lasting from a few weeks to several years, the potential donor began to consider donating a kidney to the recipient. The primary reason to give was to save a life or promote health improvement in the recipient. The main motive was to maintain family integrity, to keep the family intact. Numerous influencing factors and motives contributed, including sympathy, guilt, religious beliefs, freedom from burden of providing care, and emotional intimacy between the eventual donor and known recipient. The execution phase that lasted 3-6 months included the follow-

through steps that concluded with the nephrectomy surgery. In both phases, potential donors fell into one of three donor types: (a) voluntary donors, their desire to give was “intense,” and the active process toward giving was smooth and straightforward and they refused any financial compensation; (b) compromising type, they had a moderately intense desire to give; their process was complicated with inhibiting factors, particularly fear of surgery, pain, and living with only one kidney. They eventually became fully active and felt they had no choice but to proceed; they received some economic compensation; and, (c) passive donors, who had low intensity to give; their process was characterized as “volatile” (p. 65) as they were reluctant, ambivalent, fearful, and obligatory, with a low intimacy level with the recipient. They requested and received economic compensation. By the time of surgery, their concerns were resolved. Yi (2003) summarized that the decision process to give was complicated, involving psychological, interpersonal, familial, and financial factors with limited consideration of medical concerns. She identified two phases in the decision-making process that moved the person from the pre-decision state through the decision factors and choice to follow through.

A recent study added important data to the scant literature on PDM process by identifying stages. Laidsaar-Powell et al. (2016) evaluated patient, patient family, and HCP attitudes toward and experiences with decision-making about cancer treatment, including consultation with the physician. Researchers identified five distinct stages in decision-making. Similar to Yi’s finding that there was a stage in advance of decision-making that they identified as (a) *pre-consultation preparation* stage, when the family gained information and sometimes had formed an opinion

prior to the consultation. It was followed by (b) *information exchange*, (c) *deliberation*, (d) *the decision*, and (e) *post-decision deliberation* when any new information was factored in or the patient or family wanted to revisit the process and influencing factors. The decision stage (d) comprised a time of (i) *no family influence* in which the oncologist and/or the patient controlled the decision-making; (ii) a *time of family influence* in which the family withheld opinion while helping through proximal actions, such as information clarity or note taking; (iii) *shared family influence* wherein the family, often the spouse, and patient came to a consensus so that both were comfortable; and (iv) *dominant family influence* when the family member was charged with decision-making, by the patient. Beyond the clearly identified stages, three main categories emerged: (a) how family were involved in the decision-making process that identified family behaviors, addressed above in the decision stage; (b) attitudes about family involvement, needing to balance patient autonomy-authority with family rights; and (c) factors that influenced the family's involvement, such as culture, relationships, family and patient preferences and needs. Authors recognized that patients had complex attitudes in striving to maintain patient autonomy-authority while including the family's insights and influence on decision-making.

Several years ago, results of a qualitative study were reported on the *decision behavior* of women choosing breast cancer treatment. Rather than the actual steps in the decision-making process, Pierce (1993) identified five behavioral variations of choice: (a) *perceived salience* referred to the degree a participant was initially aware of or drawn to a specific alternative. These women had little decisional

conflict; (b) *decision conflict* occurred when the patient decision maker was attracted to more than one option. Conflict resulted in emotional distress in three circumstances. If the patient had a preference that was not offered, such as a nutritional intervention; if she was not able to distinguish between the options; or if the HCP strongly advised an option that the patient did not favor. In the latter case, the patient was conflicted about her own choice versus the preference of the person in control of her health situation. The third behavioral variation included (c) *information seeking* participants who could not discriminate between choices that led to them seek data from various sources or have others search for them. Low information seekers did not want evidence and did not feel it was beneficial. They were satisfied with the decision they had settled upon. Some had *defensive avoidance* as they avoided data that might cause distress if it called their choice into question. Fourth, (d) *risk awareness* was mentioned by a few women, however, they preferred to use the term, safety, and were either *risk-seeking* or *risk-averse*. The latter sought safer options, the former accepted risk after they had done all they could to minimize it. These women expressed concern that physicians were evasive about risk data and did not find statistics to be helpful. Finally, (e) deliberation occurred when the information seeker was dissecting the issue, options, and risks. Those who did not deliberate did not have conflict; some strategized how to seek information. Those with more conflict did more information seeking and conflict existed until a verdict was reached.

Final analyses revealed three distinct decision-making processes that the author termed as *decision styles*, listed in order of increasing complexity: (a)

Deferrers made quick decisions that were highly influenced by the HCP; they were older, had little or no conflict, and did not need to seek information, (b) *Delayers* defined the decision problem in such a way as to compare two or more options; once an option was preferred, they used what the author termed as the *first difference rule* because they were able to choose based on their preference, and, (c) *Deliberators* accepted responsibility for a careful decision, had a strategy to seek data, considered risk, expressed confidence in the decision-making process, followed by a prolonged uncertainty about whether they might regret their choice. Due to the complexity of their process, the author said they applied the *last difference rule* to arrive at their final deliberation. She suggested more research be done in PDM (Pierce, 1993).

A complex study utilizing numerous quantitative instruments sought to predict the decision-making style of cancer patients. Researchers asked whether decision styles might be influenced to change via communication with their HCPs. Their premise was that cancer patients had previously been identified as being one of four types of decision makers: *information-seeking*, *information-processing*, *advice-following*, and *ruminating*. The study was founded on the underlying concept that information was either processed mindfully or mindlessly, and that processing routes were either *central*, lasting, and less affected by the environment, or were *processed peripherally*, being transitory in nature and greatly affected by the environment. *Mindful processing* considered the problem and possible solutions choosing between identified options. In making a *mindless* decision, the person latched onto a portion of the perceived issue that interfered with her or his ability to

evaluate the whole situation and other possible options. Motivation was again identified as an important influencing variable; it was significantly affected by anxiety and measured with two tools. They used a scale that discriminated between *intrinsic motivation* for thoughtfully considering information versus wanting to avoid exerting effort to think. Although heuristics were not mentioned, this description was consistent with a heuristic approach. One instrument evaluated *decision style* through their decision processing rather than content of their decisions. Other identified aspects of the decision process were the *need for closure*, the need to come to a decision, personal values, personal efficacy, the ability to process information given to the patient by the physician based on an actual decision they had made, and directional cognitive responding. In the latter, if the patient had both favorable and unfavorable responses or ideas not relevant to the issue, they were not engaging in thought-based decision-making and were a “ruminating” type (Petersen, Heesacker, Schwartz, & Marsh, 2000, p. 673). This resembled the conflict described in the Yi (2003) and Pierce (1993) studies. Petersen et al. (2000) suggested that the physician’s presentation style might influence patient decision style. The instruments collectively predicted style; it was unclear whether the authors actually noted change in decision style. A pilot study on the decision style preferences of advanced cancer patients from very low SES backgrounds identified five different styles. The majority preferred their physicians to choose for them, saying “I am not a doctor” (Hughes, 2007, p. 551).

Contributing influences, persons, and conditions: Family and HCPs.

Review of the literature indicates numerous value-, belief-, and context-based

factors that affect and influence PDM. The patient brings the largest multiplicity of influencing factors and conditions to decision-making: sociodemographic features, including age, developmental stage, gender, ethnicity, level of education, previous clinical and health experiences (Saha, Arbelaez, & Cooper, 2003) and current clinical status, comorbidities, illness experiences, risk appraisal, expectations. In addition, they provide personal capital, such as cognitive function and knowledge level, values, beliefs, attitudes, degree of self-efficacy, personality and stress-response style, self-esteem. Other conditions include perceptions about a type of intervention, intention to carry out treatment recommendations, and self-care practices (Dijkstra, Jaspers, & van Zwieten, 2008) along with other personal strengths and weaknesses, SES and financial resources or lack thereof (Al-Ali & Haddad, 2004), social resources, such as type of social support, spiritual and/or religious beliefs and strengths, prior experience with other ill persons, illness and health education, and HL (Cajita et al., 2016; Goldstein, Siegel, & Boyer, 1984; Stroschein et al., 2011).

Other very salient influencing factors in the decision-making literature include: context, the factors that make a person's situation unique at a given time including complexity (Applewhite, 1995; Bucknall, 2007; Chang, 2015; Kelly-Powell, 1997; Kleinman et al., 1978; Montbriand, 1995); cultural-ethnic differences and personal choice-preference-decisional style (del Río, 2010; Galavotti & Richter, 2000; Hawley et al., 2008; Lewis, Groff, Herman, McKeown & Wilcox, 2000; Napoles-Springer, Livaudais, Bloom, Hwang, & Kaplan, 2007; Perriera et al, 2006); change and process, such as risk appraisal, ambiguity or conflict, (Hunt et al., 1998; Kelly-Powell, 1997; Micha et al., 2017; Wright, 2001); explanatory model(s) (Eid &

Kraemer, 2002; Gaston-Johansson et al., 2007), temporal aspects, and personal history (Biley, 1992; Petersen et al., Heesacker, Schwartz & Marsh, 2000).

The perception that one does not have options or a choice in HC can be contextually-dependent. In the case of serious disease such as CHD, CKD, or cancer, patients were interviewed following a decision and at 1 month. They reported that their view of themselves within the context of their lives was the determinant in accepting treatment for their condition. For women choosing contraception, “finding the best fit” was important based on their perception and knowledge of various methods (Montbriand, 1995; Noone, 2004, p. 13; Strohschein et al., 2011). Symptom perception and appraisal responses might be related to complex physiologic, cognitive, affective, social, socioeconomic, geographic, such as the proximity to diagnostic testing or treatment, and environmental factors (Kovatchev, Cox, Gonder-Frederick, Schlundt, & Clarke, 1998; Mac Bride et al., 2013). Several of these multifactorial variables have also been previously identified as influencing factors on health beliefs (Brown et al, 2005; Garro, 1998; Lemley & Spies, 2015) that correspond to findings that decision-making is rooted in health beliefs, preference, and culture (Domian, 2001; Tovar & Clark, 2015).

A doctoral study examined the health decision-making process of persons with newly-diagnosed (within the past 6 months) T2D in the Midwest. Three interviews occurred over 6-months to identify the factors that influenced the 21 participants’ choices about life-style changes related to their T2D. The author identified four categories of influence: (a) the degree of emotional upheaval and imbalance in life with T2D (b) various degrees and types of knowledge about their

illness included factual knowledge (medical-science knowledge in the current study), emotional and experiential knowledge (social knowledge in the current study); (c) the different perception of power participants felt over their disease, which the author termed self-agency, a type of self-efficacy; and (d) the degree of inspiration and sense of purpose to make change (Garris, 2002).

The family's influence. The inclusion of family in decision-making has been prominent in the literature as many of the same dimensions that affect PDM also resemble family influence. The family and significant others generally have profound influence on the decision-making process for HC issues through their expectations, preferences, appraisal of the situation and sense of threat, knowledge and information, personal traits, hidden motives, fears, experiences, and relationship to the patient. Many of the forces that affect the patient also impact the family in the decision process (Strohschein et al., 2011).

A recent study evaluated the effect on joint replacement PDM utilizing focus groups to relay fictitious predictions about various treatment stages. Researchers found that if patients received information from family or friends, they were unwilling to modify their expectations about surgical outcomes if they had to adjust downward. They were, however, willing to adjust their expectations upward in hopes of a better outcome. Authors termed this “optimism bias”. In an heuristic manner, participants wanted to know the “bottom line” (Barlow, Scott, Griffin, & Realpe, 2016, p. 304) rather than to have detailed information when early in their osteoarthritis process compared to advanced stages. In the past, seeking advice from a physician or having a family consult had prolonged decision time to seek

care. Nonetheless, in the Turriss (2009) study, seeking advice from family promoted earlier visits to the Emergency Department for cardiac symptoms.

Beckingham and Baumann (1990) devised a family assessment decision-making process model based on family assessment theory to assist elder families in crisis. Numerous steps walked a family through a difficult decision, from assessing and collecting data, examining strategies, analyzing assessment data, reviewing alternatives, evaluating the choice, and implementing the choice. Although the authors did not call this a decision aid, it in fact fell into the prescriptive category. It was normative in nature in that it told one how to make a decision rather than descriptive about how these families might actually decide.

Health care provider influence. Health care providers typically impact decisions made by patients based on their knowledge, preferences, perspective, definition of the situation; how well the provider knows the issues, patient, family, and his or her resources, the time invested in problem-solving; their personal traits; and other personal, environmental, social-relational conditions and indices. Doherty and Doherty (2005) highlighted three models of treatment decision-making, two involve the client: (a) the paternalistic model was founded on the provider's decision on treatment, how much information, which facts, and how (s)he chose to share those with the client, particularly if biased; this has traditionally been called medical, clinical, or treatment decision-making, (b) the SDM model allowed for a two-way information exchange and mutual decision-making between patient and provider, and (c) in the informed decision-making model, the clinician provided information for the client to make an informed decision for his or her self; this latter

process was PDM. The importance of the HCP's language and cultural savvy has been discussed. The interactional nature of relationships with HCPs, family, others, one's self, and the health care system all had bearing on decisions.

For a number of years, patients have indicated an increased interest in and expectation to participate in decision-making about health issues (Barry & Henderson, 1996). In a Spanish study on the involvement of patients in decision-making in primary care, investigators identified limited discussion of options. Less than 60% of physician-patient interactions in the 31 HC visits evaluated had any portion devoted to more than one treatment option (Ruiz Moral, Peralta Munguia, Perula de Torres, Gavilan Moral, & Loayssa Lara, 2010). Similarly, in a study on depression, very little patient involvement was noted during consultations. The majority of the HC visit was spent by physicians defining the medical problem. Authors cautioned that general practitioners should improve their inclusion of patients in decision-making and be mindful of how visit time is utilized (Loh et al., 2006). When patients perceived that they had no choice, sometimes it was due to the information provided by HCPs. Incongruence of perceptions between the patient and HCP added to the patient's conflict. Patient dissatisfaction, based on conflicting explanatory models between patients and HCPs, could reduce patient participation in HC decision-making making (Betsch, Haberstroh, & Hohle, 2002; Strohschein et al., 2011). Misinformation has also delayed re-start of antidepressant use (Dijkstra et al., 2008).

In another study of over 1,000 patients, less than 10% of the conversations between patients and providers met informed decision criteria, discussion on

intervention was noted 71% of the time, and patient understanding was assessed less than 2% of the visit time (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). Conversely, rheumatoid arthritis patients reported that, in addition to the severity and duration of their illness, guidance from HCPs was a primary influence on their HC decisions (Wright, 2001). Likewise, patients perceived that they had received support through nurses who had provided information and encouraged them to share in decision-making. They reported that they benefitted and their independence had increased (Valimaki et al., 2004).

Specific to T2D, the interaction between HCPs and patients with poorly managed T2D was examined. Authors noted that while SDM was ideal in clinical practice, it was not easy to employ. They developed a reflection/communication model of SDM in chronic care. Their goal was to help providers gain insight into patient factors in decision-making; thus, empowering PDM (Zoffmann, Harder, & Kirkevold, 2008).

At an institutional level, the National Cancer Institute developed a cancer control initiative to enhance HCP comprehension about how people made decisions. The long-term goal was to increase the number of patients who were informed and satisfied with their health care choices (Nelson, Stefanek, Peters, & McCaul, 2005). Further external systems might also have an effect on decision-making, including health care organization, insurance structure, socio-political system influences, restrictions, and requirements; and environmental stressors and social expectations. All aspects are indices of effect (Falke & Lawson, 2015; Holloway, Waldrip, & Ickes, 2009; Nápoles et al., 2009; Strohschein et al., 2011).

Ultimately, of all that influences a decision, the actual issue that requires (or offers) a choice may have the most influence. It would be valuable to understand how complex the issue is, if it is possible to grasp the key aspects, and the degree of seriousness. How might the temporal aspect affect choice, is the situation urgent; and whether the potential outcomes are known and the level of certainty. Knowing the probability risk, if there are possible alternatives and if those options might have a factual bearing on the ultimate outcomes might also be helpful to know. Other points of consideration might include how familiar the patient is with a particular phase of decision-making or what his or her perceived success has been in effective decision-making. Consideration should include how the patient and/or family might be affected by decisions including the costs to the patient, significant others, HCPs and possibly the overall HC system. Reflection by the decision-maker on how the personal strengths and deficits of the individual, family, HCPs and the HC system combine with the current need or options would be a worthwhile time investment (Strohschein et al., 2011).

Decision-making in T2D or chronic disease. Few reports on decisions in the person with T2D or chronic disease were located. A qualitatively study evaluated medication experiences of persons with T2D, most of whom were not H/L. Three major themes emerged: timing and frequency of medication administration was inconvenient and inflexible, the desire to avoid injections and/or insulin therapy, and the physical and emotional side effects of T2D. An important finding was that participants thought they had no opportunity to discuss treatment preferences or concerns with their HCPs. Authors recommend providing

support to enable patient expression and to enfold patient requisites into medication management (Hayes, Bowman, Monahan, Marrero, & McHorney, 2006). Another investigation looked at decision-making by older women with cardiac illness. They explored the experiences and decision-making practices related to sodium-restricted diet in persons with HTN or heart failure; how the HC system and contextual factors might impede or facilitate dietary compliance. Lack of patient education and information about sodium were directly related to HCP input. The study identified a strong social component; a key contextual barrier to healthy nutrition was eating alone with no motivation to cook (Sheahan & Fields, 2008).

The purpose of a 2002 by Paterson, Thorne, & Russell study was to investigate disease-specific influences on common, everyday self-care (SC) decision-making by persons with different chronic illnesses, including T2D, to compare decision-making between chronic diseases. They also sought to identify criteria clinicians would use to assess the quality of the SC decisions of patients whom HCPs considered to be expert SC managers. Similar to the current study, they evaluated processes by which decisions were made and factors that influenced decisions. The group found shared, similar SC decision-making elements in the different health issues. However, differences in *perceived meaning* and *decision significance* were found to relate to disease-specific attributes such as timeliness, biomarkers, social context interaction, healthy practice construction, and available relevant information. Suggestions were to enhance the quality of self-care decision-making through disease-specific decision features that influence specific health issues.

Unlike the current study, Thorne and Paterson (2001) differentiated decision-making factors between familiar and unfamiliar situations in persons with insulin dependent, T1DM when unanticipated BG levels arose. Familiarity with the scenario was handled in a straightforward manner and clients were self-confident. Conversely, in unfamiliar or novel situations self-confidence was lacking and a non-linear progression of steps was followed to locate a plausible hypothesis and to construct a story explaining the aberrancy. It was determined that contextual, mediating factors and circumstantial familiarity influenced decision-making processes and subsequent choices. The important outcome of this study was the irregularity of decision-making when circumstances differed from the expected.

How patients have decided. Thorne et al. (2003) sought to understand how people experience decision-making within the context of daily life. Utilizing secondary analysis, they constructed a process to describe how people with chronic disease made decisions that related to their common-day lives and how to avoid unwanted outcomes. All participants wanted to be in control of their disease, which meant that they needed to be educated about it and to develop short- and long-term goals. They often shopped for HCPs who fit their goals and showed a conscientious choice to control the course of their chronic disease as much as possible.

Using Grounded Theory, researchers evaluated treatment-seeking-delays in Canadian women who sought emergency care of possible cardiac conditions and how they interpreted those symptoms based upon their forms of knowledge. The influence of the women's social roles and relationships as mothers, daughters, and wives rather than symptomatology took precedence over their own health concerns

that affected delay of treatment. Resisting disruption to their normal lives and maintaining their self-image as being capable of continuing in life roles were primary findings. The interview analyses identified that participants resisted disruption of their lives through various "ways of knowing" (Turriss, 2009, p. 5) that they employed to interpret their symptoms. These were categorized as (a) embodied, their subjective experience; (b) temporal, the association of their symptoms to events in their day such as mealtime; (c) rationale, they gained general health information from television and other public means; and (d) relational, the perception about what could happen to their relationships if they sought versus delayed seeking HC. The latter played the most significant role in the women's decision-making because, ultimately, their concern about the impact that their decision to seek or not seek care could have on their families drove their decisions. When symptoms interfered with routines, women were quicker to act.

Another study that examined why women delayed seeking treatment when they had symptoms of an acute heart attack (AMI) identified three categories of explanation: complex clinical, sociodemographic, and psychosocial dimensions. Specific reasons for treatment delay included uncommon or atypical symptoms; severity of symptoms, especially with comorbid chronic disease that made it difficult to evaluate acute symptoms; perceived seriousness or low self-perceived risk and vulnerability to AMI; and various other coping skills (Lefler & Bondy, 2004). In another study, when elders first considered use of walking aids, their cultural views of aging interfered with that choice. Later, when gradual and abrupt changes occurred in their ability to function, although their view on aging had been

a barrier, it became a means to facilitate choice of walking aids (Gooberman-Hill & Ebrahim, 2007).

Summary of decision-making and gaps in the literature. Historically, there have been three rubrics of decision-making theory: normative, what one ought to do; descriptive, what one actually does; and prescriptive, what decision aids would assist in the decision process. In health care, medical-clinical-treatment decision-making was originally done exclusively by HCPs, particularly physicians. Over the years, SDM has taken precedence as HCPs have recognized the importance of having patients' involvement in decisions that affected their health as well as input from and concern for the effects on the family. In order for SDM to exist, the individual must be able to come to his or her own decision. Before making a decision, a decision problem was necessary, a reason to make a choice; although, sometimes patients did not realize there was an option to choose. An informed decision was one in which the patient had been provided options in a fashion that secured adequate information to allow the average person to make a choice based on accurate data and to the point of satisfying her or his questions. There were/are legal and ethical compulsions for the HCP.

The concept of PDM has been discussed in the literature for years, yet when searched, the actual *process* of decision-making was rarely described. Instead, most reports discussed influencing factors, of which there were many; although, several recurred, such as motivation, intervening, inhibiting and facilitating factors, and outcome considerations. A salient finding of a common phenomenon, heuristics (i.e., a simplistic rationalization and "return to the bottom line" approach to problems),

coincided with how one went through the process of decision-making. Resorting to naive or uni-dimensional thought, abridged rationale thought frequently resulted in distorted facts, erroneous beliefs, and mistaken reasoning. These errors sometimes led to decisions not based on facts. Uninformed intuition could interfere with decision-making and, of further concern, has not always been identified clinically.

In this literature review of decision-making and other topics explored earlier for this study, English proficiency played an important role in ascertaining information from or about the participants' decision-making process. The greater the use of English language by individuals the greater their *preference* to participate in HC decision-making. Less English skill resulted in less willingness or confidence to participate. Low HL had an independent association with patient dissatisfaction and individual regret about decisions made. Reduced English mastery might or might not correspond to another common literature gap shared between decision-making, health beliefs, and cultural learning styles (e.g., the influence of time since immigration or generation of the immigrant).

A substantial number of studies included the importance of the communication and relationship between the HC provider, patient and/or family and/or the HCP's recommendations. With rare exceptions, studies were about physicians rather than nurses or other HC providers. Several studies reported that communication between physicians and minority patients had been inferior to non-minority patients. However, when patients had the ability to discuss alternatives with HCPs, patient participation in health decision-making was enhanced. Both the influence of the HCP and the importance of culture were reported in tandem. The

HCPs' concerns, recommendations, presentation of facts, possibilities, and historical features for the patient's reflection and the style of the HCP's presentation have been known to have both restrictive or supportive qualities. Consistently, the literature has called upon HCPs to engage patients and families as appropriate in the decision deliberations for matters involving their health and outcomes.

Limited literature described the actual stages through which the patient moved to arrive at a choice. Common features included a *pre*-decision-deliberation stage; then information gathering, consultation, and risk assessment; deciding; and post-evaluation phases. What was more common were reports on the types of decision-making styles, such as *deliberate*, *delay*, or *defer*. The involvement of influencing and intervening factors for any given individual might be very extensive or more limited. Consideration of the individual's needs and life context was found to be important. Several studies identified family oriented factors: decision-making strategies and orientation, influence, and family role expectations along with the importance of weighing family influence on decision-making and behavior. For many persons, the family played a significant role and their needs and wishes generally were to be considered.

As pointed out by Garro (1998) and Thorne, Paterson, and Russell (2003), much of decision-making literature originated from evaluating single-event decisions or peripherally-related contexts, but often neglected complexity and the dynamic effects of real-life daily living with a chronic disease. The literature thus far suggested that making decisions about SC was ultimately rooted in the every-day context of people's integrated lives. The construction of decision-making appeared

to be situation-dependent, changed over time, and included the degree of skill of long-term disease management. Practicing DSM every day was inconvenient. An important summary feature noted the inconsistency of decision-making. Because contextual and intervening factors, persons, and circumstances have been shown to influence decision-making processes and subsequent choices, the very nature of the process might be more difficult to apprehend. The concept of self-care decision-making had more complexity than a patient merely learning about care of a disease and taking steps to conform to expected self-management behaviors.

The final segment of this chapter will discuss the literature available on the decision-making in H/L. As stated above, the actual process of decision-making has not been previously identified; however, factors, conditions, and dimensions that have affected Hispanic/Latino decision-making will be reported.

Decision-making in Hispanic/Latinos.

Although no literature on the decision-making process about chronic disease by Latinos was located, some literature on decision factors and experiences are discussed here. Several studies have explored women's decision-making about cancer screening and prevention. In a doctoral dissertation, Martinez (2002) explored decision-making about whether or not Hispanic females would decide to undergo genetic testing for breast cancer gene mutations. Those surveyed were known to be at familial risk for developing breast and ovarian cancer. Those H/L women who utilized avoidant and denial strategies were more likely to see drawbacks to testing; however, once they were informed of a positive breast cancer

risk status, they took more proactive positions by practicing breast self-exam and had mammograms more routinely.

Another qualitative study on informed decision-making about cancer screening in women was founded on the premise that a patient must correctly understand the purpose, benefits, and risks of a test. Through semi-structured interviews, a purposive sample of 24 socio-economically diverse women from four ethnic groups, including Latinas, focused on participant ideas about cancer prevention and screening. They found that a number of cancer-related beliefs were inaccurate, distorted facts, and/or over-simplified; these may have been heuristically-based. The authors were concerned that these errant beliefs might be unrecognized in the clinical setting despite having a significant influence on ill-informed decision-making (Denberg, Wong, & Beattie, 2005).

An important work done by Garro was a cognitively-oriented research study done in Pichátaro, Mexico in which she built a decision model and used case histories to evaluate the model's effectiveness. She included both cognitive/rational and affective components. Ultimately, she argued for a decision model that included cognition but was flexible and anchored in sociocultural processes and motivational forces. She described a decision model as a "simplified representation of what happens in the world" (Garro, 1998, p. 324). Her study of treatment decision-making had two parts. First, she had to understand what people did to construct a decision model when confronted by illness, then she evaluated the model. Using interviews, she found four recurring considerations for choice of treatment: (a) the seriousness or gravity of the illness, (b) whether a home remedy was known for the

specific illness, (c) faith or confidence in how effective the *remedios caseros* (home remedies) or *remedios médicos* (medical remedies) was for an illness, and (d) expense of treatment and whether resources were available. The Mexicanos utilized two strategies based on general principles. First, if the illness was not too serious, they started with the least costly treatment and went up the ladder of HC expertise to the physician as a last resort. Depending upon how much trust one had in *remedios* determined, in part, the choice of treatment style. The second strategy was reserved for more serious illnesses and founded on the *probability of cure*. The goal was cure; the cost was less important. The tested model accurately predicted approximately 90% of treatment choices.

Garro's team found significant cultural and social embedded features. She found that the nature an illness transformed over time, was dynamic, not fixed; an argument against normative models. This emergent quality conferred meaning and was part of explanatory models of understanding. She also noted that heuristics were active aspects of some decision-making. Framing or labeling the sickness was an important precondition as it led to different treatment choices. A summary of three goals were to alleviate illness, ensure cure, and keep costs to a minimum. It was all based on meaning (Garro, 1998).

Several studies recognized the importance of cultural sensitivity and influence on PDM. Barakzai et al (2007) examined symptom reporting by M-A patients with irritable bowel syndrome (IBS) to determine if they met the diagnostic ROME II criteria. Only 63% of the participants reported symptoms that met any portion of the criteria; there were no differences between mono- and bi-lingual

subjects. The implications were that culture impacted perception, description of symptoms that might influence diagnosis, and related patient education.

Cross-cultural preferences varied according to cultural perceptions in how men from different ethnicities preferred patient education about serum prostate cancer screening and digital rectal exam to be presented in brochures (Chan et al., 2003). Hispanic men preferred a less active role in decision-making than did NHWs or NHBs and found counseling more acceptable than medications for depression. Authors called for support of the patient's cultural and social context when decisions about depression treatment were being discussed (Cooper et al., 2003).

Another study about HC decision experiences regarding mental health treatment identified the influence of cultural and contextual factors on participation in decision-making by a sample of predominately H/L; 75% of the IVs were done in Spanish. Authors tested a mental health intervention intended to increase involvement in decision-making. The goal was to bring participants to an "activated" state (Cortes, Mulvaney-Day, Fortuna, Reinfeld, & Alegria, 2009, p. 138) to develop effective HC questions and empower decision-making. They identified an interdependent relationship between activation and empowerment; many of the skills necessary to activate patients were critical to becoming empowered.

Research focused on language as a salient cultural component that influenced decision-making was a sub-study of a larger one. Tortolero-Luna et al. (2006) reported 235 H/L woman ages 35-61 were evaluated for how the use of English affected their preference for participating in decision-making and seeking HC information. Univariate and multivariate analyses assessed these relationships.

Generally, women reported a strong desire for information and to participate in HC decisions. The greater the English language use the more significant the preference to participate in HC decision-making and vice versa for the lower use of English. Yanez et al. (2012) found that Latinas who had a greater use of English were more likely to report better communication with higher decision-making satisfaction.

Addressing a common literature-thread about family influence and role expectations in Latino families, del Rio del Río (2010) asserted that, due to the pluralistic society, both patients and families brought a multiplicity of healing and decision-making frameworks to a variety of encounters that were founded on important cultural and religious ideals.

Health care provider influence on Hispanic/Latino decision-making. As demonstrated above, the influence of HCPs on decision-making appeared as a recurring theme in the literature, even when HCPs were not a primary focus of specific studies. In one of two studies by Nápoles et al. (2009), patient-centered decision-making was found to be linked to satisfaction with physicians and health care in general. A study published in 2000 as part of the multi-state Ethnicity, Needs, and Decisions of Women (ENDOW) Project included numerous focus-groups of three ethnic groups, a large portion of whom were H/L. This aspect of the study explored the attitudes toward hysterectomy of underserved women in the “Tex-Mex” border (Groff et al., 2000, p. 39) region. Hispanic/Latinos spoke respectfully about physicians and said they would seek opinions of multiple physician and would want to know the physicians’ motives for advising surgery. They discussed consulting with their husbands, whom they thought would feel that they, as a

woman, would be less than a whole woman if they had the surgery; and they would talk with their mothers and close female friends. The sense of community, shared ideas, and decisions was consistent with the collectivist cultural approach.

In a second study (Napoles-Springer et al., 2007), ethnic differences were noted in both cognitive and affective responses to discussions about ductal carcinoma in situ; lower stage breast cancer. Latinas reported higher levels of distress than did their NHW counterparts whom had a better understanding of the diagnosis and treatment plans. Ashton et al. (2003) reported communication with patients had a core role in patient decision-making. Unfortunately, exchange of ideas between physicians and minority patients was poorer than with non-minority patients, adding to health disparities.

In the Denberg et al. (2005) study mentioned above about informed decision-making in cancer screening in multi-ethnic women including Latinas, authors also found that there was a need for effective communication between HCPs and clients in order for there to be an accurate, mutual understanding of major underlying concepts about prevention, screening, and cancer. Berrios-Rivera (2006) specifically aimed to identify components of the HCP-patient relationship associated with patient trust in physicians. Over 100 patients with chronic disease were surveyed; 43% were H/L. Patient perceptions of how much a physician was patient-centered and the severity of disease were independently predictive of whether patient's disclosed personal health information. Physician trust was highly associated with patient ethnicity and perceived style of communication. Following suit, the Levinson group (2005) explored level of participation of subjects and physicians (physicians

were the only HCP group mentioned) in HC decision-making by English speaking adults. Most (96%) preferred to be offered choices, 52% desired to leave the final decision to their physician. Women, more educated, and healthier persons preferred an active role in decision-making. Over the age of 45, the interest in an active decision-making role declined. Persons of both African- and Hispanic-decent were more likely to prefer the physician to choose for them.

One study identified implicit/explicit and intrinsic/extrinsic decision-making factors. Through an integrated literature review of research articles from 1999 through 2005, Ackerson (2007) investigated factors that inhibit or promote decisions about screening for cervical cancer by H/L and NHB women. Both intrinsic and extrinsic factors were found to contribute. Extrinsic factors, such as lack of insurance, access to care, socioeconomic issues, and acculturation influenced cancer screening practices. Intrinsic motivators related to beliefs and perceptions of vulnerability; that is, if no symptoms were present then there was no need to screen; and not knowing was better than knowing. Advice to Nurse Practitioners was to address ethnic women's beliefs and provide information and services that were culturally-sensitive at an appropriate educational level.

An interesting twist in a study by Redelmeier and associates (1993) looked at intuition as a component of decision-making. They pointed out how intuitive skills could lead people to make less-than-satisfactory or less-than-safe choices. Undervaluing partial risk reduction, distorting memories, inadequate evaluation of an action by its presumed outcome, exaggerated worry, and how one framed a

problem all contributed to suboptimal HC decisions. The recommendation to HCPs was to develop the skill of awareness of how people reason.

Finally, a study similar in aims to the current Mexican immigrant study was reported by Kroll, Richardson, Sharf, and Suarez-Almazor (2007). Aware of ethnic variations in choices about total knee arthroplasty (TKA) through qualitative analysis, researchers examined decision-making factors that influenced ethnic TKA preferences. Utilizing six focus groups, two of which consisted of H/L, authors used grounded theory to analyze transcripts of 37 participants. Four of the 30 categories that emerged highlighted ethnic differences: explanations of illness, changes in lifestyle, trust and skepticism, and paying for surgery. Researchers concluded that attitudes and beliefs varied among ethnic groups. They suggested including open communication between HCPs and patients to allow individual and ethnic experience and beliefs to enhance decision-making for TKA.

Summary of decision-making by Hispanic/Latinos. No study on the processes of decision-making about T2D or other chronic disease self-care by H/L was located. Many of the studies on decision-making with this population identified contributing and influencing factors. However, the actual processes of decision-making about HC issues by Mexican immigrants with T2D remains unclear. The literature does reveal considerable insight into aspects of decision-making that were relevant to the current study.

Specifically, the call for HCPs to be sensitive to cultural-ethnic differences was common. The impact of culture on perception and descriptions, such as symptom experience, can modify diagnosis and patient education. Cultural

differences in the import of decisions was found to have disease-specific attributes. Therefore, effective cultural sensitivity will consider variance in ethnic culture and disease or illness process. Not surprisingly, several studies identified family oriented factors: decision-making strategies and orientation, influence, and family role expectations along with the importance of weighing family influence on decision-making and behavior. Several of these studies were qualitative in nature and sought to describe decision-making factors or outcomes. Saturation was reached between 16 and 37 participants. The larger examined multiple ethnic groups.

No quantitative studies on this research question were located and there were no instruments available with which to measure immigrants' decision-making processes. Up until now, the phenomenon had not yet been described, necessitating the qualitative design of this study.

The following chapter will discuss the methodological aspects of the study. It will include information on the methodology, participants, and developmental process of the substantive theory. The Results and the Discussion sections follow.

Chapter 3

Methods

Diabetes is a serious disease affecting a rapidly increasing number of persons in the United States and worldwide. As has been established, Hispanic/Latinos are disproportionately affected in prevalence, severity, earlier onset and higher incidence of co-morbidities, and higher mortality rates. Persons of Mexican heritage have almost twice the genetic risk when compared with non-Hispanic Whites (CDC, 2014a). Similarly, Hispanics are two-to-one more likely to succumb to diabetes or liver disease (Frieden, 2015). Fortunately, foreign-born Hispanics, as those of Mexican-birth in this study, have approximately one-half of the incidence of heart disease, yet 40% of Hispanics die of heart disease or cancer (CDC, 2015a).

A research gap in the knowledge about the decision-making process of diabetes self-management by immigrants of Mexican birth was found. A qualitative study was required to describe the phenomenon of decision-making, to identify contextual factors, and whether pre-immigration antecedents might affect everyday life with diabetes. Thus, the current study identified how adult immigrants from Mexico made decisions about the self-management of their type 2 diabetes and those dynamics and conditions that influenced decision-making.

The Research Question

How do Mexican-born immigrants make decisions about the self-management of type 2 diabetes?

Specific aims. This study was designed to identify the decision-making factors and conditions that influence the processes utilized by Mexican-born

immigrants to manage their T2D. Subsequently, a data-grounded substantive theory was developed. The primary and sub-aims were as follows:

Aim #1. Explore how the Mexican-born immigrant with type 2 diabetes makes decisions about diabetes self-management through the identification and examination of:

Sub aim 1a: Identify factors that may contribute to the decision-making process and the relative significance of each, and relation between factors/conditions. Therefore, the investigator needs to stay open to these possibilities.

Rationale:

- Family, other people, roles, expectations, beliefs, cultural influences, and values affect decision-making. Latinos are a collectivist culture and the influence of 'other' is strong. Additional external factors and circumstances may influence decisions.
- Meaning is an important aspect of grounded theory; beliefs are related to values and meaning. Meaning impacts actions taken or not taken. The meaning of diabetes may influence self-care decisions.
- The source of health information influences accuracy. Choices to do self-care may depend upon whether one believes one can influence outcomes of diabetes via DSM. Self-efficacy may relate to the belief one has in the ability to successfully and accurately complete specific or general self-care tasks.

Sub aim 1b. Identify any possible previous actions taken to address DSM when in Mexico and the United States.

Rationale:

- Practices in Mexico and changes in the United States may influence behavior.
- Perspective on control and outcomes, if present, may influence decisions and efforts to control blood glucose levels.
- The influence of HCPs, related to language, may help to determine one's understanding, outcomes, and follow-up. Language skill of the individual may affect comprehension, communication, and choice outcomes.

Sub aim 1c. Explore processes in decision-making related to DSM.

Rationale:

- Asking patients about their own process may reveal rich data for analysis.

Aim #2: Explore any antecedent factors in Mexico that may have affected emigration to the United States and whether those factors may have affected DSM decision-making through the identification and examination of factors, persons, or influences that contributed to leaving Mexico. Therefore, the investigator needs to stay open to these possibilities.

Rationale:

- It is unknown whether or how those factors may affect DSM decision-making.
- It is unknown what factors may have caused people to leave Mexico or drew immigrants to the United States and how that may influence decision-making about T2D.

Study Design. Qualitative Design.

Neither a quantitative instrument for measuring decision-making processes by Hispanics with chronic disease nor a known description of the process of

decision-making by Latinos with diabetes was located. In the absence of an instrument to facilitate a quantitative or mixed methods study and lacking a description of the process, it was necessary to do a qualitative investigation to describe the phenomenon (Denzin & Lincoln, 2008; A. Hunter, Lusardi, Zucker, Jacelon, & Chandler, 2002; Lofland, 2006).

Grounded theory (GT) is a process-oriented, iterative, qualitative method for the systematic, inductive collection and simultaneous analysis of data (Richards & Morse, 2007). Further understanding of the decision-making process requires an interpretive approach (Fenwick, Chaboyer, & St. John, 2012). In all of the current methodological variations, GT allows the researcher to examine the data and create provisional, “increasingly abstract” (Charmaz, 2005, p. 509; Richards & Morse, 2007) and emerging categories that in turn further refine the focus of data collection. Concurrent data collection and analysis via constant comparison facilitates early emergence of codes, categories, and relationships (Andrew Hunter, Murphy, Grealish, Casey, & Keady, 2011). Conceptual categories arise from data interpretation. Advanced category refinement leads to more theoretical sensitivity and discrimination of emerged categories (Emerson, 2001).

Eventually, concepts that emerged from the data lead to identification of core concepts around which other categories were related. These categories and relationships formed the final theory that is grounded in and has emerged from the data. As is common to this methodology, the researcher has been an important instrument in data collection, construct refinement, and theory development. The researcher has had to maintain sufficient perspective to prevent the data from being

overly-tainted by the natural subjectivity of the researcher (Birks, Chapman, & Francis, 2006b; Richards & Morse); however, the nature of the method does not allow 'full bracketing' (Denzin & Lincoln, 2008, p. 496), as will be demonstrated.

Initially derived through the social sciences, GT facilitates exploration of issues pertaining to the social and psychological realms (Birks, Chapman, & Francis, 2006a). It "seeks to inductively distil issues of importance for specific groups of people..." (Birks et al., 2006a; Mills, Bonner, & Francis, 2006b, p. 8) and allows evaluation of a process or processes (K. Charmaz, 2006). As this research inquired about the process of decision-making, grounded theory was the appropriate method of research. The outcome led to the development of a substantive, mid-level theory (Creswell, 2003) that explains decision-making processes of Mexican immigrants with T2D.

Constructivist Grounded Theory

Constructivist GT (CGT), a significant derivative of GT (Birks et al., 2006b), re-conceptualizes the relationship between the researcher and participants as being highly interactive. It is actually through the shared experience of the interaction that meaning is constructed. Charmaz, the originator, utilizes the simplicity of Glaserian strategy, however, to reject the detached posture the researcher must take. She asserts that the researcher cannot actually 'bracket out' oneself to the neutral position (K. Charmaz, 2004). Rather, in CGT, the participant and researcher are co-participants in the process. Essentially, the researcher and the method do not stand outside the research process; but reside within it. The researcher must rely heavily on reflexivity to recognize her or his bias, perspective, or expected outcome, and

must critically evaluate one's position and meaning so as not to displace it to the participant. Reflexivity allows meaning to be interpreted in light of the contextual factors (Mills et al., 2006b).

Humans are viewed as interactive participants in life, whose actions are based on meaning as it is understood through social interaction and interaction with one's self. CGT was founded in the symbolic interactionist model whereby there is interaction between one's self and the environment, as it is understood by the individual, that is, how one interprets one's self and one's behaviors. There are five central ideas of symbolic interaction: (a) each human must be perceived as a social being, "It is ongoing constant lifelong social interaction which leads us to do what we do" (Charon, 2007, p. 29); (b) the human being must be appreciated as a thinking being. Interaction is with the social environment and the self; (c) how the person defines the environment is more important than how one senses the environ. That is, through ongoing interaction with and thinking about the social world, one determines a definition of understanding; (d) the cause of how a human behaves results from what is occurring in the present situation; and, (e) in relation to the environment, humans are described as interactive beings. Ultimately, one forms one's own reaction, not solely as a response to the environment (Charon, 2007).

Unlike traditional GT, which is positivist-based (Birks et al., 2006a), in CGT the epistemological commitments can be relativist, post-modern, and not tied to a singular epistemology. This researcher does not hold a general relativist life-view, but, respects the relativist posture that supports this methodology knowing that to bring absolutist views to the data could potentially interfere with co-construction

with participants. Similarly, it might prevent the researcher from clearly seeing the emerging conceptual data with strong other-cultural foundation.

Charmaz's "emphasis on constructivism loosens grounded theory from its objectivist foundation" (2006, p. 180). CGT acknowledges multiple standpoints and realities of both the grounded theorist and research participants (Birks et al., 2006a). CGT views interpretive renderings as situated, not an objective report or as merely a singular point of view. The constructivist views research analyses as an interactive interpretation of results from prior experiences, contexts, relationships, and one's worldview (K. Charmaz, 2006). Both data and analyses are derived from the shared experiences and interactive relationships between participants and researcher; understanding of reality is co-constructed. As the researcher is highly interactive in nature when working with patients, the constructivist version of GT methodology is a natural and fitting choice.

The researcher takes a reflexive stance toward her or his actions in relation to situations and participants in the field setting (Charmaz, 2008). During the course of data collection and constant comparison, the constructivist grounded theorist is recurrently memoing about her or his personal thoughts, biases, questions, and reflections to be aware of her or his *self* in relation to the data, to the relationships with the participants, and the meanings they convey in the data. During coding, the researcher asks her/himself, "What is happening?" and "What does it mean?" (K. Charmaz, 2006, p. 46). In traditional GT, according to Glaser and Strauss (1967), one major category is expected to emerge reflecting a basic social process; however,

Charmaz (2006) asserts there may be two, three, or four categories around which a theory is constructed.

Reflexivity and memoing. An essential aspect of reflexivity is the commitment to memoing in which the researcher analyzes, critiques, and becomes aware of her or his perspective, varying roles, judgments, questions, or biases. Interaction with the data can result in deeper levels of understanding. For example, as an advanced practice nurse, it is difficult not to be a nurse in reactions, insights, and desire to help, fix a situation, or correct frequently-encountered misunderstanding about scientific-medical information. Typically, memoing tends to expose gaps. By memoing after an interface with a participant, the nurse researcher is able to see the temptation to respond to a participant as a nurse rather than a scientist. The nurse cannot be removed from the researcher, but the nurse needs to step aside for the researcher aspect of self to be the persona interacting with the participant and, consequently, with the data. In rare instances, such as in the case that harmful health beliefs are held by a participant, the nurse may temporarily step aside from the researcher role. After data pertaining to the research question have been collected, the researcher may inform the participant that the interview will stop briefly in order for the nurse to discuss an earlier response. At that time the nurse persona can provide needed safety information.

An additional benefit of memoing can be the opportunity for the researcher to release thoughts, feelings, questions, and judgments so that fewer of these emotions distract from interaction with the subjects (Personal communication, Heilemann, 2009) or from the emerging voice of the data. Memoing is also done

during the individual transcript analysis and can occur in data-analysis discussions with committee members. There is a check and balance of pre-conceived attitudes and accountability for both nurse and researcher to be faithful to data content more so than the clinical experience. Also, what can be learned from the participants and data analysis leads to a better understanding about patient choices and responses that have previously been confusing or misunderstandings have arisen in clinical situations between patients and health care providers. The data and analyses processes enlighten the practitioners.

Regarding theory development, CGT challenges the assumption of creating general abstract theories and considers theory as grounded in the interaction and experiences of the researcher and the participant(s) (Birks et al., 2006b). The researcher is active and engaged as the instrument for theory development (K. Charmaz, 2006). Concepts become constructs when confirmed or clarified by multiple participants. This method does not allow for generalization.

Participants, Test Interview, Recruitment and Setting

Participants. This study comprised a convenience sample of twelve (12) ambulatory adults, including 10 females (W1-W10) and two males (M1, M2). All participants were Mexican-born and living in Southern California. The participants were bilingual (Spanish-English), ranging in age from 40 to 71 years-old ($M = 58$ years). All participants had been living with a diagnosis of T2D from 4 to 26+ years. The average length of confirmed diagnosis was 15 years; however, two participants had been given *borderline* diagnoses in Mexico 7 (W3) and 5 years (W4) before the definitive diagnosis was given when living in the United States. Their health care

providers (HCP) at the time of diagnosis in the United States said it was likely they actually had diabetes when they were given the borderline diagnosis. Both believed the HCP in the United States was correct based on their symptoms in Mexico.

Each participant had emigrated from various parts of Mexico to the United States. The age of emigration ranged from age 5 (M1) to age 32 (W3); most left Mexico at approximately age 20. One-half of the 10 women and one of the two men returned to Mexico for a period of time before returning to the United States permanently. The time they spent back in Mexico ranged from about six months to 10 years, although most returned to the States within 2 years and always under different circumstances than the first time they left Mexico.

Interviews spanned 4 years, from October 2011 to January 2016. The majority of the interviews were completed from May 2014 to January 2016 (W5-W10, M1, M2, W3b [2nd IV], W4 [1-year follow-up visit]). Participants partook in primarily English-speaking interviews that extended from 80 minutes to almost 4 hours in length; most averaged about 2 hours. Originally, interviews were expected to last between 60-90 minutes; however, participants often gave thorough responses and many included supportive stories. Often responses to questions and details of time sequencing were confusing or details were missing. Thus, it was necessary to take time to clarify; this required additional time. Moreover, as study concepts evolved through constant comparison, additional time was invested to explore the viewpoints and cultural perspectives of those participants interviewed later in the study.

Interviews were designed to be in English only. Recruitment brochures and verbal solicitations informed potential participants that the interviews would be in English, and that a Spanish-speaking Latina Research Assistant would be available for questions and during the interview if a brief translation was required. Several of the female participants responded to a number of questions in Spanish or required interpretation of questions. This was a deviation from the original study intent.

The Test Interview. A test interview was conducted on October 12, 2011, 16 months prior to the start of the study interviews (IVs) that began in February 2013. A delay in commencing IVs occurred due to serious personal and scheduling conflicts with the Primary Investigator (PI) and the Research Assistant (RA1), required by the study criteria. A replacement RA could not be secured. Two IVs were done in February 2013 and additional recruitment became more problematic than anticipated; months passed before another IV was secured in July 2013. Meanwhile, the Dissertation Committee Chair allowed the test interviewee to be admitted to the slowly growing cohort (W3-45L). This participant met all interview criteria of the university's Institutional Review Board (IRB) approval granted prior to the test IV.

Due to the time gap between the Test IV with W3 and with growing saturation of cultural concepts in the data, it was necessary to validate those findings with W3. Also, because several initial IV answers were incomplete or unclear, it was necessary to clarify her responses. Her command of the English language had improved during that time and she was able to discuss concepts and explain cultural phenomena more clearly than some of the other participants. She

was 49-years old at the second IV, thus the Participant Code reads W3-45/49L. Entries in the Results and Discussion chapters from her interviews have been noted as W3a and W3b, respectively.

Recruitment and study location. The location of the study was throughout the Greater Los Angeles County area. Initially, recruitment was done in the health centers associated with a large medical center. After approximately six months, a separate, medical-center IRB approved study oversight and permitted recruitment notices. During that period, recruitment broadened to Latino churches, a church-related community and tutoring center, health centers, a private health care office, and an extended family member of a RA. Attractive business cards, postcards, and flyers were distributed in these locations and other commonly-visited public locations known to be frequented by the population. All recruitment materials included contact information of the PI and the first name and phone number of the contracted, same-culture, native Spanish-speaking, Latina Research Assistant (RA). General details of the study and a brief description of the incentive for potential participants were included. Early recruitment difficulties revealed that terminology corrections were needed in hopes of attracting more participants. For example, one question asked, "Do you speak English?" Because persons in the culture often interpret that as speaking fluently, most Mexican immigrants would self-disqualify. The recruitment materials were changed to read, "Do you speak some English?" as they would commonly admit to speaking some English, but rarely to being fluent. This yielded no significant improvement in recruitment. Due to recruitment

difficulties, the university IRB liaison from Nursing granted permission to obtain participants from any appropriate location.

A physician's office known to the PI served as the site from which six of the 12 were recruited. Because of their confidence in the physician and his staff, they felt it was a safe environment in which to participate in a study. The physician introduced three candidates to the PI. Also, during office visits with two of the six participants, the PI inquired if they might be interested. One replied, "Oh, I saw that (nodding toward the recruitment flyer) . . . Yes, I'd like to do that very much". Another saw the flyer and asked the staff about it; the staff introduced the PI. Arrangements were made once criteria for the study was met in each case. In all other cases, when anyone showed interest, the PI stepped out of the process to reduce any sense of obligation or expectation. The Office Manager spoke with the potential participants because they trusted her and she was not involved in delivery of care. She explained the purpose of the study, the incentive gift card, diabetes literature, and assured the candidate that their care would not be jeopardized if they chose not to participate. Two who showed interest eventually declined, one after she broke two interview appointments. Her adult daughter insisted on coming to the interview with her small children and expressed concern about the study. A staff member who knew the potential participant and had coordinated IV dates expressed concern to the PI that the daughter did not understand the study and that the grandchildren and the daughter might interfere with the IV. The staff person reassured the hoped-to-be-participant that her care would not be jeopardized; however, she then declined to participate.

The office had offered the use of a small exam room for interviews if the patient-participant preferred to meet there instead of one's home or another location of one's choice. Four chose to be interviewed in the familiar location; the RA joined the PI on scheduled IV times. Both men preferred to meet at their homes. The wife of one was present for the entire IV and had scheduled the appointment for her husband. The other male's wife came home part way through the IV and stayed in an adjoining room. One-half of the women were interviewed in their own homes; the sister of one who was visiting interjected peripherally as the participant sought clarification about family history and another's husband was cooking a meal in the adjoining room; although he did not participate, he had made the appointment for her. The participants whose family members were present in the home during IVs were invited by the participant as is common to the culture. One participant was interviewed at a tutoring location while her child was tutored.

Other interested participants contacted the PI or RA by phone for details of the study. Those who agreed through the physician's office or a mutual contact gave their phone number to the PI who contacted them, answered questions, and scheduled IV times in coordination with the RA. In the case of W2, her Spanish-speaking husband spoke with the RA by phone. W5 also preferred discussing questions in Spanish with RA1. Unfortunately, the phone numbers for W2 and W5 later became inaccessible to RA1 and were considered lost; they were not accessible to the public.

Once it was established that a candidate met study criteria and tentatively consented, an individual interview time and location was agreed upon. On a few

occasions, either the participant or the PI had to change appointment times to accommodate other commitments; usually that was not problematic. An additional possible participant committed to the study; an IV appointment was set. She was a referral through the PI's colleague. The PI sent a text the night before reminding the participant of the agreed upon time. When the PI and RA4 arrived after a long drive, the participant was surprised, said she was leaving for Mexico, and rescheduled; more contact information was shared. The day before and three times the morning of the second scheduled IV, the PI attempted contacting her and asked for clarity due to the substantial drive. She replied that she had new family responsibilities and could not participate. She offered to call when she was available. A return call was neither received nor expected and she was lost from the study.

While support for the study at a large health center affiliated with the second IRB was anticipated, none of the patients in that facility or sister facilities volunteered. Despite annual IRB renewals, posters, and business cards, no eligible participants volunteered. A nurse practitioner colleague at the center approached people meeting study criteria; although she was trusted, all declined. After 4 years of no recruits, that IRB was closed. Meanwhile, numerous professional associates of the PI also posted flyers in their clinical settings throughout the broader Los Angeles and San Diego regions to attract eligible participants. However, interest was rare and only by non-Hispanics who did not fit study criteria.

As interviews progressed, the recruitment technique of snowballing (Mills et al., 2006b) was hoped to occur where an interviewee would tell others about the study and encourage them to be interviewed. However, that did not occur. Only

persons who were not of Mexican-decent not born in Mexico, or did not speak English came forward. Socio-cultural issues, particularly concerns expressed about possible non-legal status, appeared to be deterrence from participation. As the PI gained the trust of each participant, it was hoped to benefit recruitment prospects (Polit & Tatano Beck, 2004), especially once potential participants realized that nothing to expose legal status was explored in study questions. However, this did not increase recruitment.

The Research Assistants: Change in support, Transcription and translation, and Training.

If one RA served for the entire study, then consistency, familiarity with the study, and needed improvements based on experience could be assured; however, for complex reasons, that did not occur. Four Latinas, fluent in Spanish and English served as RAs. Three RAs were born and raised in Mexico and thus knew the culture uniquely well. The other RA was born in the United States but had strong family ties to Mexico. She was raised in a traditional Mexican home. A colleague of the PI identified RA1 in a health care setting as being from Mexico and bilingual (S. A. Brown, Garcia, & Winchell, 2002). Several times, RA1 had to return to Mexico for family reasons or was unable to serve as RA due to personal conflicts. When a volunteer expressed interest but the RA was not available, it resulted in the loss of potential participants, specifically three-to-five men. Upon her return, those volunteers were no longer available or had changed their phone numbers and, therefore, were lost from the study.

Change in RA support. When RA1 did not respond to various attempts to contact her, another volunteer came forward. Eventually, RA1 responded that she was not available. This RA served for interviews W1-W6 and W4's 1-year follow-up. RA2 was known by the PI. She was only available to assist with W7 and W8 due to a change in her family responsibilities. As interpreting issues arose with the first two RAs, it became necessary to locate a RA who was could directly translate during interviews so that important data or opportunities for clarification were not missed. RA3 was hired to be a translator-transcriptionist. She had limited time to attend IVs, but did assist with M1's interview; however, he was fluent in English and did not require interpreting. The final three interviews and the second W3 IV (W3b) were assisted by RA4, who was a colleague's contact.

Transcription and translation. RA1 transcribed the first two IVs. As the bilingual P-O, it was anticipated that she would transcribe all interviews and interject what she observed; however, she did not have the correct equipment. A second bilingual translator-transcriptionist was not located until well into the study.

During the interviews when the participant needed to describe or explain in Spanish, the RA listened, discussed as necessary, and translated a summary to the investigator. At times, some of the female participants responded in Spanish for longer periods or told various stories to illustrate their answers and experiences. Not infrequently, time sequencing or other data were unclear and required clarification and sorting. For those participants who spoke Spanish often or in long discussions, it was evident that what had been said in Spanish by the participant or RA1 or RA2, had not been entirely translated to the PI. Thus, the bilingual

translator-transcriptionist (RA3) re-translated/transcribed W4, W5, W6, and served as transcription-translator for W8. Spanish was used after the third interview; initially, interpreting was not expected to be a problem. In eight interviews, infrequent Spanish was used by participants. The primary transcriptionist transcribed all other interviews, except W1, W2, and W8, and most of the analysis meetings with a committee member.

Research Assistant Training. Each RA received both oral and written information about the intent of the study and instruction on her role. A copy of the interview guide was provided; they were informed if the interview guide was modified with new or revised questions due to the nature of constant comparison in GT (Creswell, 2003; Hatton, 1992; Schwandt, 2001). The PI met with each RA at least twice before they attended an interview and each signed a Confidentiality Agreement. RA1 participated in the test interview that was initially intended to be practice only. This initial practice allowed for questions and suggestions for improvement. The test IV allowed the RA and PI to reflect on how to efficiently work together. As the interviews continued, part of the debriefing by the PI and RA reflected on how questioning or other aspects of the interview could be improved. At one point, RA1 suggested time could be saved if the informed consent could be simplified, despite great efforts to make it easy to read and understand. While modification might have saved time, it would not have met the IRB requirements and agreement with the university; thus, it was not modified. Other minor adjustments were made, mostly by the PI being more mindful not to interrupt the participant too quickly for clarification.

Data Collection Procedures: Interview guides and Data collection.

The Interview Guides. Two questionnaires were utilized for this study. The first was an expanded demographic survey; the second was a semi-structured, research-based interview guide. The first was modified once to include the birth order of the participant as well as the number, gender, and ages of their children. Much of the data gathered through the demographic survey was not included in the study results as it could have potentially identified subjects. A request was made to the Chair of the Dissertation Committee and to the School of Nursing liaison to the IRB to expand the recruitment criteria to include persons born in the United States who then lived a portion of their life in Mexico. That request was made intending to increase the potential participant pool, but was not needed.

The IV guide was modified once to use clarifying questions that followed the constant-comparison data analysis of GT (Creswell, 2003; Richards & Morse, 2007; Satterfield et al., 2003). An IRB request was made to make a minor modification to the IV questions to include information that participants had indicated was important. As concepts developed that were not included in the original questionnaire, it was necessary to explore them. An example of an added inquiry asked what motivated the participant toward DSM? This concept had strong presence from the first IV. This request also included two direct questions: (a) what types of diabetes medicines were used, not used, and the rationale; and (b) whether they knew their blood glucose range and blood test results. In discussion with the Chair, it was determined that questions evolving through constant comparison were within the nature of questioning and clarification; therefore, it would not be

necessary to seek further IRB approval. If the direction of questions changed, it might be necessary to contact the IRB. The IRB liaison to the School of Nursing was in agreement. As other concepts arose, such as *Negotiation/Negotiating*, or *being proper*; these were added to the IV guide.

Data collection. A copy of the informed consent was given to each participant to review as it was being read to them by the PI. After securing oral, informed consent, the interviews were led by the PI in English. As the PI is partially-fluent in Spanish, it was common for Spanish terms to be interjected for further clarity of questions, such as *influencia* for influence or *verdad?* for true? In order to assure collection of accurate colloquial and contextual data, the RA served as a P-O and interfaced with participants as needed. How long the participant spoke in Spanish, how important the RA thought the comments were, or how well the RA remembered what the participant said determined how much translation was done for the PI. Sometimes scant summary was given compared to the amount spoken in Spanish. Some questions were repeated in Spanish to assure the participant understood it. Both the RA and the PI took notes in an interview guide for each participant. As P-O, the RA also took notes on body language, expressions, and reactions to questions. Unfortunately, those observations were not always detailed in the transcription; many were added later by the PI, but not all observations.

Interviews were dual, digitally-taped to insure accurate and complete recording of materials. One micro digital, audio-recorder served as the primary recorder and the second for transcription back up; that was rarely needed. During the interview with M1, neither recorder started properly. When discovered

approximately 45 minutes into the IV, the PI and RA dictated a summary of his difficult-to-follow history as recalled before continuing the IV. Summarizing was challenging as he had been unable to remain focused on a question, gave confusing or conflicting responses; sequencing was very difficult for him, although he made great effort to respond informatively to questions. M1 agreed with the summary; thus, the IV was not restarted. Both recorders were kept secure in the home office of the PI. All recordings were downloaded to a private computer and shared with the transcriptionist on her private computer. Copies of the transcripts were kept in the PI's home-office filing cabinet.

Once started, all IVs were completed. Following completion of the IV, an incentive \$30 grocery store gift card was provided to a store of their choice as an expression of gratitude for their time. Funds granted through the Dean's Research Scholar Award (2007-2008) provided compensation for the subjects. Only one participant declined the gift card; she accepted home-grown avocados. Small colorful gift bags and key chains with the study insignia were given to the participants and, where appropriate, a gift bag for their wives were also given along with diabetes website literature and numerous diabetes booklets and resources.

Data Analysis: Constant comparison, Organizational tools, Further analysis, and Theory development

Constant comparison. CGT utilizes the constant comparison method of data analysis (K. Charmaz, 2006). Data were analyzed generally following each IV using initial and focused coding. Initial coding was done line-by-line (Hoare, Mills, & Francis, 2012b). Initially, all coding was done using the interpretive computer

software program NVivo 10 and 11, which helped to track focused codes, categories, and allowed for the insertion of memos. After re-analyzing W1 – W3, analysis was done by hand or on the computer using color coding and a comments/reflection column. This allowed for more visual line-by-line detail and, due to the researcher's use of color/font coding, trends and concepts were more readily appreciated. Although, the methodology calls for constant comparison after each interview and for analysis to be completed before the next interview takes place, this in fact could not always be followed. There were several delays in the transcribed interviews being returned timely to the PI. Several weeks could elapse due to the transcriptionist's workload and other responsibilities. Early in the interviewing stage, there were a few potential participants who were lost from the study because the analysis on the previous interview had not been completed. Analysis on each transcript required a minimum of one 40-60 hour-week; some took two full-weeks or longer. Due to the loss of volunteers from transcription delays and/or unavailability of a RA, the PI decided that when a volunteer and RA were both available, the next IV would take place regardless of analysis completion on the prior IV transcript. Thus, sequencing was not always orderly. The Chair was notified.

Debriefing with the RA immediately following each IV often identified potential adjustments in future IVs, particularly in the earlier IVs. For example, during the IV with W1, the concept of *motivation* had a significant impact on her decision-making and consequently, those *factors that motivate (motivating factors)* participants needed to be explored in future IVs. That line of questioning was added to the IV guide before the interview with W2 3 weeks later, at which time it was

determined that the concept was important to decision-making. Prior to starting IVs, it was understood that there would be factors that *affected* or *influenced* decision-making, but the exploration of *Motivation/Motivating factors*, had not been included in the IV guide. Analysis of the data further affirmed the decision to add questions on *Motivation*. Also, the PI's reflective-memoing influenced the questions that needed to be modified or added to the IV guide in future IVs.

An important dynamic in CGT coding is to utilize descriptive terms spoken by the participants that carry symbolism and "capture meaning or experience" and may be "insider shorthand" (K. Charmaz, 2006, p. 55). These terms are coded as *in vivo* terms. Numerous times, *in vivo* coding was utilized. For example, during the IV with W6, she stressed that everybody in the culture would commonly, "play dumb" and later described the critically important, cultural requirement to "be proper". Both of these *in vivo* terms became *in vivo* codes and developed into significant concepts within the *Sensing social expectations* construct in the theory.

Relevant to all GT is the use of coding with gerunds to assist the researcher in detecting processes within the data. A gerund is a verb that is transformed to act as a noun when *-ing* is added as a suffix (Gerunds, 2017). For instance, acceptance was a critical aspect of the decision-making process, as a construct; the active form became *Accepting* diabetes. Likewise, to play dumb became *playing dumb* and to be proper became *being proper*. Both *in vivo* coding and use of gerunds assisted the researcher to remain grounded in the data. Following the IV with W6, the PI reflected on the salience of exploring the concepts with future participants. In

summary, no significant concepts that needed to be explored in subsequent IVs were found to have been missed once the previous transcript was analyzed.

Coding of subsequent interviews compared codes from one set of data to the next. In the process, a theory matrix was constructed and added to consistently, both cumulatively in the *common findings* section, and as a section for each individual. Focused coding occurred when the researcher identified the most significant and/or frequent initial codes; several of these were evident from early interviews. Data were compared to other data in order to create the focused codes. The most frequently seen codes (e.g., *motivation/being motivated, pretending*) had clear relationships to other codes and continued to rise up in importance (K. Charmaz, 2006). Following six interviews, focused codes began to cluster together more clearly, indicating a category was developing. For example, *Being proper, pretending, and needing permission* fit together under the *Sensing social expectations* construct.

Each category had sub-categories, aspects of the same concept that might be temporal, hierarchical or comparative in nature. For example, a category about *role or having role expectations* developed with sub-categories about *machismo/being macho*, for men, and *needing permission*, for women. Some of these had further sub-categories (Personal communication, Heilemann, 2009). Subsequent layers became increasingly more abstract. Abstraction of concepts reflected essential meaning; thus, categories of similar concepts fell under larger or more abstract rubric or categories. For example, several participants mentioned relationships that influenced their decision-making, especially the love of family. Rather than have a

separate category for mother, another for father, parents, siblings, or grandparents, the concept of *love of family* covered all of these categories. Because the term, children, was repeatedly mentioned, there was a category for *children* and another for *other family*. These all fell under the higher category of *Being motivated/Motivating factors*, a study construct. Primary categories and/or categories that constitute constructs of the substantive theory (e.g., *Negotiating*), stages or progressions in the decision-making process (e.g., *Accepting*) and category headings in the theory matrix and theory Outline (e.g., *Intervening Conditions*) are denoted with capital letters to distinguish their importance.

As new or dominant categories arose, such as *Being in the battle*, it was important to ask subsequent participants questions to further explore the concept; this emerged as a study construct. The original questionnaire did not access some aspects of the salient data but served as a tool to identify focused coding content and higher abstraction levels (Hoare et al., 2012b).

Once progressive steps or categories of the decision-making process were identified, e.g., *Pre-discovery/Before discovering*, *Discovery/Discovering diabetes*, and *Mastery/Mastering DSM*, specific, intentional questions were used to explore and validate those concepts further. As categories demonstrated importance and more participants addressed those concepts and categories, the data from earlier IVs were constantly compared to previous and then to upcoming participants. For example, the concept of *shared caring* originally presented distinctly in the second interview (W2). It was again observed clearly in the fifth IV with W5 and later with others. As the concept was developing, the earlier IV transcripts were reviewed once more for

the *shared caring* code, identified by a specific colored font. If the data had not been coded, coding was added to the earlier transcript and that coding was reflected in the theory matrix under both the *common findings* and in the participant's page and that participant's code was added to that category *shared caring* on the Outline.

Theoretical codes took the analytic process to a more sophisticated level. Theoretical codes "specify possible relationships between categories you have developed in your focused coding . . . are integrative; they lend form to the focused codes" (K. Charmaz, 2006, p. 63). Charmaz asserted that this in turn assisted with telling the analytic story, not a summarization, but a conceptualization of the relationships between substantive codes and moved the analytic story toward theory. Multiple codes pointed to *Negotiation/Negotiating* as the means by which decisions were made.

Organizational tools. The grounded theory matrix, developed on a landscape, legal-sized, word-processing page, was a four-column, visually-horizontal collection and sorting tool used to track data, as supporting evidence, into the framework categories for theory development. The theory matrix was developed in the early stages of GT. It was not commonly reported to be used in CGT; Charmaz did not use it, in full, but recognized its benefits for researchers (K. Charmaz, 2006). As this was the first attempt by the researcher to use this methodology and the GT matrix was a tool familiar to the committee chair, it served to delineate the various processes and outcomes in decision-making it provided visual and conceptual organizer. The first column, Context, was used to collect contextual factors that were common and/or foundational to all of the participants; this contained essentially

cultural influences. The second column identified Intervening Factors and Conditions that might or had affected decision-making. *Being motivated/Motivating* factors and one's degree of being socially independent emerged as important intervening factors. Thirdly, the Interactions and Decision-making Influences column content eventually clustered around the constructs of Being in the battle and *Negotiating*. The final column categorized the Consequences and Outcomes of the decisions that were made and interactions that occurred that were based on the Intervening Conditions (e.g., Motivating factors, having general self-efficacy) and contextual influences (e.g., Sensing social expectations). Different colors and fonts helped to differentiate concepts/categories and sub-concepts/sub-categories. Thus, the matrix tool served as a visual location to correctly distinguish concepts and ensuing categories in the decision-making process; for instance, was the concept an intervening condition versus an interaction in the decision-making process? One had to ask, "Is the process of Accepting the diagnosis of diabetes an intervening condition because it affects decisions? Or, is Acceptance a decision one arrives at and from which consequences follow?" Many supportive participant quotes were injected into the matrix codes as supportive evidence for writing Chapter 4: Results. Simultaneously, an extensive Outline of the four dimensions of the theory-matrix was developed in a visually-vertical format. The color-coding and font varieties used to distinguish concepts and categories on the theory matrix and the corresponding Outline differentiated content area, especially in light of the increasingly large amount of data that required sorting. This allowed a visual reference to the major contributing factors for each process stage. For example, *Being motivated/*

Motivating factors, shared caring, effects of stress clustered under *Intervening Conditions*; they held content that intervened in, affected, and/or influenced decision-making. The Outline served as a location for supportive literature, as it was identified, for writing Chapter 5 Discussion. As supportive data accumulated under the concepts, behaviors, and thinking processes, it became recognizable that participants had described their decision-making process and that the process of routing through the daily challenges of diabetes meant they were *Negotiating DSM* throughout the day.

Further analysis: RA insights, Committee member analysis and Theory construct construction. In addition to the PI's reflexivity, memoing, analysis of line-by-line and progressively higher levels of coding, and use of organizational tools, two additional forms of content and analyses validation were utilized. Clarification of cultural factors by the RAs and co-analysis by a doctorally-prepared Nurse Practitioner working with the same population contributed to maintaining analysis was grounded in the data.

RA insights and clarification of cultural factors. Using her personal understanding and/or experience of Mexico's socio-cultural-religious, geo-political, economic, and/or environmental-ecological factors, one of the roles of each RA was to clarify antecedent factors of pre-emigration if mentioned by the participants, if she thought they were applicable to the investigation, and facts about which the NHW PI might not be familiar. This was in order that no important culturally-relevant cues, comments, or attitudes would be missed during the interview. As intended, periodically the clarification by an RA added to the accuracy of the PI's

understanding of the participant's response, such as content pertaining to factors in Mexico prior to and/or since emigration. Thus, accurate data were reflected in the constructed categories and subsequent theory. The RAs periodically clarified or reflected upon what a participant meant culturally in reference to a comment or expression. For example, during the PI-RA debriefing following the first IV, RA1 questioned why W1 spoke negatively about Mexico when RA1 had observed that many of W1's practices, comments, and beliefs noted during the IV were "very Mexican" in nature, including her accent, after living in the United States for 50 years (personal communication, 2.8.13). This knowledgeable reflection brought clarity to the non-Hispanic PI. During a post-IV debrief with RA2, she excitedly affirmed comments by W7 that men had a pride that drove them to "do it my way; even if it is wrong" (personal communication, 5.8.15). Each RA contributed important cultural insight following IVs, some more than others. W3a mentioned the rise of crime in Mexico as part of the reason she left Mexico. RA1 nodded her understanding, so the cultural point would not be lost to the PI.

Committee member as analysis associate. Finally, common to the CGT methodology, a second researcher analyses the transcript to compare to the analysis of the PI for coding and construct reliability (personal communication, Heilemann, 2009). A doctorally-prepared committee member (CM) reviewed a blind copy of each transcript, without access to the PI's view, findings, categories, questions, or reflections. The CM and the PI met to discuss findings on each participant an average of two times, sometimes more. After sharing her (CM) general reflections and detailed ideas, ponderings, questions, and insights, the CM and the PI compared

insights. The majority of the findings and categories, and some questions and reflections, were shared in common. Occasionally, the CM did not agree with the PI and more discussion was required. Out of those discussions came further clarity. For example, the CM asserted that the participants knew a lot about diabetes, whereas the PI felt they were lacking in information. In discussion, it became clear that they were each referencing a different type of knowledge about diabetes. The first was socially-shared, observed knowledge that each participant had gained through life experiences. The second was health-science knowledge; what they knew from a science or medical-health-fact standpoint. When the PI recognized the perspective differences, the former then became identified as *social knowledge*; knowledge that participants had gained through social sharing and observation. The PI saw that participants lacked knowledge about the progressive loss of insulin production and its effects on the disease; this was *health-science knowledge* (personal communication, McPherson, 2015).

Following that and similar other discussion, there was clear agreement when either of these concepts about knowledge arose. Several times, the CM added important insights and shared linkages between categories. She frequently asked thoughtful, theoretical, and probing questions; often rhetorically. This furthered development of the theoretical underpinnings. No significant differences or disagreements about categories, influences, or phases in the decision-making process remained. At times, the CM felt she lacked perspective because she did not attend IVs or listen to the recordings; she had only the transcripts. Unfortunately, sometimes punctuation was incorrect or confusing. She was also at a disadvantage

being several interviews behind by the time the co-analysis meetings took place. However, as the number of interview analyses increased, she understood more about the insights, questions, and ponderings of the PI because she had gained more understanding of the same foundational data. Also, findings from each participant were applied to the theory matrix and reviewed by the CM to assure inter-rater reliability using the matrix. Her participation in analyses assured contextual and process accuracy, categories, and linkage between them. Twenty-seven analysis meetings took place from December 2014 until March 2016 and lasted from 2 to 4 hours, averaging over 3 hours each. There were periodic breaks in the meetings based on the CM's scheduling availability. Each co-analysis meeting was recorded and transcribed, then analyzed by the PI for themes, categories, concepts and solidification of constructs as an additional means of constant comparison and visualization of construct linkage.

Construction of theory constructs. The interactions with the participants added greatly to the researcher's understanding of the data. The practice of reflecting back to the participant what the PI understood was essential for accuracy and co-construction of the constructs that eventually made up the theory.

The consistent habit of reflective-memoing in varying formats, discussed above, was critical to conceptual growth and analytic process (K. Charmaz, 2006). This happened primarily in analysis and co-analysis and was strengthened or clarified using NVivo, particularly in the collapsing or grouping of individual codes, called *nodes*, into larger, more general categories, increasing the levels of abstractness (Wuest et al., 2006).

The analysis reflections in the *thinking* column, adjacent to the interview content, along with color coding and fonts of concepts and constructs, were essential for this very visually-sensitive researcher to be able to see the data concepts and constructs emerge. These were reflected in the theory matrix and the Outline, which also served as essential reflective tools. All three of these practices and visual logs kept the investigator constantly connected to and grounded in the data. These contributed significantly to the development of an early theory that arose from the data, was driven by the data, and assisted in interpreting the data (Denzin & Lincoln, 2003).

Theory development. In a developing, substantive theory, one or more important concepts are at the center to describe the phenomenon around which all other major and minor categories relate and explicate the data-grounded theory (Charmaz, 2005). When the PI sensed a tentative category or incomplete emerging ideas were forming, such as the data was “intriguing but thin” (K. Charmaz, 2006, p. 96), or the direction of the data was unclear, the researcher continued to return to the empirical setting for theoretical sampling. This was done to ascertain if that particular data were actually relevant and to solidify concepts that had clearly been emerging. For example, early on, two ideas appeared; one was that the severity of disease prior to diagnosis might be related to when the participant sought assessment of the undiagnosed diabetes symptom(s). Another was the importance or effect of *Motivation* on DSM. The latter, discussed above, emerged as very important; however, as interviewing proceeded, disease severity did not appear to be of relevance to most participants. Thus, the latter did not prove to be a category.

By gathering more data about the properties of the category, the process of theoretical sampling began to “saturate” (Hoare et al., 2012b, p. 586) the categories until no new properties emerged. Charmaz (2006) described theoretical sampling as the process of seeking out salient data contributing to the development of the emerging theory. The primary purpose of theoretical sampling was to further develop and distill categories until saturated. Saturation was achieved when recurrence of the same concepts appeared in the absence of new concepts. Theoretical sensitivity was reached in the saturated state in this study (Hoare, Mills, & Francis, 2012a) and the major concepts and constructs then comprised the theory.

Human Subjects Protection: Consent, Data protection, Reassurances, risks and benefits

All recruitment materials related to the study were overseen by the Dissertation Committee Chair at the University of San Diego (USD) and the Human Subjects Protection Committee at USD and the medical center where the second IRB oversight was obtained. Any questions were addressed prior to data collection. No personal identifiers appeared on the questionnaire, interview (IV) notes, or digital recording devices. Any data that required de-identification were treated as such to protect participants from unintended disclosure of identifying health status or revealed responses. Each participant was given a code; W for women/females and M for men/males. The order in which they were interviewed by gender gave them an identifying number: W1 was the first female interviewee and W8 was the eighth, M1 and M2 were self-explanatory. W3 was actually the test Interview, thus the IV was done many months before interviewing commenced. When she was added to the

cohort, extensive analysis had already been done on W1 and W2; memos already addressed them as W1 and W2. The PI decided that to change W1 to W2 and W2 to W3 would have caused confusion. Thus, the test participant was labeled as W3 and no confusion occurred. To help the PI remember participants clearly, their age and the first initial of their first name completed their code (e.g., W1-58T, M2-69E). However, in reporting results in Chapter 4 Results or Chapter 5 Discussion, they are referred to by W or M and their corresponding IV number only. For this report, no initials appear as a means of further de-identification. When their names were said during the IVs, the transcriptionist was directed to use only the already-identified first initial, preserving privacy but allowing the participant to be addressed by their first name in the IV as they requested. The transcriptionists all signed confidentiality pledges that were kept in the PI's home filing cabinet.

Consent. It was expected that the USD IRB would require a signed informed consent. A standard written consent was suggested by the IRB member who was liaison for the School of Nursing. However, because English is the participants' second language and there was neither a guarantee nor a requirement that they would be literate or be able to read English above a fifth-grade level, it was determined that the standard written consent could not be used. A second point of concern was that a required signature would likely frighten away some potential participants who might not want to disclose their identity or signature. This would have interfered in recruitment. The IRB determined that a verbal consent would suffice since all of the data on each participant was de-identified. Thus, the IRB committee member - Nursing liaison drew up a simple verbal consent that met IRB

criteria, including the purpose and simplified background statement and procedures; risks of discomfort, benefits; and the right to stop or withdraw at any time. Participants were given an assurance of privacy and confidentiality outside of the privacy of their homes and other IV settings. The consent draft required only minor adjustments and was uncomplicated to read; all participants had a fifth-grade level of education or higher (Table 1 in Chapter 4 - Results - Demographics).

Voluntary physical participation in the study and verbal consent signified permission to participate. Each participant was given a copy of the verbal consent that had been written out to read while the PI read it to them; a copy was provided to them for their records. These consents were not signed by the participants because they actually served as a script for the PI. Their code and the date and time of their verbal consent were entered on the PI's scripted consents; no names or other identifying data were recorded. These dated unsigned consents that had been used as scripts for the PI were kept secure with the IV guides and corresponding transcript for each participant.

The IRB was contacted once for a simple modification of the Demographic Guide and Interview Guide as reported above. Annual updated applications for continuance of the study were submitted to the IRB when requested. The PI maintained currency of the national Human Subjects certification as well.

Occasionally, a participant was asked if they could be contacted by the RA or PI for possible follow-up to clarify content or ask new questions and/or to ask for verification of accuracy of interview content. W1 was contacted once, she clarified a few simple questions and offered to help but due to family and health matters, she

was not available for a follow-up visit or phone interview; the RA was also not available. W3 was re-interviewed 4 years after the initial interview, as reported in the section, Test Interview. W10 and M2 both offered to be contacted again if necessary. They had long, informative interviews so were not re-contacted. Responding to the expressed wish reported by W4 for more information on diabetes, the PI and RA agreed to make a subsequent visit to provide standardized educational materials. The participant verbally consented to a follow-up interview that was scheduled at a later date.

Data Protection. Content of each dual-digitally-recorded interview was recorded on dedicated-digital recorders. The interview recordings were uploaded from the digital recorders onto the Researcher's personal computer, external drive, and an interview-dedicated USB drive, and stored in the PI's home office. Recorders were cleared only after the data was saved so that no data was lost. The USB drive was hand-delivered to the transcriptionist. Early on, a copy of the completed IV guide and interview notes were also taken to the transcriptionist, but it was too difficult to listen, type, and read handwritten notes; thus, some of those elements were added later by the PI when punctuation was reviewed as well as during analysis. The PI downloaded both recorder copies of each interview onto the transcriptionist's computer, who then loaded both copies onto her dedicated USB for backup so that no data were lost. Source and translated documents, a copy of each transcribed interview and analysis, interview documents, and the USBs were stored in dedicated file drawers at the researcher's home where they remain to

confirm data accuracy should there be questions and to be used in the preparation of a future manuscript.

Reassurances, risks, and benefits. A private area for the interview was provided to allow subjects to freely discuss issues without fear of interruption or being heard. The four who had a family member present in their homes during the IV had planned for them to be present as is customary in their culture. Only one participant was in a recessed area of a community space without a door for privacy. Her privacy was not compromised because no one was nearby; however, there were extraneous sounds in the adjacent areas when the tutoring time was over. No participants refused to answer questions or left before the end of the IV. Interview guides were placed in individual sleeves in the subjects' presence; the tapes were turned off in their presence. Contact information of the PI, RA, and Committee Chair were located in the consent in the event that the participant had questions or for referral of others to the study; neither of which was known to have occurred.

Each participant shared potentially personally-disturbing or threatening information involving family and friends, including unresolved grief, multiple losses, betrayal, sexual abuse, witnessed violence or suffering by others. These are reported in the following chapter. In addition, each participant expressed gratitude at the interest of the PI and the RA. Ultimately, some emotional stirrings occurred, but it did not appear that any trauma or resultant emotional distress occurred or remained. Although unintended, following the IV, some participants did receive direct benefits from the nurse-researcher sharing relevant educational information on T2D that they needed to know but had never received. Overall, they expressed

that they were satisfied that they contributed to help other Mexican immigrants with T2D, and were grateful someone cared about their story and their insights.

Reasons for a NHW to Perform this Study.

From the inception of this study, there have been professionals, often of Latin-decent, who have politely wondered why a NHW person would undertake this study about health care to Mexican-born émigrés. To begin, it had to be undertaken by this particular non-Latina because of the unanswered questions that persisted while providing primary health care to this population. Along with an anecdotal lack of knowing and comprehension among HCPs about the decision-making process of this population, virtually no literature existed for reference. Additional factors were detected in the process of the study that have supported a non-Latin-cultured provider undertaking this exploration. Those are reflected upon in Chapter 5 Recommendations for Further Research. The following chapter will provide the study results.

Chapter 4

Results

Cultural Foundations - Context

Demographics: Participants and Tables

Participants. As detailed in Chapter 3, 10 adult females (W1-W10) and two adult males (M1, M2) ranging in age from 40-71 years, all Mexican-born and living in Southern California, participated in primarily English-speaking interviews from October 2011 through January 2016. The test interview participant was added to the cohort as W3-45/49; her IV was accepted as appropriate data and verified 4 years later at age 49. Chapter entries reflect the test interview as W3a and W3b.

Table 1

Participant Code, Gender, Age, Ethnicity, and Years of Education

Participant Code	Gender/Age	Self-Defined Ethnicity	Years of Education	
			In Mexico	In the United States
W1-58	F 58	Mexican-American	5th grade	9th grade
W2-42	F 42	Latino	5th grade	1.5 yrs. Middle School
W3-45/49#	F 45 & 49	Mexican	College/BA	ESL x 1 yr.
W4-62/63†	F 62 & 63	Not reported or lost	6th grade	Few months English classes - incomplete
W5-40	F 40	Mexican	6th grade	3-4 months English classes - incomplete
W6-70	F 70	Mexican Latina	12th grade	ESL; Childcare (12 u)
W7-58	F 58	Mexican	9th grade	0 (regrets)
W8-71	F 71	Latina. Hispania Latina	College/BA	0
W9-53	F 53	Mexican	6th grade	7-12th grade 2 yrs. Comm. College
W10-71	F 71	Mexican, within Hispanic	3 years	Adult School
M1-57	M 57	Mexican-American	0	12th grade & Trade 6 mo.
M2-69	M 69	Spanish. Hispanico	2 yr Technical	Few Adult Education

Note. W = Woman, Age; M= Man, Age; # See Test Interview above for reason for two ages for W3;

† = 1-year follow-up with W4; ESL = English as a Second Language courses.

The self-described ethnicity of participants included two-thirds ($n = 8$) self-reported to be *Mexican* or *Mexican-American*. The remainder used *Latina/o* or *Hispanica/o* descriptors. Some demographic data were not recorded on W4.

At the time of the interview with W4, the PI recognized that she suffered from a significant lack of diabetes education and comprehension that adversely affected her DSM and short- and long-term diabetes outcomes. In good conscience, the PI and RA1 returned to W4 with educational materials to discuss the PI's concerns. It was found that many positive changes had occurred during the year-between-visits. The new information gathered about W4 impacted data collection and analysis –reported later in this chapter. The 1-year delay was because W4 was a contact of RA1 and the RA needed to be available to attend the follow-up.

The number of years and level of education completed varied significantly between participants, ranging from college graduates to elementary completion. Four completed college; two women had 4-year degrees and two others completed technical or commercial programs. A fifth participant completed junior college, two finished high school; one included a 2-year Nursing program and Adult Education, the other completed a brief trade school program. Two finished ninth grade; one regretted having not completed more education. Three finished only 5th or 6th grade with limited additional education. The education level did contribute to comprehension of diabetes information and how they lived out their DSM, as results will demonstrate.

Table 2 reveals that all but two participants came to the United States for the first time by age 21; the other two came 2 years either side of turning 30. Over one-

half ($n = 7$) came with their family as children, youth, or with a family member to reunite with family in the United States. The other four came alone; three as young adults, one as a teen. At least eight of the families left Mexico for better jobs and/or educational opportunities in the United States. The average time living in the United States was over 38 years.

Table 2
Age Came to US (1st/2nd Time); With Whom Came; Birth Order

Code	Age Came to United States			Family Configuration
	1 st Time/ Time Here	With Whom	2 nd Time Permanent	Birth Order/Total # Siblings
W1	10-11; for life	Family		1st of 6
W2	15 x 1 year	Alone	^3rd of 5	
W3	32; for life	Brother; family here	--	2nd of 9
W4	±17; work few mos. ~22 x ~2 years	Large Family w/1st husb. X 2 yrs.	~26 +2nd husb.	4th of 11
W5	20; for life	Family	--	6th of 8
W6	28; for life	Husband/children		1st of 5
W7	14 x 6 months	Family	17	3rd of 7
W8	21; for life	Alone	--	6th of 11
W9	11 x 7 years	Family	21	6th of 7
W10	19 x ~7 years	Alone	33 w/dtr.	5th of 7
M1	5; for life	Family	--	2nd of 3
M2	20 x 6 months	Alone	21	1st of 2

Note. ± First time to United States for extended time without intent to emigrate from Mexico; ^ = oldest in home

Birth order in-and-of-itself did not directly affect the data analysis process regarding decision-making; however, it revealed important community-orientation on the primacy of the family as community and how the whole was seen as more important than the individual. Their cultural perspective is discussed later in this section in Community-orientation. The salience of commonality revealed important

insight into how indistinct the individual was in comparison to the family as a whole. This had significant impact on decision-making, especially for women.

Table 3 reflects language. All of the women spoke Spanish or mostly Spanish in their homes, except W10 who spoke English exclusively when married and raising her child with her English-only husband. Once divorced and living back in Mexico, she spoke Spanish and English; she speaks Spanish with her Mexican family.

Table 3
Languages Spoken; Where Learned to Speak English

Code	<u>Languages Spoken</u>		<u>Where Learned to Speak English</u>
	<i>In the Home</i>	<i>By the Family</i>	
W1	Spanish	English and Spanish	In elementary school in Mexico In U.S. schools and at work
W2	Mostly Spanish	Husband speaks Spanish She & his kids are bilingual	Middle school in Arizona Work In United States; her kids
W3	Mostly Spanish	Children are bilingual	English classes at Mexico university ESL in community college
W4	Spanish	Adult children are bilingual	Work in United States; from children Knew English alphabet in Mexico
W5	Spanish	Children are bilingual	In United States: school, work & home
W6	Spanish	Adult children are bilingual	In the United States: school & reading & from her children
W7	Spanish	Adult children are bilingual	In the United States: work & children
W8	Spanish	English and Spanish Mex-born/US-raised; husband spoke English to their children Adult children are bilingual	In United States: husband & children
W9	Spanish	Adult children are bilingual	In United States in school
W10	Spanish/English	Adult child is bilingual; American husband spoke only English	Parochial school in Mexico Classes, marriage & work in United States
M1	English	Speaks Spanish to his mom American wife speaks & children speak English	In elementary school in California
M2	English	American wife speaks only English Children/families speak English	English classes in Mexico + private college; learned from wife/work

Note. ESL = English as a Second Language.

Her mostly-U.S.-raised adult child is bilingual; she speaks mostly English. M2's wife is non-Latino. He reported that, by necessity, he had to learn to speak English in his marriage and at worksites. His children speak English. W8's Mexican-born bilingual husband was raised in the United States and speaks Spanish with W8 and his friends; he will only speak English with their children. M1 came early to the United States, spoke Spanish in his home, has spoken English since school-age, and speaks Spanish with his mother. All participants' children speak English and, with the exceptions cited, most are bilingual and have helped Spanish-first parents to learn more English. Of interest, W1 & W10 had first learned English in elementary school in Mexico's public and private schools. W4 learned the English alphabet in Mexico.

Table 4 illustrates how all benefitted from having health insurance, except W4 who did not have insurance until the Affordable Care Act facilitated it. At the time of the 1-year follow-up visit, she had insurance and a new health care provider (HCP). Initially, two were diagnosed as *borderline* in Mexico. All were given the diagnosis of type 2 diabetes in the United States.

Age of onset varied from 32 - 62 years and the length of time of diabetes ranged from 4 - 26 years; the average was 15 years. Four of the 10 women's first diagnosis of diabetes was while pregnant. The insulin-controlled diabetes first identified in W1 and W5 each resolved after delivery of their child. There was a 14-year period between the recurrence in W1 and 4 years for the younger W5. W2 and W9 have not had a disease-free period, whereas W9 immediately began care of her diabetes upon discovery; W2 used medications for only 1 year post-natal.

Unfortunately, due to very demanding life issues and lack of support, she had gone

for almost 12 years with no medications - once again she sought care just prior to the interview. Pregnancy was not the first time W3 was diagnosed with diabetes; it was the final time. She had gestational diabetes twice but was dual-diagnosed in Mexico as *borderline* and *diabetes*.

Table 4
Health Insurance; Length of Time with Diabetes; Country of Diagnosis

Participant Code	Health Insurance				Onset, Years/Time with Diabetes	
	None	MCare	MCal	Private	First Time /Length	Second time
W1-58T			X		GD @36yrs./4 mos. with 3rd pregnancy	@ 50/8 yrs
W2-42M	X [in past]			X	GD @29 yrs./cont. 13 yrs. with 3rd pregnancy	Restart Tx @ 42
W3-45/49L				HMO	@27 Mex <i>borderline</i> /18 yrs. GD	@ 34 start med
W4-62S	X^		X+	HMO	<i>Borderline</i> in Mex @ 47, dx'd @57/ 5 yrs., sx's x 10 yrs.	
W5-40F			X		GD @32 yrs./6 mos. With 2nd pregnancy	Age 36/4 yrs.
W6-70G		X			Age 44/26 yrs	
W7-58S				PPO	Age 42/16 yrs	
W8-71A		X HMO			Age 50/20 yrs	
W9-53L				PPO	GD @ age 41/12 yrs With 4th pregnancy	
W10-71S		X HMO			Age 62 /8yrs	
M1-57M				Lg HMO	Before 1992/>23yr	
M2-69E		X HMO			^^20 years	

Note. MCare = Medicare, includes Supplemental; MCal = MediCal, includes other public insurance; Private = through participant or spouse, includes HMO and PPO; Dx'd = diagnosed; GD = gestational diabetes; Sx's= symptoms; Tx = treatment; ^ = 1st visit [pre-Affordable Care Act]; + = 1 yr. follow-up [after insurance through ACA]; ^^ = tested 2-3 yrs. before dx'd.

All participants were either married or had been married; three were widowed, one had remarried; two were divorced, one had remarried. Years of

marriage ranged from 10 to 53 years. Each participant had at least two children and up to seven children. Regretfully, two had lost children. The effects of their losses on their diabetes self-management will be discussed in Intervening Conditions and the Interactions and Decisions sections of this chapter and in Chapter 5: Discussion. The younger and middle-aged participants (40-58 years) had children living with them; the generally older ones (62-71 years) did not. One participant lived alone; often her sister visited for extended stays. All participants had families living in the greater Southern California area; many lived close by and visited often. One-third ($n = 4$) worked outside of the home, one-quarter ($n=3$) were retired, another one-third were homemakers-housewives and two were disabled due to work-related injuries. Two-thirds ($n = 8$) were Catholic and the other four were active as Christian Protestants; religious-spiritual influence will be examined in the following sections.

The primary and supportive demographics have been illustrated to show the participant codes, ages, gender, self-defined ethnic identity, and number of years of education; these had an impact on the study. Table 2 established the ages, birth order, and with whom participants came to the United States; several came twice. These factors also had bearing on the study. Table 3 demonstrated the languages spoken and where and from whom English was learned; English comprehension was important to the study results. The final table displayed type of health insurance and age of onset of first and second diagnoses of diabetes; these factors impacted self-management decisions.

Substantive Theory – Where the Results are Headed

This chapter provides insight into the substantive theory rather than presenting findings that systematically lead up to revealing that theory. It should be noted however, that the substantive theory was derived inductively. Due to the large volume of data being presented, the researcher has chosen to introduce the theory first, allowing the reader to envision how the findings fit within the theory.

The primary decision-making process by study participants was the act of *Negotiation*. They were *Negotiating* with themselves and the world around them about what they were eating as they were trying to keep the long-term goal of well-controlled BG over time in order to prevent or reduce the risk of poor diabetic outcomes, such as organ failure and loss of limb. The *conflict* they faced daily was the temptation to overeat good tasting Mexican food, which often had significant meaning and brought immediate satisfaction. The risky aspect was that it caused rapid excursions of their BG. At the same time, they had to respect the strong sociocultural expectations and norms that required them to *at least taste “a little bit”* of what had been prepared; to not do so was *to offend*, especially the hostess; but also, the community-based culture. Thus, in the short-term, they *battled* the desire for the pleasure of taste while they felt constrained to eat what was offered, while they knew they should not eat because of the short- and long-term negative effects on their T2D. When they complied with social expectations and ate what they should not eat but wanted to eat, they knew it would taste delicious and have immediate gratification. There was palpable satisfaction personally and socially.

Although, since recurring short-term BG surges had a yet-unmeasured, cumulative effect on them, the brief enjoyment now had more enduring consequences.

Nevertheless, the real goal for each of them was protection from lasting ill-consequences. Each short-term satisfaction they had, ultimately, went against their most favored goal to be healthy, to be well for their family, and/or to avoid the horrors of T2D that they had all witnessed others experience. The long-term offered no immediate satisfaction; it was elusive and made keeping the goal in mind an everyday challenge. They *negotiated* in various ways through various mechanisms to find a balance between the short-term drive and sociocultural obligation, in which there was satisfaction, and long-term intangible protection. The challenge was to become so consistent in making correct choices all day that they worked toward and achieved *Mastery* of their DSM and, thus, their T2D. On any given day, they might have been both successful and less-than or not successful. Over time, some participants had phases of sound self-discipline in which they were *Masterful*, but at times they were inattentive and not consistent in practicing self-control; they did not achieve or sustain *Mastery*. All along, there were intervening conditions and dynamics that influenced their efforts at control. *Mastery* required keeping one's eye on the long-term, every day, while fighting the *battle* of short-term enjoyment and social norms. From their daily *battle* effort arose the substantive theory:

*Negotiating every-day diabetes self-management decisions
about conflicts between culture, personal enjoyment, and long-term outcomes
toward mastery of type 2 diabetes by Mexican-born adults.*

Describing the Contextual Categories of Decision-making in Mexican-Born Immigrants

The Context of decision-making by the Mexican-born adult participants with T2D living in the United States developed into three major contextual categories: (a) the Community-Oriented Culture, (b) Cultural Characteristics, and (c) Cultural Perspective on Diabetes. Exemplars for each of these major contextual categories and the respective primary subcategories will reveal how each category was identified. The inter-relationship between primary subcategories will also be shown. For example, within the first major contextual category of Community-Oriented Culture, four primary subcategories emerged: living the community-orientation; not being different – social pressure to conform; maintaining strong cultural values; and keeping cultural norms, expectations, and obligations. Due to the large volume of data in each primary subcategory within the major contextual categories, multiple dynamics emerged. Thus, it was necessary to distinguish further subcategories that will be identified at the beginning of each primary subcategory. Aspects of the Community-Oriented Culture will now be established.

Contextual Category - Community-Oriented Culture: Community orientation; Not being different; Cultural values; Cultural norms, role- and rule- based society

From early in the interviews, participants shared about the centrality of their families and how important it was to be part of the Mexican community. They expressed pride in their Mexican heritage and their culture. Overall, even those study participants who had lived in the United States for many years and were

routinely exposed to the highly-individualistic American culture had retained a strong community-oriented outlook and approach to life. Three subcategories within the Community-orientation included: (a) the community (and family) comes first, it is always of prime importance; (b) having connections to Mexico are fiercely strong due to emotional and identity associations; and (c) the salience of commonality that is based on the belief that all Mexican persons are *the same*. To be clear, the term *community* is a broad rubric that can refer to the culture functioning as a whole, to a region or neighborhood, or to a smaller group such as the extended family, a group of friends and neighbors, or co-workers. The term, community, will be used to identify any size group of Mexican persons functioning as a communal unit of any size for any purpose. Occasionally when referring to a specific faction or grouping of people, such as at a social gathering, the term *group* may be used to distinguish it from the larger cultural phenomenon or influence, since group pressure results from socio-cultural influence.

Living the community-orientation: Community first, Connections to Mexico, and the Salience of commonality. Ten participants indicated that, from childhood, it was both normal and more important to think about *we* than it was to think about *me*. W9 brought great clarity to the reasoning behind this cultural standard.

PI: "... what is this 'I don't want to stand out and be different than the group, than the community, than the culture?' 'than the rest of what my huge family is doing?' What's that about?

W9: They just want to be the same.

PI: ... Want to be the same ... Not different from the community or group?

Because the Mexican culture is such a communal and collective, it's not nearly as individualistic as I was raised in. It's a more community-oriented.

W9: Much more.

RA4: Yes, much more community. . .

PI: It's much more community oriented I think. Is that part of it, that people don't want to feel different than the ...

W9: Because everybody's the same.

PI: Is it safer to be the same?

W9: That's what you think, yeah.

PI: Why is it safer to be the same?

W9: Because you're raised like that. Just the way everybody thinks."

Only those two persons who were raised from childhood or youth and did not return to live in Mexico demonstrated stronger American cultural tendencies, although still Latin in many ways (W1 and M1). However, W1 was quick to clarify that, while she was born in Mexico, she did not claim an allegiance to Mexico. Yet, she demonstrated that she held numerous cultural beliefs and practices. One interesting observation was when she was seating the PI and RA at her kitchen table for the interview. Casually, the Mexican Latina RA hung her purse on the back of her chair while the PI started to set her purse on the floor next to her chair. W1 reached to grab the purse before it rested on the floor and insisted it would rest on the adjoining counter. She commented that she would not allow the PI to put her purse

on the floor. Later, privately, the RA shared with the PI that it is a superstition-like belief that if a woman leaves her purse on the floor, she will lose her money. The RA commented that although W1 did not want to claim much about Mexico as her own, she had an obvious Mexican accent, practices, and beliefs that she had embraced. She used to make piñatas for fiestas that she enjoyed attending. She stopped because she tended to eat too many of the Mexican candies while making the piñatas. In this exemplar, she clarified her relationship to Mexico as the PI read the purpose of the study written in the consent.

PI: "I want to explore how people who are born in Mexico, who have type 2 diabetes, how they decide to make decisions about their... about how they take care of their diabetes.

W1: Uh uh [affirmed with a furrowed expression].

PI: You got a curious look on your face, did you...

W1: No. I was born in Mexico, but I... I was born there, but I was raised here, my parents were born in Phoenix, Arizona, so I have nothing to do with Mexico - have no idea of what's going on over there [brushing her hand to the side]. Ok?

PI: Ok, yeah. Thank you.

W1: I'm being honest ..."

The community comes first. Another sign that W1 had deep linkages to the Mexican culture was that she had a time-limit for the interview because she needed to leave to go to a neighborhood community meeting where she was active as a community leader. She also spoke of knowing about several neighbors in her

development who had diabetes or had suffered and died from the disease. When the local pharmacist was diagnosed with diabetes, terrified, she called W1 for advice.

As will be demonstrated, this foundational community-orientation had a profound impact on the decision-making process for DSM of the Mexican-born participants with T2D living in the United States. Within identity of a cultural group, there are often segmental variations based on generational differences, social class, and regional experiences. All of this was appreciated in this study. In particular, gender, role, and sometimes age were also found to have prominent effects. Within the community-focused perspective, a natural offshoot of thinking about and putting the whole before the individual parts was the import of social unity in the culture.

Having connections to Mexico. Consistently, most participants (W2, W3, W5, W7, W8, W9, W10, M1) said that originally, they did not want to leave Mexico or that they had always wanted to return to live in Mexico because they loved the culture of Mexico and/or had a happy family life there. All 12 liberally expounded the quality of life, beauty, human warmth, and enriching culture, food, and people of Mexico.

Uncharacteristically, two did desire to leave Mexico because of family problems they wanted to escape. W2 struggled with her father's repeated sexual abuse starting at age 15, the age when she first left Mexico to live with relatives in Arizona. Her mother, who worked away from their town for weeks at a time, reportedly continuously turned a blind eye on her husband's behavior. Struggling with the language in the Arizonan Middle School, she missed the cultural comradery of Mexico and her younger siblings. Following some months of attempting school in the United States, she returned to Mexico for several months, but she again had to

flee because the incestuous challenges in her home were intolerable. Both times, at ages 15 and 17, she came to the United States alone, crossing the U.S.-Mexican border without an adult. M2 had serious issues with his younger sister relating to their mother's estate. He chose to avoid the conflict and planned on using his college education to advance his life in the United States. After being raised by his grandfather and having a variety of work experiences, he came to California. After a few months, he too went back to Mexico briefly before he returned to permanently live in Los Angeles County.

It was unexpected that most participants had no desire to live in the United States except to facilitate educational and work opportunities for themselves or, later, their families; sometimes via a U.S.-birth. It was surprising to learn that once here, one-half of the participants went back to Mexico within 2 years, then returned to the United States at a later date.

The salience of commonality. Commonality was reported by W4, W5, W7, W9 and M2 and inferred to by W6 and W8 to be highly valued in the Mexican culture. Partway into the interviews, further clarity was brought to prior discussions when W7 described the people in the culture as "everybody is the same," referring to whatever was being done or eaten. W9 went on, "Just go with the flow, I mean everybody's doing that ...so let's go ahead and do it." Since culturally it was important not only to choose to benefit the group as a whole but also important to not be different from the group when referring to Mexican persons, she added "they all just want to be the same."

An interesting finding embedded in commonality was the lack of awareness of birth order and family sequencing found in some participants. Each interviewee was asked what number (s)he was in her or his sibling line up. A few knew right away that (s)he was third of five or seven, the firstborn of course each knew (s)he was the oldest, but almost half had to think through the names of older siblings or to count up to their own number in the birth order. The response by W4 illustrated this well:

PI: “And where were you in the lineup for the children – what number are you?”

W4: Wait... Pedro, Carmen, Dominique. I’m the fourth.” (Names and two genders have been changed)

An example of a more convoluted but not uncommon interviewing experience of figuring out one’s birth order or other criteria with the aid of the Latina RA, W5’s response:

PI: “...Five brothers ... And how many sisters?”

W5: Three ... uh two, and me!

PI: And what number are you? Where do you come?

W5: [pause] Yo soy de las mas lista otro chico, lista otra ...mas chicos ...

[Counting the two younger on her fingers]

PI: Out of eight she is six? Es cinco mas older – five older and two younger?

RA: Okay, she’s number 3. [pause...] Okay, en sister numero seis, en lista?

PI: Are there five brothers and sisters older than you?

W5: Cinco, si. ... La seis.

RA: Okay, she's number six!"

Culturally since everyone is the same (per W9 and W7), then one's birth order did not appear to matter except for the eldest, nor did it appear to change anything. This illustrated the community mindset that the individual had a less unique position; it varied from the American culture in which children commonly know their number in the birth order (Su, McMahan, Williams, Sharma, & Sudore, 2014; Van Volkom & Beaudoin, 2016). This finding raised an interesting issue of how one's thinking from a community-culture individuates her- or himself from the communal whole. As will be seen, this outlook had bearing on DSM decision-making.

The second primary subcategory of the major contextual category of Community-Oriented Culture is *not being different; social pressures to conform*. Within this primary subcategory arose four subcategories that explain the dynamics of the primary subcategory. These include *feeling subtle social pressure, having responsibility, feeling less-subtle social pressure; and the importance of perception—seeing me is seeing my culture*. The latter has additional sub-subcategories that demonstrate the *pride of being Mexican* and *having less distinction of personal boundaries within the spirit of generosity* of the Mexican culture.

Not being different: Social pressures to conform – Subtle, Responsibility, Not subtle and Perception. The need to maintain the primacy of community has been well established. Because the community was more important than the individual, to choose one's self could devalue the group. There was strength in the collective group; thus, it was important not to violate the integrity of the group as. An important aspect of cultural identity became evident when social

pressure was both subtle and not subtle. One was to share commonality, to avoid being dissimilar from others, to *appear* to be the same, and to follow social codes. The latter will be discussed in detail further below.

Feeling subtle social pressures. Since it was reported that one creates discomfort by not blending in to the group, some participants (W3, W4, W8, W9, M2) relayed feeling fear of judgment if they were different or unique. W4 was afraid of how her friends thought of her when she could not keep up with their social activities because of her diabetic peripheral neuropathy. She told RA1 who translated, “she doesn’t want to be *socially uncomfortable*.” W9 asserted that there was security for the individual in not standing out as different from the crowd, that one does not want to protrude as distinctive but rather to be mixed in with the whole group. “People want to be part of everything and be like others, not separate.” An unspoken message from the time one was young was to not vary from the social norm. Atypical to the American culture, one was not rewarded socially for being unique. Since people in the Mexican culture tended to be part of a group, this left one open to some vulnerability to other people’s opinion. W3 reported that “some Mexican people are bothered by what other people think about them.”

Having responsibility. Because blending in was a social requisite, it also provided a security socially. Thus, group decision-making was also safer for the individual. When the group, whether family, social, or work team was involved in the decision-making process, an individual had less personal responsibility and there was less room for that person to be blamed or left responsible for something if she or he had made or executed the wrong or suboptimal choice. By defaulting to

the opinion of the group, it could become the fault of the group rather than the individual; therefore, there was less social risk for the person. According to W6, “everybody does it.” W3b said “they don’t want to be wrong.” In some way, there was a protective mechanism of having others involved in one’s business. A constant comparison question identified by the PI was to understand why one would seek to solve one’s own problem by taking a risk of standing out from the crowd, being wrong, or meeting disapproval when the benefit was for the family, group, or community, not one’s self and to explore how this might have a bearing on decision-making for DSM.

Feeling less-subtle social pressure. Another social pressure that arose was caring about what others might think; this was not a subtly. When they were concerned about the opinion of others, they felt socially pressured to maintain conformity. An apparent cultural concern was that it was common in the society for people to gossip. Simply explained, they do not keep information about others to themselves accord to W8, W10, M1 and M2. Participants often reported feeling judged for not following cultural expectations that could result in being talked about by others. It was also common to talk about health issues only with those to whom they were close, a concern voiced by W4, W6, W8, W9, and W10, each of whom were very cautious to whom they would disclose information, even if they knew people for many years. “Oh, I’m really selective about who I talk to because I don’t know who to trust” (W8). W4 was concerned about what her friends would say if she could not keep up with them when shopping. Gossip or fear of gossip about the men served as a means of setting social boundaries for themselves as well, according to

M1 and M2. M1 said he could not trust some of the men in his previous worksite because they sometimes talked about or made fun of others if they did not understand that man's health issues or they thought they were *tougher* men; implying they were more macho. M2 asserted that men in his culture make fun of other men and talk about them if the offender was not close to the affected person. He said this was seen more often in men who tend to be more *macho*. He explained that some men arrogantly behaved in a way they thought the *traditional* strong man *should* behave. He worked with a group of men for a number of years. He talked about times when several of them had *machismo* attitudes. One illustration he used to describe one of the unpleasant, ridiculing encounters was:

PI: "Do you talk about diabetes with other people, or do they talk with you?"

M2: You know, no, not really because you never know what their reactions or something, the friends gonna be against you, or that issue, you know?

PI: Yes... I've been hearing that sometimes people feel like they have to hide, kind of keep that private, keep it hidden. Tell me what that's about, especially as a Mexican man. What is that about, to kind of keep that quiet, or hide it...

M2: ... But you know actually I talk to really close people... Close friends. Somebody I can be confident with.

PI: Yes. So, you know they're not going to gossip.

M2: No, you gotta know what kind of people you're talking to... and you never know what the answer gonna be. When I have the seizure at my work, they were making fun of me. One of the guys, and I was [thinking

to myself] ‘man, this guy’s...’ which was very ... [said in a discussed, resolute tone]. I didn’t pay attention to it, you know, because that’s the way it is. It’s what you deal with... [referring to a macho work environment]

PI: and that person you never trust.

M2: Exactly... so, you never discuss problems with.”

Part of the foundation of these concerns became clearer when discussing differences between life in Mexico from the United States. W10 remarked about America, “I like that people are less pretentious... A lot of people mind their own business. They don’t gossip.” Despite these social pressures, these were people with deep Hispanic cultural and ethnic pride.

The importance of perception; “Seeing me is seeing my culture”: Pride in being Mexican, Boundaries and Generosity. An important aspect of their cultural identity as Mexicans and Hispanics was how participants appeared or presented themselves to others. They expressed pride in their heritage and were offended when it was misrepresented or judged to be of lower quality. Various participants talked about the importance of making a good impression on other people; it carried significant value culturally. They conveyed that making a good impression was both about how they were individually perceived and how the culture was perceived through each of them. Being a community-oriented culture, they saw themselves as representing not only their own person and family, but also the whole ethnic group with which they proudly identified – being Mexican or Hispanic. Because perception mattered, what another individual or another group of people thought of them

personally and how they represented their group was significant. When the PI clarified her understanding of perception, “how you are perceived; how *I* present myself so you think good of me?” W7 confirmed with conviction, “Yes.”

Pride in being Mexican. As seen earlier, demographically, eight of the 12 women and men self-identified themselves as Mexican or Mexican-American. The remainder used Latina(o) or Hispanica(o) identifiers. Being part of the broader culture essentially included, “how you see me is how you see my culture.” Providing more clarity in the final interview, W3b verified that as a Mexican, it meant she belonged to the whole, so however you see *me* is how you see *my whole* (culture). In the following excerpt W7 explained this dynamic very well as the PI sought to further construction the concept.

W7: “I think that the Mexican, the Hispanic is always try to impact people.

You never, never, never want to look down [be looked down upon], you always try to, gonna be better than them. I think it’s that.

PI: Okay ... So it’s about the self-concept ...?

W7: Yes.

PI: Or is it about the cultural concept? ... Do you understand my question?

W7: Well, I think almost everybody is the same thing. For me, all the people around is like that.

PI: I want to understand. They want to look good in that they are doing the right thing? ... for themselves or in front of others?

W7: In front of others. In front of everybody!

PI: Okay.

W7: I think so, but... and you know what, people think, when they think about ...

PI: So it's how people perceive? Perception?

W7: Yeah.

PI: It's about the *perception* of the Hispanic? And it's for the persona, but por le en toda tambien [using arms to indicate inclusion of a large group].

W7: Yes, yes.

PI: So it's how I present myself so you think good of me. But I am everybody else. How you see me you see the rest of my people. Am I on this right?

W7: Yes!

RA2: Yes! [The Latina RA re-iterated the import of this factor during Debrief]

W7: Yeah, and you know what? People think like, oh, 'Ah well some Mexican people is a lot of mistakes.' That's why the people think like 'oh, Mexicans is no good.' But no, but Lima and Guadalajara, or over there, is a lot of education. ... You can be like 'Wow, that's Mexican?!' ..."

With even more detail, W10 lent personal insight to the issue. The PI sought her experience and understanding of this important cultural concern, "Some people have told me ... 'that I as an individual from Mexico, I represent all people from Mexico. And I have that responsibility to represent my culture, my country.'"

W10: "Oh yes ...

PI: "... And so I would like to know what that's like for you as a Mexican woman?

W10: Oh yes, we are very proud of being Mexicans, and we are very proud of our cultural heritage.

PI: Yes, uh huh. I don't blame you.

W10: And we like to dress well, for that reason because

PI: Like present yourself well? Is that what you mean? [W10 Nodding]

W10: ... You know when we see that Latin people do wrong things, we feel bad. And you say 'why did they do that?' You know, that's against our culture.

PI: Ahh.

W10: It harms our image... and what we try to do is ... you know ... At least I see my sister and my other sister. We're very proud of our culture.

PI: ... So, it does hurt, doesn't it?

W10: It does. It does. It does. It does. You know when they say, for example, that 'Mexicans come to harm the economy of the United States', but I see it the other way around. I think they generate income because they buy food, they buy clothes, they buy, you know, and they're consumers.

PI: Yes, constantly. They're consumers, yes of course...

W10: I see it the other way around. And not everybody ... I don't think are raised any race should be addressed or regarded because of a few bad apples, because within that same race . . .

PI: Yes, 'cause every culture has that -

W10: Uh huh, because within that same race there are great people, great scientists, you know. And it hurts when they say negative things about you know ... they generalize 'oh they're Mexicans.' Even my boss here in America, when we cross the San Clemente or something, she says 'No, no, no, don't say you are Mexican.' I said 'Why not?' 'No. No. no, don't. Say... You are not a Mexican.' I say, 'Yes, I am Mexican!' So, you know ...

PI: That there are some bad connotations.

W10: ... Um hmm. Stereotype.

PI: Yes, I guess that's the way to put it. So, I do understand that, but what I'm hearing you say, and what I heard this other lady in particular say is that you feel a responsibility

W10: Oh, yes.

PI: As a person from Mexico to continue... to put the culture out (publicly) well.

W10: Oh, yes. ... Yes. Yes."

From a different perspective, W4 felt embarrassed when she could not keep up with the activities of her friends due to the neuropathic pain in her feet. She had always been a very active, social person but became restricted by how poorly she felt. "And I with my friends, they call me to go someplace or do something and I say 'Well I don't know, maybe I call you because I don't know how I'll feel.' And they give me a look like 'you're not able to do it?' But sometimes the way I feel, I feel not to go

outside ...” Because she could not participate in the customary, socially-accepted manner, she felt that she was looked at as being outside her social group’s norm.

Having less distinction of boundaries. The spirit of generosity. Another aspect of the community was the generous nature of the Mexican people to express open-handed qualities, “they give everything they have” stressed W3. W10 called it a *culture of sharing* and described the Mexican culture as being more *fluid* in nature with fewer partitions and barriers between people; it was more important to help each other than to refrain from helping or to protect the individual self. She illustrated her point by discussing differences between countries and cultures; American and Mexican. Talking about differences in cultures:

PI: “And what about food? It seems like that’s a big part that’s different?”

W10: Yes, and also *sharing*. You know before I get the food I remember I was just 2 or 3 years married and we lived ... this manager had ... one court were the elderly, and another court the pregnant, and another court with children. So anyway, we were in this court where all the pregnant ladies were, and so some of them didn’t feel well or something and I said ‘well, maybe I’ll give a remedy for her so that she will ease her pain.’

PI: And this was in Mexico or here?

W10: No, no here in the States. And then my husband (an American) said ‘don’t you dare do that.’ I said ‘what do you mean ‘don’t you dare do that?’ He said ‘no, because if you give them something that is bad

they're going to sue you.' And I said 'what do you mean suing?' 'I couldn't get it in my head! ... That was very shocking for me.

PI: Your culture says 'I have something to give, I'm gonna share!'

W10: There you go [snapping her finger]. They're very willing to share...
We're a very sharing people."

This example demonstrated the distinct differences in personal boundaries experienced commonly between the less individual-focused, more group-oriented Latin culture of the Mexican people – wherein a person had less of a sense of being individual – compared to the far more distinct personal *my* boundary space found among individuals in the dominant American culture. During several of the interviews, participants shared similar examples that distinguished personal boundaries unique to each culture.

Due to the reduced boundaries between persons, W1 implied that their family could be in one another's business and health issues, or made each other feel the other member was being punitive, especially if the other person was an older relative or someone in authority. In the case of W1, she made it her habit to tell others, especially her younger siblings, what to do on a regular basis to convince them to take better care of their diabetes. She issued directives with gusto.

W1: "Yeah, we gotta be responsible for your sugar. Then, my other sister, had diabetes, maybe about a year or two, and she said, 'no I don't have diabetes' and I go 'they tell you, you have 350. That means you have sugar in your system!' [Sister] 'Well I don't have anything ...and don't tell me because I get angry' [W1] and she *will* get angry. And I said, 'the

sugar is making you angry. Check your sugar or otherwise you gonna...

It's not from the outside you are gonna see the defects, it's from the inside of your organs. So, guess what? First, it's gonna be your toes, your legs, your kidneys, your liver, and you are gonna end up losing your teeth.'

PI: Teeth?

W1: Yes, sure enough, she lost all of her teeth; and she is 51, I think she is."

The third primary subcategory of the major contextual category of Community-Oriented Culture is Maintaining cultural values. While the culture holds many values, the two most deeply-embedded values that separated themselves from other cultural norms were *Family being first in importance* and *Having faith in God*.

Maintaining cultural values: Family first and Faith in God. The two primary cultural values that emerged as essential foundations of their culture revealed that the family came first in importance and faith that God was involved in the daily affairs of most of the participants. Family presented as a microcosm of community and was found to be at the center of each participants' life. They each reflected how core the family was to the society as a whole. Secondly, faith in God and God's participation in health and life was made evident as a broader, deeper, cultural core-belief that shaped many facets of how they approached life and their diabetes.

Family being first in importance. For women, especially, the daily function of life was around the needs and persons of the family. From this community-oriented culture, it was evident that when participants thought about the bigger

picture of the society, focus on the family was the day-to-day expression of life being about the *other*; first the family, then the community. M2 described it best, "...You grow up a certain way that you always think the family's first than anything else." This was consistent with the evidence above in which it was not the individual who stood out, but the family. It was well summed up by W5 when talking about the challenges of keeping her BS in balance:

"My problem is that sometimes I am busy and I always put priority in doing things for my kids or prepare their food, and it's always one thing or another, and I always leave myself for last. Then I feel tired because I didn't eat at the times I was supposed to."

This focus away from the individual person with T2D, especially the mother in the home, did prove to interfere with DSM as will be demonstrated in the following sections of this chapter. As will be exhibited below, having the family come first presents a very important challenge for the mother in the family with T2D who has responsibility of routinely choosing the needs and benefits of family and family members over her own needs, including care of her diabetes.

Having faith in God. The importance and normalness of faith in God was a recurring theme for most of the interviewees. In seeking to clarify constructs, the PI inquired of later participants. W3 brought more understanding about this during her second interview [W3b].

PI: “Tell me the piece about trust in God. It doesn’t have to be yours. I’m really looking to get to this cultural piece - because you mentioned that. You said ‘Oh I think God...

W3b: [talking over PI] Let me tell you some really clear example. When we need rain in one of the little towns near where I grew up, I grew up in Guadalajara, but ... when they need water, they will take up the virgin in whatever the name of the town... and they will and go and pray the rosary and sing and most of the time it will rain. But they say ‘God hear us.’ And, so people in Mexico are really faithful and I think I completely agree.

PI: It’s beautiful... You say Mexicans are very ‘faithful’; and [do] you mean in terms of the trust and faith they have in God?

W3b: Right.

PI: ...Really kind of what you were saying with your example of them carrying the virgin of their community around and praying, etc., there’s really an underlying confidence that God’s involved in every day, right? [having heard this from prior interviewees]

W3b: Um hmm. Yeah, it’s true, but sometimes there are things that need to be done in order for God to act. [Referring to being responsible in self-care she had discussed earlier in this second interview]

W3b: ... that is just one fact about faith that we have with trust in God. It doesn’t matter which kind of education you have ... which level...”

As the concept of the influence of faith in God developed in the study, M2 was queried about his viewpoint on how faith might affect how people managed their diabetes and their expectations in general about God's intervention in healing.

PI: "...because they are thinking that God will heal them? Does that sort of pull them off the focus of actual day to day care? ... Do you think there are some people in the culture that happens with, or why do you think that happens?"

M2: No, no. I mean you know what happened? My family grew up with their religion, I grew up with a religion and my mom was very strong person with a lot of faith and matter of fact she died of cancer. But she always has way of thinking that faith is gonna heal you. So, which is one fact that I believe that it help you to control your mind, wise, to take care of yourself.

PI: Okay. So ... you're saying that people can put a lot of hope in their faith, and basically, it's hope in God, ...But that doesn't necessarily have to make people not do what they're supposed to do with their diabetes. But do you think that some people do get so focused on their faith that they don't do other things to take care of themselves?"

M2: No, no ... Not necessarily, no. Not really."

The fourth and final primary subcategory of the major contextual category of Community-Oriented Culture is Keeping cultural norms, expectations, and obligations. As the data has revealed, there are numerous, culturally-based expectancies and pressures rooted in what persons in the culture have come to

understand as normal mandates that each Mexican person is to fulfill or address. Two broad subcategories are further identified when participants inferred that they were living in both a *role-based* and a *rule-based society*. Both role-based and rule-based subcategories have sub-subcategories that elucidate and support the strong subcategories and are influential in decision-making choices.

Keeping cultural norms, expectations, and obligations: Living in a role-based and rule-based society. Coinciding with cultural values of putting the family first and showing respect for authority, further conceptual construction of the Mexican culture evolved during interviews. Two fundamental structural functions gave both directions for behavior and set boundaries to the operational aspects of the culture. First, the well-defined roles that so clearly marked this society lent an important framework to how corporately individuals were expected to perform through traditional gender roles for women who must address family needs before their own, and men, including the influence of machismo. Several participants validated the role distinctions between women and men (W2, W3b, W6, W7, W10 and M2). The second function, importance of social rules, added considerably more configuration to the culture as the society was found to be rule-based with specific societal obligations that were deeply ingrained and understood by its members, specifically respecting authority and *Being proper*.

Living in a role-based society: Traditional gender roles -Conflict of priorities and Machismo. Participants expressed two aspects of living in a role-based society. First, they reflected on having learned about how facets of the role of their particular gender affected their lives and how those facets impacted the

culture around them. They described distinct differences in how males and females approach life and how these distinctions influenced their choices in life, including about their diabetes. In describing how a young girl was raised in the culture and the expectations girls were assumed to fulfill, W7 shared memories of what and how she learned from her mother and grandmother. Her experiences were not unique from other female participants. She shared her observation first about her mother and her values, then later about her grandmother.

W7: “And I’m always you know, staying in the house, helping with my mom, and you know she was very good person. She told us ‘you have to be honest, responsible’ and you know... and what can I say about her?”

PI: She had very good values.

W7: Yeah.”

About her grandmother, she reflected on cooking and baking skills she learned:

W7: “And I’m overweight, because you know my grandma? I think I got it from her because she never got diabetes but she cook a lot of candies and things. I’m always close to her, and she showed me, she said ‘oh look it’, that’s why I love to cook and that stuff because she was very good to cook and I spend time with her.”

Traditional gender roles: Women. Being that women have primary responsibility in the Mexican household for the family, including its welfare, organization, community matters, and healthy functioning, the work of many Latinas in the home required a great deal of time and energy and demanded even

more for those who worked outside of the home. W3 validated what other women discussed about the demands of the family responsibilities as she talked about the time she had worked fulltime out of the home and still had her woman-of-the-home mother-wife responsibilities in the Mexican family living in the United States.

W3b: "...actually here in the United States both have to work. So, I think it's even... Women need to have more support of men because of the background culture. You know there are some women, for example myself, I used to wake up and get lunch for them [her 2 kids and her husband] and go to work and then come about 4[pm], really hungry and I still needed to cook [dinner]. And I still needed to pay bills, and make phone calls, appointments, to do everything because they think their only job is to go to work and that's it.

PI: Let me get that. Man's role is to go to work. [Taking a clarifying note]

W3b: So even I was working - and I see this happening in a lot of Hispanic women, that they have to work and besides they have to laundry, cooking, make phone calls, everything..."

In this example, very common to what was repeatedly heard, keeping the needs of the family in front of her led to recurring neglect of herself, of more concern due to her diabetes. There was evidence that others were challenged by their multi-caregiving roles and the complexities of managing their diabetes simultaneously. W5 expressed the conflict very well in her comment about not having time to eat on time because of all she had to do for her kids and putting their needs first, as recorded above in Cultural Values - Family being first in importance.

Conflict of priority: Role versus family needs. Despite all the challenges facing women, the multi-role of a woman: mother, wife, older sister, and neighbor is well-validated in the culture that brought a great deal of satisfaction and meaning to these Latin women. Nonetheless, sometimes fulfilling their roles did become the focal point in their life. Instead of the role serving her family, in the case of M1's mother, there was a time when she was more concerned about doing the work of her role as mother that interfered with her actually providing what her son needed. Once she learned what his real needs were, she changed her focus to address his needs rather than focus on doing her role as a primary cook in the family. Her choice helped to improve his failing health. When M1 was seriously ill with multiple health issues for an extended period, his Mexican mother finally realized she had to modify her cooking style and let go of making traditional, high-calorie Mexican foods that tended to be heavy, which he could not eat. She had to relinquish her satisfaction in making and serving the traditional foods because her son himself got to the point where he would not eat the heavy meals. He knew his cardiac and diabetes risk factors put him at risk of not surviving; he had already had one heart attack in his late 30s, was obese, and had T2D. Her role was modified by the significant needs of her adult son; she came to understand that if he was to eat the food she prepared, she would have to address his needs and not the traditional role she had been raised to do and became accustomed to fulfilling over many years. This mother had to change to a much lighter, non-Mexican dietary preparation for her adult son when cooking for him. In that way, she allowed the role of Mexican mom-cook to focus on the needs of her offspring rather than on meeting her personal need to fulfill the

role as the Mexican mom-cook. M1's response supported this finding when asked the question, "What kinds of things help you take care of your diabetes?"

PI: "Okay... You already said your wife is a great help ...

M1: Yeah.

PI: Is there anything else that helps you?

M1: My mom. But then she wants to ... Now when she asks me 'do you want to eat?' she makes a tuna salad or something like that."

Traditional gender roles: Men. As discussed above, a very important gender role for men was that of provider for the family. As W3 pointed out it was common in today's American society for both husband and wife to work in Southern California due to the cost of living. An important way that males were raised in the Mexican culture was to be strong, healthy, and successful. As evidenced above, the appearance of how one presents was very important, affecting how the individual, family, and culture were seen by others. W3's description was, "...Imagine with men... that they think [they] are more macho... That they do not want to look weak in front of society. They want to show strong personality and healthy and successful." As a woman who grew up in Mexico, she learned about important aspects that defined a man from a woman. While only two men were interviewed, both interviews were quite lengthy at almost 4 hours; several of the women contributed important information and perspective about the role and impact of the role of men in the Mexican culture. An important factor was brought up by multiple women and confirmed in interviews with the two male participants: the presence and effect of *machismo*.

The influence and effects of machismo. When a man was feeling vulnerable about the potential of being exposed in some uncomfortable way or was shown to be wrong, made fun of, or was misunderstood, the air of machismo was put forth. W3 shared, “Instead of show weakness, they are acting more macho...because they don’t want to ...” PI: “So they may act macho basically to cover up?” W3b: “Right.” PI: “to cover up their vulnerability?” W3: “Right.” According to W6, pride was an aspect of machismo. Reportedly to demonstrate or admit that something was wrong, or not done correctly, or if there was a lack of information or skill, a man felt exposed or that he *might* be exposed. Culturally, he was expected to be able to do almost anything typical of a man. They learned this reflex to be self-protective or to defend themselves from a very young age.

Since the appearance of things (i.e., how things look to others) was of such strong importance in this culture, even if the man did not really have a weakness or susceptibility, if it appeared that he did or might, it was not acceptable to him because he wanted to look strong, as W3 asserted in Traditional gender roles above. In the case of diabetes, this had important ramifications. According to both male and female interviewees, when men hid diabetes, it was [due to] machismo (W3, W10, M1& M2). Per M1, a man whose “machismo is strong” might not want to admit that he has something “wrong” with his body. W3b explained, “When a man shows he has it [diabetes]... [it] shows he might be weak ... [DM] gets looked at like it’s a weakness, a vulnerability... and imagine with men ... that they think are more the macho.” In an extensive discussion about her father’s never-controlled diabetes, W10 felt similarly as M1. She claimed that Mexican men rarely went to the doctor

due to machismo. “The problem with men is too macho to go to doctor!” indicating that man was putting forth the air of “nothing is wrong with me.” Both she and her older sister, who was visiting at the time of the interview, described this was an important, although heart-breaking element, of why their adored father developed such advanced, untreated diabetes in Mexico.

The *machismo* factor was identified as being stronger or more prevalent in Mexico than in the United States as the effects of *machismo* have been lessened in the United States due to Mexican men living in a non-Hispanic-dominant culture in which *machismo* was less common or important (Davis & Liang, 2015; Getrich et al., 2012). “Mexican men are more understanding ... in United States. In Mexico is still the same. Machos.” W3b. M2 explained that the culture of *machismo* was now less influential in Mexico than it had been in past generations. “Things have changed in Mexico in past few years ...” inferring that the frequency and intensity of *machismo* was less than when he was growing up in Mexico. Nevertheless, an active dimension of *machismo* was when a man considered himself to be more important than others. Within the culture, men were considered authority figures over others; women would often have a lesser place of importance. Sometimes that was to such an extent that a woman might be expected to have a servant-like role. Offering an explanation, M2 believed that *machismo* was more commonly seen and expressed in less educated men. “I believe it all depends the way you grow up, which family you grow up with...” He went on to say that families with less education tended to expect more of the woman in a servant role, “and if the family that don’t have that much education... *if there’s a lot of machismo in there...to rule the wife... and to me, that’s*

where it is.” There was less support for that woman to tend to herself, especially if she had T2D or other health issues. M2 and his wife, who sat in on the IV, told a story about a woman they visited in Mexico who suffered serious heart and HTN problems. They told how she was so ill with her high blood pressure that she could hardly stand up, was actually stumbling in the kitchen trying to prepare an egg for her husband. Despite her terrible condition, he simply sat at a table waiting for her to cook for him. They were disgusted at the degree of *macho* he showed, his selfishness, and how he put her health at risk. That was an example of a man with severe *machismo*, as M2 described, “... a lot of *machismo* in there...to rule the wife.”

The influence of alcohol. Both male participants talked about the influence of alcohol in their lives prior to the diagnosis of diabetes. M2, initially discussed this issue with reservation, but then gave a very good explanation as to the function of alcohol for men in the society in Mexico indicating why it might also be of frequent use when one moved to the United States; because in Mexico, it is a normal activity for men to drink. To begin, he labeled “the drinking issue for men ‘may be a problem’ ... “Maybe the culture unfortunately has a drinking problems.” Both he and M1 mentioned that men “Grow up with alcohol” as normal activity; it was common practice. M2 admitted, “the way it is in Mexico ... is nothing else to do. Unfortunately, we all have that mentality to be on the same pattern.” He went on to say, “In Mexico it’s easy ... We ... grew [up] with it... We all think that way.” Giving the explanation “cause there’s nothing else to do.” M1 also spoke openly of his alcohol use before his diagnosis. He too asserted that the use of alcohol was a common thing for men to do and that he had used it liberally at times before his diabetes diagnosis.

Some of the women also referenced the influence of alcohol in the culture, in the lives of men, particularly W2. The issue of alcohol use had significant bearing on the DSM for W2 shortly after her diagnosis of diabetes in her late 20s. While raising three young children, she learned that her husband was not caring for their children in the evenings. She was then compelled not to go to DSME classes after work because she had to be home with her children since her husband was out. When asked if she knew how she got diabetes, she replied, “No, I was going to... when I had my boy I was going to classes like nutrition. I had to stop because my husband he didn’t go home. I had to stay with my girls, he was drinking outside. I said ‘ok I’m going to stay with my girls; I don’t have to leave them by themselves’ thinking that he was in the house and he was out, so I didn’t get a lot of information” W2. W3 added a sad example about an uncle with diabetes:

W3a: “I have an uncle who has been drinking problem. He says ‘the day that I want to stop I will stop.’ He’s diabetic. ... He says that he can control the illness – diabetes, by going, he runs really fast. He’s really athletic ... but I have seen him in the last months, he’s been losing control. He’s drinking way too much. ... because his problem is not too much on diet, his problem is about alcohol.

PI: Right, his body is not getting the nutrients it needs.

W3a: It’s... one time I went with him [running] and I couldn’t make up with him. But now I don’t know, it’s really sad that he. . .”

In discussing the DSM behavior of her husband’s aunt and uncle with diabetes W4 noted they ate differently than they used to, but the primary difference

was that he stopped smoking and drinking when he was diagnosed. Like M1 and M2, they too have remained off of alcohol during the years of their diabetes. About her husband's aunt and uncle:

W4: "Well, they eat different... Yeah. Because sometimes, they like um... his uncle, he stopped drinking and he stopped ... And you know all that smoke and all that. He stopped and start, you know, eating... [somewhat better]."

Women reported that, at times, they also felt social pressure to accept alcohol even if they did not want it. The younger sister of W8 was an attorney working in a mostly male attorney office. She developed diabetes about 5 years previously and often looked to her older sister for guidance on handling diabetes issues.

W8: "And she ask me, "X - you do this?" [demonstrated taking a straight shot of alcohol] [W8 thinking] 'Oh, no, don't do this' because.... because she likes to drink straight cognac.

RA2: Ohh

W8: And I tell [her], 'No more cognac.' She is lawyer okay, and they are going for all guys. Some many there is more guys!

RA2: Oh yeah?

PI: So she feels some pressure?

W8: Yes, uh-uh, and everybody drinks this, this [demonstrates taking a straight shot]. I say, I tell 'Not even like this' [gesturing sipping]."

Although she tried to discourage her sister from drinking cognac, there were times in social settings when she too felt the pressure to accept alcohol when she

was not interested in drinking. W8 “But ... I don't drink beer because I don't like beer. Does everybody drink beer, and is 'oh yes ... more, I want to' [making gestures, about people offering her beer; wanting her to take beer, take beer]. RA2 interpreted what was said in partial Spanish: “She is not a drinker. She's not a drinker but the fact that people offer her, she's not going to say 'no'” so she takes the beer reluctantly.”

Living in a rule-based society: Respecting authority and Being proper. In this community-based society in which each member was a functional component of all other members, it was important that there were social guidelines for each person to follow in his or her individual life. That way, each one could behave within the expected social boundaries of the culture. It assured some social conformity so that people knew how to behave in expected ways and not outside of what was 'normal.' Beginning with the second interview (W2), some of these expectancies were noticed; however, W6 clarified that the concept that was developing was the social importance of “being proper”, a type of respectful response toward other persons whether or not they were in a position or role that would normally require respect, such as leadership or legal. The concept was explored with subsequent interviewees.

Respecting authority. During the interviews, a distinction between the general respect shown by being proper and a more specific respect reserved for those who were in authority was noted. Women often deferred to men and both genders deferred to HCPs, particularly males. Showing respect to elders was also expected, whether or not their advice was correct or welcomed. There was a

cultural social standard not to defy elders. Thus, if an opinion or expectation was expressed or required by an elder, the social practice was to not present another option for the sake of being honest, or stating the truth, or to decline cooperating. Essentially, if someone in authority told the person what to do or not do, the social requisite to demonstrate respect superseded the ethics of honesty; even if Grandma was known to be wrong, (s)he had to heed the advice rather than challenge it. The PI was told by a number of participants that it was more important to demonstrate respect than to say what one honestly believed or knew to be fact (W3, W6, W7, W8, W10, M2). This was strongly confirmed by three Latina RAs. With hierarchy came rules and expectations of how to cooperate in the culture (W6).

The importance of Being proper. One lesson was that the role of *Being proper* in this cultural group was extremely important; in fact, it was a very high priority. Being respectful and polite was part of *Being proper*; it was a cultural expectation (W2). When one showed respect, one was being socially proper (W6, W8). PI: "So, there really is a 'proper' piece to this and politeness is part of the properness?" RA2: "Right." ... W8: "Yes." Latina RA1 clarified in the interview with W6, "*being proper*... is to have 'good manners;' one is expected to *be proper* 'so as not to offend.'" In a complementary fashion, W10 affirmed the import of proper social behavior.

PI: "... And is that because someone is trying to be proper? Trying to do the right thing socially?"

W10: Yes, definitely.

PI: And it is a social expectation, right?

W10: Um hmm ...

PI: Okay. Expectation ... How important is properness, doing the proper thing socially? How important is that as a diabetic, when you go someplace with other people, or to someone's home?

W10: I would say it's very important. Um hmm. Yeah...."

W8 added that the less well one knew another, the more one felt pressure to behave more properly. The PI, in clarifying this point asked, "But the 'proper' has to do with someone being less familiar?" RA2 "Yes, what she is saying is [it's] less worrisome if you know the person well." PI: "...So, that, when you don't know the person really well, that's when this proper piece comes in more?" W8 & RA: "Yes."

A recurring theme that had significance for the person with diabetes was the need to show respect to a hostess in order to satisfy the hostess' need for approval of her preparation of the meal; fulfilling an important part of her cultural role. In the discussion with W6 about what was the expected social etiquette when offered food that was not healthy for the person with diabetes to eat, it was gradually learned that the underlying rationale for her response, and that of the following participants', was an essential social rule that it is *inappropriate* for one to make others socially uncomfortable, particularly in group settings. Earlier, W4 had mentioned she was uncomfortable for the same reason. The PI sought to clarify with RA1 about W6's perspective on how W6 handled some challenges and her reasoning. Understanding her motivation assisted the researcher to better grasp features in the culture that had an important impact on decision-making. The RA assisted with some Spanish in order to capture the concept accurately.

PI: "... She doesn't want to make someone socially uncomfortable? Is that right?

RA1: Um hmm.

W6: Yes. It feels, one thinks that the person is doing it as a rejection [of the food she made].

PI: Are there times when it's 'mas facil' (Spanish for 'easier') for you to say, "Oh, no thank you"? Or is it always difficult for you, Señora?

W6: So, I eat something, or 'a little.'

PI: So that's how you do it? ... You just say 'thank you' and take a little bit? ... What is the word [in Spanish] for 'gracioso'? Because in English we would say that someone is *being gracious* when they don't want to offend and they ...

RA1: It's more like 'proper' ... you try to be *proper*. *Spanish to W6* ...so as not to offend.

W6: [Spanish] Because you don't want to offend the person, or for them to feel like, after having prepared the food with so much gladness, you are like... 'NO!'

PI: So it's to *be proper*, and not *gracioso*... So it's very important in your culture to be *proper*, so [to make] no offense, so not to offend another person?

W6: Si. No, *no* offend.

RA1: It's *very important*" [stressed by the RA].

It became clear that there was more social pressure to *Be proper* when one was trying to impress someone, especially from a societal class above oneself, although someone in the upper class did not need to impress anyone lower. This clarity came through W10 in response to questions about life in Mexico and visiting.

PI: "... so someone is higher in the strata, and you are with them [in whatever setting]- you want to impress or look proper, or get their approval. The higher up they are, the more you want to impress them?"

W10: There you go. It totally depends on the strata. ...Uh huh ... They have more pressure on the higher level, less pressure on the middle level, and hardly any pressure at the low level ...

W10: ... and they feel more comfortable, I would say, to be on the same; if they are on the same level then less pressure."

At times, there was pressure to get approval from the hostess of the social event. Therefore, despite the status equality, pressure to impress might remain high.

W10: "Well, if, I guess somebody that also wants to get approval.

PI: Ohhhhhh. So maybe they want to get approval from the hostess?

W10: From the hostess" [Nodding].

Similarly, as reported above, since there was reportedly less gossip in the United States, there was also less pressure to impress. Discussing differences between America and Mexico, W10 commented:

W10: "And at least myself I like that people are less pretentious.

PI: I wondered that... because of this 'proper' thing? Is it because of that?

W10: Yes. It's more relaxed [in United States]. At home when we were young we could never wear tennis shoes. [implying the social norm in the United States was less formal]

PI: Less proper, more relaxed [taking a note]. Less pretentious.

W10: More relaxed. People dress more sport ...”

Summary of Contextual Category: Community-Oriented Culture. In summarizing the contextual category of Community-Oriented Culture, four primary subcategories, each with sub-subcategories, were reported. Living the community-orientation meant the community came before the individual; there were deep, meaningful connections to Mexico and the Mexican culture and participants reported that it was important to “be the same” as others, not to stand out as unique. The primary subcategory of Not being different; social pressures to conform, the data revealed they experienced both subtle and less-subtle social pressure to conform to culturally-prescribed ways of behaving. They also found that it was easier in the community or group setting to not have to take responsibility for one's decisions. One could depend upon the group to take the blame for influencing decisions that were not good ones. An important aspect of their society was the importance of how one was perceived by others and by those outside of the culture. Each Mexican represented their family, self, and all Mexican or Hispanic persons. Finally, having the community mindset meant that they had less distinction in their personal boundaries because they saw themselves as part of the greater whole that was further based on their willing, generous spirits.

The second major contextual category was Cultural Characteristics. There were four primary subcategories that described and supported this major category. They were, “We are a party person! The importance of socializing together; Personal Enjoyment: The culturally-essential meaning of food and taste; Seeing generational differences. A different kind of fatalism; and Influencing cultural health beliefs. As noted in the prior major contextual category, subcategories to the primary subcategories support the primary and major categories. These will be introduced before each primary subcategory.

Contextual Category - Cultural Characteristics: Importance of socializing; Personal enjoyment, the Meaning of food; and Generational differences

Four distinct characteristics of the culture distinguished themselves from Community-orientation, cultural values, and perspective on diabetes. First, the importance of socializing together for Mexican people, enjoying festivities, and being with one another was a fundamental dimension of their lives together. The second primary subcategory was critical to socializing in the culture. Due to the centrality of food in social activities and home life, the essential meaning and taste of food developed into a key study construct. Much of their cultural expression and enjoyment was through the preparation and partaking of a wide variety of delicious and often irresistible food and drink. They talked at length about how meaningful and emotionally-linked food was to their lives and those whom they loved; food was far more than sustenance or pleasure alone. The depth of the salience of food in the culture could not be overstated. Thirdly, they described age group differences, particularly as they saw those differences related to the unique approaches to

diabetes and self-care. They described distinctive generational differences. Finally, but of no less import, there were strong influencing cultural health beliefs.

“We are a party person!” The importance of socializing together. “We are a party person!!” This was the proclamation W3b made when she emphasized the significance of gathering together frequently to illustrate features of this energetic Latin people [implying ‘party people’ in a party/social society]. She clarified about the gregarious nature of the Mexican people, that they were “raised to be enthusiastic, hard-working, sociable”, and were generally “happy and have a positive” outlook. These social dimensions commented on by several participants meant the gathering for festivities, parties, and socializing together were of great importance to the function of the culture. Talking about her family growing up and all of the social activities, W7 said in a wistful tone:

“...And I have a lot of cousins and everybody go to the ranch and go swimming and a lot of trees, mangos, every kind of fruits. My grandma would like have... at that time I’m very lucky my family have very good life. A lot of parties and very fun...

W10 also described the importance of social gatherings in Mexico.

W10: That we party a lot. I don’t know how we do it, but we used to work and...

PI: In the past you partied a lot?

W10: Yes! Very nicely, when my students, you know, I had always invitations for all kinds of things.

PI: Oh, you were invited to the different fiestas and celebrations?

W10: Yeah, we partied a lot, we 'convevir' with a lot of people.

PI: It was camaraderie.

W10: Uh huh, camaraderie. Yeah and my students, I still have students that call me and they come and visit me.

RA4: Awesome, huh?! [RA4 identified with socializing]

W10: The interaction was so much nicer, well ... it's warmer.

RA4: It's more joy.

W10: ...more personal... You live with your students more, you share with your students more, you are more involved with them in their lives, and everything. So, I would say I miss... not now because I get tired - but partying and comradery and that's what I miss ..."

A curious factor discussed in detail by W3b was that one of the reasons social activity was so important was because there was an "anxious" quality to people in the culture, "... and our culture, the problem that prevails the most is about we are so anxious." PI: "Anxious?" W3b: "Anxious... Really anxious." Later she added, "Because we are an anxious culture, we have to have something going on [socially] ... need to be active with others." This made for an interesting study question that may shed light on more of the social dynamics. Remembering that social gatherings and conformity were expected, this placed the Mexican person with diabetes in a quandary at times with having to choose wisely for DSM, which could run the risk of one being or appearing less than social. W3b gave the example of others expecting everyone in the extended family to participate in social gatherings each time they occurred. She shared that, to avoid temptation, she and her family had been limiting

the frequency of family parties that happened very often. Giving an example, she exclaimed, "Let me tell you. In your [our] family you have a lot of invitations for celebration. So lately one of my aunts told my mom 'she [W3b and family] never wants to come to our celebrations,' and I said, 'Mom, I cannot go to all the celebrations that we have'" Contrasting with conviviality was a pattern of 'inactivity.' "Part of the culture is to be 'inactive', being comfortable just laying back, just 'hanging out.'" This aspect was not about being active together but quietly being with one another (W3b). Also, when getting caught up in socializing, the person with T2D could easily forget self-control limits (M2, W3, W7, W8, W9).

W3b: "... but you can ... *you forget about the diet*, because you [think] 'oh, on Sunday will be somebody's birthday.' So, you cook and you have everything, cake and jelly and...

PI: Bread! [laughs]

W3b: And conchitas. And for example, the festivities has having end yet. Still we have our celebration on February 2nd, and we will have tomas, chandurado ..."

The next primary subcategory became an essential aspect of the theory construct, *Personal enjoyment*. Within Personal enjoyment were two central findings: Food is core to the Mexican culture; exemplars demonstrating how are presented. Nonetheless, food was much more than a necessity; taste, sight, and smell played an interactive role for each Mexican participant.

Personal enjoyment: The culturally-essential meaning of food and taste.

Being that the culture was a highly social one, it stands to reason that food and

activities around food were a key aspect of socializing. Several participants talked about how significant, meaningful, symbolic, historical, and satisfying Mexican food was to them and their families. Some of what they shared brought considerable light to why they had such a struggle with setting boundaries for themselves when it came to their food. There was much more conflict from a cultural standpoint than had been previously appreciated. The following will describe the reasons.

Food is core to Mexican culture: Importance and pleasure. When exploring the function of food for the Mexican with diabetes, W2 made a sweeping comment that opened the concept of why resisting food was sometimes so difficult, “Sometimes, we are Mexican...” and went on to explain that, “we like our food more than our health.” The PI, in wanting to explore this with M2 reflected, “In some cultures food or eating together is very important, but in the Mexican culture it’s extremely important. It’s a key thing, right?” He replied, “It’s very important.” Further, W10 explained that food, “it isn’t just about the taste and the smell. It’s meaningful.” A lengthy final discussion with W3b, who had served as an RA, gave a broader more historical Mexican perspective.

PI: “Why is the taste of food so important and what does it represent in your culture?”

W3b: In our culture, I think it represents a lot. It combines feeling good feelings, pleasure... Being social ... I think in our culture food is part of the tradition. The history of every town, every state that visit they have different culinary special dishes. That’s why we have a rich, rich variety of special plates. ... So everywhere you go they have specialty food...”

Food also combined good feelings with pleasure, being together and social. Several described that, for the Mexican culture and the persons who comprise it, food was nurturing and comforting. W10 wrapped her arms around herself and rocked gently, caressing her arms when she said, "It's like if your mother caresses you with that food." It was emotional and familiar "I *grew* up with it" claimed M2. As seen, food was tied to pleasant meaningful memories. Discussing the importance of food with M2, the discussion revealed to the symbolism and meaningfulness of special foods for family and cultural memories.

Wife: "... Like the bread.

M2: Bread!

PI: They [Mexican persons] do like bread.

M2: Yeah. I mean Spanish people, we love bread ... Yes, we grew up with it.

Wife: Like the cocoa.

RA4: Hot chocolate!

M2: You know. Every breakfast you have in Mexico you have a piece of bread with milk, or you name it. But you have to have the bread in the morning.

RA4: And the hot chocolate - like she said [nodding toward his wife].

M2: Exactly. Then after that you're going to have a big dish of chile with beans, all of this stuff."

Later he recalled a discussion he had with his aunt about the traditional cultural importance of bread and milk. This expressed the cultural relevance tying individuals and families into the long-term community-oriented culture. M2 said, "I

discussed this with one of my aunts; she lives here up north, and she says ‘you know we grew up eating bread and you know, and the milk we used to drink was straight from the cow.’”

Finding importance and pleasure in taste, sight, and smell. Not only was food meaningful and provoked emotion, but it was specifically pleasurable. For the Mexican person, the pleasure of taste was a cultural experience. “Fresh milk has a special taste ... Bread dipped in warm milk with a little coffee (in it) ... Reminds me of my family, of home; it’s comforting” (M2).

W7, in describing what it was to eat Mexican food, made one of the most salient comments of the study. She said, “That’s why you know like you eat a lot of stuff, it’s good because the taste is good. But it’s *no good* for you,” she said shaking her head slowly. Several participants commented on how central the pleasure of eating sweets was to the culture, “You know unfortunately we have those habits that ... we eat some sweets” (M2). W1 actually included sweets in her daily habits most days, “Yeah, I have to have sweet after my lunch, on my breakfast, my dinner. I’m a sweet person.” W5 blamed excessive intake of sweets as the cause of her diabetes. PI: “How do you think you got diabetes?” W5: “A lot. I eat bread and candies.... A lot.” PI: “Oh, a lot?” ... W5: “I like candies and bread.”

Wondering about any unique cultural differences between genders, the importance of taste for a man was explored. PI: “What does it mean when a man gets to eat what he wants to eat?” M2: “The flavor of the food ... When a Mexican man eats what he enjoys eating, it is very satisfying” as illustrated above. It should be noted that M1 had an uncommon relationship to food because, earlier in his

diabetes, he had a very hard time resisting eating; finally, he had gastric bypass surgery over 10 years ago (although at one time he said 20 years, but with several attempts to understand his time sequencing, it was never clear if it was 10 or 20 years). He had to modify his eating habits considerably, intentionally avoiding tempting foods, and had an ongoing concern about his weight because he knew that his diabetes could once again get out of control; at the time of the interview, it had been diet- and exercise-controlled. Additionally, due to his chronic pain medications, it was not easy to keep him on task to answer questions; it was not possible to explore all the facets of the study in detail. Thus, some of the meaning of food to that man was not identified.

To W3b, however, food had a sensation and it was more than taste or meaning. In clarifying about the relationship of food and memory, she persuasively claimed that food colors and smells trigger the memory of what it tasted like and stimulated the desire to eat, similar to what had been said above:

For example, the green... we are rich in having all the kinds of fruits, and the mango attracts me with the color, the taste. ... And the strawberries.

Everything [about food] is important in our culture... the color, the smell ... I think food mixes together like a rainbow but in a natural way.

She encapsulated her thoughts about food, "It isn't just about the taste, smell and the color. It's meaningful..." W3b brought the conversation back to the importance of the meaning that food had for this culture. A final interesting insight by W3b about food was her observation and conviction that genetically, Mexican persons had more sensitivity to taste and smell. She shared, "I think our genes are

more sensible to [taste]." PI: "Sensitive?" W3b: "Sensitive to the taste, to smell, all our senses are more sensitive to taste." She gave this illustration "And I see my son [11], he has the same senses as me. He says 'Oh Mom, this is sooo good!' He enjoys everything that I do [cook], he says 'Oh Mom, this is *really* good!' Even if I do lentil soup, 'oh this is so delicious mom!' I think it's because he has really developed his sensory" [referring to and pointing to his palate].

While there was not an opportunity to inquire of the earlier participants about this idea, it lent an interesting perspective that deserves a study of its own for another day. It may have some bearing on the importance of food in the Mexican or Latin culture and affect DSM.

The third primary subcategory within the major contextual Cultural Characteristics category was generational differences, particularly as pertained to the outlook on and self-management of diabetes. A unique feature of many elder Mexican persons with diabetes was reportedly their enjoyment of food and life even though they were aware that their diabetes would one day be their demise. Rather than a negative fatalism, they had a positive outlook on the pleasure of eating until they would no longer be living.

Seeing generational differences. A different kind of fatalism. Participants reported they thought there were generational differences in how people addressed their diabetes; some of these unique features were observed through the interviews as well. The most notable uniqueness was in the attitude about diabetes and how they thought people from different generations responded to it. M2 quickly added his perspective. Through his observation of elders with diabetes in Mexico, he said

“Well, they don’t put attention to it [referring to DM].” Reflecting on her grandmother from Mexico, W9 commented, “Back then, I don’t think they had anybody telling her, “This is the way you should eat.” PI: “So the education was missing about good diabetes management?” W9: “Yeah. I mean there was no one to tell you what to eat, what not to eat, the amounts ... No diabetes classes to tell you; like I did. ... they just had to live with it.” She expressed that essentially these elders knew that they would die from the disease. W9 made a comparison between the very old generation in Mexico and the younger one in the United States, how each generation approached eating.

PI: “How do you see that different than the younger generation?”

W9: Like my generation? Even though I know I can eat everything, but smaller portions, but yet I’m afraid of overdoing it.

PI: Okay, and you don’t see that in the older generation?

W9: No, they don’t care. [similar to the comment by M2] Especially like my mom... her mom, probably, I don’t know ... Maybe it was the same thing. They knew they were going to die so, ‘So what?’

PI: And do you think that some of that has to do with the fact that they were born and raised in Mexico and the kind of health care system?

W9: Right, because – yes.”

Conceptually the discussions about the different generations led to an interesting discovery. What was reported about the attitude of the very elderly was that, although they understood it was their destiny with diabetes, they did not have a type of resolute fatalism in which one felt (s)he has no control over one’s fate in

which the outcome, despite personal effort, was determined by God. Thus, there would be no need to make any effort towards DSM as the thinking would be that “it wouldn’t matter anyway.” To illustrate this point, W1 had this exchange with her younger sister with serious diabetes, W1 reported, “... because she had sugar 1,000... and I go ‘What!! Oh X you could be in a coma!’ She goes, ‘Don't scare me.’ [W1] No, I'm not scaring you, I'm telling the truth. You got to have your sugar lower than 200. [Sister] ‘Oh, I'm used to it. I feel ok ... I'll leave it to God.’”

What began to surface was that, while elders seemed to accept their eventual death they chose enjoyment of life, *being happy in the moment*, preferring to enjoy the short-term pleasure and taste of good Mexican food over the long-term concern for risk of and battle against complications. W6, age 70, felt they did not want to struggle every day to take care of themselves when they would die anyway.

PI: “Did your father take care of his diabetes?”

W6: No, not too much... He liked to eat a lot.

PI: He ate a lot?

W6: Yes. [Spanish] He said, ‘I am going to die anyway’ [laughs]... He said, ‘meh ...’ [gesturing that her father did not care]

PI: Oh, I want to enjoy it [*commenting on how people chose to enjoy eating over taking care of themselves*]. Tell me about that Senora. Why do people do that? Why do people say ‘oh I don’t care about my sugar, I just want to eat?’ Why? They like the food or...?

W6: They like the food, I think so. Laughs. *Spanish*.

RA1: But, what are other reasons you think people say, nah...?

W6: Nah, 'I am going to die anyway.'

PI: Okay, in English, la palabra, the word for 'I'm going to die anyway' is fatal, fatalistic. Do you understand what I'm saying? [W6: Um hmm.]

RA1: [Spanish] There are people, who are very fatalistic because they think, 'well, I am going to die anyway.'

W6: [Spanish] Yes, we are going to die anyway. They don't want to take care of themselves; it's all the same to them. They don't want to battle; I don't know ..." [shaking her head in disgust].

W9, age 53, summarized what she believed the thinking of elders to be based on her mother's comments, "I want to enjoy myself because I'm going to die anyway ... We will die anyway so let's enjoy ourselves until then."

PI: "Do you think that's a fatalistic view when people say 'well I'm gonna die anyway?'"

W9: Well, we know that we're all dying, but ... I still want to be healthy. [indicating a different generational mindset]

PI: But I'm asking when people make comments like your mom did, was she saying 'oh, well, it doesn't make any difference what I do, I'm going to die anyway' ... sort of 'its fate?' Or was she more saying 'I really want to just enjoy myself because I'm going to die anyway?'"

W9: I think that's the reason why. She just wanted to enjoy what she liked no matter the consequences.

PI: Interesting ... Cause I'm seeing that in several people's interviews ...

W9: Yeah, especially the old generations, Mexicans."

While this may be observed in persons younger than the very old, it was thought to be more common in the older generation of Mexicans raised in Mexico who chose to be *happy* in lieu of worry about what they did not believe they could affect anyway. PI: “So it had to do with wanting to enjoy, and you think that attitude actually goes a little bit more with the older generation?” W9: “Um hmm.” On the other hand, some younger persons did not have a fatalistic view at all. W2 [age 42] mused, “... some people refer to it and they’re scared and they say ‘I’m going to die.’ I don’t think that. I only think that I’m sick.” W9 [age 53] said, even though she knew she could eat “a little bit,” she knew the possible risks of higher blood sugar so she was afraid to “overdo it.”

The final primary subcategory of the major contextual category of Cultural Characteristics was health beliefs. The participants reported numerous health beliefs; however, two main sub-subcategories evolved. The first was very important as an underlying approach to illness, including diabetes. They indicated very clearly their preference – and the cultural preference – for herbal and *natural* remedies rather than medicines. Some also expressed the importance of the influence of faith in God. This latter subcategory had two further sub-subcategories - our bodies will heal themselves, and prayer is sometimes equivalent to *wishful thinking*.

Influencing cultural health beliefs: Preferring natural remedies and Having faith in God. Some participants brought a great deal of clarity to the issue of why Mexican persons with diabetes did not like to take medicine and often preferred herbal and natural products. They revealed cultural preference and lack of confidence in medicine/pills. They talked about the role that spiritual and religious

influences and faith in God had on their choices. At the first interview (Test) with W3a, she expressed fears that her mother, who had a long history of diabetes, took a lot of oral medications. W3a was afraid of all that she took and wanted to know why her mom needed a medicine for her cholesterol and for sleep and more. She was frightened by it. She added that she was afraid that if she ever had to take a lot of medicines, “I will forget them.”

Preferring natural and herbal remedies. “Our culture is about herbs” claimed W3b. She went on to explain that people in Mexico were (are) raised knowing that their health issues were commonly treated with herbs and other natural substances. Thus, they were culturally accustomed to home remedies and self-care of ailments themselves. Individuals and families preferred “natural and home remedies,” W9 described about her culture. Not only was this a long tradition, but resource availability had an impact as well for the common person living in Mexico. With health care resources reportedly truly lacking in Mexico and limited access to effective care for the average Mexican person/family, discussed in Access to Care below, it was of necessity for families and communities to be resourceful and to use resources available in the home and community. Talking about her aunt’s illness, W3b shared:

W3b: “... So I think in that case it was belief about illness will cure by itself and...

PI: But why? Why do they believe that?

W3b: Not having their really true access to the medical system

PI: I got it.

W3b: Also not having ... a lot of confidence in pills.

PI: Right, because the culture is more geared towards herbs.

W3b: Yes, more natural ...”

As has been discussed cultural practices were handed down from generation to generation from those in authority, meaning there might not appear to be a need to try new things but sometimes to do so would be to challenge one in authority and culturally that was not acceptable (W8). The solution then was “I’ll treat with medicine in a natural way,” W3b meant the use of herbs and other organic products. Thus, it was not uncommon to hear what W3b said clearly, “We get help only when we really need it.”

There was a respect for those in authority (HCPs); there was a general cultural reverence for those in medical authority (M1, W1). Each of these study participants relayed they had at least periodic health care visits and the use of medications for their diabetes. As will be demonstrated, however, some had waited longer to utilize Western medicine than had others (W2, W3, W5). W7 mused, “and Hispanic people they like take teas or things like that. My mom she take, you know, that cactus with the pineapple and she put a lot of stuff and she eat it for so many years, every single day, every morning. Sometimes I do, sometimes I feel tired, but you know I do things like that too.”

In describing their daily routine, W3b and M2 discussed the use of cinnamon as a more recently effective herbal product for BG. W3b commented, “And then I have my coffee, I put some coconut oil and cinnamon for controlling. ...”

M2: "I take coffee, but you know what I've been doing? And it's been helping me a lot - drink cinnamon.

PI: Okay, and you put the cinnamon in the coffee?

M2: Cinnamon ... no. I make cinnamon alone... I don't put no sugar in it at all."

In a more creative fashion, W10 used an actual concoction daily.

W10: "... I just really get up and we have a tablespoon of olive oil for our liver... And then chop half of garlic which we chop real well, but in order to get it through we put ½ cup of water with ½ cup of lemon and agave.

PI: That has some sugar in it.

W10: Uh huh. That's the only time I use the agave (a cactus-like sweetner).

PI: Okay. And you do this, every morning?

W10: Yes.

PI: Is this like a cleanser ...For your system or something?

W10: Yes. We always do it, every day. Take us time, but ...

W10: ... And I forgot to tell you I also have a raw egg.

PI: A raw egg?

W10: A raw egg in the morning. I squeeze a little lemon with it."

Having faith in God. Beyond herbal and natural substances, the sample also had beliefs about the capabilities of the body being able to overcome illness. "People are sort of in general positive and think 'oh my body will take care of it', and you're thinking 'if I keep doing the right thing, my body will take care of it'" (W10). This

coincided with faith in God, knowing God could heal if God so chose. There was trust that God was part of every day; therefore, part of the healing. W3b: "... that maybe God will cure me, or the faith, you know? Or I'm gonna do this and this that... They don't want to be attached to the pill [medicine], or to go to the hospital."

Our body will heal itself. Three participants, W3, M2, and W10, lent great clarity to the body's self-healing capacity, "Your body tells you if something's wrong" reported W10 and how it is rooted in the larger cultural belief that God was both involved in personal lives and that God was able to and sometimes chose to heal. Regarding lack of confidence in medicine but trust in God, W3 added:

W3b: "Right, and also in God, 'God please God help us.'

PI: ... Okay, so belief that illness... that it will pass, that the body heals itself.

W3b: Right...

PI: Thank you. [summarizing] And then there is a lack of confidence in medications and a preference for natural remedies... Belief that illness will pass, the body will help cure itself, there's a problem with not having adequate access to good care ... and then you all said trust in God."

M2 saw the cultural commonness of people believing the body was capable of self-healing, especially when one was younger.

PI: "I've been told that some Mexican people think that they can get better without medicine. And ... that sometimes they think that their own body is going to take care of it. Is that kind of common in the culture?"

M2: I believe so, I believe so. Some people don't really pay attention to it.

PI: But I mean do they ... think their bodies are going to fight it, or manage it...?

M2: Well when you're young I believe you can fight that. You know.

PI: So, it might have to do more with the young person?

M2: Exactly because that stuff is really 'win.' I mean when you are young you can fight it easier."

Further clarity to this issue came when exploring why in the culture was it hard for some people to accept having diabetes? W10 elaborated on the underlying confidence that one would regain health either through the body healing itself or through faith in God's intervention to heal.

W10: "Because they are expecting that their own body will take care of it. ...

PI: ...That's why they say that they're going to get better! [connecting ideas]

W10: ...Oh yes, 'I'll get better' and they truly believe it - that they will get better.

PI: That's what people tell me ... So, is that like an optimism in the culture?

W10: It has to do with our religious background. [interrupted by the phone]

PI: OK, so you were just saying that there was an optimism in the culture that people will get better and it's related to their religious belief. Talk to me about ...

W10: Well you know we believe within very deep inside of us, that the good Lord will heal you, and you pray for it.

PI: Yes, I'm hearing that from people ... And people pray specifically 'Lord, heal me. Make me better'?

W10: Oh yes, yes, definitely. We pray for health and though we know, or in spite of the fact that we know that we may or may not be healed ... we might not get better; it's the Lord's will. And then if you don't heal the way you were expected, you accept it.

PI: ... So, there's a process that the person goes through... where they're optimistic, ... hopeful, and because they're prayerful, and there's underlying trust, people know 'God can heal, He might heal me.' Sometimes He does that, so I'm going to keep asking and at some point, if I don't see that, then I begin to accept 'I guess God isn't going to heal me....'"

W10: Yes.

RA: And they say 'It's God's will?'

W10: Uh huh ... It's because the Good Lord's decision, but there is some reason behind that that we don't know."

M2 confirmed that it was common in the culture to involve God in getting well. The PI asked "So are you aware or do you think that some people ... in the culture are asking for God to heal them or help them not get worse, or...? M2: "To be healed." PI: "Okay, so that's pretty common?" M2: "Yeah, to be healed."

"Dreamers about the magic" or "Wishful thinking." A fascinating concept was brought up by W3b. She broached the idea that, just as faith could be a support and an encouragement, it has also been a distraction or excuse when some persons

needed to apply their personal responsibility to self-care but used God as a means of evading personal liability for their choices. She saw this as a culture-wide way of handling one's failed self-care obligations. Rather than take full responsibility for DSM, too often as a culture one had the attitude 'God is going to cure my ...'

PI: "...So that's how He [God] answers prayer. He uses doctors and nurses and clinics and stuff.

W3b: Exactly, it's not magic.

PI: That's a very good point. Not magic! But what you're sort of saying is that some people kind of treat it like it is? (magic)

W3b: Right. So, on one side you like a lot of being together and you are really emotive ... into enthusiastic ... to have reunions and to have good food. So, on one side you're asking God [to make you well], but on the other side you're [not doing your part] ... It's we don't take care the way that we supposed to take care of it. We leave everything to God sometimes ... so God is on one side but on the other side we are not being really cooperating."

By wishing for a desired healthy outcome without putting in any consistent DSM effort, she said in actuality that the person acted in opposing ways to God by not taking the steps needed for good DSM. This behavior or attitude placed their faith that God was certainly able to help or heal in opposition to their choices. Instead, someone behaved as though God, or faith in God, was or acted as a magic potion and somehow miraculously would do for the individual or family what they wanted or needed but simultaneously the person believed they did not have to

practice self-control – because they asked God to help with the health problem. She explained that they saw God was at the whim of the person to fix what was needed. The unique description she gave was that, as a people, they were *'dreamers about the magic.'* “So, we are dreamers about the magic, you know? They think that ‘God is going to cure my family’” ... After giving a description of the American concept of *wishful thinking* to W3b, the PI asked if that was what she referred to as *'dreamers about the magic.'* “So, it is a wishful thinking?” W3: “Right, wishful thinking – without being strict with ourselves about diet.” The PI in clarifying asked, “If I just think that ‘it’s going to be okay’ ... If I just think it? ‘It is going to be okay?’” W3 “Uh huh.” In essence, the individual many times over in the culture was, according to W3b, “not really cooperating” but rather “dreaming about magic” was being a wishful thinker.

Summary of Contextual Category: Cultural Characteristics. The major contextual category of Cultural Characteristics revealed the salience of socializing in the culture. The most significant aspect of this category was the quintessential nature of food interwoven into the culture. The sight, smell, and taste of delicious Mexican food provoked the desire to eat and stimulated meaningful memories and emotions about family. Food was shown to be far more important in the culture than nourishment or socializing. Generational differences between elder Mexicans in Mexico and some in the United States were shown to be unique from the viewpoint of the younger Mexican person with diabetes. The latter had access to current medical intervention and preferred small amounts over the attitude of “eat, drink, and be merry, for tomorrow we die,” as was attributed to the former. The primary cultural health beliefs reported by these participants were the preference

for natural and herbal remedies over Western medicines; this was said to be a culturally-held belief. Finally, there was evidence of faith in God and God's ability to intervene in one's life and health. They believed that one's body *is* able to heal itself and sometimes prayer to God about health was in a wishful manner and lacked cooperating with God by not being self-responsible.

The final major contextual category dealt with the participants' Cultural Perspective on Diabetes. Two primary subcategories delineated the participants' views on diabetes: Stigma of diabetes; and Social Knowledge. To begin, there was a strong and deeply fearful stigma to diabetes. A person with T2D was thought to be less strong than those persons who do not have the disease; this was based on chronicity. Because most of the information that they had on different aspects of diabetes was primarily gained through social sharing and life-long observation of others with diabetes, especially in their families, that was the standard way they gained knowledge; however, social information was not always accurate.

Contextual Category - Cultural Perspective on Diabetes: Stigma of diabetes and Social knowledge

All of the participants knew about the terrible outcomes that were possible if people did not take care of their diabetes. As the interviews proceeded, it gradually became clear that diabetes was/is a stigma in the culture. Four sub-subcategories support the concept of stigma: chronic illness as a root of the social issue, what diabetes means in the culture, needing to hide DM, and owning diabetes. They not only had a fear of poor outcomes, but a chronic disease, particularly diabetes, represented weakness in the person that compelled them to hide their diabetic

status. Once one embraced their diabetes status, they took ownership and indicated they made decisions based on the fact they were responsible for their diabetes. The first discussion will be about the stigma.

Stigma of diabetes: Root of the issue – chronic illness. Socio-culturally, it was very well communicated that diabetes was seen as a vulnerability. With diabetes, one appeared more susceptible, “Well you don’t want people to think less of you,” said M1. This could be an embarrassment to the affected person worsened by having to live with the very undesirable illness of diabetes. When asked about the culture’s viewpoint, “Is diabetes seen as a disability?” W3b replied, “Yeah, they just don’t want to let them [others] know, ‘Oh, I *can’t drink* alcohol, I *can’t eat* cake because of *that ...*,’ said with exaggeration ... “So, they don’t look vulnerable or weak.” Both men and women clarified that Mexican persons with diabetes tended to hide their diabetes so people would not see them as sick (M2, W8) or as persons who might die sooner, “In my case, I didn’t want to feel that I was sick. I didn’t want everybody and see me and say ‘oh she’s going to die sooner than the average.’” W3b defended when talking about hiding her diabetes at work. Simply put, she said it was “embarrassing to admit I have diabetes.”

The root of the social issue: Having a limiting chronic illness and What diabetes represents. The stigma of diabetes, however, was derived more from a deeper social perspective. When one had a chronic illness, (s)he was seen as having a personal vulnerability (W3b). Three main concepts evolved that best described how diabetes was seen as a vulnerability in this population. First, a person who had diabetes was weak. He or she was a person with physical liabilities, making the

person less strong and at risk for not being able to fulfill his or her personal, familial, and social responsibilities. For example, while working as a supervisor amongst other Hispanic people, mostly from Mexico, W3b explained, “Well I don’t want people to write me off, ‘Oh *she’s* done!’” (said in a somewhat sarcastic tone). “They look at you like ‘*she’s* weak’ or (have) weakness.” In a community-collectivist culture in which each person’s role was important to the whole, this could make a person appear to be unable or less able to meet his or her societal responsibilities. As determined above, appearances in this culture were very important.

Secondly, since “everyone is the same” or expected or thought to be (W7, W9), then having diabetes made one different from society’s norm, a variant from the group that had been established as the standard. Also, already recognized was the premise that it was socially unattractive and inappropriate to be distinctive, to be different. “Some people don’t want to show they have diabetes. They want to be ... and there is a lot of celebrations and they don’t want to show that they have some kind of disability. They want to be just the same as everybody else” W3b articulated. Thirdly, one had a reduced ability to participate in normal social activities, especially those involving food, which was core to the socio-cultural function of the society. RA2 translated for W8:

“And when they offer her at the parties and stuff, she will just go ahead and take it. She’ll ... just grab it because of, you know, they are handing it to her.

PI: Oh, I see. [Speaking to W8] You are being polite.

W8: Uh-uhm, many times you feel embarrassed”

In the culture, being strong, the same as others, and participating in food-related activities – essential to Mexican social gatherings – were highly valued. One's limitations made one different; an outlier, not just weaker.

Alternatively, the youngest participant at 40, W5 described how good she felt when people said they were not aware she had diabetes. The PI inquired, "What do the people in your family or your friends say about your diabetes?" W5 smile, saying, "Nothing. They say, 'you have diabetes?! You can't tell.'" PI: "Oh they don't even believe it?" W5 smiling, "Yeah." RA1: "She doesn't show it." Even though diabetes was seen as a handicap from the wellness perspective, she was seen as strong; she exercised vigorously at least 90 mins daily and was very active with her family. So people in her culture did not think she had the disease because she did not *appear* to be ill or weak, but was able to function with vitality with or beyond others her age. Thus, although there was a perceived vulnerability associated with diabetes, because W5's diabetes did not show, her vulnerability was hidden. She did not need to conceal it, not at that point in her life. In a similar way, W3b reported, "... some people don't know [that I have DM]. Some people just think that I'm good. I'm doing exercising, healthy food, and some people already know and they're just fine [they do not think less of her] because they see me well."

The meaning of diabetes; what diabetes represents. In developing the interview guide, it was clear that it would be important to learn from the interviewees their perspective on what diabetes was, how they got it, and what it meant to them as one's perspective has been known to affect how one might respond to having to be responsible for self-care; the primary management of

diabetes. As the IVs progressed, participants revealed more about their own and other people's opinions and attitudes about T2D. W2 said, nodding toward her husband, "Yeah, he lost his sights, so I know diabetes is bad to have it, because it can damage your organs inside and even outside too." Responding to the question "What does it mean to you to have diabetes?" M1, remembering when he had a severe foot infection while hospitalized years ago and that the surgeons seriously discussed amputating his lower leg, quickly said, "Cutting of the legs. It seems like when a person gets bad, the legs are first 'cause they have the least ..." [motioning with his hand in referring to circulation]. Three participants described it as having a malignant quality. "It's like cancer, I mean you can't do anything about it. It's progressing. Diabetes you can control it to a certain degree" (W9). Addressing the question, "Now tell me what you think diabetes is," W7 replied, "Yeah, for me it's very bad, it's like a cancer ... Like you can control, it depends what you eat. But, for me it's very bad." The two most common reported fears were amputation of a limb /limbs and/or loss of vision, "diabetes means amputation and the consequences of it getting out of control," asserted M1. The fear of T2D was accompanied by a fear of loss of independence as well. Several people (W1, W3, W5, W8, W9) reported they did not want their children to have to take care of them as they aged or had diabetic consequences that interfered with their daily activities. W8 said she was specifically afraid of being placed in a "home," a convalescent facility or with strangers.

On the other hand, W1, having very good blood sugar control, saw it as a non-threatening illness at times. When asked, "Please tell me what do you think diabetes is?" she replied, "To me it's another illness. It happens; you can control it; if you

want to - yes." PI: "But what is it?" W1: "To me, it feels like having a cold." Ironically, at another point in the interview when discussing the early findings of her diabetes, she exclaimed, "Diabetes, it eats you up!" More commonly, however, it was referred to as an illness or sickness by the participants. Replying to the prompt "Tell me what it means to you to have diabetes. When you think 'I have diabetes,' what does that mean to you?" M2 thoughtfully responded, "When I have diabetes, that is an illness that I have. That I've got to take care of, and I have to live with it, and not to be worried about it. Just take care of it and you'll be fine."

"Diabetes is my life...." Owning diabetes. In reacting to the question "What is diabetes?" W6 calmly replied, "Diabetes is my life." This was one of the most potent statements of the hundreds of pages of interview transcripts. In a similar fashion, M1 exclaimed, "Diabetes is about your whole life!" when asked, "Is there is anything else that you could tell me about yourself or your diabetes ...?" Finally, the elder who was still attending classes for self-development and personal interest at age 71, W10's response to the question "Tell me what it's like for you to have diabetes? What does it mean to you to have diabetes?"

W10: "Just part of my being.

PI: Part of my being... [thoughtfully taking a note]

W10: It's in my genes ... my DNA.

PI: Wow, okay. So, there's almost a destiny ...

W10: A destiny? Yes, yes.

PI: [Reflecting] Because it's in my genes, I was destined ... I've never even explored this concept. [clarifying concept construction further] But I'm sort of 'destined to have it so it is part of who I am ...'

W10: Yes, it is part of who I am."

Needing to hide one's diabetic status. While there might be acceptance of the disease for some for reasons demonstrated above, it was identified by the majority of participants that most people in the culture who had diabetes felt the need to hide their diabetic status. While exploring why people wanted to hide the fact that they had diabetes, M2 indicated that he did not hear a lot of talk about diabetes while growing up, surmising that maybe people did not discuss diabetes because it was a cultural taboo. He added, "you know, to say something about it, until people know that you have it ..." indicating reluctance in revealing this private health information unless he gained a personal sense of safety in relationship with another. He kept the revelation of the diabetes diagnosis to himself and thought possibly people around him did the same where he grew up in Mexico. W4 commented that when she was young, "no one talked about serious things around us kids."

One of the reasons identified for wanting to hide one's diabetic status was because of fear of gossip, of being exposed. When offered non-diabetic food at a social gathering, W3b mentioned with some frustration "there are people that [say] 'oh thank you' [taking the food] and they're diabetic but they don't want to show that they have that problem." This tendency was revealed by most participants. W8 said "oh I'm really selective about who I talk to because I don't know who to trust." This was related to the concern about gossip and what people would think and say

about the person with diabetes. For example, W8 had been playing a common card game on a monthly basis with several other women for about 20 years. She reported that most of those women did not know that she had diabetes and she had no intention of sharing that information with them.

W8: I don't have a lot of friends... I play Bunco and there is 24 people, all the time, okay ... They are not all my friends...Because, when I go to play Bunco, and I see [the same people] for 20 years, but ... I never really talk to them. ... I have two good friends and that's all.”

This illustrated how lack of trust in people, what they might say or repeat, could interfere with friendship development and was related to the need to hide one's health status when this serious chronic disease was the illness. Hiding was a means of dealing with one's vulnerability status (W8, M2, M1).

The second and last primary subcategory in the Contextual Category: Cultural Perspective on Diabetes was Social knowledge: The cultural standard of knowing. This primary subcategory has three sub-subcategories that supported and defined it. The first was the commonness of diabetes. Despite the stigma, diabetes is/was a common disorder in their culture, thus, it was sometimes treated as though it was a *normal* thing to witness. The social knowledge ideas of how one got or developed diabetes offered very interesting stories and insights into the cultural context of viewing diabetes. It was important in the culture to have only borderline diabetes and the fewer meds one took, the less serious (and weak) the person with diabetes *appeared* to self and others. There was a bias against insulin as it reportedly represented a terminal-like condition to many Mexican persons.

Social knowledge: The cultural standard of knowing, the Commonness of diabetes, How one gets diabetes, and the Importance of being “borderline” and taking “only one medicine.” Each one of the participants had some knowledge of what diabetes was and what it could do to a person; some knew quite a bit. This knowledge seemed to be gained unintentionally and passively, being informal. In other words, like a form of social knowledge. There was an ingrained fear of serious consequences from diabetes across the culture. Only two (M2, W8) did not have family members with diabetes before themselves, thus did not have close familial observation. The other 10 all had family members who had diabetes. Most of them observed family members and/or other relatives suffer the extremes of the disease. For instance, RA1 had to translate the more complex ideas that W4 was not confident she could share clearly in English. RA1 reported about W4’s leg pain when she was having high blood sugars, “and so she didn’t like her life style, she didn’t like being in pain, and she was afraid that she would get ulcers on her feet, and you know, how she was saying that she’s afraid of getting amputated?” Regarding the actual loss of extremities, W4 relayed her observation, “My aunt died from ... they cut both legs [using her hands to indicate amputation] ...And they cut both legs and then she was in a wheel chair and she died from that way.”

Both W9 and W7 were traumatized by observing their mothers suffer through dialysis treatments and wanted to do all each one could to avoid the same personal destruction. W9, in describing the consequences of high blood sugars in diabetes reflected:

W9 “The most important thing is that, like I told you, I don’t want to go through the side effects. So, I try to control it.

PI: Okay ... You’ve seen that enough. You really want to avoid it.

W9: Yes, my mom went through dialysis, and I used to take her. I don’t want to go through that. It’s devastating.”

Every participant was aware of vision loss in advancing diabetes. “I’ve seen people that are blind because of diabetes” said W5. W4 shared her fear, “Well, even [if others] don’t told me, I see people, they have diabetes, they lost feet, they lost vision, and a lot of struggles, and it made me scared.” All participants had known someone with diabetes prior to their own diagnosis; most had known several. “They see around them a lot of diabetic people from our culture” explained W3b. In a nervous voice W7 said, “Well, believe me right now, I’m more scared because I see my mom and my aunt - and she have dialysis and right now I’m very scared. The vision for her she can’t see. It’s almost gone.”

The commonness of diabetes. As interviews progressed the concept that diabetes was commonly found in the Mexican culture and there was a sense that, for some, it was rather normal. The commonness factor seemed to have affected the way some participants and those they knew made their decisions. The observation developed that if diabetes was viewed as a normal finding in the culture, it seemed like it blunted some of the seriousness of the disease, at least the approach to DSM. Thus, the concept was explored with later participants. When first explored, the concept was initially thought of as *normal*, meaning it was a normal thing to see in society. W6 indicated that diabetes was completely normal in Mexico when she

responded to the question, “What does it mean when you see that? ... diabetes just around, particularly in the Mexican culture? W9 added important insight when she casually replied, “It’s very common especially in Mexicans. I’m not sure if it’s the diet that we have when we are little, or ...?” With further investigation, she helped to establish that the term *common* is more fitting. She illustrated how living out diabetes was modeled to others, which made it seem common. Those who were interviewed after W9 confirmed her terminology.

PI: “I’ve gotten the impression from some of the other people ... They’re 70 and above, and even if they’ve been here a long time ... they talk ...about other people that they know with diabetes. They will talk about it as though it’s kind of a normal thing to have diabetes. And so, I’m wondering ... if you think that might be the case with the older generation?”

W9: Probably. They think that it runs in the family, it’s hereditary ...

PI: That’s what I mean. Yes.

W9: It’s modeled.

PI: ... okay, so possibly there is something kind of normal or at least common.

W9: Common, yeah. ... *Comun*...

PI: ‘Comun’ is a better term?

RA4 and W9: Yah. *Comun*.”

Rather than diabetes being normal, it was commonplace. Additionally, first generation immigrants came from a culture in which it was not unusual for people

to have advanced diabetes, not have good care, and to have diabetes complications. Per the above, previous generations handled diabetes differently than many Mexican people do presently; especially those currently living in the United States. Hence, between the everyday incidence of diabetes in the culture and health care deficiencies, it was understandable why diabetes was common. It was logical that they thought of diabetes as being normal to observe. W1 illustrated this normalness when asked, "What is it like to have diabetes?" She responded, "Well, to me is something normal. If you keep in control your sugar you won't have no problems. I see it like that, yeah, 'cause diabetes runs in my family by my dad. He says, 'if you don't have diabetes, you are not my child.'" She and others made the prevalence of it sound so normal that the high incidence of diabetes in the culture would normalize or 'common-ize' its presence in the minds of many Mexican persons.

For those who did not see recurring family cases of diabetes around them, when they became the first one of the family to have it, it was surprising and disturbing. W8 expressed, with large-eyed expression, "When the doctor told me, just I am scared too, because I only are my family diabetic, and after - I know that my brother ... Okay, but I am the first one in my family diabetic." Due to familiarity, culturally in the other participants and the frequency of witnessing the outcomes of poorly controlled diabetes, it was evident that these individuals had pre-conceived ideas about diabetes. Despite that diabetes was commonplace, it eventually became clear that there was a stigma associated with having T2D.

In exploring what the participants knew about diabetes, how one "got" diabetes, what caused diabetes, what caused *their* diabetes, it became clear that

there was a lot of knowledge about diabetes, but much of it was inaccurate. Some of the information the participants had was from observing family members and others; it was knowledge gained socially (i.e., social knowledge). Consistently, it was observed that there were large gaps in what they did not understand of the health-science aspects. To do their best possible DSM, they needed some degree of both kinds of knowledge: social and medical; the latter to be reported in Intervening Conditions.

Getting diabetes: How one gets diabetes. Why participants believed that they and/or others developed diabetes had an interest range of reasons.

Explanations based on accurate scientific data included heredity and being overweight. Plausible triggering factors involved extreme emotional duress. More culturally-embedded beliefs were explained as another family member had gotten angry about something (W7).

Heredity, overweight, uncertainty, inaccurate causes. Several of the interviewees reported the hereditary factor in diabetes; a close family member had it and maybe that was how she got it or it was known to run in the family. The PI asked W1 to clarify the family connection. “Now you said that your father has diabetes?” W1: “Had. ‘Cause he passed.” PI nodding, “Who else do you know who has diabetes?” W1: “Ok, I’m the eldest one, two, three, four, five of his children have diabetes, and my daughter.” She indicated above that diabetes ran on her father’s side of the family and he claimed that, “unless you have diabetes you are not his offspring.” To this comment, her brother rejected the idea and consequently the whole family. Similar to others, W4 knew there was some relationship through

heredity but had also heard of disease sequencing and once a person had one serious illness, it felt that (s)he will eventually have diabetes.

W4: "I don't know much because they say is ... how do you say, 'hereditario?'"

RA1: Hereditary.

W4: Or just got it from ... I don't know [chuckles]. I don't really know, but sometimes they say, um, when you have high-blood pressure, that's the next ... if you don't take care of yourself, [diabetes] is the next ... But I don't know what make it or ... what cause it, or I don't know much.

PI: Okay, but you know it has to do with heredity.

W4: Uh huh."

Some believed that the start of their diabetes was related to the kinds and amounts of foods they ate. "... so maybe I think because my overweight and I like sweets a lot, maybe that's why I got it," wondered W7. Five of the 10 female participants had gestational diabetes. The diabetes in W2, W3, and W9 continued after delivery; although it was not necessarily treated. W1 and W5 both had a recurrence of diabetes at a later point (Table 4) when neither was being careful to avoid it returning. An ongoing struggle for W9 had been her inability to understand why she developed diabetes since she was slender and always had been. When the PI explored if she knew how she got diabetes or what caused her symptoms she replied:

W5: I think it was during the pregnancy ... You know what I read a long time ago? A person is very easy to have diabetes if it runs in the family; if you

have a baby over 9 pounds, and actually I had all three [of her children weighed over 9#].

PI: Really!

RA: Yes, and also, I was ... my periods were not normal. I have all three.

PI: Yeah, I don't know that the periods have really been borne out ...

W5: Yes, and ...Well my mom ... [her mom had it for 50 years]

PI: Yes, the family ... So you have the heredity factor. You have large babies.

Okay... What have you been told about the cause of diabetes ...?

W5: ... Well, I thought being overweight was one of the causes. And the main one.

PI: It's the one that tips the scale.

W5: Yes. So, that's why ... *Why am I diabetic if I'm not overweight? I don't understand*" [said with near-exasperation]. At another point, she brought it up,

W9: "... I'm not saying that I'm thin, but I'm not overweight. [laughs]

PI: You're certainly not overweight, oh no.

W9: No, and it's usually for people who are overweight. I *never* thought I was going to be diabetic."

This focus on overweight and exclusion of two of the three other, more predictable causes or warnings signs about the potential for diabetes development rang of "wishful thinking" discussed above. By not paying attention to the things that were true for one's self but focusing on what one hopes or wishes would be the warning of impending diabetes (e.g., overweight). As she had always kept her

weight trim, through wishful thinking, W9 had hoped she would prevent the familial link and somehow thought she could ignore having had three oversized babies, even that her misconception of abnormal menses being related to diabetes would somehow stave off the disease. Her focus was on the one aspect that she could control and she had hoped these deep wishes would override more foreboding and uncontrollable, non-modifiable links to the development of diabetes.

For some it was believed to be a combination of factors such as the heartache of missing family and culture in Mexico; having sadness in the absence of key relationships, and/or in combination with the drastic change in nutrition from the fresh produce-based diet of Mexico to a much heavier, less healthy diet in the United States was a huge cause of onset of diabetes due to the predisposition to the illness in the ethnic group. “The fact that people is not having good food, supposedly in United States, missing their relatives in Mexico, their parties here, and having all that kind of bad stuff, bad food, I think that it’s a huge cause of having diabetes, because we have genetic ... [predisposition],” summarized W3b.

Most participants said they really did not know how their diabetes started. W2 “I don’t know ... I don’t see it like a disease, I just said that. I just have it for some reason, maybe I don’t taking care of myself when I was little, maybe when I was an adult I have to be working at night, or sometime when I was a teenager, I don’t know.”

The effect of stress, trauma, worry and “upset.” Several interviewees indicated that high levels of stress or worry, emotional trauma, and being very upset were direct links to the genesis of their T2D. As will be discussed in more detail in the

Intervening Conditions section, strong emotional triggers including depression, loss, anger, shock, and distress have all been attributed to the cause of individuals' T2D and how persons responded. Probably the most dramatic story of stress-induced diabetes was by W10. Articulately, she described a situation in which she felt forced to act in an illegal fashion because she was asked to do so by her eldest sister whom she could not refuse because of her role as the younger sister, due to the socio-cultural roles-based and rules-based society described above. W10 felt she was culturally required to "obey" her sister's request, even though it would jeopardize her own financial stability and risk serious legal outcomes. The older sister asked her to do something that involved another member of the elder's family. W10 had also shared earlier about a work-related emotional trauma that had deeply upset her. This following family - legal situation was the third major life-stressing circumstance.

PI: "But why do you think your diabetes happened at that time?"

W10: Well, first we had my marriage; was not very good, with my husband.
I'm sorry to say.

PI: But that was a long time ago...

W10: Yeah, I think it was a series of hard events on my life ... Difficulties in my life. And the last one was when I really felt was ... [describes the life-changing situation of feeling forced to act illegally by her eldest sister]

W10: Well My eldest sister asked me to do XYZ. I couldn't deny it because she was my eldest sister and she says, '... why don't you XYZ?' And I said 'well' ... I couldn't deny it. She was my sister you know. So, I did it.

PI: And that's ... forgive me. This is a very heart-breaking and important thing you're sharing, but I want to clarify: it was your *role* as the younger sister. Am I correct?

W10: Oh yes, yes, because she asked me. She was my eldest sister.

PI: So role as younger sister ... to basically obey her ... So, you couldn't refuse. So, you XYZ.

[Senora tells the story and goes on to say...]

W10: ... so it fired back.

PI: What? ... Back fired? ...It came back to you in almost an explosion?

W10: Back fired. Yes. And [the third person] was very aggressive when that subject came...She told me she was going to do this and that and that and ...

PI: She threatened you?

W10: She threatened me."

PI: Because she was being exposed ... and she was going [to have her own consequences]?

W10: Yes, and I never ... [Senora tells how she did not expose the relative, and did straighten out the legal aspects for herself]. And she threatened me [sadly telling more of the story]. ...Yeah, that she would expose me. It back fired, you said? [PI nodding]

W10: ... I felt bad. THAT WAS MY LAST ... And that's when I really felt coming down with the diabetes. It's like it was the *last drop*.

W10: [Hesitatingly:] I don't say it at all. [implying she rarely shares that story with others]

PI: [Shaking head, 'No', PI indicates she will guard Senora's privacy] ... So that you had severe stress ... emotional stress.

W10: Yes, very *very* severe, yes ... [then recounts] "a very stressful marriage. A very difficult time with my husband."

PI: I'm sorry. Truly sorry.

W10: And then that's when I felt I got the diabetes. It was like the last drop after so many stressful events. That was the last event, the last drop.

PI: ... I think you felt betrayed.

W10: Yes. It was a very bad experience, but I just ... it's confidential for you, as you say?

PI: Oh, completely. Yes... completely.

W10: Because you need it for your study.

PI: Yes, but ... even when I report this, I would simply say that there was a very serious emotional trauma in the family ... and your role as the younger sister being obligated.

W10: There you go! That's it ... Yeah, that was the word: *Emotional betrayal* ... It was a bad experience. ...

PI: It must have hurt your relationship with your older sister?

W10: Yes, it did.

PI: It was never really quite the same?

W10: Exactly, uh huh, yes.”

This painful recount of a culturally rules- and roles-based decision that could have ended in a much more devastating fashion served to illustrate the potency of an individual fulfilling her role based on the cultural rules of the society. Essentially, the social/cultural expectations overrode both the moral and the legal aspects of the situation; these were very potent obligations to oblige. The extent to which the excessive stress triggered her existing familial trait to have diabetes was unknown to this investigator. However, it was clear that she had multiple extended stresses in her life and the diabetes appeared near the end of this final blow, the “last drop.”

M2, in a far less dramatic fashion, also attributed stress as a cause of diabetes in addition to elevated blood sugar. Above he demonstrated lack of knowing about pancreatic function.

M2: “You know what I believe is that involves a lot to get diabetes is stress ...
Is one of the biggest problems I believe that people with diabetes you
know.

PI: Well, I was going to ask you ‘What do you know to be the causes of
diabetes?’ So, stress obviously tips the scale, stress definitely matters.
But what else do you know about the cause of diabetes? Do you know
what causes diabetes?

M2: You know this is so many things ... stress, getting upset. You know when
my son have big problems in Mexico with my sister and it’s kind of ... I
was already here [in California]. But it was kind of differences of the will

my mom left. And we just kind of fight with each other and I believe that was one of the problems that I started with it.

PI: That was my next question: What was happening in your life and why do you think you got diabetes when you got it? ... So, significant family stress?

M2: Yeah, stress and upsetness, and stress on the job ... so many things on the job that you gotta balance yourself and take care of yourself cause you never know.

PI: Okay. So, you think that is actually why the diabetes started for you when it did?

M2: You know, and besides that the sugar. The sugar was ... It was out of control you know? You eat so much sugar. I was eating sugar and we noticed that results that I was going to come up with and ...”

Much to the distress of her husband, W8 blamed the cause of her diabetes on an extremely upsetting situation that unintentionally involved him at a neighbor's party 20 years ago. Prior to that time, she did not have any signs of diabetes and there was no family history. Two months after this distressing event, she was shocked when she was told by her doctor that the results of a routine blood test indicated she had diabetes; however, it did come out that she had prediabetes prior to her diabetes onset. She told the story of how her husband was invited to a bachelor party given by their neighbor. Because the party was directly across the street from her home, she was able to view from her front window what was happening inside the front room of the neighbor's house. The host of the party hired

a female stripper as party entertainment for the men and was videotaped. W8 told how she helplessly observed the naked woman sit on her husband's lap as he sat in front of the window! W8 became "so angry" watching this ...

RA2: "Oh, so they were videotaping? ...

W8: To videotape! And we see everything!

PI: No!

W8: Oh, yeah! And I am mad ... And I am mad! Because the lady sit in my husband!

PI & RA2: Ahh!

W8: And I tell my husband, 'Oh maybe this is the [cause of] diabetes.' He says 'You are crazy. You are crazy.' Maybe that one [as the cause of her diabetes] ... Because my family and I ... I never had nothing!

PI: So, this is before you had the diabetes?

W8: Yes! And some couple of months, couple of months of this, this hum ...

PI: Right... is when you had the discovery?

W8: But this, uh-hum, this I feel, and I tell my husband ... 'Okay. No, no, no. I told him, it's the first time you sleep in the floor ...'

PI: [Inhaled surprised]

W8: He goes, 'you know what, I don't want to. I sleep in my bed ...' I said, 'You sleep in the floor' - just that day. And I think, all this time I tell my husband the same thing, he says, "Oh, no, no, you are crazy. Is not this."

W8: I don't know why [referring to why she has diabetes; turning her palms up in bewilderment with shoulders shrugged]

PI: So, you think maybe, because you were so angry ...?

W8: Maybe that's why!

PI: That the anger contributed to you getting the diabetes?

W8: The diabetes. Oh yes!

PI: Okay.

W8: And I tell my husband ... [He says] "Oh, no, no, you are crazy, I don't do nothing." [meaning he didn't touch the woman and didn't entice her to sit on his lap]. 'You don't do nothing but she seated in your lap!'

PI: Yeah, okay. Mmm ... So, you think that's when it's started then, at that time... 'Cause it was only 2 months later... [that she got the unexpected diagnosis].

W8: Yes. I think, I think this one is the cause why I am diabetic."

A final story about emotional trauma marking the start of diabetes treatment was told by W3 during the second interview [W3b]. She had been symptomatic for some time [chronology was never clear in either interview] *and* considered *borderline*. During the second interview over 4 years later, she discussed more openly three emotionally distressing circumstances that preceded her apparently abrupt transition from borderline to needing to be on medication.

W3b: "... I don't like to mention this but it was a really scary situation. My best friend from the university she got gunshot on her head, and I was with her.

PI: So, severe stress? Emotional.

W3b: Right ... But after that I started losing maybe 15 pounds so is when I was completely aware that I have that problem [diabetes]. I needed to take care of it, maybe with medicine or something else. That was the situation and also. . .another loss...

PI: So, you had this terrible emotional situation with the friend who was severely injured from the ... with true violence, and you were there?

W3b: Right. I think it was after the diagnosis, uh huh.

[Clarification about the timing of her diagnosis with her college professor.]

W3b: Oh, my aunt, she was 40 years old and she didn't go to doctor ... [she died]

PI: But she died, and she died very young.

W3b: Right. ... so, that's another thing that marked the family.

PI: Yes.

W3b: And that kind of situations ... My car got stolen.

PI: I remember you mentioned that. You said there was a lot of [vandalism in IV#1]

W3b: Series of it. I think was everything in the same year or between 2 years.

PI: Okay, so I want to make sure I understand this ... So, you had ... because what you're telling me here, if I'm hearing right, when you had these terrible emotional situations all very close together, at that point you had to go on to meds?

W3b: Right...

The importance of being “borderline” and taking “only one medicine.”

Numerous times during the interviews, participants indicated that their goal was to need the fewest number of medications possible and never to need insulin. It became clear it was important to have a borderline-diabetes status instead of the actual disease and to hold off the full diagnosis for as long as possible. W3 spent several years doing only diet and exercise because, even though she was symptomatic, she had been told early on that she was borderline and had diabetes. She clung to the borderline diagnosis for several years longer than she later realized she should. They preferred to manage diabetes on their own for as long as they could. W5 also tried for 6 months to avoid medications. She exercised aggressively and was meticulous about her diet; finally, she had to “give in” and take medication, but only after she had proved to herself that she had done all she could to avoid taking medicine.

It was important in the culture to avoid having the disease, if possible. W8 hoped to remain in the borderline status as that was preferred rather than to actually have the disease. She apparently had had a borderline test result sometime in the past. The day she found out she had diabetes, she told the doctor “I am borderline” but the doctor said, “No, there is not a borderline, when you have diabetes is the same thing as you pregnant or not pregnant ... You are diabetic.”

A defining feature of the severity of their disease was the number and frequency of medications one had to take. W7 was proud and motivated to take only one medication. She also demonstrated lack of understanding that the disease would not progress.

PI: “So part of what motivates you is being able to keep good [BG] numbers?”

W7: Yes! Exactly. When I see that I say ‘okay, I’m doing good and getting better and better and my goal is to take only one pill a day [holding up one finger]. I don’t want to take two, because I know it’s good to keep my sugar a good level, but I know it’s not good for my liver or kidneys.”
[referring to her concern about medication safety]

When M2’s physician reportedly told him several months before the interview, “I’ve got to put you on something else” [another medication, because his A_{1c} was climbing]. M2 said “Oh no. I’m going to take care of this myself!” Since that discussion, he was so troubled that he might have to take a second type of medication, he consistently maintained a lower BG and reported at the IV that he had maintained a lower A_{1c}. W8 made it clear that she understood the importance of medications, but she did not like the idea of them, commenting about medications, “I only take one.” Ironically, she also indicated that her A_{1c} had been creeping up.

Errant believing about how medications function. An interesting finding was a lack of understanding and not infrequent misunderstanding about how medications work; their individual function. For several years W3, while living in Mexico, was considered to have borderline diabetes. Utilizing older testing methods and now outdated diagnostic criteria. She was maintained on diet and exercise. There was also serious access to health care issues (see below). When it came time for her to take medicine for her diabetes, which was actually past the time, she did not want to take the recommended metformin because she was concerned she would be

communicating inaccurately to her body and adversely effecting her pancreas.

Clearly, this was another example of a participant, very well educated, who did not understand the declining insulin levels and eventual loss of pancreatic function. W3 reasoned:

If you give yourself the medication that you're actually telling your body "you don't have to work so hard because the medication is going to take care of it" and so then the body stops taking care of itself. So, it just [says] "okay, then I just won't do it anymore."

When asked by the PI if that was a common belief in the culture she responded "No, just me;" however, similar comments were made by other participants. This was a supporting example of the underlying cultural belief that the body will take care of itself and that, whenever possible, people in the culture prefer not to use medications; they sometimes did not know very much about the utility of the medications; particularly when exogenous insulin was discussed.

Bias against use of insulin/insulina. Several of the study participants expressed knowing someone close to them who had to use insulin and it was often initiated late in the disease process, when it was essentially too late for insulin to be of significant benefit. That was particularly true for those in Mexico. Most of the participants had seen someone die relatively soon after the initiation of insulin. "... Once you use the insulin, you will die sooner," said W3b. When the participants were asked. "Did anybody ever tell you anything about the pancreas, insulin? Anyone ever tell you about the changes in your body?" W6 replied, "Oh yes, they told me about insulin; that it was dangerous, and that I shouldn't take it." But she did use

insulin. Talking about a friend who used insulin, W10 was adamant that she would not be one of those persons, “One of them she says ‘she’s very tired of getting a lot of insulin’, and that’s what I don’t want to get: insulin shots. I refuse to give in. That’s why I like to make my exercise and that’s why I don’t feel well now that I have this doggone thing, you know ... This virus [she had been ill with a serious virus for several weeks] ... that I don’t make exercise.”

Others knew people who had to take insulin several times a day (three to five times); fewer seemed to know someone on basal insulin. In a rather typical authoritarian-like voice, W1 shared her experience with a friend on insulin. At this point, W1 was not open to further discussion or to clarification about the use of insulin being different than her pre-conceived idea or narrow exposure.

W1: What they do now, is they give you high doses on your insulin, and I think that's a prison, because you have to do in the morning, in the afternoon, and dinnertime, 3 times a day,

PI: Sometimes, people need to use less ... many people use it only once a day.

W1: No. She does it 3 times a day.”

During discussion about the findings with one of the committee members, the possibility was raised that the use of insulin was seen as a failure of self-control by the participants. If this was the case, it might suggest that participants would want to control their own health. Talking about other problems attributed to insulin, W7 reported that her sister had DM and used insulin “... yeah so you know she stopped taking insulin because she got a lot of weight; because of insulin. She’s

getting better.” Either way, insulin was misunderstood by several of the participants. Some believed that once started, one must stay on it, even if one’s other criteria improved such as significant weight loss or if insulin was not taken alongside oral meds. W1 provided a good example of this misunderstanding.

W1: “Well yeah, once you use insulin, you can’t stop.

PI: Tell me about that. You said once you start...

W1: It’s because you cannot stop using it. Because that means they give insulin, because you can’t control your sugar ... your sugar levels are always high ... and that's why they give you insulin.

PI: But what if somebody was heavy, like your friend, and let’s say she did like you did, she got serious about it, got her weight down, she might not need any insulin anymore?

W1: No, and if she ... Yes, she will now use the insulin.

PI: Ok, so just because you start it, doesn't mean you have to keep taking it, but you have to keep taking it if you don't change?

W1: No Miss. If you are taking tablets, and you control your sugar, you are not going to use insulin, at all. But in between, if you can’t control it, your doctor is gonna give you, 'you know you can’t control your sugar no more. You need your insulin; that's going to help you a lot.”

Some interviewees knew someone who had been maintained, essentially kept alive, for many years on insulin. Referring to her mother who was on insulin for many years, W9 shared, “She passed away 2 years ago, in December - because of diabetes, all the consequences. She was 86.” RA4 “Oh my goodness!” W9 “Even

though she didn't take care of herself. She was on ... insulin, different medications of course for all those years ...”

In the following case, the PI was doing some side bar teaching about the ‘normalness’ of insulin following IV questions.

PI: “... So nobody wants to take the insulin from outside; you know if you don't have enough on your own. But if people live long enough with this disease...

W7: You have to ...

PI: Yes.

W7: Well my mom she use it for over 30 years.

PI: That's wonderful ... She couldn't have lived without it for 30 years ...

W7: Fifty-two years with diabetes and the doctor says “Oh, I can't believe’ because she, when she died she's 86. She never caught nothing, but she still, she was a very strong lady, believe me. But she suffered.”

Being borderline rather than have the full-fledged disease was a priority; holding to the partial, lesser diagnosis as long as possible. Likewise, use the smallest number of medicine types and actual pills as necessary. Finally, avoid insulin as long as feasible. However, despite the cultural avoidance, those who knew others (W3, W5, W6, W7, W9, M2) who had used it, knew the insulin-using person lived much longer using it than if (s)he had not used insulin when she or he needed it.

Summary of Contextual Category: Cultural Perspective on Diabetes.

Diabetes has been illustrated as a stigmatized, unwelcome chronic disease that represents fearful outcomes, personal physical weakness, and the threat that one

may die sooner than expected. This contributed to participants hiding their illness status. Once diabetes was owned and the participant built their life around diabetes, the conflict was reduced. Socially-acquired knowledge was what the participants based their understanding of diabetes on and their socio-cultural perspective. Although, diabetes was common in the culture, it did not reduce the stigma. They accurately blamed heredity and overweight status to the cause of diabetes onset. However, several admitted or demonstrated they did not know or understand the reasons diabetes developed; some simply had inaccurate reasons or did not know the genesis of diabetes. The effects of stress, emotional trauma, “upset” and being worried had an uncanny time-correlation to the onset of diabetes in several participants to which they ascribed the cause. Sometimes this was with the understanding they already had the genetic predisposition. Due to what diabetes represented, it was important to hold on to the *almost* diagnosis of borderline for as long as possible to avoid having to “own” the full diagnosis of diabetes. Likewise, they preferred the minimum number and type of medications for control. Some understood the basics of what their medications did; some did not. The bias and stigma against the use of insulin actually exceeded the stigma of the disease. The commonness of diabetes might have contributed to this difference.

Summary of Context

The culture of the participant Mexican émigrés with T2D was highly community-oriented. The community as a whole was more important than the individual. Being the same as and blending in rather than standing out was desirable. To not conform to the cultural standards led to social pressures both

subtle and not-so-subtle. Being less distinct was safer, too, because no one had to take responsibility; it belonged to the group. How one was perceived was essential beyond representing one's self and one's family, but each H/L represented the culture. Sometimes the requisites for how one was to present one's self meant there were not clear boundaries between persons. The culture valued family first above the individual, and women in particular were responsible for holding the family unit together. That was a challenge for mothers with T2D who needed to choose to meet their T2D needs but struggled with putting themselves first before family as it violated societal and ingrained role standards. Yet, those who did not choose to care first for their diabetes resulted in family suffering, both in the short-term and long-term; especially the person with T2D. For some, faith was a pivotal aspect of their cultural and personal lives. The society was both role-based and rule-based. Men and woman had distinct role differences and issues that impacted behavior and choice. In the rule-based society, respect for authority was important, but, often not more important than the requisite to *Be proper* and *not offend* others, particularly the hostess at one of the many, frequent social gatherings.

Cultural characteristics included being a culture of people who celebrated and needed to be active in festivities together. Of predominant importance to the culture was the centrality of food, including taste, smell, appearance, and were emotionally-memory-provoking at essential festivities. This presented constant temptation and conflict for the person with T2D who was driven to enjoy the good food, obligated to at least taste *a little bit* in order to *be proper* at each recurring celebration. There were generational differences in how older persons with T2D

with deep Mexican roots who had not had the advantages of modern HC; they knew they would die anyway, so often chose to enjoy the tasty Mexican food rather than lament or struggle. Cultural health beliefs revealed a strong preference for herbal and natural substances over less-than-trustworthy medicines that they believed would have damaging side effects. Faith in God had two key aspects: the body will heal itself and they knew God could heal them, so prayed for God's healing.

Sometimes their prayer was "dreaming about magic," they wishfully thought God would make excess calories magically disappear or simply heal them. Then they did not have to practice self-discipline. Those persons with T2D who practiced wishful thinking were not considering the long-term, only how to adjust individual BG.

The cultural perspective on diabetes revealed that the frequency of diabetes in the culture made it common. Diabetes had a true stigma. Most who had it were perceived as or believed to be weak, vulnerable, sick; the root of which was chronicity. Diabetes had many meanings, ranging from something like a cold and normal, to cancer; something bad. There were some who had built their lives around diabetes to the point of saying, "diabetes is my life." Because of the pervasive negative view of diabetes in the culture, there was a compulsion to hide it, pretend it was not there especially in social settings, and that is what they did. There were various ways they saw that one developed diabetes; much of it was errant, but most knew about the heredity factor. A few looked for specific signs and symptoms; when they did not have those particular signs, they had a low suspicion of the disease. Stress, significant emotional trauma, and depression were attributed to be the actual triggers for some who had had true trauma shortly before their symptoms and

diagnosis. Some held onto the diagnosis of borderline, not really “diabetic” yet, so they did not have to admit to the full-fledged, socially-suspect disease. Along with wanting to be borderline rather than diseased, based on their understanding of medicines they put off taking medication when possible or having only a small amount. The cultural bias against insulin – again based on different beliefs – resulted in there being some who refused to ever use it. On the other hand, one did use it because she expressed that she understood that she needed it. Others knew family and friends who had used it successfully; however, it remained a taboo for most and was said to be taboo within the culture at large.

The Substantive Theory

The substantive theory is founded on the conflict between short-term enjoyment of tasty food, personal pleasure and socio-cultural duties to eat food at frequent gatherings against the long-term need to protect against unwanted T2D consequences due to recurring high BG. The need and the goal was to work toward *mastery* of diabetes all-day, every day. The substantive theory is:

*Negotiating every-day diabetes self-management decisions
about conflicts between culture, personal enjoyment, and long-term outcomes
toward mastery of type 2 diabetes by Mexican-born adults.*

Conditions Influencing Diabetes Self-Management

Conditions and dynamics that were found to influence DSM fell into two major conditional categories: Aspects of the actual practice of DSM and key factors that were identified as influencing DSM. These ranged from socio-cultural, to personal and interpersonal, to life events, language, and access to care. It was first essential to indicate how the participants addressed or met DSM guidelines as this provided a view toward their mastery based on western medicine standards (of which all participants were aware) and what was required to master DSM in order to control their T2D based on current scientific evidence. Terminology will be presented as relates to terminology of the substantive theory. Following will be the commonly accepted aspects of DSM: diet, exercise, medication use, testing, HC visits, how they learned about diabetes self-care, and the management of co-morbid conditions that might affect T2D.

Clarifying Diabetes Self-Management

Participants were aware that the western medicine goal for all persons with T2D was to maintain their *sugars*, the name they gave to their BG, as close to normal as possible and that it was their responsibility to manage their BGs every day. Most BG test results were within these generally desired ranges (Chamberlain et al., 2016; Dlugasch & Ugarriza, 2014), although not always. They understood the major aspects of DSM included paying attention to what they ate and how much, getting some exercise, taking their medications, SMBG (supposedly daily), and having routine HC visits and laboratory blood tests. In general, most of them were practicing these behaviors; they were keeping their BG within the 'normal' range

defined by both American (Fox et al., 2015) and international diabetologists (Y.-S. Yang et al., 2015). Each one was well aware of poor consequences because they had known and seen others suffer serious outcomes of poorly-managed BG. Although they might not have liked all the aspects of DSM, they knew they should make choices every day to avoid unwanted results. Each one expressed a sincere desire to extend and protect their overall health and life quality and prevent *bad*, long-term outcomes.

Participants did not use the term *diabetes self-management* or *diabetes self-care*. Most seemed to understand the term when it was used; it was introduced carefully in the context of the discussion and almost always with a following, clarifying statement, such as “the way you take care of your diabetes.” Often, someone needed more explanation of the questions; exemplars follow. Also, as one might expect, there was a great variation among study participants about how DSM was addressed; for some there was variability within one’s own year-to-year practices. For example, within the previous year, M2 reportedly did not check his BG regularly and was not aware it was creeping up. He admitted to having a sweet-tooth, “that habit that we have” and was under less control at the same time. He told of going to “my doctor” following a quarterly blood test for BG averages (A_{1c}) and was told he needed to have another medication added to get his BG under control because he had had a sizable jump in his overall glucose control.

M2: “You know, once I came to see the doctor and my numbers was very bad ... was very bad! ... And I got kind of disappointed in myself. And 3 months later I told the doctor ‘I gotta take care of it.’ And I went back

and the numbers changed so back. ‘How you do that?’ (the doctor asked). But I just did it!”

It should be understood that whether one had successfully managed or failed to manage her or his diabetes, each one did some form of management, whether it was intentional or haphazard. The term, management, neither directly implied they made efforts to control their diabetes nor suggested success. It simply was how they dealt with their diabetes or addressed their DSM (W6). Each person with diagnosed diabetes had choices to make – all day, every day. Thus, how they actually addressed DSM was related to their day-to-day recurring choices and their personal resources. This distinction became clear in the course of IVs; people were making choices all the time regardless of how they applied or did not apply efforts to control their BG.

Terminology: “positive DSM” and “negative DSM.” As IVs proceeded, it became clear that some of the activities and DSM choices that participants reported led toward good health and long-term desired outcomes, while other decisions led toward long-term risk of poor/poorer health results. Those DSM actions and activities that moved the person in the positive direction of good BG control, meaning their choices and actions were beneficial for the immediate and long-term good health are referred to as *positive DSM (+DSM)*. Correspondingly, those choices and actions/non-actions that led toward negative (e.g., harmful, inconsistent, poor, inadequate) glucose control and consequently poor outcomes were termed *negative DSM (-DSM)*. These were, however, not mutually exclusive. It also became clear that it mattered *how* and *when* an aspect was addressed or applied or not utilized that determined benefit or not. For example, having a piece of fruit was neither positive

or negative in-and-of itself. However, having one-half of a fresh orange was quite different than when W7 chose to eat multiple oranges daily for 2 weeks, already overweight and known to be in the pre-diabetes, borderline state.

PI: How did you find out, how were you diagnosed?

W7: Oh, because when I go to the doctor, she told me I'm in the border to have, because my mom was diabetic for 52 years. All the time when I go to the doctor she said 'be careful; because your mom she is diabetic – you can get,' because in that time I was more heavy.

PI: Oh, you were heavier?

W7: Yeah, so that's why. And then I remember she told me that and I work for 2 weeks I eat a lot of oranges, because some guy, he bring a lot of oranges and I like the fruits ... I like everything, vegetables and everything but the fruit [said smiling, wide-eyed]. I remember I eat 5, 7 [daily] at the same time so after I went [back to the doctor] I got diabetes.

PI: So ... but she said first you were borderline?

W7: Yes. She told me 'be careful' but I didn't listen... *Now* I pay the consequences.

PI: I see what you're saying. The first time or earlier you went and she tested and said 'you are borderline,' 'be careful, your mom had it', she warned you about it. And you thought 'okay, okay,' but you didn't pay attention to it?

W7: Yeah. And when I had the oranges and afterward I went I feel like ... I never feel thirst or ... no tired or losing weight ... I just go because I had a little headaches ... but not too much. I just went because I think I had the flu and she told me ... [‘now you have diabetes’].”

This exemplar suggested that how much and when W7 chose to eat fruit, the aspect of diet, was what made the difference. The mere fact that W7 had an orange was not her problem. The problem was her choice in her overweight, pre-diabetes state with high risk family history, she gave herself high BG every day for 2 weeks due to excessive high fruit intake. In-and-of-itself, the aspect of *diet* was neutral. Many exemplars below further illustrate this point.

Relationship of terminology to the substantive theory. Consistent with the substantive theory that the goal of DSM was *toward Mastering* diabetes control, the following exemplars revealed the extent to which participants effectively managed DSM. The direction toward or away from *Mastering* was indicated by terminology established by the PI to demonstrate the *direction* of DSM taken by a participant at any given time. Since the person with diabetes chose *throughout* the day whether she or he would seek to maintain blood glucose control, the individual might decide in a positive/beneficial direction toward *Mastering* DSM and successful diabetes health as described above. Or at any given time, she or he might choose not to seek blood glucose control that led in a negative direction, away from *Mastering*; this choice was known by participants to result in poorer diabetes health, thus, the term “positive DSM” refers to variations in the ways participants made choices that contributed to decision-making that led to beneficial blood glucose control and

reduced risks of consequences of poor diabetes control, per national guidelines (Chamberlain et al., 2016; Dlugasch & Ugarriza, 2014). Contrastingly, the term, negative DSM, refers to the choices and application of, or lack of, aspects of DSM that led toward inconsistent, inadequate, and poorer glucose control with a higher risk for untoward effects (Phillips et al., 2014). For example, the exemplar of the excessive eating of oranges by W7 was a poor choice that led to a negative outcome, poorer DSM, *away from Mastering*. Many exemplars of both +DSM and –DSM will be shown in the remaining sections of Chapters 4. There was considerable variation about the extent to which the participants adhered, on a routine basis, to the standard guidelines for DSM in terms of diet, exercise, use of medications, self-testing, routine laboratory testing, periodic health care visits, attending diabetes education (DE) classes, and management of co-morbid conditions. On rare occasion, there was complete failure of DSM.

Diet. Dietary issues were found to be of three categories. The first was the day-to-day *battle* of maintaining a very challenging diabetic diet. The second dietary matter had to do with the attitude of these, and reportedly other, Mexican persons with diabetes when they traveled; they usually chose to enjoy the break from the daily diet struggles when at home. Finally, a selection of exemplars about the differences in diet and food preparation in Mexico compared to the United States and reasons they believed it was often easier to have eaten a diabetic diet in Mexico than in the United States.

Day-to-day: Being in the battle. All of the participants understood that the core of their diabetes control was through their choice of diet – types of food, how

much, how often, how it was prepared. Not all participants understood what was considered “ok” to have or what type. For instance, W2 who was to restart on medication at the time of the IV and whose husband had been diagnosed with advancing diabetes only 2 months earlier, was proud of their efforts to modify their diets to be more diabetes-compliant. In addition to the vegetables and protein that W2 reported, the PI asked ‘What [else] do you do to take care of your diabetes...?’ W2: “Before I was drinking a lot of soda, now drinking water or juice.” PI: “What kind of juice do you like?” W2: “We use Tampico Orange-Mango, and we eat a lot of fruit too... [*Jokingly*] a lot of beans too.” They were unaware that there is a high added sugar content in that orange-juice brand, according to the label on the bottle. She also did not know of any resources to find out about what foods were appropriate to eat and drink. They had no idea of portion size, “Because we get our plates and we get a lot, so we do not know how many calories, or portions that we have to...” But, she made a very clarifying comment about one’s resources and how what was actually already available in the home to eat dictated what the family would eat. “You have to see what you have [to] eat before you know what you can cook.” The remainder of participants did not face food resource issues as adults with diabetes – at least two did as children, W3 and W4 – or they did not admit to food shortages during the IVs. Several made it clear that getting the food they needed was not an issue (W1, W3, W4, W6-W10, M1, M2).

W1 proudly asserted how one should approach the timing and content of meals, “yes, and I stay between every 4 hours. You want to eat small portions, like no rice, no pasta, more vegetable.” She had very good quarterly control for +DSM.

Most participants relayed that they understood that portion was almost as important as what they ate; others made no inference. M1 had recently started a new dietary program for persons with diabetes who wanted to reduce or eliminate their diabetes. In the past 2-3 months, he had already lost 11 pounds on the diet. He, like all of the other participants expressed how challenging it was every day to battle every day to eat the right foods in the correct amounts and to avoid the culture-wide enjoyment of sweets and treats.

W6 shared an enlightening perspective on the day-to-day struggle with diet for the person with diabetes. When being queried for clarification about the concept of 'fatalism' that had been brought up by others, [PI]: "There are people who are fatalistic because they think 'well, I'm going to die anyway.'" She replied with great understanding – and some frustration or disgust, "yes, we are going to die anyway. They don't want to take care of themselves; it's all the same to them. *They don't want to battle... I don't know...*" Later when describing Mexican food and how hard it is to resist, she said, "It's because it's really good."

Diet when traveling. Differences in diet in Mexico from the United States.

For some, going back to Mexico to visit or other travel meant that, in order to enjoy the lifestyle, there and their families and friends or the local foods, they stopped checking their BGs and/or ate what they wanted until they returned from their vacation. W3 stated, "But when I go and because I feel like I am on vacation, I kind of give me a little bit of freedom ... I try to do exercise, because it's really good food. In United States, I just say, 'no.'" W9 summed up the common thinking of many Mexican persons with diabetes when they travel:

W9: The majority of the people, yeah, when they travel and they go back to Mexico they say 'Oh, it's only for a few days. I'm going to eat anything I want. No one is going to stop me from doing it.' It is very common. Okay, two days, no one stopped me... They say 'I'll eat what I want, I'll eat what I enjoy. When I come back, I'm going back to my discipline, exercise' and everything you do.

PI: Okay. So that's specifically if they go to Mexico?

W9: Or anywhere if they travel.

PI: Okay, any travel.... That's a better point - travel. Okay.

W9: When you're on vacation you're 'oh, I'm not going to worry about my diet. I'll go back to my routine later ...'

RA4: They think 'I'm on vacation!'

Coming from Mexico these participants were familiar with food that has been traditionally very fresh, free of preservatives and additives, and lower in starchy carbohydrates. W2 suggested that there might be less need for medications because the diet was healthier.

W2: I don't know maybe the food there is different - doesn't have a lot, how do you say como que no tiene mucho almidon.

RA1: It doesn't have a lot of starch

W2: So maybe over there you don't have to take a lot of medicine to be in good health.

PI: Oh I see, so the diet here in America - it makes it harder [to eat a healthy diet].

W2: Yeah, it makes it harder, because sometimes the food has lot of sodium and a lot of calories.

When they made the move to America, each found very different foods and ways of preparing food in the United States. Whereas, often food in Mexico was harvested or killed the same day it was eaten.

W7 responding to the question about food differences: "Well, any kind of food. A lot of food. Everything is fresh. Nobody buy. The meat every day you buy fresh. Tastes very good. My dad he have everything on the ranch, onions, radishes, fresh. I remember people help us... Everything so, very happy."

W9 commented similarly:

PI: "And the food is different. How is it different?"

W9: Because especially where I go, it's a small town. They kill the cows and the pigs and everything and they sell the meat that same day.

PI: Yes, it's fresh meat.

W9: Directly from the cow.

PI: Are there more vegetables [in the diet]?

W9: They are actually from the same day.

PI: Yeah, the people pick it - so the food is ...

W9: Organic."

M2 worked on his grandfather's farm. He saw and tasted the freshness of the produce and water used to grow the plants. He marveled at what he had been a part of in Mexico. RA4 exclaimed with joy the memory that everything was fertilizer-free.

M2: "I believe one of the reasons is that the way we used to eat, we was eating healthier, because everything was [no] fertilizers [using his open hands back-and-forth to indicate 'none']. Everything. I grew up in the fields with my grandfather. I used to get out the ladders, cleaning it [produce] watching what the water was going through. Shake 'em [vegetables] and eat them. Tomatoes, same thing. It was the water, move it dust away [rinse the fruit], and drink the water in there.

PI: Right. Very fresco.

M2: Because - see it has a pump for the fields.

PI: Yes, yes of course.

M2: Everything was so healthy, *everything*.

RA4: Exactly, everything organic.

M2: Everything so natural... cause I grew up with it."

W5 also compared the freshness of the food, but added her struggle with weight her that she did not have when living in or visit Mexico. One of the most troublesome examples of stark differences that bothered her, even years later, was when she saw additives added in larger bulk to lesser meat products when she worked at a meat packaging plant.

PI: "How was life in Mexico different, Senora?

W5: More walk. The food, more different ...

PI: And how is it better?

W5: Yes, Mexico is more better, more fresh.

PI: Yes, everybody says that.

W5: And the farm there, la tierra (smiling about the fresh earth)

PI: Yes, it's fresh from the earth.

W5: Yes. I am from a small ranch, so ... And bean fresh, and meat fresh ... And eggs ...

PI: It is easier, Señora? [having been told by others that it is]

W5: And more vegetables; more eat vegetables in Mexico maybe.

PI: Yes. So for a person with diabetes, maybe it's easier in Mexico?

W5: Yes, more walking.

PI: It's maybe more difficult here?

W5: For me it is [said in a lamenting tone]. [Spanish] Because when I go to Mexico, I lose, in a week, I lose 5 lbs.

RA1: Every time she visits, she loses 5 pounds when she visits.

PI: Wow! Every visit to Mexico for one week is 5 pounds down ...?

W5: Um hmm. And the moment I get here ... [pointing down to indicate back in the United States] ... I gain

PI: You had a job, but the food isn't as healthy. [comparing what she had earlier said was a good thing about being in the United States]

RA1 & W5: No. [laughing].

W5: Too much hormones.

PI: Yes, okay, and what does that mean to her, L [RA1]?

RA1: Muchas hermones? ... en la comida?

W5: Yes.

RA1: Okay, she means that the food has a lot of hormones.

W5: [Spanish] Because I worked in the, ... I worked in cold cuts I saw all the things they would inject on meat...

RA1: She was working at the cold cuts. She would see all the things they would make.

W5: There were small pieces of meat like this [holding hands in a ball to indicate the size that went into a machine], and they would come out like this [making gestures indicating the size of the meat was more than twice what went into the machine].

RA1: They were that small and they would come out of the machine this big.

PI: Oh, that's terrible.

W5: [Spanish] The nitrates and [unintelligible] ... All the stuff they put on pepperoni!

RA1: All the nitrates and some stuff that... She would see what they put into pepperoni and she didn't like it."

Summary of diet in DSM. The natural limitations of a healthy T2 diet that can lead to +DSM caused participants to have to *battle* every day, all day, to maintain *normal* BG levels. Part of the struggle was to limit portion size in addition to the types of foods and beverages. At least one participant had to see what was available to eat before she could plan a meal; most of them did not have this issue. It was helpful to have a routine to practice eating a healthy diet. Those who traveled often set aside their dietary struggles to enjoy vacation; they returned to a stricter diet once back in the United States. For many, it was easier to eat a more balanced diet in

Mexico because the food was fresh from the fields or butcher, with less starchy food. Hormones were not common in food in Mexico as they were in the United States.

Exercise. Eight of the 12 participants exercised in some way or another on a regular basis; this ranged from W1 who walked only one-to-two times weekly and said that back pain from a work-related injury interfered with more frequent walking, to W5 who had a very vigorous 90-minute work-out daily, or W3 who hiked 1 full-hour each morning. Several tried daily exercise. W8, who did not like walking, refused to walk more than 1 mile but was committed to that daily mile. W6 walked most days, but if some of her seven adult children came and asked her ‘Mommy, cook me some food; I’m hungry’ or a friend came over to visit before she had gone on her daily (~1-hour) walk or to the gym, she often missed fulfilling her goal. She said her social responsibilities took precedence and she did not want to refuse her children or make friends uncomfortable. M2 liked walking 1-2 miles/day and at time went bike riding “I love to ride the bike.” He also enjoyed working in his garden. W9, very committed to exercise, replied to the PI “What all do you do about your diabetes, to take care of your diabetes?” W9: “I exercise.” PI: “And how much of that do you do?” W:9 “At least 30 minutes daily, maybe more.” PI: “That’s fantastic! Like what type?” W9: “Walking, treadmill, stationary bike.” Prior to the IV, W10 was walking for extended times daily, took various classes, and attended Senior Center activities. Due to a serious illness, she had stopped exercising but was getting ready to add it back to her schedule daily; she was anxious to improve BG control because exercise was her primary control. W7 walked thousands of paces throughout the day in her workplace; she also walked outside on her breaks or after work.

Some participants did not have consistent exercise habits. Sadly, it was very difficult for M1 to walk due to back pain. He said that he liked to ride bikes and talked about returning to the gym with his wife. He knew exercise was important and wanted to get back into the habit of it, but pain did interfere. W2 wanted very, very much to walk every day; however, her schedule was difficult as she worked from 3 p.m. to 3 a.m. 6 days each week, then slept from 3:30 a.m. until about 11:30 a.m. when her husband made them lunch. Between the meal, preparing for, and driving to work, there was no time to walk. She did not walk by herself, although her neighborhood was safe during the day. Her husband wanted to drive her to the store and everywhere they went, even though she asked if they could “go walking.”

PI: “Do you do any sort of exercise?”

W2: No, only he has [gets] to walk. Me no. Like I told you I don’t have time, because sometimes I wake up at 11:30[a.m.], and come to eat breakfast, then I have to get ready to go to work.

PI: Yeah, those are hard hours.

W2: And right now, like before when I was by myself, I have to go to the store, I was walking, so that I was doing exercise, but now if we go to the store we go in the car, we don’t walk a lot ... Yeah, because I told him, ‘we have to go walking.’

PI: So maybe when he walks you can walk with him - you can do it at a time you could go.

W2: Yeah, only in the morning, like on the evening around 3:30 from here we go to work at 3:00.” This latter time frame was confusing because time wasn’t sequential.

W4 had in the past been someone who walked a great deal and enjoyed walking around shopping with friends. Over the course of time, she had developed peripheral neuropathy in her feet that caused her pain daily. No matter how many shoes she bought or the type, she had progressive pain and reduced function so she was not exercising regularly because she ‘didn’t even want to go out.’ However, at the 1-year follow-up visit to deliver DE materials, she was much healthier, no longer had neuropathy, had lost weight, and was again doing some exercise. The specifics of that story are told later in this section under Motivation.

Medication use. All but two participants (M1, W2) used medication for treatment of their diabetes. M1 had controlled his diabetes mostly with diet and periodically with exercise over the past 10+ years since he had gastric bypass surgery. At the time of the IV, he was fighting his weight again and was afraid that if he did not get it back under control, which he was doing successfully through careful dietary intake, he would be at risk of needing medications again. He did, however, take multiple meds for several other medical conditions, including hypertension and chronic pain with secondary-drug addiction that was well-managed and improving. W2 had been diagnosed with diabetes in her late 20s and was treated through her last pregnancy and through the first year after delivery. Then due to life struggles, she did not treat her diabetes with medications for 12 years. At the time of the IV,

her labs had been drawn and she expected to go to the doctor within the week to get medications so she could control her diabetes for the first time in years.

Using oral medications. W6 used oral meds and had recently started insulin. The others used only oral meds; however, prior to recent changes, W4 had used a non-insulin injectable daily that she was not using at the follow-up visit when her weight was down. W8 claimed she had a long list of medicines that she took every day but did not complete the list beyond her diabetes medicines due to how the conversation unfolded about her BGs. W10 was proud she still only took one pill/day despite rising BGs due to reduced exercise because of the illness from which she had nearly recovered.

PI: “Okay, so you started off with the Metformin. Would you take 1 tablet a day, or 2?”

W10: Yeah, 1 tablet. I only take 1 a day, and I’m still taking 500 [mg].

PI: Okay, and has your dosage changed?

W10: No.

PI: So maybe that’s one of the reasons that your sugars are not under better control. You still only take it once a day?

W10: Um hmm.”

W7 had a complementary story. Consistent with the cultural standard, taking only one medication indicated less severity of the disease for these participants as well as W10 and M2. None of them boasted about their illness severity requiring multiple medications. The names of medications were often hard for people to say and frequently syllables got mixed up. For example, several people were taking

'met-for-min' but they commonly called it *met-mor-fin*. In describing how she was told she had diabetes and started on medication, W10 recalled, "And then when they told me, the doctor prescribed...metmorfin?" PI: "Metformin?" She nodded. W3 also said "In my case I have in my mind that the latest, I knew that eventually will start taking metmorfin." PI: "No, *metformin*." W3: "Metformin. Okay." W7 called it "morfin." Some participants knew the name of the medications they took. When asked, M2 said he knew the name of the medicines and jumped up from the table and brought his medicine back to the table; thus, it was unclear if he actually knew their names. He did know their use. The same occurred with W4.

Some participants understood at least part of how their medications worked for their T2D, but some did not; it was unclear about others. W5 understood the basics of what her metformin did for her. PI: "How does the medicine help you?" W5: "It lowers ... how does it help me?" PI: "Yes" W5 "The low ... my sugar." PI: "It lowers your sugar?" W5: "Yes." On-the-other-hand, W7 eventually said that her BG came down on the med; however, her information was mixed with inaccuracies.

PI: "And then, how do you think that the metformin helps you?"

W7: Well I think it works very good.

PI: But how do you think it works for you?

W7: How I think it works?

PI: To the RA 'How do we ask that? D'you understand the question? I'm wondering how she thinks the metformin helps her?

RA2: [Spanish] Oh, Como le ayuda? Le afectados.

W7: Yeah, I think it helps me to get my liver, to get my liver ...

PI: Oh what?

W7: To get the liver down.

PI: The blood sugar?

W7: Yeah, the blood sugar. But I don't know. That's why you know I'm always have a doctor and he can take me for my liver and my kidney because I don't want to be ...

PI: You mean the tests?

W7: Yeah, the tests."

Fear of insulin. A complicating aspect of insufficient T2D knowledge was the fear of insulin. "Insulin is normal," said the PI when answering several participants post-IV questions. Those who produce sufficient insulin do not have diabetes. For H/L in general, insulin heralded death, "once you use the insulin, you will die sooner," said well-educated W3b. Thus, the need arose in a few post IVs for a clarification about the use of exogenous insulin due to progressive loss of pancreatic function, but cultural Social Knowledge dictated one should not use insulin because people from Mexico die or have been maimed after starting use. "I think if I brain wash myself with that idea ... would help me not to get [insulin] shots" (W10). In part, insulin might have been seen as a failure to self-control. It did appear to indicate a more serious, "she's got it *real bad*" case. As a stigmatized disease, this was unfavorable because this kind of misinformation was prevalent and reportedly was shared liberally within the culture. When one's T2D was severe enough that insulin might be required, many persons were quick to dissuade its use.

Sometimes people expressed fear of having to use a needle daily or a few times a day. A question that arose regarding insulin use was, “Is it really the needle or is it the fact that insulin is equated to ‘okay, I am really doing poorly. If I have to take insulin that means that my diabetes has really crossed the line.’” It might equate to the fact that, “your diabetes is sort of beyond being able to resolve on its own; you might not be in control of it” (M2). The complicating aspect in the culture to have a “tendency to pretend,” of not believing what was taught but pretending not to know. Likely this was a barrier to accepting insulin information (W10).

Summary of medication use in DSM. Most participants were committed to taking diabetes medications on a daily basis. M1 had not used medications since gastric bypass 10 years previously; W2 expected to re-start medications shortly after the IV. W4 was on oral meds but stopped a weekly injectable after getting her diet and weight loss under control with a new HCP. Some participants wanted to take only one med daily, even if their BG indicated they needed more, not less, because it was/is culturally important to take the fewest meds possible as this appeared to indicate a lower degree of illness. It was common for the names of meds to be mispronounced and for participants to not know how medications worked. Fear of insulin was spoken of by several participants. W10 and W3 strongly asserted apprehension about it. W7, W3, and W9 had parents who had lived several years because of using insulin. W6 had recently started using it to gain control of her T2D despite that others tried to dissuade her using a drug they thought might kill her. The cultural tendency to pretend might have swayed some participants’ responses.

Testing during ongoing diabetes management. There were, and are, two aspects of recurring testing during diabetes care (Chow et al., 2016). The first is the recommended daily testing by self-monitoring of BG (SMBG) (Fox et al., 2015) done by the participant. The second is the periodic A_{1c} test, usually done quarterly in laboratory or clinical settings as ordered by the HCP to evaluate the 3-month average of one's overall BG level (Menke et al., 2015; Phillips et al., 2014); and to have an objective FBG.

Self-monitoring of blood glucose. Self-testing of BG or SMBG is the standard means all but one [W2] of these persons with diabetes used to know their BG at any given point in any day. Most of the participants at the time of the IVs had been testing their daily BG, some check at various times throughout the day. In W2's story above, she did not have the supplies (e.g., glucose meter, lancets to prick her finger, or strips to measure the sugar level in the 'glucometer'). She hoped that when she started medications the following week that she would have all the supplies she needed. Since W9 did not check routinely before her visit to her physician shortly before the IV – because “always, it was normal” - she had started to check regularly. Her A_{1c} had gone above the standard 7.0 for the first time in 10 years. M2 was more diligent than he had been several months prior when his A_{1c} had spiked, so he was checking more regularly. However, in some responses he indicated he checked regularly “oh yeah, I check,” and in other responses he hesitated and admitted that he checked when he felt his sugar was up. M1, like M2, had stopped routine checking until he found out his weight had gone up considerably. PI: “Okay and do you check your blood sugar?” “Yes ... I stopped and ... what was the question? Sorry.” PI: “About

checking your blood sugars.” M1: “I wasn’t doing it for a little bit, maybe 4 months, and then now I started when I found out when I weighed 200 [about 3 months ago].”

It was common for the participants to say they knew their BGs and some seemed confident they knew what was their highest and sometimes their lowest. They consistently wanted to talk first about the highest unless one of them had a low BG/hypoglycemic event; then that was the topic about which they primarily spoke. It appeared that the participants knew to test before eating breakfast and knew what fasting blood sugar [FBG] meant. It is possible that W2 did not know this since she had been away from testing for 12 years. It was interesting though that several did not know that if one tests after a meal, the recommendation was to check at 2-hours post-prandial. They checked when it was convenient, when they thought of it, or in the case of W3, when she was feeling poorly.

PI: “And you check your sugar most mornings, right?”

W3: Right.

PI: In the last 3 or 4 months, what’s the lowest that your blood sugar has been fasting?

W3: 70.

PI: OK. What’s been the highest in the last 3 or 4 months fasting?

W3: 156

PI: Fasting?

W3: No, no, no. Not fasting.

PI: We’re only talking fasting.

W3: Fasting highest was 110.

PI: Okay, so really good range [70-110]. And then when you do these, the other times.

W3: When I feel really bad and I think I'm out of control ... 156.

PI: So, the highest, and that was that 1 hour after you ...

W3: No, I have 176.

PI: When you had the 176, was that 1 or 2 hours after a meal or just random, you don't even know?

W3: It was 1 ½ hours or something. I checked it because I was feeling bad, and I say 'I didn't eat too much, why I feeling this way?' But as I told you, if I have some stress, will be go up."

In contrast, the next exemplar illustrated that the concept of 'range' [lowest – highest] was very difficult to convey, especially about the FBG range of the recent past. W4 illustrated how difficult it was at times to get a direct answer to a question asking about BGs and how rather stray information needed to be attended to so as not to miss an important feature or answer.

PI: "Do you ever check your blood sugar in the morning before you eat?

W4: Um Hmm.

PI: You're fasting ... what do you get with that? What is your range?

W4: 120, 135 something like that.

PI: Okay, and that's normal for you?

W4: Well, not is... [mumbles]

PI: Before breakfast.

W4: Uh huh, just a little high, because sometimes I have 97, 105, 105, like that sometimes.

PI: Uh huh, what would you say is the lowest in the morning that you've ever, that you remember or that you see very often?

W4: 120, 120.

PI: Okay

W4: The most though

PI: Most of the time it's 120. In that range.

W4: Uh huh.

PI: Does it get below 97 very often?

W4: No.

PI: Ok, so that might be the lowest.

W4: Uh huh.

PI: Okay, and then, in the morning before you eat, what would be the highest? ...Would that be the 135?

W4: No, 120, 135 sometimes, not all the time, but most 120 is most.

PI: Most of the time, uh huh. Alrighty. So, you may go anywhere from 97 to 135, but most times is in the 120 range?

W4: Um hmm

PI: Okay, and when in, during [Interrupted]

W4: But sometimes I check, sometimes, they go up to 210.

PI: In the morning?

W4: Before I eat, yeah."

It was not unusual to observe them say they remembered their BG numbers. On occasion, when asked by the PI if they knew what was the lowest and highest BG in the morning before breakfast (desayuno), one of the participants would get up quickly to grab her or his BG log and insisted on showing it to the PI, even though she declined needing to see the log book. When the PI viewed the log, as a courtesy to the participant's efforts to share the information, it was clear they did not remember accurately. The exemplar about W10 below illustrated both of these points and her lack of familiarity with the quarterly A_{1c} test. Some participants did not seem to keep a log but tried to remember their range. They also often lumped all of the numbers into two categories, the highest of all BG and the lowest, not considering that it was to be expected that the FBG would be lower than when one had eaten 2 hours earlier or had meals and snacks in the day. On the contrary, M1, who had lived in the United States most of his life, was able to address the concept with help in focusing by the PI. "Are you checking in the morning before breakfast?" M1: "That's it. Just in the morning." PI: "Okay. What are your fasting blood sugars? ... I'm looking for the lowest and the very highest in the morning." M1: "110, the highest and lowest 47." PI: "47??!" M1: "Yeah, I felt sick."

Most participants checked their BG daily, sometimes more than once. Some checked when they felt it might be too high or low. Sometimes participants got out of the habit of routine testing and their quarterly BG and/or weight got out of control. It was common for participants to think that they knew the range of their BG but their log showed they did not remember correctly. The concept of *range* was difficult for several of them to understand or focus on; high numbers were more

important than low ones unless they had hypoglycemic events. W2 hoped to restart testing once she got new supplies and medications and W9 had to start checking because her previously 'always normal' BG were no longer always normal.

Laboratory testing. The other testing that was discussed by participants was the Hemoglobin A_{1c} test that they usually had drawn in a laboratory or health care facility about every 3 months, according to national guidelines. A few interviewees understood the test gave a picture of their overall BG level for about 3 months. Some knew a little about it and others knew very little; they went obediently to the lab but did not understand the test. Likewise, some did not remember their number and others, such as W1, W7, and W9, knew the goal was to stay below 7.0. W1 proudly exclaimed hers was usually around 6.0; although because she ate "raisins covered with chocolate," it had gone to 6.3.

W1: "I always check my A_{1c} 's every 3 months to 4 months - that way I know how my levels are, within those 3 months.

PI: Do you know what the A_{1c} is?

W1: Yeah, they check my sugar for the last 3 months back.

PI: Yeah that's very good you understand that.

W1: This Monday it was 6. 3; 3 months back it was 6.0..."

W3 kept a close watch on her A_{1c}. One of the reasons she stopped working was because it went up from 6.0 to 6.6 in 3-6 months "because of the stress." Others, for instance W5, did not recall the number or what it represented; instead she talked about the FBG level. Getting the two numbers confused was often observed.

W5: "And check the my, um, sugar ... And test the laboratory

PI: Laboratory, uh hum.

W5: Every 3 months.

PI: Oh, that's very good. So, do you know the name of that test that they do at the lab? Is it the Hemoglobin A_{1c}?

W5: [Spanish] No, they only give me everything and they check everything. They give me the paper and I go to the laboratory.

RA1: She doesn't know the name of the test, they just check her and give her a paper and she goes to the lab.

PI: Okay. Do they tell you the number, after the lab?

W5: Yes... [Spanish] I go and it's... One... 150, 150?

PI: 150? Yes?

W5: Yes. Um hmm... That's what it comes up to most of the time.

PI: And this is without food, con no comida, fasting, right?

W5: Yes."

This exemplar by W10, well-educated, always-taking-a-class-to-better-herself demonstrates how the A_{1c} was not even clearly known by name, but was done faithfully each quarter and was easily confused with the SMBG. It also demonstrated how even those who record in a log did not always recall accurately.

PI: "I know you get your A_{1c} periodically, so do you have any idea what your A_{1c} was in the early ...

W10: I don't understand what the A ...

PI: That's the 3-month blood test that he [her doctor] does pretty often for you.

W10: Oh, A_{1c} is its name?

PI: It's called A_{1c}.

W10: A_{1c} . Okay.

PI: Anyway, I know you get that done.

W10: Oh yes, every 3 months.

PI: Exactly, you're very good about that. Do you have any idea what that number was when you started with your diabetes 7 ½ or 8 years ago?

W10: It was about ninety-something. [describing a SMBG level, not the A_{1c}]

PI: Nine-something?

W10: I have it here. [she looks it up on a small log booklet]. It used to be 123 before breakfast.

PI: Oh, these are your fasting blood sugars? This is before breakfast?

W10: Yes.

RA4: The highest you ... [interrupted]

W10: It was ... [interrupted]

PI: Okay, so that wasn't the 3-month test - and it's okay if you don't know it. This is the one before breakfast, right?

W10: Yes. I been pretty much 105, and this month I have been ... one day I was 115, 134, 145.

PI: So, 115 to 156. [naming the range in the log booklet]

RA4: And what's the highest that you had?

W10: 150.

PI: Well let's talk about maybe the last 3 or 4 months. What's the very highest in the morning before breakfast?

W10: Before breakfast I would say 127.

RA4: Fasting?

PI: But I thought this was [looking at the log booklet] ... is this after or is this fasting?

W10: No. Before, before.

PI: So, 156 would be your high [fasting], right? [this is 30 points off what she thought]

W10: Okay, yeah..."

W6 dealt with diabetes for many years and worked hard to keep it under control. She was able to correlate her sharp rise in A_{1c} to recent elevated BGs.

PI: "A_{1c}?"

W6: Yes. In July, it was 7.6 and now, the doctor is seeing me, that's why she is seeing me, 8.9.

PI: It went up, I wonder why... From in July it was 7.6.

W6: Yes. In July I have 7.6. 7.6 - 8.9, but now, in this month, last week 8.9.

PI: Porque? Why?

W6: [Spanish] Because my sugar was [She made gestures to indicate her sugar is not stable.] Up and down, 300 and I think 2..."

Summary of testing during ongoing DSM. Quarterly lab testing for 3-month averages, the HgA_{1c} test, was faithfully done by most participants despite whether they knew what it was for or what the number was. Several did not know their

number, what it meant, or got it mixed up with the FBG. Three did know what it was and their number. Those who knew it were more likely to have better day-to-day control. “when you know what your A_{1c} is, does it help you with your DSM?” W3b: “Yes, now I know I see that I know ...” PI: “It helps you make decisions, doesn’t it?” W3b: “Right.” Stress contributed to it going up as did eating foods sweets or traveling to Mexico and eating without restrictions while on vacation with family.

Keeping routine health care visits. Most of these participants went to their HCP on about a quarterly basis; M1 might have gone every 6 months. As well-established, W2 was just starting to re-engage in DSM. Per the Lab section above, most were having quarterly A_{1c} labs drawn either before or after the visit to their provider. In addition to going to her HCP every 3 to 4 months, W1 also did annual health maintenance, “I always take a physical every year – regardless if I need it or not.” W6-W10 and M2 also had annual health screening. The variations in visit times between participants depended upon the health status of each person (including comorbidities), insurance coverage, resources, and availability of their healthcare providers and staff. These determined how often and frequently one was evaluated. W4 did not have insurance initially and went to her free or low-cost clinic monthly for assessments; probably necessary to receive county medications and coverage for quarterly labs. However, despite going regularly, she did not feel that her needs were being adequately addressed.

PI: “When you go to see your doctor or nurse – whoever you see – do you ever take the numbers for your blood sugars?”

W4: No.

PI: And they don't ask you?

W4: Yes, they tell me [unintelligible] 'they still like that?' [referring to the number she reports] 'Yeah,' but they don't pay much attention.

[Chuckles]

PI: Ohh, I'm sorry to hear that ... [then all laugh]

RA1: Me too [Chuckles]

PI: Okay. And, how often do they check you?

W4: I go to the doctor once a month.

PI: Ok. That's very good, but you say they don't pay much attention to your sugars?

W4: Yeah, because check me, and when they check me 'that's not too bad,' yeah, or they tell me 'you check your blood pressure,' 'do you log this morning?' I tell them what I have then.

PI: Do you ever write it down, like, morning and the date?

W4: No. I don't have the... that. ... I have to do it [meaning she sees the value of taking BG log to the doctor].

PI: If we were to give you a paper [log] like that would you use it and then take it to the doctor?

W4: Yeah, sure."

After she secured health insurance (Table 4 in Demographics), W4 went frequently to the new HCP; when stable on the new plan, she went less often. An important aspect of the care from the new HCP was provision of the nutritional

guidance she desperately needed along with other T2D educational components and status assessment that should normally be given by HCPs; she benefitted greatly.

Learning about diabetes self-care. Learning about T2D and how to manage it fell into two categories. The first was the information received from and questions answered by one's HCP – both at the initiation of treatment and periodically at routine HC visits. This was informal teaching and learning. This also included learning through literature received in the practice setting, purchased in stores and online; diabetes organization websites or library resources initiated by the participant. The second was when the participant was sent to structured DE classes provided by health care educators, usually diabetes-trained nurses, in more formal settings. Usually this was insurance-paid.

Informal learning about diabetes. It was common for the participants to have received some DE from their HCP when they were first diagnosed with T2D. Some felt they had been provided with adequate diabetes information and teaching from their HCPs and/or had received adequate reading material to feel they knew what to do at the start of their diabetes and how to maintain +DSM. W10 never attended any DE classes, but was given a lot of good literature from her physician when diagnosed 8 years earlier. She was well-read and felt she received the education she needed. There were some aspects of basic diabetes information that were missing in her understanding; whether she did not receive that information or did not remember it is unknown. she was willing to go to a refresher course.

Some, however, did not feel they received adequate information. For example, W4 did felt she did not have adequate guidance on types of food and

appropriate portions, thus, at the IV (first visit) she struggled every day with her dietary needs, intake, and often had high BG; often 200-400. Per above anecdotes, following her attaining insurance and a new provider, she did get the nutritional instruction that had been missing. W1 was proud of the information she had received from her physician (years ago); however, the information was not current so she was operating on outdated information, not consistent with current standards (Chamberlain et al., 2016), and shared that with others, including her 21-year-old daughter, the newly diagnosed pharmacist-friend who had called her in a panic the day prior to the IV, and her non-compliant, in-denial sisters. W1 continued to have a goal to keep her BG below 200, whereas newer standards would find that too high (Chamberlain et al.). Also, the diabetes food standards used currently include all vegetables (including starchier vegetables in moderation) and would not be limited to only green. Similarly, current fruit standards for persons with diabetes allow for a broader selection than in the past (Akresh, 2007; Lujan, 2008).

W1: "So then I went to see my doctor, and I told him what was going on, so he took a blood test, so then he says 'it shows you are a diabetic...'

PI: Oh, so you got the information that day...?

W1: Yeah, because my sugar was 350.

PI: Oh yeah, that's a definite diagnosis.

W1: Yes. So, he told me 'you are gonna take medication and you gonna have to lower your sugars below 200.' ... I eat small portions 4 times a day ... ok so, I avoid fruits - because fruits have a lot of sugar ... and the rice and the pasta, the portions..., but I would avoid the fruits 'cause they

told me I can 'eat all the vegetables I want - as long as they were green' - and if wanted some fruit, it 'had to be a green apple.' So, I said 'ok,' cause I want to control my sugar, because I have glaucoma.”

Later in the IV, W1 admitted that she had never seen any diabetes literature at her low-cost clinic; neither did they have any DM classes. She said that because of her tight control (A_{1c} at 6.0-6.3), the providers told her she was a prime example to others of good DSM. They thought she was current on all information, but she was not; and she did not know she was not.

Most interviewees did *not* receive ongoing advice on diet; some received regular reminders to do exercise, check their sugars, be tested for quarterly FBG/A_{1c} analysis, and brief updates or reminders on medication use. The majority of participants indicated they did not have access to diabetes literature in their provider's offices. Essentially all of them felt they could have used more current and regular informal office teaching and/or resources.

Attending formal DE classes. The amount, length and depth, frequency, and current status of therapies taught in DM Ed classes was dependent upon associated costs, insurance coverage, timing, ease of access, and language issues. Some participants received adequate DE early in their diagnosis - these ranged in length and depth. Better classes reportedly taught the very basics of the disease process, dietary guidelines, BG testing, the importance of exercise, and the benefits and consequences of not practicing consistent DSM. There was, unfortunately a wide range of DE classes for this cohort. Also, unfortunately, some of the classes were so long ago that the participants did not have current information. W9 had some

diabetes classes 10 years ago, at the outset of her disease, “When I was diagnosed I was sent to this program to learn how to eat” PI: “Oh, a diabetes program”? W9: “...Yeah. To [through?] my insurance.” PI: “...what did they have you do about your diabetes?” W9: “Just learn how to eat, what to eat, the portions, and I basically did that” [indicating compliance]. She had also learned a lot through helping her mom in her advanced disease process. Nonetheless, during the IV, it was clear there were some things she did not know and would have benefited from an update; she was willing to go to a diabetes class as a refresher. M1 took classes years ago and read material; he also received some education from his providers.

PI: “Where did you learn about diabetes?”

M1: ... Yeah, I started going to classes.

PI: Okay, did you do any kind of reading on your own, people brought you books, what else?

M1: Just like ... *Sugar Busters*, I think that’s ... but that’s not like... It’s like just taking coffee, no sugar.

PI: Okay, so you read a book, but the main thing was going to the classes...

M1: Both. I got a little out of both.

PI: Of what you read - and did your healthcare providers provide some information for you?

M1: Um hmm.

PI: So, it sounds like to me that you got good information early? Some patients haven’t.

M1: They don’t check your glucose.

PI: Well, some do. They taught you to do that right away, did they sir?

M1: Yeah, they right away gave me ... [a glucometer]"

M2 also got his initial information through classes; he felt he had enough information to know what to do and how to take care of his diabetes. At the time of the IV, W6 was taking (another) series of DE classes that her physician sent her to since she had just started insulin use prior to the IV. She did not benefit as much as she or someone else might have benefited, as will be discussed later in this chapter in Interactions, Actions, and Decisions. W5 did not appear to have had actual diabetes classes but had learned a great deal from her mother who has good control and whose cooking kept her father in good control. She had learned from observing and participating in their +DSM. W8 had never been to a DE class. She had had the disease for over 20 years and never attended a class. She was originally sent, but due to some insurance and DE class changes, she did not actually ever receive education in the class setting. Because she is an avid reader and constantly looked for books and literature on diabetes, she was essentially self-taught.

A surprising find was that some who did not have very much information early on did not seek to learn more about diabetes. W2, who went 12 years without diabetes care admitted she had not tried to find information. W7 knew a fair amount and was motivated to have very good control, but she had gone for a few years without trying to learn new or updated information. While W8 was well self-taught, she did not seek to go to a class over her 20 years with the illness.

Summary of learning about diabetes self-care. Learning about diabetes and DSM was accomplished for most participants through informal means,

especially through HCP teaching, literature, and self-learning means, and through structured DE classes in more formal settings. For some participants, the literature or teaching or class education received at the onset of diabetes was considered adequate to know how to maintain +DSM. Others did not receive sufficient DE. W4 had to wait several years before she had insurance to get a HCP who taught her what she needed to know; W5 might never have had adequate educational information outside of her nuclear family who practiced +DSM. Several had either class, HCP teaching, or literature, but it was so long enough ago that they were not current or information had become inaccurate. Each one who was asked if they would like to have diabetes update classes was interested to do so.

Treating co-morbidities. Although this is not the focus of this study and little will be said about co-morbid conditions, this aspect of DSM is being briefly mentioned for two primary reasons: (a) Co-morbidities such as high cholesterol, hypertension, kidney disease, and heart disease (the latter two may be related to or unrelated to diabetes) all added risk to the health status of the person with diabetes and impacted some of the participants' choices and rationale; and (b) Participants mentioned these disease entities in IVs, sometimes often; sometimes even getting them mixed up with diabetes. They seemed to understand there could be a relationship between diabetes and other diseases; not everyone reported other conditions as it was not a survey question. Generally, they were motivated to manage these co-conditions as well in order to have the best control of their diabetes outcomes. Interestingly, while high cholesterol (hyperlipidemia or hypercholesterolemia) was often found in persons with diabetes, none of these

participants identified as having cholesterol, at least not requiring medication. W4 was told it was 'a little elevated' but she 'didn't need to have it treated.' W7 reported periodic, brief, strange sensations in her legs; she had not had any close to the time of the IV. W5 was treated with several medications commonly used for diabetes preventively against other disease processes. Although she had limited coverage (MediCal), she was given the appropriate medications from the start. W6 was taking nerve pain medications; she had full function of her extremities. W4 at one time had been given a neurologic medication that her physician hoped would help with her peripheral neuropathy. Due to her fear about the side effects and that she did not like to take medications, she chose not to continue that medication. For all of them, no other disease caused as much concern as did their own diabetes. A small sampling follows.

PI: So, you knew that you had high blood pressure? Do you mind telling me what else you had?

W4: The doctor told me I had arthritis.

W4: I frustrated, because sometimes my blood pressure is okay. I have real bad blood pressure, always real high, and the doctor had to give me, you know, two or three pills (PI: Yes) for ...because one pill don't do nothing for my blood pressure...And then, I have my blood pressure controlled, and my sugar is real high.... [shaking her head]

W4: ... And like a burning ... And I can't walk that much because I can [not] stand, because my, my feet, I can't stand my feet up that much."

Both gentlemen had multiple health issues; some interfered with DSM.

M1: "So, I haven't had a seizure since before the surgery. I haven't had one since then. And I was having them pretty often. I'm still on the medicine Dilantin and phenobarbital. Later he mentioned, '...have high blood pressure... had a heart attack in 2005.'

PI: Are there any things in your life that get in the way of your taking care of your diabetes?

M1: Still my health, because I have a back problem... [earlier he said] It's been a little hard because I can't exercise right now because of my back. Twice I've been walking and I end up hunchback, you know like down, looking at the floor.

M1: I have arthritis in my spine, or here too [neck?], and my knee. Both knees actually, I've had surgeries on both knees.

PI: You also mentioned your heart, that chest pain [that you still get periodically] ..."

M2 has a long list of health issues he continued to deal with daily. He talked with pride about how he had overcome some of these and was resolute about continuing to deal with others.

M2: "You know what else I have too, of the past against seizures?

PI: You had what?

M2: Seizures. [He asked his wife how many years ago? He was told it was a long time]

PI: Were you drinking at the time?

M2: Yeah, I think so ... yeah [said a bit sheepishly; avoiding eye contact with his wife at the other end of the table].”

By history, he apparently went into a coma with the second one that was very disturbing for his family and frightened his wife. He had been told by his family that he had no idea what he went through, but it was apparently traumatic and very hard on the family.

M2: [Later] “You know I used to have cancer back then but it was when I get diagnosed. I was going to [a different HCP] I remember then, and I became with some other problem, which is sleep apnea.

PI: Sleep apnea?

M2: So, I was dealing with that too... I went to be checked for that twice and they say...’so you need to live with a machine.’ So, yeah, I put the machine on myself ...yeah, I’ve been sleeping perfectly ...yeah, more like forty (years)...”

Summary of clarifying DSM. In summary, all of the participants understood how essential keeping to the diabetic diet was for daily BG control and how difficult that had been for them. All of them relayed, that there was/is an inner battle, a struggle that took/takes place, on most days for the person with dT2D to remain steady on the diabetic diet - including correct portion control. W2 and W4 did not know correct portions; it did not seem to be as much of a struggle for the others, but might not have been disclosed. As reported, all of them knew that daily exercise was an important way to control their BGs; most did some form of exercise at least a few times a week, or had in the past, or plan to in the future. Due to health/injury

reasons, some of them had sound limitations (W1, M1); M2 has significant schedule issues. With the exception of M1 (diet controlled) and W2, each of the others were taking medications and W2 planned to restart. Only W6 was using supplemental exogenous insulin along with oral medication. Each participant knew the importance of keeping track of their daily BGs. Several had had T2D long enough that they felt they knew when their BG was in control or if it was high or low; reportedly there was fair accuracy, but not complete. Thus, some did not SMBG daily. Most had the standard quarterly A_{1c} lab test approximately every 3 months with the exception of W2 as discussed above. Initial DE was far less standardized with some having good classes, others having good reading material, and some having received little or incomplete education. Several were willing to go to refresher classes (W7 - W10); W6 and M1 were in current classes. Most mentioned other disease/ illness factors; some might have given only a partial list. Each one who reported another ailment did indicate interest in keeping it in control or that they did not want it to not interfere with their T2D.

Key Factors Identified as Influencing DSM

The second major Influencing Condition category was the Key Factors Identified as Influencing DSM. Within this important category, eight primary subcategories were identified: Social and cultural influences and expectations; initially validated as a contextual dynamic in Context, earlier in this chapter; Scientific health care knowledge; Personal characteristics; Experiencing conflict and life difficulties; the Importance of having support; English language comprehension and use and differences in cultural understanding; Access to care; and Pre-discovery

signs and symptoms. Each primary subcategory has sub-subcategories, as seen in previous segments of this chapter. Key Factors Identified as Influencing DSM.

Facets of life, culture, and personhood substantially influenced DSM of the participants. As interviewing ensued, the following dynamics, conditions, and issues that influenced the decision-making and DSM choices of the participants unfolded. Powerful, deeply-rooted, socio-cultural factors such as norms, expectations, roles, and social rules, discussed previously in the Context section of this chapter, had significant impact on the participants' decision-making. The role of permission for a woman to care for herself, at times before the family, and the role of machismo directly affected the decisions about and execution of, or failure to execute DSM; the social requirement to *be proper* were all critical factors. Many previous exemplars suggested a wide range of understanding about the health science aspects of diabetes and care; how these impacted DSM will be elucidated to reveal the influence of a cultural filter on understanding health science information. Personal character strengths and qualities that played an important role in DSM will be demonstrated with attention to those dynamics that motivated participants toward DSM. While struggles and conflicts were normal aspects in life, there were a number of potent issues such as loss, trauma, and grief that significantly affected their abilities to address DSM. The importance of various types of support and influences of unique language differences will be reflected; these were important to the participants' understanding and HCP communication. The necessity of access to care had a clear effect on this cohort's ability to strive for +DSM.

Social and cultural influences and expectations: Role – permission, machismo; “a little bit”, Being proper; and Cultural myths. Based on earlier entries, the most pervasive Intervening influences were the social and cultural effects. This ranged from issues of role, being proper to employing cultural-based health practices. Of particular interest was the concept that a woman needed approval or permission for self-care; this had important ramifications for the role of mother in the family. Strong elements of societal rules, particularly *being proper* and respecting cultural expectations, had significant impact. Cultural and individual health beliefs, passed on for generations, were salient filters through which T2D and DSM were viewed. The influence of culture was remarkably strong, deep, layered, and far-reaching

Role. The importance of permission. Within the first two IVs, it was noticeable that some women approached DSM with more personal liberty than did others. For example, W1 had a very different life experience than did W2. W1 did not care what others thought of how she managed her diabetes. She did not worry whether she satisfied a hostess or offended someone in declining food the other had prepared for her.

PI: “... Does the way they [family and neighbors] take care of their diabetes, affect, any...?”

W1: “No, it doesn't affect me because ... I know what I have to eat, and not to eat. If I eat at my house and I go visit her and she is having dinner, they offer me something [she demonstrated], ‘No thank you. I already ate’ and I take [took] my medication, I have to wait.”

Throughout that IV, it was consistently clear that W1 did not need anyone else's approval or permission to practice positive DSM. She had her own permission to do whatever was necessary to manage her diabetes with great success. Being raised most of her life in the United States, it was apparent that she was more individualistic in mindset than most of the other women interviewed (W2-W8). There was a stark difference in the approach and underlying attitude of W2. During that second IV, it became clear that W2 needed some type of *permission*, although it was generally unspoken, in order to feel comfortable and valuable enough, to make choices to actively manage her diabetes. It was as though she needed permission from her new husband, who was supportive, and eventually from herself. The several-year delay in seeking continuous diabetes intervention due to life hardships and not being able to act on her own behalf, had seriously impacted her diabetes. It went unaddressed for most of the twelve-year gap between her diagnosis to shortly prior to the IV when she was about to be restarted on medications. She had treatment only during the first year of T2D. The following excerpt demonstrated that she had more personal permission when her husband suggested she might need treatment. It showed motivation for care, with the intention to not lose a digit or extremity due to diabetes. Finally, it demonstrated that they worked together on their diabetes. He was diagnosed only two months before the interview.

PI: "... and then recently you have, you returned to the doctor for medicine, so that's another thing that you are doing. And that's new again, because it's been the 12 years I guess. And then now, with him using his insulin,

did that help you to think, 'oh I should do the medicine, too?' So, did that help to motivate you also?

W2: Yeah.

PI: If he didn't take the medicine, do you think you would have gone back to the doctor to take the medicine?

W2: No, because like I told you I was feeling good, and then I had my ingrown nail and I was feeling bad. I said 'why is that?' and he told me 'maybe because you are not taking medicine, maybe because your sugar is high or you don't know...'"

A recurring theme in women was that they either felt the need to have permission or, moreover, a permissive attitude from their own husband or other family members. W10 brought clarity in her response when asked about the concept of '*permission* for women to take care of their diabetes:

PI: "Sometimes women especially, seem to ... 'need permission' to... I mean inside they think 'oh, it's okay for me now, because my family's okay, and now I can take care of me.' Or other people in the family are saying 'something's wrong, you need to go' [to a HCP]. And so, they either feel 'okay' about it inside themselves, they have their own permission... or the family or other friends are ... giving them permission. Do you understand that concept?"

W10: Oh yes, yes definitely.

PI: ... talk to me about that. Why is permission important?

W10: Yes, definitely ... It is. Permission is very, very important because it's within our culture. We were taught to obey in spite of anything. And so,

PI: As women?

W10: As women. And so even with... It happened to me when I was just married, I would ask my husband if I had permission to do this and permission of that, and he would look at me and says 'I married you, I didn't buy you!' [He was American]

PI: Ah, so he 'gave you permission,' so that wasn't a problem for you?

W10: Uh huh.

PI: You know that's a very interesting thing for a man to say. [her husband]

RA4: Exactly. Different cultures.

W10: Exactly, different cultures, and in Mexican or Latin culture, you have to be allowed to take care of yourself, or to do anything without your husband's permission ..."

Interestingly, even those women whose husbands were very supportive of anything the women needed to do for their diabetes, looked out for the welfare of their wives, and supported choices that benefitted them, several women still felt the need to find permission from their husbands. Often these women indicated they also wanted or needed the support of their families. For at least one participant, W5, it was revealed to her during the IV discussion that she actually needed permission from herself. She discussed the challenge of being busy, having to put family first and not eating correctly during the day; often before her long, daily, exertional

exercise. She repeatedly lamented her hunger for bread, cakes, and candies, and disappointment about her frequent lack of self-control over those urges when hungry and fatigued.

Following data gathering for the study, W5 expressed exasperation that she did not know what to do about her low BG symptoms and fatigue after exercise. Aware that the participant lacked understanding about calorie use when taking medication and doing vigorous exercise (Park, Park, Quinn, & Fritschi, 2015; Swavely et al., 2014), the PI (in a nursing role) responded by making two suggestions on how eating more before she exercised would help her to avoid low BG after and help to manage her cravings. While patient education is typically not done in a research study, in good conscience, the Nurse Practitioner-PI, could not deny responding to her questions. When given practical advice, W5 responded with exuberance that she would have a way to approach those challenges more successfully. Due to her lack of confidence in communicating in English, RA1 assisted with mutual translation

RA1: "So, she's always busy with the household and her kids so she doesn't eat when she's supposed to eat, and then at the end she takes care of herself and that's when she feels very fatigued and down.

PI: So, that's one thing she can change that will help her feel better.

RA1: [Spanish to W5] Maybe that's something you need to do to feel better.

W5: Yes. I *have* to do something for myself... in the same way that I exercise I need to start doing something for myself first.

RA1: But you can eat one slice of bread.

W5: One slice [holding finger up and nodding head]

RA to W5: Spanish: Because your body will burn it right there [during exercise].

PI: She also won't have as much fight [inferring battle] inside: 'I want the bread. I can't have the bread' [using hands apart to show one way then another] Comprende senora?

W5: Yes! [Smiling]

RA1: If you eat some before the exercise.

PI: She'll feel better with the exercise. And she won't fight as much. But I think that will help her with her energy, and ... [explaining the use of glucose better] ... So, if you take a little better care, you eat more regularly, Señora, it's a possibility you'll feel a little better. And then you practice that ... every day.

RA1 to W5: per the above in Spanish.

W5: I promise you I will. I will now. I know I have to do it" [Said with relief and conviction].

Sometimes a woman needed external permission before internal. W3a, who initially was the test interviewee, originally gave the impression that she felt free to care for her diabetes, in part because her husband was so supportive. As this and other concepts developed, it became important to inquire of her about the major study constructs, especially because she had served as a RA and had given thought to the line of questioning. She told the story of how recently she finally came to have personal permission to care for her diabetes before caring for others, when needed,

because she had always chosen her family first. Later, she clarified that, in her personal self-reckoning, even with her husband's support, external to her, she had to have it inside herself. [See Social independence in Personal Characteristics]

PI: "You're socially independent. You are taking care of yourself.

W3b: Yes, but I'm starting. I just recently, maybe 3 months ago ... 5 months ago, but before I was kind of reluctant.

PI: Wow... What's required for a woman to be socially independent, to do what she wants to do whether others understand or not, for her to take care of her diabetes? What changed in you, because you just said 5 months ago ...

W3b: For my family. I want to take care of my children.

PI: Okay, so you realized 'if I don't take care of myself I'm not gonna be here, so I have to take care of myself so I can ...

W3b: Right. ... And the reality is if you have a huge family, nobody else is going to suffer more than your children and your husband ... Yes, that's what make me change, completely change.

PI: Wow. I wish people understood that. So, it was really understanding that you have to be the one to do it, right? [personal permission]

W3b: ... Right, I like to know that they are safe. I want to prevent them from getting some kind of illness - the same as I have.

PI: Good for you. And so, what interferes with a woman being independent? And it sounds like you were feeling obligated that you had to serve others first, before you felt free; 'cause now you feel free.

W3: Right, but when I was working, I was hiking and I will eat whatever I had and then start working because I wanted to give them [what they need]. And then we will sit everybody together, but I was really hungry and I was myself second place because I wanted to cook first ...

PI: Right, so the interference was that your value was 'I have to serve my family first.' Okay, and that actually did interfere [with her BG]?

W3b: Right.”

It was eventually clear that some participants needed to sense permission from God to practice positive DSM. As evidenced in Context - Cultural Health Beliefs, faith in God demonstrated the need for some to gain a sense of God's permission also, prior to being free to routinely practice positive DSM (W7, W10).

There were very distinct differences in the need for permission for DSM between genders. Since the men were questioned later in the IV process, most of the women were interviewed prior to seeking the men's clarity about this concept. When the inquiry was made of M2 about this concept from the perspective of a man, it was very difficult for him to discuss it. He appeared to be a bit embarrassed – hesitated with an uncomfortable look on his face and he tensed up at the question – about the gender aspect of his culture, but he clearly understood the concept. Neither the PI nor the RAs sensed any need for permission for DSM from either man and comments by the female participants supported that finding.

PI: “Now I'd like you to help me understand something important about the differences between men and women in the culture who have diabetes and how they take care of it. A few of the Mexican women have said that

they have to take care of their families before they can take care of their own diabetes, and ... it's important that they have encouragement from their husband, and their husband actually gives them permission to take care of their diabetes before they feel free inside to take care of it themselves. Does that make sense to you?

M2: Yeah, uh..." [nervously nodding comprehension and fiddling with a napkin.]

He uneasily explained the importance of the family as always being the first priority and eventually blamed the matter on machismo. Per the earlier example (see Context - Machismo), the more macho the family orientation, the more this type of attitude was seen. Due to the focusing issues and lengthy health history stories of M1, this concept was not explored with him. Further searching the issue W3b affirmed that men typically have their needs addressed in advance of women.

PI: "Is it different for a man to take care of himself?"

W3b: No, I don't think so. Men are even less responsible to take care of themselves.

PI: But that means they have more liberty to take care of themselves?

W3b: Yeah, more liberty.

PI: So there is ... 'cause it seems like if both people need help, it's more often that the woman makes sure the man gets his stuff taken care of [first].

W3b: Right."

The role of permission for women in DSM was an important factor as illustrated. This was one of several socio-cultural role dimensions that impacted decision-making in DSM. More women required external permission to address daily DSM than those who did not. There were deeply entrenched, cultural foundations supporting this community- and family-oriented social requisite. Women needed permission from their husbands, sometimes their families, at times from God. No matter from whom the permission came or how much was offered, even by generous, kind, and concerned husbands, for some women it was not until they had permission from themselves that they took better care of or, as in the case with W5 who had gained personal permission during the IV process, planned to apply new practices based on her new conviction that she had to take better care for herself and her family. Men had an opposing factor that influenced and affected their choices and how they made DSM choices.

Role. Machismo. Various aspects of machismo were spoken of or alluded to throughout a few of the IVs. It was actually W10 who went into extensive detail about it and how profoundly machismo could affect DSM. She shared a lengthy and detailed story of her father who had T2D most of his adult life. He was bright, well-read and successful, involved in real estate, and fought for the social rights of those less privileged; those who worked in the fields. He was a very principled man who refused to sell his real estate to people who would build homes and take away the livelihood of fieldworkers. Her father was respected broadly and adored by his family. Sadly, he caused great heartache for his family because he refused to care for his T2D. When her older sister, a nurse, repeatedly pleaded with him saying, “you’re

risking your legs, your circulation” because he refused to exercise, his response was “Let them cut my legs. They’re mine to cut!” Initially he lost his toes, then his ankles and knees, eventually his legs were cut off. She shook her head and said over and over “I could never figure it out.”

During a lengthy discussion, she and her sister visiting for an extended stay discussed the Spanish/Mexican terms that described the macho aspects of her father that made him refuse to practice positive DSM, to essentially ignore his T2D. She attributed two important descriptive terms within the concept of machismo. The first term, *orgullo*, [pronounced orr-gu-ooe-yo] had been brought up in previous IVIVs. The sisters described the notion of *orgullosa* as an arrogant pride; the second was *soberbia*, being arrogant. W10 and her sister in the adjoining room discussed *orgullosa/orgullo*. They described *orgullo* as a type of arrogant pride, that their father had the attitude,

“Nobody tells me what to do. I know what to do. It’s my own body because I’m more intelligent than anybody else’, and he was ... He was but, that’s why if he was intelligent, that for once it did not *click* with that intelligence.”

They wondered how such an intelligent man could act so un-intelligently. She further reflected, “so I guess intelligence and the wise-ness is different thing.” PI: “Yes... wisdom does not equal intelligence.” Another term had been used in prior IVs that resembled the meaning of *soberbia*, but this fit their father better. Eventually, she summarized that he initially had arrogance, *soberbia*, as the one who knew the most and no one could tell him what to do. Later, he simply was too proud, *orgullosa*, to do anything he was advised to do. “First, it was *soberbia* – arrogance.

Then it was, *orgullo*, pride,” all within the realm of machismo. They indicated that his arrogance and pride completely interfered with his health; it confirmed the force that machismo could exert on DSM. Ultimately, he ignored what was taking place and eventually had serious arteriosclerosis worsened by his uncontrolled T2D; he died far less of a thinking man.

Exploring the idea of *hiding* diabetes (see Interactions, Actions, and Decisions), a revealing conversation with M2 arose wherein he validated these machismo concepts with illustrations. Interestingly, he was inadvertently “put on the spot” somewhat by the PI’s question about machismo. When he hesitatingly admitted that *orgullo* and *soberbia* might have something to do with why a man would be more likely to hide his diabetes in a public/group gathering than a woman, he actually illustrated how machismo could cause a struggle within a man to have to admit something he was not comfortable admitting; whether about himself and/or his culture or both.

PI: “One of the things that I’d like to hear from you as a man is that some people think that it’s more likely that men are going to hide it [DM] than women. What do you think would be more likely from a culture standpoint? Would it be more common for a man to just not admit he has diabetes in the setting, or would it be more common for a woman in a party setting ... to not admit she had diabetes? Do you have any idea about that?”

M2: I believe it is a man, the man is more common.

PI: That's what I've heard more often. And tell me why in the culture ... would a man be more likely to hide that information, than a Mexican woman?

M2: Why men? I have no idea. I say it depends, I guess [?]

PI: Well I'll tell you why [I ask]. I've had a couple of people talk to me specifically about orgullo and also soberbia. Sort of the arrogance and the pride-end of the man's person ... and I wonder what you think of that as man? Do you think that might make a difference for some men?

M2: [silence]. [Looking intently at PI with a serious and somewhat questioning look on his face; questioning how to respond; prompting her to say:]

PI: That's a hard question. I understand, for a non-Hispanic woman to ask a Mexican man. I understand that's hard, and I'm not trying to put you on the spot, but I would like your insight as a man from the culture. So please, I hope you're not offended by that-

M2: No, no, no, no.

PI: Because ... I would like to understand it better, because when I work with people, I want to respect where they're coming from better ...

M2: Right, right.

PI: So, going back to the question about hiding it ... if you think it would be more likely that a man might hide his diabetes than a woman – at a party or a fiesta or something, do you think it would have anything to do with orgullo or soberbia?

M2: I guess so [laughs nervously]. I guess so. Yeah ...

PI: Why do you think that? From a culture, it's from the culture standpoint.

M2: One of the reasons I believe this that when you mentioned that kind of ...
see the culture is normally [pausing], I mean [pausing], you can
embarrass somebody I believe.

PI: Oh, okay.

M2: You know to say anything about it until people knows that you have it,
or when [?]

PI: Okay, that you're embarrassed about diabetes?

M2: Well, to, to say that I have diabetes is [?]

PI: Yes, embarrassed to, to say, unless you have to ...

M2: Exactly, unless is a person that knows I have it, then that's fine."

He went on to give an example of when a [Latino] supervisor of his made fun of him when he needed to take a break to eat because of his diabetes. The other man responded "It's not time. But, you know what? I'm diabetic too. *I'm diabetic*" [inferring that if the boss could wait, so too could M2]. So M2 could not deal with his diabetes at the time as he needed. He added that 1 year later, that young supervisor, "he is younger than me!" had surgery for a foot infection from which he never recovered. M2 said the thought, "this guy was making fun of me and look, he's gone ... he's dead." Processing this story, the PI understood he was illustrating an aspect of machismo and asked:

PI: "That looks to me like orgullo. Doesn't it? [referring to the prideful attitude of the supervisor]

M2: Exactly, exactly.

PI: ... and forgive me if this is offensive ... but I don't mean it to be at all; but a little bit machismo like 'oh, I'm gonna put this face forward that 'I'm okay and everything is right,' but obviously not everything was right...

M2: Yeah, that's right [nodding] ... yup, yup."

Another *macho*-related term that was used by a participant was '*testarudo*', which was described as "stubborn, a proud stubbornness." W7 said "this is how I'm going to do it. You can talk all you want and I'll say 'yes,' but I'm going to do whatever I want to do and do it my way." W10 described "*tosco*" as "coarse, rough, unpolished;" these terms were said to apply to some men's form of macho. Because of the high social status of W10's father and personal refinements, this did not fit him. In explaining it further, RA2 confirmed this when she said somebody was so strong-headed, "even if they know they're doing wrong they say 'I'm going to do it my way and if it's wrong, it's wrong, but I'm going to do it my way, not your way, because my way is better!'" Shaking her head, chuckling in the conversation, she added, "that's how my uncle and my father are – they're going to do it their own way, even if it is not the right way!" (personal communication, RA2, 2015).

Machismo was a strong force in some men which interfered with them addressing their diabetes needs. The worst case was the provincial and dignified father of W10 who ultimately failed DSM. His arrogance (*soberbia*) about diabetes and his pride (*orgulloso*) caused him to do things his way, whether right or wrong, led to the loss of both legs "they are mine to lose," cardiovascular complications of routinely high BG, and loss of his life. When queried about these machismo

dynamics, one male participant was guarded in a macho kind-of-way to admit this about Mexican men, but he did admit it and gave an illustration of how his supervisor's macho interfered with M2's DSM and led to the other man's demise. The RA confirmed that she saw aspects of machismo in her male relatives as well; strengthening the dynamics.

Needing to have "a little bit." As is common for Mexican persons to hear the cultural mantra, "Have a little. It won't hurt" and "Come on! Just try a little. Try it." referring to foods, desserts, and all sorts of beverages that were, at times, forced onto people. M1 relayed, "And there have been times when I'd go to a party or something, and they have the cake all cut up and they're like, "You want some?!" [demonstrating how people force cake toward his face similar to a bride and groom at a wedding; and he had to pull back away from the somewhat forceful gesture]. The common saying, "it won't hurt" apparently became internalized because some of the participants said that this was what others told them, especially at social gatherings. It appeared to be common to believe this mantra.

PI: When they tell you, "yes take it, yes take it" does that interfere with your plan; what you want to do to take care of your diabetes?

W8: No, no. No, no. I take, or I take whatever and I am easy going. Yeah, I am ... Because I don't like to, I don't like to argue, I don't like to fight. I am not good at fighting ...

RA2: She just accepts it, that's it." [Indicating she will take what is offered or pressured upon her so as not to make a cultural disturbance.]

Several participants used the term “A little bit” indicating (s)he ate a small portion or tastes of various kinds of foods, especially when offered, which was routine. Discussing how she tried to always take care of herself, W6 reported “... I’ll just eat a little bite ... I like cakes a lot but I eat ‘just a little bit.’” RA1 interpreted after W6 spoke partly in Spanish, “she’ll just have ‘a little bit.’” W7 illustrated how having “a little bit” can satisfy one who does not want to wait to eat something healthy,

“But sometimes you feel like you want something and you can’t wait, like you can’t do it because you say ‘ah, well maybe I eat a little bit or this piece of cake is not going to kill me, it’s not gonna be’ ... It’s hard sometimes. It happens to me sometimes.”

It was customary in the culture to have food and drink forced on them at gatherings with the underlying attitude and insistence of “it won’t hurt.” It was also customary to try, “just a little bit” of whatever was offered. Conversely, sometimes they just could not resist and the way they dealt with the temptation was also to have just “a little bit.”

Being proper. “I cannot say ‘no’.” A significant intervening condition was the importance of *being proper* in order to be socially polite. As established in Context - Social expectations, social expectancies were/are a very important aspect of this community-oriented society. Initially, W6 brought up the significant importance of *being proper* within the culture. The PI inquired if it is sometimes or always difficult to decline food that was offered? W6 replied shyly, “sometimes it’s difficult for me to say ‘no’ ... So, I eat something or ‘a little.’” This helped to also

explain why “a little bit” was so important; it was reportedly part of how people in the culture maintained being respectful and proper. When exploring this concept with M2, who understood and spoke English well and was married to a NHW American woman for over many years, it brought clarity to the importance of *proper*. Additionally, in further support of the concept of “just a little bit” above, he illustrated how having just a little bit could satisfy the cultural need to be proper. The following lengthy exemplar illustrated both of these points very well.

PI: “Okay, so let’s put it in a situation where ... there are definitely foods that are not healthy for you to have, or to have very much of. What’s expected of you? Is it expected of you to at least try things?”

M2: Well, if it’s there you have to try something, you know?

PI: Okay, so there’s sort of a social obligation?

M2: Exactly.

PI: Okay. So, there is a social obligation to try, to taste. And what does it mean when that man ... you, but when you say ‘No thank you’ to a lady, she prepared food, she expects you to eat it, and you really feel like you have to say ‘no thank you.’ Are you able to say ‘no thank you,’ or do you feel that just to be proper and to do what is right from the culture and not to offend, it’s just important that you taste anyway.

M2: Well, yeah. Taste anyway. *I cannot say ‘no.’*

PI: Okay and part of it that really is being socially proper, isn’t it?

M2: Exactly, that’s all. It’s the biggest point ...

PI: Well, the reason I ask is I've had several women tell me that it's a lot easier to say 'no thank you', or 'I already ate.'

M2: No, that's ...

PI: That's not true for a man?

M2: Yeah, it's 'just a little', have a little taste ...

PI: It's not okay? [to say 'no']

M2: Exactly.

PI: But it sounds like it's specifically not okay for a man.

M2: No, I mean you gotta show yourself respect for what they offer you ...
You cannot say 'No, I won't eat that stuff.' I mean I can['t], it's ...

PI: Cannot say 'no.'

Wife: That would be *rude* [said firmly to support that she understood the cultural expectation].

M2: *Exactly.*

PI: Right, okay. It's rude. Thank you."

Soon after, when clarifying the construct further with W3b, the PI questioned, "So what does it mean when a man says 'No thank you' to a lady who prepared food for him.?" W3b: "It's wrong!" When asked about gender differences in declining food, W3b asserted, "No... don't think it makes a difference if it's a man or a woman." She supported the underlying social requisite that people in the culture were expected to accept, and try "a little bit" of food offered to avoid being rude and disrespectful to the hostess; this was how being proper was expected. In this case, the social pressure sometimes exceeded one's self-care needs [W6, W8].

Interestingly, there was some room for exception to this important social rule when the person with diabetes was known by the hostess. W8 talked about the importance of trust in a relationship. Being polite/proper was most important when one did not know the person or did not know them very well. She indicated one could decline if one knew the person, it was okay to say, 'I don't want any, no thank you'... 'Or, if it's someone they know you are sick [have diabetes], they'll know that it's bad for you or something like that...' RA2 translated "what she is saying is it's less worrisome if you know the person well ... If she really knows that person well, she is going to say 'no.'"

An aspect that made it more difficult for participants to escape having to accept some food or at least try 'a little bit' was the social pressure mentioned in Context – Proper. W3b illustrated the persistence of those hosting, PI "There's a lot of social pressure in the culture?" "Exactly. Because they want to meet you or to have you at their celebrations, and you say 'No thank you, I'm full', she said the hostess quickly insists, 'oh, just a little bit.'" W8 described the insistence on accepting food as temptation; the hostess tempts people with food because she knows the appearance and smell will tempt people to eat her food or eat more of it once they tasted it. W8 said that she would eat/taste "A little of a little" ... "It's more like temptation." Another aspect of the social pressure was to not want to stand out, "Cause everybody, *everybody* take it [indicating others say] 'yes'; I say, 'oh no ... [thank you].'" In this, W8 indicated that she stood out from the others as different. Because standing out went against the cultural standard to be like and to choose the group before one's self, she has felt pressure to blend in so she has felt compelled to

take the food. There were times when participants had declined food and saw that the hostess appeared offended or hurt. So as to not offend or hurt the other, they felt the social insistence to take food as they specifically did not want to hurt the other person's feelings.

W8: "You feel better ... they say, 'oh come on, eat, yeah, come on.' 'Okay, okay, just a little bit then,' then a little bit, I take just one piece.

PI: ... Again, is the politeness thing.

W8: [nodding] And sometimes they insist and you feel bad ... okay, just 'a little bit.' And I take the plate, and I take a little bit.

PI: Yeah, you just taste it and then you are done.

W8: Yes..."

Curiously, it was made clear by W6, and later by others, that there was a distinction in comfort in declining food when one was in the United States versus in Mexico. While it was difficult to decline food that was offered, "say no" here in the United States, it is reported to be much more difficult to "say no" when in Mexico. W6 described the pressure she felt as "Yes, come on, come on! It's really good. Look. Look!"

RA1: "A great example is for her - it was hard to say 'no' because she was visiting, so it's hard to tell people "No, I don't want the food you make for me."

PI: Oh, Okay. She doesn't want to make someone socially uncomfortable? Is that, right?

RA1: Um hmm.

W6: Yes. It feels ... one thinks that the person is doing it as a rejection.

PI: So, would the other person be offended that you said 'no' because they think you don't want it?

W6: [Spanish with a little sassy tone]. Yes, 'Oh, such a nuisance! She doesn't want to... she doesn't want to eat my food!'

RA1: She says the other people say 'oh, she doesn't like my food!' 'She's annoying' ...

W6: Oh, how annoying, just because she comes from the United States. [Still referring to the way people react]

PI: So they take it personal ... Is that, right?

RA1: People take it personal and she's visiting from the U.S. so people would think 'oh, she thinks she's better.'

PI: Ohh, 'she's too good to eat our food.'

W6: [Spanish] Here I could say, 'no thanks' I already ate something, but over there... [slowly shaking her head]

RA1: And its part of the culture. And our people come and you serve them whatever you made for them ...

W6: [Spanish] 'No thank you.' I say, 'I already ate.' They don't get offended or anything, because like you said, we are different here ... We are different here and different in Mexico.

RA1: Yeah, and here she can say 'No thank you, I already ate', but over there it's very offensive if you don't eat what you've been offered.

PI: Okay, so let's talk about that. So, you can say, it's okay here in this (United States) culture to say 'oh, no thank you, I already ate', or 'I'm not hungry.' It's okay here?

W6: Yeah, here, yes.

PI: Okay here to say 'no.' When you are here, Senora, do you say 'no?'

W6: Here? Um hmm. 'No thank you' I say. Yeah.

PI: Yes ... right. [understanding what was said]

W6: I came here, I was 'no thank you.'"

W8 lent further insight to the roots of this social requisite and demonstrated how it was easier all-the-way-around to decline in the United States, the social requisite to properly take from the hostess had not been eliminated.

PI: "But it's much more difficult to decline when you're actually in Mexico?

W10: Yes.

PI: And that it's really sort of an insult ...

W10: There you go, that's it. You got it!

PI: Okay ... it's easier here [gives an example of declining here]

W10: Uh huh. I would say it very politely, 'Thank you,' but in Mexico ...

PI: You really can't?

W10: It's very difficult because they might feel insulted.

PI: Yes, that's what I've been hearing. And ... that it's - partly because in the culture it's literally more proper to eat what you are served because the hostess or someone has prepared or paid for, whatever's being served and it's your role as the guest to eat that, whatever that is.

W10: Um hmm.

PI: But there's less pressure here in the States for that?

W10: Oh, yes, oh yes, all the way around... Yes, it's less pressure here."

Although culturally it was not appropriate for women to say "no thank you" to a hostess, it was easier to do so in the United States and amongst people whom the participants knew. In contrast, in the matter of saying "no" to a hostess, gender made a difference. When asked whether there was any difference in saying "no thank you" in the United States or Mexico, there was a definite difference for a man; he did/does not have the liberty socio-culturally to say "no" in the United States or Mexico as reported by M2.

PI: "... So, when food is offered that you shouldn't eat, is it easier to say 'no thank you,' ... Let's say one of your children is married to a woman whose mama is in Mexico and you go to visit for a holiday. Is it easier to say 'no thank you' to someone in Mexico or to someone in the U.S., or is there a difference?

M2: No, it's, I mean, I think we feel bad to say 'no,' I mean you get it to be ...

PI: You feel bad either way?

M2: Exactly."

As discussed above in Context – Roles, when he was young, M1 felt more social pressure to be proper. The sense of social obligation diminished when he had multiple severe injuries and illnesses that required a change of diet and habits. He learned to "say no" as a function of changing habits to preserve his life and health. He felt he had no choice but to decline.

W3b offered some insight into these location-influenced decisions. She mused that what might be part of the basis for the cultural expectations. “Well that’s the case of when you live in little towns. It’s maybe not even related to the gender or the generation. It may have to do with the culture within the town or the city... more metropolitan... More [cultural] freedom [in the big city].” When the PI questioned if maybe “people in a small town are probably struggling to make ends meet, and if they make food for you it would be rude to not eat the food they spend their little bit of money on?” W3b agreed with the surmise, “Right.”

As established in Context, being proper was one of the most essential social requirements of the culture. In the case of food and festivities, men had particular pressure on them to have “a little bit” because they “cannot say ‘no’” because it is wrong socially. Some female participants were able to say “no” if they knew the hostess; others were trying to learn to be more courageous and place their diabetic needs at a higher level. Other women took what was offered to avoid being socially different. It continued to be more difficult to say ‘no’ in Mexico because social properness had higher criteria. In the United States, for women it was easier to say “no” and the culture sounded like it was moving more in that direction. One male participant was finally able to learn to say ‘no,’ especially to his family because he realized his health was more important.

Practicing cultural health myths. Another socio-cultural aspect that impacted DSM were culturally-embedded beliefs and values that had, in part, created sometimes-less-than-accurate health ideas compared to Western practices supported scientifically (Chamberlain et al., 2016; C. P. Wang & Hazuda, 2011). At

times these information bits had a cultural myth-quality as the information was not substantiated by health-science knowledge of positive DSM. It was/is true that this population knew/knows a lot through the cultural avenues of T2D; however, having this passive knowledge did not mean it was correct or adequate for DSM once an individual had his or her own diagnosis (Coffman, Norton, & Beene, 2012). Simply having gained information by overhearing others talk or observation did not guarantee accuracy (Weller et al., 1999).

Naturally, cultural health beliefs and practices have been passed down from Mexico, such as the pineapple juice with cactus mentioned in Context - Preferring Natural and Herbal by W7 and similarly by W10. However, sometimes cultural information did not help control BG, according to W1, whose sister said she would “Leave it to God,” who was more enculturated in the American culture; having been raised in the United States since age 10. Some reported social-cultural knowledge had truth but an aspect of it was not true, having an inaccurate or myth-like quality. However, to clarify, from the view of the Mexican person with diabetes, it was not seen as incorrect or a myth. The example below demonstrated what happened when one depended upon cultural health information and practices over known scientific facts (Rogers, 2010). It led to elevated BG, offered a false hope of getting well, and interfered with sound health science advice that had been known to lower BG levels. In the following lengthy exemplar, W3b described what she used to believe in the past. At the time of the IV, she continued to think that this perspective remained a common view of how medications affected and worked in the body. It was a clear example of how an incorrect choice was made about medications based on

inaccurately viewed information. This false or mistaken belief delayed BG control for several years; she had since learned accurate information and was practicing safer BG control.

W3b: "I knew if I delayed the use of metformin I would do my body less resistant to the sugar.

PI: Okay, I want to understand that...

W3b: The use of any kind of medicine for diabetes, then I would delay the process of my body to be more resistant, to create resistance.

PI: Alright, if delayed the use of diabetes medicine, will delay the development of resistance [taking a note]. That is misinformation...

W3b: Uh huh, I was ...

PI: People don't know though ... Instead, the sooner we have medicine, the sooner we protect our organs.

W3b: Exactly.

PI: I'm sure you do [know] now. And if this is the undermining philosophy, then I'm going to be able to help people who are first diagnosed, or who are at risk.

W3b: I understand and tell people they not be ... it's a normal situation [diabetes] that can be controlled. Is not for ... the medicine will not kill you. This is the one [diabetes] who will kill if it's not in control.

PI: Exactly.

W3b: And I just didn't want to have ... I never take any aspirin, you know? I never take any kind of medicine so why I was going to be attached to a

daily routine of medicine, you know. They will kill. [in her prior thinking]

PI: ... So, what is resistance to the 'degrading of glucose?'

W3b: Resistance for your pancreas.

PI: Okay, now this is what you believed before, not what the truth is.

W3b: Oh yeah. I believed before that my pancreas needed to work by itself in the beginning, because I was thinking about having my pancreas being lazy.

PI: Oh, my gosh.

W3b: And I say if I take the medicine then my pancreas will stop. Eventually maybe I gonna go on insulin.

PI: But you were afraid that the oral medicines were going to eventually make the pancreas not function?

W3b: Exactly, to develop more resistancy.

PI: Oh, my gosh.

W3b: So, I say 'I know eventually I'm going to have pills, but I want the most I can hold it [using hand to indicate to keep the BG level down] with exercise, but I think that I remember still the time that I was so tired and is when I made it for sure to take the medicine.

PI: Something wasn't working?

W3b: ... weary mind. And I was confused and I didn't ... so yeah, I should take it since the beginning. I should take ... the medicine since the beginning.

PI: Yes, for sure, absolutely. But you're taking great care now ... Okay, so you thought before that the pancreas needed to work by itself, and you were afraid that the meds would make the pancreas not function?

W3b: Uh huh, or be lazy, not producing the amount of insulin that should be producing without any kind of outside effect [meaning stimulus]. You know?

The culture practices founded on inaccurate beliefs were revealed.

Sometimes the information was based on beliefs that were founded on cultural beliefs or deductions about what was claimed to have been helpful. Complying with those beliefs sometimes meant participants had inaccurate information on which they made decisions. These cultural health myths occasionally were due to inaccurate health science information or knowledge (Rogers, 2010) that has been shared through social knowledge or was outdated as reported above. Errors in health science knowledge will be demonstrated in the following segment.

Summary of social and cultural influences and expectations. The role of permission in DSM for Mexican women had an important impact on whether she had liberty to choose care of her T2D before the needs of her family. At times women needed external permission from husband, family, God and/or self. Once a woman recognized that she had to care for herself in order to be well to help her family, she gained personal permission to choose self-care. Choosing self-care was choosing the health of her family. Men did not require external permission or to gain self-permission, rather the culturally-ingrained machismo qualities sometimes interfered with a Mexican man's ability to care for himself, to take advice from

others, or see his need for self-care. The pride of *orguloso*, the arrogance of *soberbia*, and the stubbornness of *testarudo* hindered men from effective DSM.

Another cultural feature was the underlying attitude of being expected to, at least, taste *a little bit* of the food or beverage that was often offered or forced upon them in social settings. The underlying attitude was that it was important to comply because “it won’t hurt.” Having “just a little bit” was also a simple way to manage temptation. Due to the high importance that *Being proper* had in the culture, it was not possible for a man to refuse food offered by a hostess; to do so would be a social affront, it would simply be rude. The rare exception to this societal rule was if the person knew the hostess well. In that case, either a man or a woman could decline due to health issues about which the hostess would have already been aware and accepting of the situation. Otherwise, to decline was to behave differently than others in the culture, which made the person stand out as unique; it was not a culturally-accepted. Also, they wanted to avoid hurting the feelings of the person who had prepared food. In Mexico, this social requisite was stronger with higher expectations and social costs to the offender. A final social-cultural influence was practiced based on inaccurate or false cultural myths that were inconsistent with scientific knowledge. The prime example was the delay of medication use due to a false fear that the medication might cause the pancreas to become lazy and produce less of the needed endogenous insulin. Once the error was rectified and medication was utilized, W3b recognized that she should have used medications from the beginning of her diabetes several years earlier. She now shares her convictions with others. More information on actual medication knowledge will now follow.

Health science knowledge. The report on Health science knowledge follows Social contributors because the cultural aspects influenced and were part of the filter through which health science knowledge was understood. In Context, Herbal exemplars established that long-believed idea that herbals were safer than medicines and spiritual faith could both guide people or lead to “wishful thinking” instead of practicing DSM responsibly and consistently. Concoctions were practiced also. Culturally-held beliefs about the function of the pancreas and the effects of medications on it were provided above. These give evidence that some cultural health beliefs can lead to inaccurate choices (Hatcher & Whittemore, 2007). Below, how these misunderstandings influenced health science knowledge is introduced.

Inquiring what participants understood about the causes of diabetes was part of what prompted the exploration eventually leading to understanding the difference between the cultural social knowledge and actual established health science or healthcare understanding of the disease process and how to manage it. As established in Context - Social Knowledge, what was known and shared culturally was/is not necessarily accurate to health science information. Overall, regarding the causes of diabetes generally, a large scientific, health care knowledge gap was identified, as well as understanding about some aspects of care. Several participants did know it was hereditary, “hereditario” (W4). W4 believed that it became the next illness after one had high blood pressure. When asked to discuss the pancreas,

“I know there’s something in the pancreas, but uh, what did they make it that start it? You know, I even there, there is in family, I don’t know the ... I take

better care myself, I never had it ... or I don't know. I have so many questions.
I don't know (PI: Alright) what's going on in my body - what I have."

To illustrate the apparent and pervasive deficit of health care facts found in this cohort, the IV with M2 was revealing; other examples followed. Being more protective not to admit that he really did not know or understand how the pancreas functioned in diabetes, M2 responded a bit self-consciously that he could not converse about these fundamentals.

PI: "... where does the science piece come in, in terms of the pancreas?

What do you know about that in terms of the problem inside the body with regulating sugar?

M2: I believe the medication is what ...

PI: Right. But I mean what is it that happens to the pancreas that makes you need the medicine? ...

M2: Looking very puzzled. [The RA noticing his uncertainty joined the inquiry]

RA: Or why is diabetic, or being diabetic? [No response by M2]

RA: But do you understand? ... what is diabetic?

M2: Well, diabetic is a big issue that affects your body parts of you.

PI: Yes. Okay. And do you know what the pancreas does? Some people know that, some people don't [said as a buffer so as not to make him too uncomfortable].

M2: No, I don't.

PI: Okay, because the pancreas is actually what makes the insulin.

M2: Oh, makes the insulin.

PI: And when it doesn't make as much, then we need help.

M2: Exactly.

PI: Okay, so you understand that part.

M2: Yeah.

PI: [Realizing there was a significant health science knowledge gap and so as not to embarrass the gentleman, the PI comments] "It probably wasn't the right question. I'm sorry."

M2: No, it's okay. But I never get so into that, but I know."

When asked to explain, what diabetes was/is, as though she was telling someone else, W1 replied, "well it has to do with your pancreas. It's behind your stomach, isn't it? PI: "Yes" W1: "Its not producing enough insulin. And then if we put more sugar on it, its double sugar in your body." Later, in talking about her 20-year-old daughter who was diagnosed 2-3 years before, she described how well her daughter was controlling her BG through diet and exercise. W1 claimed her daughter controlled her "sugar" better than did W1 but the participant did not take into consideration that her daughter was in a very different stage of the disease; W1 was not considering the reduced pancreatic function that she had after 8 years of the disease.

W1: "And she had problems, so she has been diabetic for ... 2 or 3 years but she controls it better than I. So, I gave her my method [of BG control]: You got to check your sugar in the morning, after lunch, 3 times a day,

take your medication, drink a lot of water, and she can control it better than I.

PI: Oh, you must be very proud of her.

W1 Oh yes, because sometimes she [referring to her young adult daughter] doesn't even take medication ... and her sugar is low. She would eat a lot of maybe heavy dinner when she comes from school 'cause she is in college, and her sugar will be better than mine in the morning."

W9 had had T2D for over 10 years and had always been extremely well-controlled on diet, exercise, and with MF 2,000 mg daily. However, shortly prior to the IV, her A_{1c} had gone up without any behavioral or medication changes. At that time, she finally understood the progressive nature of the disease from the doctor.

PI: "So what do you know about the reason, in terms of what happens inside the body?

W9: Well, pancreas ... it doesn't control the sugar?

PI: Okay.

W9: Either too much sugar in the pancreas and it doesn't ... well I know the pancreas is the one that controls the sugar ... It produces too much or not enough?

PI: Well it produces insulin [PI briefly explained the pancreas' production of insulin] So does that make sense compared to what you've known before?

W9: Well, more or less. Cause I read about it.

PI: Yeah, so you're at least aware that it's related to the pancreas."

The PI took a few minutes to teach about the basics of the progressive loss of insulin production by the pancreas, finishing with “But, it is a progressive loss of insulin.” W9: “Yes, that’s what the doctor told me the other day when I saw him.”

Some people knew that aspects of the pancreatic function loss was related to insulin decrease. W8 had never been to a DE class, but she had done extensive reading. When the PI asked “what do you think diabetes is?” she identified the primary components of the pancreas.

W8: “What do I say? That my, my, what is it? Part of my ... they don't work.

PI: The pancreas?

W8: The pancreas, they don't work ... That's the, that's the only thing. My pancreas they don't work ...

PI: And what, what is, do you know what the pancreas does? ... What does it make?

W8: That they don't work, they don't produce... the... the... oh my God...

[Trying to remember what the pancreas does]. ... Insulin? The insulin.

PI: Okay

W8: Sufficient insulin for my ... that I need.

PI: Okay, yeah, you're right. Insulin is normal and we need it.

W8: Yeah, uh-hum!”

M1 also had a fairly sound basic understanding of the function of the pancreas. He repeatedly returned in the IV to the time when his T2D was out of control because he had been morbidly obese prior to gastric bypass surgery 10 or 20+ years ago.

PI: "So tell me what you think diabetes is.

M1: Diabetes is your ... pancreas doesn't ... it starts going wacko when you're that heavy. It starts not producing enough insulin.

PI: That's really true isn't it. Okay. Do you understand that diabetes is a progressive disease?

M1: Yes.

PI: And what does that mean to you? When I say it's progressive, you connected to that right away. What does it mean that diabetes is a progressive disease?

M1: Because some people don't try and then they just keep on getting heavy and it gets worse.

PI: It does, and the reason it gets worse is because eventually the cells in the pancreas that make the insulin don't continue to make it, right?

M1: Right."

The culturally-entwined social effects were found both in Context and above in Intervening influences to have profound sway on persons of Mexican heritage. Cultural beliefs and practices, roles and expectations influenced the DSM of these participants. Both the female need for permission to do self-care - especially for mothers - and the male machismo constraints and expectancies had an effect on approach to DSM. The requirement to be socially proper and respectful played a dominant role in protecting participants from offending others - which was/is socially frowned upon. The participants' cultural health myths led to inaccurate beliefs and decisions about DSM.

In summary, all of the participants demonstrated gaps of understanding in their health science knowledge. There was a range of understanding about the causes of diabetes and the science of diabetes, particularly involving the pancreas and insulin, how medications worked, and what information was gained from different lab tests. A critical finding in the study was a lack of understanding among all 12 participants about the progressive decline of insulin production as a hallmark of the disease. Participants all knew the control of BG was key to controlling diabetes; some of them knew that involved a lack of their own insulin or something about the pancreas. All of the participants knew that if they did not control their BGs that over time they could eventually suffer the same losses as those they had known with organ failure and possibly death due to unmanaged BGs of diabetes. Not a single participant understood that, no matter how good of control they practiced, because of the nature of the disease, they were at risk of eventually not making enough of their own insulin. This was after IV questions about diabetes knowledge and understanding was completed. It became clear there was a large gap in understanding which led to self-doubt and serious questions in the participants about what they were doing wrong, especially when they had not changed their positive DSM nor previously experienced higher BGs. Ultimately, inaccurate and/or incomplete health science knowledge had or might have led to inaccurate practice of DSM with the potential for both short-term and long-term BG elevations and untoward outcomes.

Personal characteristics. The first and second IVs provided the foundation to learn how important one's personal characteristics were to successful/positive

DSM. Each subsequent IV validated the import of personal qualities. These ranged from self-discipline and willpower to the level of one's ability to be personally efficacious and have a sense of self-responsibility. Ultimately, similar to *Personal permission* discussed above, in this community-oriented culture, the degree of independence that one had from her or his social and role obligations was a significant determinant in how one applied her or himself to being self-responsible for DSM.

There were several personal qualities in individuals that made it easier for some of them to be more independent in their focus on DSM; they had less socially-derived conflict. Several women in particular had evidence of being less influenced by the strong socio-culture requisites that made it easier for them to practice positive DSM. Those who were more independent in their food and activity choices in social settings and/or had a strong sense that they were able to accomplish the various aspects of DSM, and/or knew they could figure out a way to do what was needed for good BG control, had better success. This was true of women and men who had the resolve to consistently use their willpower to remain disciplined, took responsibility for their actions and the outcomes of those actions, and developed and applied adaptive skills to the challenge of daily, and at times, hourly self-control of their BG. The first of these qualities was named for what several participants demonstrated: *social independence*.

Being socially independent. The characteristic of being socially independent was initially observed during the first IV (W1). There was a sense that she was somehow *independent* of the *social* opinions and influence of others and therefore

was able to assert herself to assure her own needs were met. When she was asked “What are the kinds of the things that get in the way of you taking care of your diabetes?” She replied “I prefer people being out of the way. ...For me.” PI: “OK ... sometimes people say ‘oh, you know when they offer me the apple pie, I can’t resist.’ D’you know what I mean?” W1: “No, if I know that I already ate, and it’s been 2 or 3 hours and I already checked my sugar, and if I know I can eat it ... I will eat it.” Otherwise, as an example above showed, if she could not eat it because of having eaten a meal a short-time before, she simply declined and would not eat what was offered; no matter how the person offering it might feel or react. In contrast, this was not the case for W2 (see Permission). A strong example of this was seen in the determination of W9. She agreed to the idea that she was/is socially independent.

PI: “Is there anybody or anything that kind of gets in the way or interferes with you doing what you want to do with your diabetes?”

W9: Umm, no. Because I think I have my mind set that no one is going to stop me from doing what I do.

PI: Okay, interesting. And your mind is set: mindset nothing will ... [taking a note]

W9: I don’t want anyone to interfere with that. I mean I do what I do. If they offered me ‘hey come on, eat this’, I say ‘No. No!’

PI: You’re very determined. And do you know what you just told me? You just told me ‘I have social independence’ and ‘I don’t care what you want me to do. I’m going to do what I want to do. I’m not dependent on pleasing you, or satisfying, making you feel good about what you’re

telling me, what you want me to eat.' 'Here, taste this it's good!' You're saying 'No, I'm socially independent of ... That's the idea that came to mind. Does that fit for you?

W9: Yes, that's how I feel."

In the situation with W4, at times she was able to do what she needed to do for her diabetes, but at other times, especially in the presence of social friends, she was constrained by concerns of what they would think if they knew of her diabetes struggles. Comparing the physical independence, she had prior to her foot pain due to neuropathy from inconsistent diet control, she reported:

W4: "And it's hard, like before you [I] go to Mexico or whatever, Miami whatever, and my food too ... when you're called obese, you say 'I'm not eating that.' I feel like ... and I be uncomfortable and all that.

RA1: [clarifying] And she feels uncomfortable socially saying that she can't eat those or she can't eat when she's out (W4: Yes, uh hum) and about with other people.

PI: Ok, so that's actually something that kind of interferes ... You just used the right word. It's not embarrassed, it's socially ... uncomfortable.

RA1: Yeah because you know they might think she's picky or something.

W4: [Spanish to RA]. Uh huh, I don't like to make people uncomfortable.

RA1: And she doesn't want to make [others] feel uncomfortable."

In subsequent IVs, it was identified that those with more social independence, who were able to act on their own accord with little or no concern for the opinion of others and were not controlled by external social forces or other

people generally had good BG control. For those persons who did not want to stand out as different but preferred to be like others, (e.g., W9: “They just want to be the same”), consistent social independence was more difficult.

Several participants demonstrated a type of self-confidence and determination to make their diabetes their priority over social obligations and rules. Despite how others felt or reacted, they appeared to keep the long-term in mind so that the expectations of others did not take priority over protecting their own diabetes outcomes; both in the short- and in the long-term.

Having personal effectiveness and internal confidence; and being valued. As implied, those who exhibited more social independence more consistently demonstrated individual self-care within the boundaries of this closely linked community-based culture. Correspondingly, it was intriguing to observe how various participants possessed and displayed a general sense that they were able to be efficacious and effective in their diabetes self-care. They displayed a personal self-confidence that they knew they could do what they had to do to accomplish the many facets of DSM. It was observed that those persons who had a personal sense of being valued by others demonstrated more consistent effort toward +DSM. In comparison, those with a lesser degree of the ability to control factors in their lives who had a lesser sense of personal value appeared to struggle more with consistent +DSM. Two contrasting examples support these findings.

First, as suggested earlier, W2 had significant personal difficulties in life, some of which interfered with her ability to do DSM. At 15, her father began sexually assaulting her. Alone, she fled to the United States to live with relatives and attended

middle school for about 1-1/2 years. Missing Mexico and her siblings, she returned and was again assaulted. Although not yet an adult, she escaped to the United States permanently. Once married, she developed gestational diabetes that did not resolve post-delivery. She was unable to attend DE classes because her husband was not available to care for her children. She often worked two jobs. At a later date, she lost relationship with her two young adult children. Three years ago, she remarried to a man who treated her with respect, served many of her needs, and was concerned about her well-being. She had never experienced love, care, and support as in that relationship. From what she shared, for the first time in her life she made choices for her betterment and sought the care for her diabetes that she had not done in years.

At the initial IV, W4 lacked self-confidence and clearly did not feel she had the personal strength or consistency to accomplish successful DSM. She did not feel confident that she knew how to manage or perform DSM or that she could positively affect the outcomes of her health. She repeatedly said she needed a nutritionist so she could learn what and how much to eat, and learn to regulate her eating, BG, and frequent food impulses. By self-report, she floundered most days, was fatigued, and developed peripheral neuropathy from inconsistent and frequently high BG excursions.. She had no insurance and she felt that the provider at a free or low cost clinic whom she saw monthly did not understand or address her concerns. Clearly, W4 lacked a general sense of being able to repeatedly do successful DSM. She did not have confidence about her long-term health and was not a socially-independent person with diabetes. In fact, she had become reclusive with constant pain and was discouraged daily. However, upon the PI and RA's return visit 1 year later (RA1,

W4's contact had returned from Mexico), the intention of the PI was to deliver educational materials because, during the original IV, the PI was concerned about the lack of understanding, health science knowledge, and resources that were not available to W4. When W4 answered the door, it appeared as if a different person presented herself. W4 had lost 40 pounds, no longer had daily foot pain, walked without a limp, and happily told how she had found a new healthcare provider after she secured healthcare insurance. She was getting the nutritional and medication guidance she had longed to have. W4 was developing and practicing positive DSM habits regularly. Finally, W9, W6, and W3b all knew what they needed to do to protect their long-term health and each of them faithfully practiced all facets of DSM with confidence. As W6 said, "I do what I have to do."

A beneficial finding was that some participants displayed the general or overall sense that they knew they could manage their diabetes every day. They had self-confidence to complete the goals they set out to accomplish; for most, that included having completed aspects of DSM routinely. They were efficacious in their efforts. The range of presentation was wide, varying from W2 crossing the U.S.-Mexican border alone as a 15-year-old and again at 17, to W4, who was not succeeding at DSM at the time of the IV. She believed she could be successful once she received the nutritional guidance she longed to get. A common thread was the mental outlook of "I can do..."

Being motivated. Having motivation. From the first IV, the importance of motivation was clear as a potent function of how they approached DSM. The two primary forces of motivation were love for others, especially children, and the

contrary emotion or rationale of fear, being afraid of the negative outcomes of diabetes that occur when one did not “take care of your diabetes.” There were additional factors that motivated participants toward +DSM as follows.

Having love for others. In a surprising fashion during the very first IV, the powerful construct of *motivation* was clearly introduced and developed with each subsequent IV. All but one of the participants [W9] indicated it was importance to take care of their T2D so that they would be alive and well in the future for their family’s sake (W1-W8, W10, M1, M2). The *motivation of love of others* compelled them to do self-care for the sake of those whom they loved; this was one of the two strongest motivators identified. The concern to be well for family members, particularly children, even adult children and the next generation was the primary love *motivator*. The divergent, equal, or at times more powerful *motivator* was *fear* of the damaging physical outcomes of inadequately controlled BG over time and the suffering that would result. Responding to the question, “How do you decide what to do about your diabetes?” W1 introduced the idea of being motivated toward +DSM:

W1: “Well what made me decide? Well I do it for my daughter. [age 21]

PI: Wow... that's huge.

W1: I do that for my daughter. Because I know she is in university - is gonna be 5 years - and she has no boyfriend, nothing, just study, study. So once [she] has her house, her family, then I'm ok. Thank God, for Him to take me, I'm ok, I can go.

PI: Uh huh.

W1: Meantime I have to take care of myself for her, because it's just me and her."

Later, W1, broadened the base of her motivation when asked, "What other things in your life make you decide to take care of your diabetes?" "W1: my daughter... my daughter, and my five grand kids, but its more my daughter." Likewise, W5 spoke of her young children. RA1 helped with interpreting. RA1 in Spanish, "What else helps to take care of your diabetes?" W5: "What helps me? ... My kids ... My son and my daughter" [pre-adolescents] PI: "Oh ... motivation?" W5: "Yes." PI: "Okay. For you, you take care, for your children?" W5: "Yes... So, I can be around longer for my children." In reviewing the transcript of the earlier test IV, (W3a), the PI noted that motivation was also examined in the initial discussion.

PI: "Who and what do you think will have a part (*contribucion*) in how you decide what you do about your diabetes? [referring to the future]

W3a: My family.

PI: Certainly; your husband?

W3a: Exactly. Uh huh.

PI: And your mom's model? [her mother practiced consistent +DSM]

W3a: Uh huh.

PI: I'm not trying to put words in your mouth in selecting the things you've said so well.

W3a: Exactly. My kids because when I have something happen with me but I don't feel really good, I just, they are the first ones to come into my mind. I don't want to leave them alone ... my two children. [pre-teens]

PI: Oh, so they kind of motivates you to take care of yourself.

W3a: Exactly, yes.”

W2 expressed that her motivation was related to her relatively new husband and her appreciation of his care for her.

PI: “So the ... way they [other family members] take care of their diabetes, makes you want to take better care of yours?”

W2: And him (looking toward her husband cooking another healthy meal for them)

PI: ... *motivacion*? Is that verdad [true?] is that what happens here, you are motivated to take care of him?

W2: Yeah. I want to take care him, the way he takes care of me - a lot.”

Later, regarding her own health, W5 replied to the question, “What else helps you, besides the motivation for your family?” W5: “For myself, for my... PI: “So you feel better?” W5: “Yes.” And, after 26 and 20 years with diabetes, W6 and W8, respectively, were concerned about their adult children. “What is the motivation?”

W8: “Motivation?”

PI: Yeah... What is the motivation for you to take care of your diabetes? What do you think when you say, ‘I am going to take care of my diabetes because ...’

W8: Because I want, how can I say... want I live, I want to live well.

PI: Yes, your life is good.

W8: [Spanish] That’s how I want to live, I want to live well. Now, if God has me ... well. But, that’s why I take care of myself.

RA2: Okay, she wants to live the way she wants to, but the healthy way. She takes care of herself, she feels that she takes care of herself.

PI: Oh, you do, yes. But what's the motivation? What makes you ...

[Interrupted]

W8: My kids! My kids!

PI: Your kids, ahh!

W8: My grandkids!

PI: Kids, family and grandkids...

W8: Oh, yes, it's my kids!"

Just as love for others motivated participants toward positive DSM, love of self, served as a positive motivator, as was seen with W2 and W7. While exploring "why do we not do what we know we should do?" W7 insightfully replied,

W7: "You know what, the only thing when you don't want to do it is because you don't love yourself?"

PI: [Deep breath of surprise].

W7: Yeah because - let me tell you, and you for example right now, and you explain me everything, and I explain you everything, why and I don't do this because I don't love myself, because then I know how I gonna do it. It's like you killing yourself. I don't want be killing myself. I want to go when God tells me. Until now, God give you [me] the life to live happy, healthy and, you know. That's what I think. If you don't do it, that's because you [I] don't love your [my] self. Maybe I don't say it right.

PI: No - you said it beautifully. I understand very well. So, it's no respect, también?

W7: Exactly, and you don't respect yourself ..." [She equated respect and love]

During the years following diagnosis and returning to diabetes care, W2 eventually gained an adequate sense of personal value, as discussed above. She finally moved toward positive DSM.

Feeling fear. As established earlier, all of the interviewees were afraid of the potential consequences of poorly controlled diabetes. The impact of one's personal experience of having watched someone with serious consequences was a strong motivator to avoid the same. Both W7 and W9 were motivated to take care of themselves because they each watched their own mother suffer on dialysis. For W9, it was exclusively the reason she wanted to take care of her diabetes because she watched her mother with so many illnesses and dialysis. She repeatedly discussed her concerns. PI: "What motivates you?" W9: "The experience I've had with my mom." ... "Yeah, 'cause I don't want to be in a situation like going through dialysis, or losing my sight, or ... I try [to do +DSM]. It's hard, but I try. It's not easy."

Congruently, W7 replied to the prompt, "Is there anything else you do to take care of your blood sugar?"

W7: "Uh, no, well that's the only thing. [Watch her BG what she eats and exercise]

PI: You know what else, I think you said though earlier - is you remember what can happen to you, right?

W7: Yeah.

PI: But I mean it seems like you keep that in mind. Is that a motivation?

W7: Yeah, I think so. Yeah.

PI: I do too, but I didn't want to put that word in your mouth. But it looks like you're motivated to take care of yourself.

W7: Yeah, because I know how, I see how my mom suffered, and she always said 'don't get [advised against getting diabetes], try to take care of yourself,' because she suffered all the time. Especially when she got the dialysis. It was terrible. One day I call, and I take her and pick her up, when I see ... Ohh, I say 'that's sad.' Very bad, very bad.

PI: Yes, you want to avoid that. So, you do a lot of the right things. You do the right things because you are hoping to avoid the bad things.

W7: Yeah."

Fear of the consequences of uncontrolled or inadequately controlled diabetes was a primary motivator for several participants who were afraid of losing independence. It was also an important motivator toward +DSM. Several mentioned it. For example:

PI: "Is there anything about diabetes that could happen to you that you are a little bit afraid of?"

W8: [Spanish] My diabetes or whatever, if they put me in one house, to put me in one of those houses ...

RA2: She feels that if she doesn't control her diabetes, or to the extreme to where, you know, the family may put her in a retirement home or convalescent home.

RA2: [Spanish to W8] And they would do that to make you take care of it? Okay. ... How is it you think that if you don't take care of your diabetes, why do you think you will end up there in a retirement/convalescent home? [she means convalescent]

W8: Yes, no ... because I may feel bad, because if there is something wrong.

RA2: Because there is something wrong and they can't take care of you?

W8: That if there is something wrong they won't be able to take care of me since it's just my husband and I, and I don't want like my daughter say, and my son say, 'how come you don't come to my house, we have a huge house' and nah... I don't want. I want to be in my house ..."

W1 was fervent about not wanting to continue on if she were to lose independent function. She would rather be taken by God than have serious limitations of function.

W1: "I already told my children, 'and if I go to the hospital because they cannot control my sugar, and they gonna cut my legs, let me die. I do not want to live, or I do not wanna get up and not see my legs, because then I'm gonna think negative, if it's time for me to go, then, let me go.'

PI: Ok, you just said something very interesting, if ... so that's really another kind of motivator, is in it for you?

W1: Yes!

PI: Then you are really actually motivated ... another motivation, is fear of loss of your legs?

W1: Yes, that scares me.

PI: Ok.

W1: Because once is your legs, then is your kidneys ..."

M1 had already had a frightening scare years before from a serious toe/foot infection. Doctors argued about whether to amputate his foot and lower leg. Fortunately, the physician who had a more positive attitude that M1's foot could heal, that it did not have to be amputated, won the argument and W9 still had his limb. He had gastric bypass sometime after that infection. Nevertheless, the fright was never far from his thoughts, PI: "What motivates you to take care of your diabetes? M1: "I don't want infection and all that" PI: "And leg cut off" M1: "Yeah, there you go...That's a *fear* there." W6 had good DSM practices and worked hard at good BG control. When asked "Are there things about diabetes that you are afraid of Señora, if you don't take care of your diabetes?"

RA1: [Spanish] "Is there something about diabetes that you are afraid it would happen if you don't take care of yourself?"

W6: [Spanish] It's ... about the kidneys ... dialysis.

PI: Oh, dialysis. Okay. you don't want dialysis or problems with your kidneys.

W6: [Spanish] I am scared for dialysis ... I am scared, how do you say 'miedo'?

RA1: Scared?

W6: [Spanish] I have scared for dialysis. Another thing? To get my leg chopped off.

RA1: To be amputated?

W6: [laughs] ... one little leg...

PI: To be amputated. So, you don't want your arms and legs to go, to be gone.

W6: [Spanish] But I am more afraid of dialysis."

A final contribution by W5 underscored the motivation to be well and available for ones' family/children, fear of loss of independence, and the risk of death. Others inferred or referenced being permanently unavailable as illustrated prior, but she said clearly, she was afraid of dying:

PI: "So, motivation for your family...

W5: Yes, yes, for my kids.

PI: What else helps you besides the motivation for your family?

W5: For myself, for my... o, I can be around longer for my children.

PI: So you feel better? [She had been talking about not feeling well and fatigue]

W5: Yes.

PI: Did I hear her right? [Q directed at RA1]

RA1: So she can be around for her kids. [Did not answer the question about *her*]

W5: [Spanish] Because I don't want to die.

RA1: She doesn't want to die.

W5: I don't want to end up blind and have my kids guiding me ..."

Similar to those who had observed the poor outcomes of diabetes in others, the knowledge W2 learned by observing people with diabetes who had not taken as good of care of themselves as she was at the time of the IV, she said she believed it was important to do DSM differently.

PI: "What do you think you've learned from watching your mom, your grandma, your ex-husband's uncle, your friend, these people with diabetes? Have you learned anything from people who have diabetes?"

W2: "Yeah, you have to take more care of yourself when you have the disease." And later,

PI: "How does the way others take care of their diabetes affect you *influencia, afectar*, how does that affect you?"

W2: I don't think it affects, I only see, I don't want to be like them, I have to take care of myself maybe better [*than*] the way they are doing."

Looking forward to life – the benefits of success. Motivation could be renewed; it was renewed in W4. During the IV (first visit), W4 reported she was in pain, discouraged, and fearful of the worsening damage due to her BG frequently being out of control. She was desperate. In her anguish, as soon as she got health care through "ObamaCare," she was proactive to find a new HCP who would focus on her nutrition. Through a newspaper ad, she located an uncommon specialist who addressed diet, timing of meals, and testing. On the 1-year return visit, the PI and RA1 took educational materials that W4 had lacked at the original IV. It was obvious when she opened the door that she had a new-found motivation for DSM. She was

smiling, had obviously lost weight (~40 pounds) and surprisingly, she no longer suffered nerve pain; thus, her crippling walk was gone! The health care she received in the months between PI visits helped her take control of her diabetes. During debriefing about the unrecorded session, RA1 and the PI marveled about her physical and mental health improvements.

RA1: “Umm, her feet don’t hurt, she’s not fatigued any more...

PI: Oh, because she’s basically motivated ... she has a new motivation and her new motivation ... is (repeating what W4 said:)

W4: I feel good, this [new health plan] is working. This new diet is working for me. I want to be disciplined because I see the results every week. I feel better, my weight goes down. Other people are noticing, and I feel good instead of bad like I felt, so I want to keep doing the right thing ‘cause it works for me.

RA1: Yeah, yeah. I agree.

PI: So it’s a new level of motivation, but it’s really because she has seen ...

RA1: The results ... And she wants to feel better, not necessarily lose weight. That was another thing that she pointed out, that she wanted to feel better, and through that effort to feel better, she lost weight.”

Positive BG results also motivated W5 and W9, both of whom were successful in keeping their BG numbers down with frequent exertional exercise; good results promoted positive DSM. Acquiring a taste for healthier food enabled positive DSM habit change and development that motivated M2 more.

PI: “And what was your diet like?

W2: Was good but you know, sometimes we are Mexican and we have to do some changes on the food, so I was. I really don't like the taste, like vegetables, but now I like it, because I can take care of myself. But before, no, I don't like it. You have to change your eating habit.

PI: Yeah ... and that's hard... And you said it's easier now?

W2: Yeah, it's easier now."

M1 had been through a great deal of physical, emotional, and relational struggles and difficulties. Being re-married, he had a stable life and was successfully working to get his weight back under control. Several aspects of life were positive, so he was motivated for a better future than he thought he would be able to have.

PI: Because of your telling us so much about your story, I think you are really, truly motivated to preserve your health.

M1: My brother-in-law helped me. You know, he gained all the weight back. ... now that my brother's lost weight ... Henry (name changed) gave my brother ... some of his clothes 'cause they don't fit him at all now. And my brother, he's losing the weight!

PI: Isn't that great! So, a lot of your decisions are going to be based on your motivation for your health and the weight is part of that.

M1: I've got a lot to look forward to!

PI: Good, now tell me about that: Lots to look forward to?

M1: I didn't know this until a little bit ago, but [my wife's] mom has [a house] she's giving us ... I thought I'd never have a house, you know?

PI: Yeah, so you want to enjoy that with her?

M1: Yeah, and it needs work and stuff, but I've been handy all my life. I've fixed things and like that chair right there, I fixed part of it ..."

Summary of Being motivated; having motivation. All the participants reported and demonstrated *being motivated* toward +DSM. *Motivation*, especially for the love of family and fear of the consequences of inadequately managed BG were the primary motivating factors for +DSM. Most had love of family and wanted to continue to be available for their families; they had a very strong impetus for keeping the long-term in mind. At the root of love, W7 felt that self-love was the reason to practice +DSM. While not the dominating *motivation*, all were *motivated* out of fear and, for some, it was strong. W9 in particular and W7 were motivated more by fear of the same consequences that befell their dialysis-dependent mothers. Some were *motivated* by the desire to maintain independence; they were afraid of losing it and/or being a burden to their children. Still others had fresh reasons in life that *motivated* them to maintain good DSM habits to have longer, healthier lives. For others, being *motivated* to practice +DSM because they felt better on medications. Having fewer symptoms and improved relationships with others, knowing they were guarding against the future was satisfactory *motivation* for others to feel that would be worthwhile to take their unwanted medications. The benefits of *motivation* for decision-making toward long-term protection resulted in +DSM and generally well-controlled BGs. Once motivated, an important aspect that helped to maintain +DSM was to have developed a *habit* of +DSM practices. Some participants had a generally-consistent daily routine; others were more likely to do some management elements depending upon how they felt.

Why having a habit mattered. Those participants who had developed positive DSM habits were better able to maintain healthier BG and quarterly A_{1c} levels. Being in control was part of DSM and developing good habits helped participants to accomplish this. As demonstrated above, one of the ways that W2 was able to make better DSM choices was because she learned to like the taste of healthier food. Having developed this taste for nutritious foods and eating them routinely had helped her to develop better eating habits. W6, the participant who said “diabetes is my life,” talked about how having her life focused around her diabetes made her DSM a normal way of living since she was first diagnosed years earlier. She consequently had had good BG control. W9, who kept her A_{1c} below 7 for over 10 years, until just prior to the IV, had always had a habit of daily exercise, three regular meals with no snacks, and faithfully took her medication. Until the A_{1c} of 7.2, she only rarely performed SMBG because her BG had always been normal while taking her medication. After the higher A_{1c}, she said she had to check routinely; she was willing to do so because she wanted to keep her level in a safe range. She was adamant about maintaining a good habit.

Although it became clear that W1 did not have consistently current information about diabetes, she did have a fixed daily routine. PI: “How do you control your blood sugar?” W1 “Yeah, if you check your sugar in the morning before eating, and lunchtime, and dinnertime, three times a day, you will be good. I checked my sugar this morning and it was 117.” PI: “That was before you ate?” W1: “Yes you got to do that when you are fasting.” Due to a back injury, she was less consistent in her walking; only 2 days/week instead of daily. W3 detailed her routine: she

checked her FBG, hiked 1 hour after eating breakfast, and took her med. She was very disciplined. Once she was not working and did not have the stress of work, she regained control of her BG and was motivated to maintain her successful habits. W7 relayed that, when she was unable to exercise, it led to increased BG.

M2 did not seem to understand the concept of habit that was being asked. Even when RA4 tried to assist him because he was talking about dietary practices and hobbies instead of DSM. On the second attempt to ask the question, the PI sought to clarify it, "We're talking about your self-care of your diabetes, and I'm wondering do you have sort of a habit or ..."

RA4: "Program for doing ..."

PI: Program that you do through the day?

M2: You know what, I always have them in my mind that have to take care of it."

Later...

M2: "You know that help you so much. Be active.

PI: Yes.

M2: Be active! Take your medications. Take your medications, they help you.

Check yourself your sugar.

PI: And do you do that every day?

M2: I do it myself and I notice myself when my sugar level is up because I better watch! I better watch that because unfortunately we have so many bad habits that can break you away from it." [he had already talked about having a challenging sweet tooth.]

It was very difficult to determine if M2 actually had a routine daily habit that he followed for his DSM. On several attempts by the PI and then RA4, he admitted to checking his sugar in the morning when he felt his sugar might be higher than it should be. Later, he said he checked it routinely. It was unclear if he said this to say the correct answer or if he actually misspoke or did not understand when he gave his first answers. On the other hand, W6 had very consistent +DSM habits that she practiced most days.

PI: “But are there other people that you have known with diabetes who have taken care of their diabetes, done good like you are doing ... that helps you to do good too?”

W6: [Spanish] Like ... other people?

RA1: [Spanish] Yes, like someone you may know.

W6: I know people who have diabetes, but ...

RA1: [Spanish] But do they take care of themselves in a way that you say, ‘oh I am going to what XX is doing?’

W6: [Spanish] No... they don’t take care of themselves.

RA1: No, the people she knows, they don’t take care of their diabetes.

PI: Okay, alright. So, you haven’t really learned from other people how to do it?

W6: [Spanish] No. If I learn from other people as ... I ... better not!

RA1: If she starts learning from other people she’s just gonna learn about things [that are not good habits], so she’d rather not.”

Having consistent +DSM habits helped several of the participants to be successful in their self-care. Learning from others who did not have good habits was something to be avoided.

Summary of personal characteristics. Personal characteristics, particularly, motivation that helped to empower social independence and personal effectiveness played essential interventional roles in DSM and whether participants were able to utilize their best qualities to be consistent and efficacious in managing their self-care. Developing a daily habit of diabetes care and around diabetes care was an important determinant in self-discipline that was/is core to DSM. For those who were relatively firm in their habits, remained motivated, and utilized internal strengths, they were, generally speaking, better able to manage the conflicts and difficulties typical in life and those circumstances which were much more challenging.

Experiencing life conflicts and difficulties. The significance of high stress being related to the onset of diabetes has been provided in exemplars in Context - How One Gets Diabetes. In addition to high stress and emotional trauma being credited with the start of the disease or treatment for several participants, various types of stress, emotional, physical, and relational, were also identified to have significant impact on DSM. The presence of loss, grief, and unresolved grief were noted to have led to distress and/or sadness; these in turn affected either choices or one's BG. People who had been depressed or discouraged also talked about the effect upon their DSM. Feeling worry and anxiety impacted DSM in women and men.

Being effected by stress. W3 provided important insight into the effects of stress on one's daily BG control. She reported that stress was a common trigger in the culture that caused people to lack self-discipline by eating the wrong foods, "... everybody in common, our culture, sometimes when we are under stress we can lose control [of what we eat]" ... You know, to have something in your mouth..." She emphasized that it made her stressed when she did not have control and self-control was more difficult when she was stressed. "So, if you have a lot of stress in your life, you don't even have to care about your diet, you just eat something fast, and you don't do exercise because you feel depressed, or tired and it's a cycle." She also relayed that stress might be significant enough to raise one's BG day after day that might raise the quarterly A_{1c}. When she was working full-time and tried to run her active household, she was under a lot of stress, "... that I was working I went up [to] 6.6 [from 6.0]." In a frustrated tone, she said that even when she was not eating very much, her BG went up as a result of her stress. "When I'm under stress I can't even eat [have eaten] too much and still my BG is high. If I'm mad because of something; have same problem."

When W7 talked about not getting enough sleep [chronic], she said she noted she was less able to manage stress. She also indicated that, even when she ate correctly, if she was stressed, it affected her BG. When asked, "Okay, so most people have ... stress in their life and I wonder if stress affects you in how you take care of your diabetes?"

W7: "Yes.

PI: How does it affect your taking care of your diabetes?

W7: ... And I think when you got stress I think that it made me, my [sugar] level in my diabetic, I can tell, like it ... [uses her thumb to show 'up']

PI: Your sugar goes up? Is that what you're saying?

W7: Yeah because when I eat - well, I know. My portions and everything, and my sugar it's [up]."

Within the month prior to the IV, W9 found out that her A_{1c} had climbed above 7.0 for the very first time. RA4 engaged a clarifying question after W9 was asked about the effect of stress on her BG. W9: "I think it does affect everybody when you're under stress and to make a decision." RA4: "... with stress at all, your blood sugar...?" W9: "I think when you are under stress - still high, no?" RA4: "Exactly. Yeah." W9: "If you're under stress your sugar level is going to go ... up."

W1 clarified how important it was to avoid stress of various kinds such as depression and worry because these emotions tended to raise a person's BG. She felt it was important to remain positive.

W1: "Diabetic or no diabetic, you have to be positive.

PI: Well that sounds like something that actually helps you with your diabetes.

W1: Yes.

PI: Is having a positive attitude, is that correct?

W1: Yes. Because the more you think about it, you go in a depression and that's gonna high up your sugar levels, your sugar goes up.

PI: Oh, I see.

W1: Your sugar goes up, if you worry, if you're sad, all these things make

your sugar go up.

PI: Very interesting. So actually ... that is, those are other factors that influence ... taking care of your diabetes.

W1: Yes, I wanna...avoid that. That's not for me.”

Feeling worry and anxiety. In Context - Cultural Characteristics section, W3b described the culture as being “anxious, really anxious.” She spoke specifically about how worry affects women in their multi-layered roles and responsibilities. “In women: We are more sensitive, taking more care giving for the whole family and sometimes the man he just go to work but they don’t care about anything else. So, we have to solve everything and all the stress is on women.” Rather than the burden of family responsibilities, W7 described her worry and anxiety interfering with her sleep. She reported never getting enough sleep because of her worry. Most of this started after the death of her son and she worried about the consequences of diabetes as her mother had. “I know when I am stressed for something or thinking and something I worry sometimes and don’t sleep too much, I have that [elevated BG].” Later, responding to the question, “Was there anything else besides feeling sad?” she went on to say:

W7: “No. Well ... I’m scared, I tried to be eating whatever I’m supposed to, but I don’t know for some reason sometimes I still get my diet, but I worry too much maybe, because after my [adult child] passed away well, my life changed a lot and now I take care about my food and everything because I lose a lot of weight after that. But it is still sometimes my sugar is a little high, because I don’t sleep too good.

PI: Are you still worried? Pre-ocupada?

W7: Yeah, uh well, that first 2 and 3 years I sleep only 2 and 3 hours and maybe that's why I get my diabetes get more ... because there's no reason..." [that she can think of other than this issue]

W2's answer to avoid having worry about diabetes was to make good decisions:

W2: "Decisions for good, to be better with your health and to, not to get a lot of stress, you don't have to have a lot of stress, if you don't have to care of yourself. [PI clarifying]

PI: You don't have to have stress, if you take care of yourself you *won't* be stressed. [W2 nodding] Ok, I see."

W9 was rather traumatized by her mother's dialysis treatments and death. She worried a lot that she could befall the same experience.

W9: "I try not to worry, but I do.

PI: About the consequences?

W9: About the consequences, yeah.

PI: It seems like people who are conscientious, like yourself, do kind of have that in the back of their mind.

W9: Yeah, 'cause I don't want to be in a situation like going through dialysis, or losing my sight, or ... I try..."

Suffering loss, grief, and unresolved grief; distress; sadness. It came as a surprise how many participants suffered from loss, grief, and some from unresolved grief. Regarding loss of relationship of important people and/or trust in those

relationships, some of those anecdotes were shared. Grief and loss for others included: W1 lost her husband and the ability to work due to a painful injury; W2 was violated by her parents when she lived in Mexico:

W2: "That's why I said 'I don't want to be here' the way he was touching me, I said 'No.' That's why I had a lot of anger with my mom, because if she knew - how come she didn't do nothing? She let it pass.

PI: How long did that go on?

W2: Like I was going to be 15, on my fifteen, he started touching me, now it was only me ... But my two sister, he abused my little sister, but they never told me, only when I was here. I was married, she asked me 'is my dad is coming back?' I told her 'yeah' she said 'I don't want him to come back.' I was, I had a lot of anger, *con mucho rancor...*

RA1: Resentment.

PI: Resentment, yes.

W2: With my dad, how could he do that to his own girls?"

She also had a difficult marriage without support, lost the functional relationship with her two, young adult children, and only infrequently saw her teenage child:

PI: How many kids do you have?

W2: I have three. One ... is going to be 25, and the middle one ... is going to be 21, and the small one ... is going to be 13.

PI: And, where are they? Do you get to see them sometimes?

W2: They're with their dad. Yeah, only my [youngest]. The [older] are separate..."

W4 lost her husband and for a time lost her independence because of the reduced function of her painful feet. W5 tearfully reported she had lost some aspect of her sexual function and was no longer sexually active with her husband. This was a heartache for her. [Tearfully in Spanish], "Because before I used to be That's what makes me feel like little by little I am ... shutting down in everything, because I used to be very sexually active, but I am not anymore. And it makes me feel very sad that I can no longer be with my husband" [no details].

W7 lost an adult child at age 20 [no details offered] about a decade previously and had subsequently essentially lost most of her marriage because her husband was apparently despondent since the death; he interacted minimally with the family. PI: "and you said your husband doesn't bother you about the [diabetes] food?" W7: "About nothing. He just, he's very quiet. He don't talk much ... And then after my [child] pass away, he's [husband] just stay home. He never go out, not even with my family. Nothing. He's like that." She also lost her mother to advanced, dialysis-dependent diabetes. Likewise, W9 lost her mother to severe diabetes and had great sadness in her mother's recent passing and suffering through dialysis. She had suffered other profound losses including her last pregnancy; shortly thereafter, she found out she had diabetes, so lost her plans for a diabetes-free life. She also experienced the passing of an older sibling.

M1 had suffered the most extensive losses. Over 20 years ago, he lost a young child due to an extended illness. A few years later, he moved away from his drug-

addicted first wife to get himself into drug-rehabilitation, but she accused him of leaving her. Within a few days, she died unexpectedly. He expressed that he was traumatized by this. Unfortunately, she had spoken ill of him and spread a false tale that he had left her; apparently, she told everyone around her. Their older children essentially rejected him, having believed what their mother had said about him. At the time of the IV, he had been separated from them for years until recently when they occasionally had made pleasant contact. For years, they had shamed him through mean accusations. He lost his father and then a brother ... He spoke at great length, for a very long time, more than once during the IV, which lasted 4 hours, about these sad situations. He had pain and grief in his voice, despite many of these tragedies being two decades prior; he had not resolved some of his deep grief.

Having discouragement or depression. Some of the exemplars given in the pages above have given glimpses of how one's discouragement or depression had interfered with the participant's DSM. The example by W5 of not eating correctly before her exercise led to very real discouragement, as had her inability to continue with regular sexual satisfaction with her husband [due to her diabetes]. These contributed to her overall discouragement at the youthful age of 40. W7's inability to sleep adequately and her ongoing worry had been disheartening to her and added to the stress that she believed contributed to her elevated BG at times. Similarly, W9's had a surprising increase in A_{1c}, attributed to her stress. Worry and fear led to consternation that had not benefitted her BG. W4 reported discouragement several times in the IV, often about her neuropathic pain and how her fatigue interfered with her daily life and enjoyment.

W4: “No, because I’m tired ... I feel, you know fatigue

PI: So, you want to get rid of the fatigue?

W4: Yeah, I want to feel better to live my quality of life that God, you know ... I want to be, I don’t feel that way, because maybe I keep saying ‘maybe I feel better later, later.’ And no, they [fatigue] don’t go away, I don’t want to be like that.

PI: Uh hum

W4: I want to be, you know, not healthy but not feel that way ... They [her fatigue] stop me to do things ... ‘No, because I don’t feel like it.’

PI: Uh huh... you are discouraged! ... That’s really what I am beginning to hear.

RA1: Uh hum

PI: The confusion [about nutrition] at this point and the fatigue make you feel discouraged.

W4: Uh huh, I want to stay home ... and, because before I’d go to San Diego, and Tijuana, and wherever, and...”

But, at the root was her disappointment in not practicing consistent self-control, not being disciplined in what she ate, how much and when.

W4: “But, uh, I have to get disciplined in that, that’s all because I am not ...

RA1: She needs to be disciplined and that’s it. [Assisting with partial Spanish]

PI: Oh, okay. Actually, that’s a very important part ... that’s excellent. Thank you for your, ... for your truth. Thank you for being honest Señora. But

you know, you ... point out something ... that interferes – is your own discipline.

W4: Uh huh

PI: Okay, that's very insightful ... So, it's really your own ... kind of lack of self-discipline. When you feel like you don't have enough of it, you don't always apply it. [W4 nodding] OK..."

Being tempted. Over the course of the IVs participants talked about being tempted by the good Mexican food that they were around daily, especially at social gatherings. As described in detail in Context – Taste, taste is very important to this culture. W7 shared that taste was part or could be all of the temptation. She also made another very insightful comment about battling the temptation of taste: if she already knew the taste of a food that was not good for her diabetes, then why should she taste or eat it? That would actually defeat her hard efforts at managing her BG; it would be “wasted” on a taste she already knew. The PI was giving an example of how one might be tempted by attractive food.

PI: “So instead of thinking ‘... I’m gonna eat another mango, but it will hurt me, I better not.’ So, I choose to do the good. But sometimes we say ‘No, it *tastes really good*, I don’t care! I’m just gonna do it!’ Verdad? [True?]”

W7: Yeah, yeah. Sometimes it happens. Yeah, I know, but you don’t have to do it all the time. You can do it once in a while. It happens because I can say ‘oh, I don’t do it. Maybe I can do it one of these days. I don’t know, but right away I don’t have to do it every single day because I know it’s

gonna be bad for me. My hard work is going to go only to taste *and I know that taste already.*

PI: Wow!! That was awesome! 'Cause I know the taste already' ...

W7: Well, yeah because if you don't know, then you are really curious to have a bite, but if you know how it's bad for you and after that you [BG] gonna be very bad. So, you know like ..".

W3b, who described Taste and Smell in detail discussed the challenge of not eating unhealthy food at a party and that being around the food at gatherings made her nervous. She wished her husband liked to dance so she could be distracted from the temptation of the food instead of being tempted to eat it; also, she knew she would burn calories by dancing. "But for me that will be a nice way to take off my anxious about not looking at the food. Looking at the junk food, because I think I'm talking, I'm laughing, being social - also I would love to dance." When W8 was discussing being tempted by the food at a social gathering, it clarified that, in addition to feeling pressure to comply with social expectations and take some of the food being offered, she replied that temptation was a genuine issue for her. "It's more like temptation." PI: "Okay, there is a temptation?" RA2 translated, "It's not because, like, oh, but, basically the temptation is there." W8: "Yes, basically, it's how you feel [at the time and what is presented that might tempt her]." M2 talked about taste temptations and the conflict of wanting to eat what they want to eat - but could not. Before getting assertive to get his BG back under control a few months prior, he described nights when he battled the temptation to avoid eating sugary foods and treats. "Once I got up before bed - but these have been a few months back, because I

wasn't, you know ... exactly [practicing positive DSM] ... try not to eat sugar at all and that was affecting me too..."

One of the other factors that helped some participants was developing a habit of self-control so that temptation was less of an issue for them. W10 talked about having learned to practice self-control as a child.

PI: "How hard is it for you to fight temptation?"

W10: No, it's not hard. I can do, because within our culture, with the nuns, you are taught or trained to have self-control.

PI: ... so, you're saying... I was thinking, 'she's saying she has good self-control.'

W10: Well, they taught us - the nuns train us."

Summary of experiencing life conflicts and difficulties. Loss, grief, unresolved grief, stress, worry, anxiety, discouragement, depression, sadness, and distress or emotional trauma all impacted the DSM for this cohort; none were exempt from painful life wounds or challenges; some had considerable burden. Temptation also led to negative emotional feelings that adversely impacted BG and/or DSM. Most of the group had positive things that had happened in their lives that brought some balance to their troubles, or their stressors were less than in the past. As will be shown in the following section, support that had been offered in many of the difficulties reviewed above had beneficial effects.

The importance of having support. Three types of support were described by participants. Social support offered by family, friends, healthcare providers, and coworkers was evident for several of the participants. An interesting aspect of

support that was mutually shared by these persons with diabetes developed into an influencing concept - shared caring or sharing care. The importance of spiritual/religious support was noted by several participants (W3, W4, W6, W7, W9, W10, M2) also. As described earlier, generally when participants received support for a serious illness, those who had consistent, reliable, and/or broad support in their social environment usually were more successful with positive DSM, although not entirely.

Having social support. M2, who had good family support offered this brief exchange to demonstrate how his extended family supported him during the challenging dietary times of holiday seasons:

M2: "This is what we do actually on holidays.

PI: Oh, okay. Talk to me about that.

M2: You know they make some things that - one of my daughter-in-laws, she cooks and she always bring stuff that gonna be not affecting me.

PI: Okay.

M2: And my sons already know ...

PI: Meaning that she cooks none or less sweet things? She always takes your needs into consideration?

M2: That's it. That's it. Everything that she always does, she go to Whole Foods and says 'not this, and not this.' 'This is what we're gonna get for you.'"

M1 overall has good social support, now. In the past when his first wife was regularly using drugs to manage chronic pain, he did not have her support or the

support of their oldest children; his parents offered strong support at times and his siblings were concerned. Being remarried, he had good support from his current wife, mother, two living siblings, and mother-in-law. His children, after a number of years absence, were starting to have a relationship again, although not involved in any way in his DSM. His sister had been supportive in the past (paid for drug rehab), but at times was not helpful with his diabetes. Often, she did not understand the complexities of his chronic drug dependence (methadone) and sometimes expected more from him than he was capable of doing; she blamed his lack of alertness on the way he managed his T2D. PI: "Okay, so most people support you with your diabetes except this one sister?" M1: "Yeah." PI: "Alright. Does anything that she says make it hard for you with your diabetes, or is it just annoying?" M1: "Yeah, it's annoying."

In contrast, W9, who had been raised part of her youth in the independent-natured American culture, might have been the most isolated of the participants and leaned less on others for accomplishing her DSM goals. Due to the terrible experience with her mother's diabetes, she was fervent about DSM and would not let anyone detour her.

PI: "What things or people in your life help you take care of your diabetes? Are there people who help or support you or at least don't get in your way?"

W9: No, I don't have anybody that supports me cause they're not around me, I guess. My family, no.

PI: Does your husband - who doesn't have diabetes - it doesn't sound like he actually interferes.

W9: No, not really.

PI: So when you do what you need to do about your diabetes, he just leaves you to do it?

W9: Yeah, he leaves me alone because he knows that I'm gonna do it!"

In addition to various types of social support an important aspect for these person with diabetes persons was to not have interference in their DSM, as W9 commented on above. W2, when asked "How does what they do help or make it hard for you to take care of your diabetes? It sounds like they are encouraging you," W2 replied, "They don't get in my way of taking care of myself." PI: "It sounds that you have a lot of support." W2: "Yeah, a lot of support" [mostly from her husband]. As indicated earlier, this was a stark contrast from what she had most of her life. When W7 was asked, "Do your friends know about your diabetes? Do they say anything about it? Do they support you, or help you, or tease you, or?" exclaimed,

W7: "No, never, no. In church only, yeah, 'Oh, Sister, remember your sugar.'

PI: Oh so they remind you? [not to eat inappropriately]

W7: Yeah, they remind me, yeah.

PI: ... Does anyone do anything that makes it hard for you?

W7: No."

Sharing Care. During the IV with W2 it was noted that the times when she had good social support and/or was sharing DSM with another person, she was much more successful in her +DSM. Unfortunately, much of her life, she did not have good social support and during those times she did not appear to address her DSM.

As explained earlier, when diagnosed with gestational diabetes in her late 20s, she

did not have adequate support from her husband or family. A few years later, she lived with her mother who had diabetes and generally took good care of her diabetes. W2 told the story of how they both took care of themselves and their diabetes through sharing supportive care.

PI: “So X, have you learned anything else from people, like did your mom do anything to take care of her diabetes?”

W2: Yeah, she start with diet, a lot of diet, the way she used to cook, she changed her habit of cooking ... she was using a lot of oil, she start using olive oil.

PI: That’s very good oil. Alright, so you observed her, you saw her doing good things for her diabetes. Does that help you with your diabetes?

W2: Yeah, when I was living with her, we would talkin, we would work, but when she cooked we would take care of ourselves. Both of us.”

Shared care was observed with most participants. Some did shared care with other family members who had diabetes. W1 shared diabetes care with her college-daughter; both were helped because they were accountable for the foods they prepared together. Because her daughter had such good control, W1 was motivated by her daughter’s results, “she controls better than me.” Role modeling served as a means of sharing care support. W3 and W5 both had a parent and sibling(s) with diabetes and they shared activities, menus, suggestions on how to keep BG under control, exercise, and mutual support. Both had learned a lot from observing how their mothers prepared meals for their fathers. W5’s mother had been one of her

most supportive people and helped W5 considerably with her diabetes. She shared this,

PI: “And what about your Papa and his diabetes? What does he do?”

W5: [Spanish] My dad... he, my mom takes care of him a lot. She takes care of him. She cooks for him; she gives him a lot of vegetables.

PI: So, your mother cooks very careful ... So, she’s helping him?

W5: Yes. Right now, my dad’s - is controlled.

PI: That’s wonderful. When you see your mom cook good, does that help you?

RA1: [Spanish] With your diabetes? Watching her cook healthy, does that help you? And if it does, in what way does it help you?

W5: Yes, because I can see what she gives him and how much she gives him, and then I can do the same at home ... Or she gives me ideas.”

Sometimes they were sharing care with people who did not have diabetes but were actively involved in the diabetes care of the participants, as illustrated below by W3a when she talked about the example her husband set and how he strengthened her resolve.

PI: “Are there people in your life or any other things you think of that affect how you decide, how you choose to? [*Referring to her husband*]

W3a: Like as in he always help me to be conscious. When we go to a party he says ‘Oh you aren’t going to eat this, you aren’t going to eat this ... ‘

PI: So, he ... reminds you?

W3a:He helps me a lot. He reminds me, exactly and sometimes he says 'let's go and play basketball' so and then sometimes I don't want to walk, and he says 'Let's go around the house,' and I feel better. I feel better... She added,

W3a:Uh huh. Yes. He's really control himself and so that's helping a lot because he thinks ... when he's about to eat something with a little [bit? of sweet?] he's fine. If ... it's really good, it doesn't matter. He can say 'I don't want any more.' And sometimes I don't, even more. So, he's in really good control and that's makes me, helping me a lot."

The husbands of W6 and W8 did not have diabetes, but provided a great deal of support; the same was true for the wives of M1 and M2. The family of M2 would not allow him to eat any sweets when they were present, "No, Dad. You can't have even one bite." As reported, one daughter-in-law prepared only diabetes-friendly meals at holidays. The family consistently assisted him in keeping his BG under control over holidays when he had added temptations to his admitted sweet-tooth. This had a significant impact on his short-term SMBG, which he knew impacted his long-term health. The wife of M1 went to his atypical diabetes dietary classes and cooked for them daily. Despite his not being able to exercise (due to an injury), he lost 11 pounds on the diet alone. This reduced his SMBG levels; he did not have to re-start diabetes medications. The husbands of W7 and W9 were not involved in sharing care or DSM; however, they did not interfere.

When W10 was recovering from an extended illness, her visiting sister, who did not have diabetes and was a very good cook, provided nutritious support,

nursing care when ill, and served as a walking partner when W10 was regaining strength; clearly a type of sharing care. This support helped W10 to recover and return to +DSM exercise habits. She was expectant that the brief rise in her A_{1c} while ill would return to the 7-range because of the healthy diet and increasing exercise. These are sound examples of how *shared caring* was empowering for those involved. The only participant who seemed to lack consistent shared care, besides W9 as demonstrated above, was W4 at the IV prior to obtaining effective healthcare, although she did say sometimes her adult kids or sisters reminded her not to eat something she should avoid. It seemed she might be somewhat isolated and readily admitted to having less control than most of the other participants.

Holding spiritual beliefs and having spiritual support. For some, spiritual support was of great importance. W3, W4, W7, W10, and M2 all expressed the positive influence that faith, particularly faith in God, meant to them and how it had helped their diabetes improve. While it was not surprising that most participants discussed some aspect of faith and awareness that God was active in their lives, as discussed in Context, how one's spirituality affected DSM was interesting. It has been established that a faith in God and belief that God could affect healing were common in this population. M2 believed his faith helped him remain positive in his daily battle to keep his BG in control. W10 previously described how praying for God's intervention to heal one could also leave one peaceful in the outcome of prayer by trusting God's will. W3b, when describing the active faith of people in small communities in Mexico, said that "people say 'God hear us.' And so, people in Mexico are really faithful and I think I completely agree." When the PI clarified that

when she said “faithful,” she meant faith and trust in God? W3 quickly responded, “Right.”

Thus, faith had a supportive influence for several, but it sometimes distracted from optimum self-care. It was further identified that while faith usually had positive benefits, sometimes the method in which it was applied could, under certain conditions, also have less-than-ideal or negative effects. Either faith or lack of it could stimulate positive or negative DSM. W7 illustrated how, through her genuine and deep trust in God, she was sometimes distracted from doing her best DSM practices. At times, she had a wishful-thinking type of prayer because she wanted to use less medication than her BG might have required. Having just said that her A_{1c} had been creeping up, she pondered, “... So right now my goals is to live only maybe one pill a day or maybe nothing. I have a lot of faith in God and I say, “God, you know me, you know my heart” [meaning God knows she did not want to have diabetes or at least did not want to take more than one pill daily]. But sometimes, right now I don’t know, maybe I feel with and I worry or something ...” While her personal faith and relationship to God strengthened her, it posed a risk to distract her from full commitment to DSM as she prayed and wished that God would intervene to lessen her diabetic status.

In very distinct ways, W4 believed that the venous insufficiency she had at the time of her diagnosis in the United States had been healed through prayer. She had been told it would not go away and, at the time and over the next couple of years, her BG was poorly controlled but the problem resolved anyway. Her HCPs did not know why; she readily believed it was God’s answer to her and her family’s

prayers. She had also prayed for a new HCP for nutritional guidance. Approximately 3 months after she began diabetes management under a new HCP, she had remarkable results: a 40-pound weight loss, her neuropathy resolved so she was no longer house-bound or embarrassed socially about her diabetes-caused limitations, and her BG were under control, having decreased from 200-400 down to the 120 range. She attributed these significant improvements in her daily, short-term function to God responding to her prayers, that God had answered her prayers and benefitted her health. In her case, faith had a very supportive influence; for others, it sometimes distracted from optimum self-care.

Interference and barriers. Fortunately, the majority of the participants did not have identifiable interference in DSM. It was clarified that early on in the diabetes of W2 that she lacked significant support and had commitment constraints that interfered with and prevented her from seeking care or DE. When other participants were directly queried about anything that interfered with them completing their DSM responsibilities, they indicated that there was nothing or very little interference that was external to their own temptations and self-discipline. However, several of them indicated there were some situation or forces that acted as a type of obstacle. For example, W7 and W9, as established above, both worried a great deal about whether they would suffer the same terrible outcomes as their dialyzed mothers. Both of them had seen an increase in their overall “sugars,” because their A_{1c} was higher than in the past. W7 expressed multiple times that she felt her worry made her BG worse. Wb3 confidently asserted that when she was under stress, including anger, her BG would inevitably rise. M1, W1 and W4 all

suffered physical pain that interfered with their ability to exercise. As will be discussed below, language comprehension and understanding came to bear on several participants, particularly for W4 and W5. As will be demonstrated, insufficient or inconsistent HCP support and understanding was an interference at the gateway to HC.

Participants who found themselves in situations in which they were tempted to eat things they should not eat learned that, on those days, they did not manage their sugars well; at some point, this was experienced by essentially all 12 participants. The confusion of not knowing what was right and portions to eat interfered with consistent DSM for W2 and W4; however, the latter eventually learned what she had needed and had successful DSM at the follow-up visit. Several of the female participants had or felt responsibility for their children that oft times interfered with completion of their own DSM (W2, W3, W5, W6). Spiritual struggles, conflict, or distress, such as W10 faced when she was emotionally betrayed by her older sister, also had the power to trigger BG imbalance.

Summary of having support. In summary, all three types of support served to promote overall, better and more consistent DSM habits and choices. In all of these cases, the involved participants with T2D were empowered by family members who helped in the short-term, which facilitated and protected the long-term goal of well-controlled BG. Most had social support; W9 was lacking support but made up for it in her self-efficacious approach. Shared care was a unique finding and clearly one of the primary support mechanisms in which participants shared the burden of diabetes care with one another or had family who participated directly in

the diabetes care of the persons with T2D. Spiritual support was identified as helpful in the lives of nearly half of the participants. It may have been an influence in the lives of others but was not reported. For some, it could serve as a form of wishful or hopeful thinking, yet served as an important support. When asked directly, participants did not think there were issues or dynamics that interfered in their DSM. However, several of them did have interference that they did not readily identify as such. Mothers in particular, had their daily or occasional DSM interrupted by the needs of their offspring and home responsibilities. There were temptations and cultural pressures and some faced spiritual matters. Language comprehension was an obstacle for some and the difference between the meaning of the same word in English and Spanish was sometimes uniquely disparate; as demonstrated below.

English language comprehension and use, and differences in cultural understanding. An interesting finding that had some impact on DE and had/has potential for significant impact on DSM was to have found that, on occasion, a word commonly used in English had a corresponding word in Spanish with a completely different meaning. This uniqueness arose on three different occasions.

Variations in meaning. The same word with opposing meanings. This first exemplar was in part used to illustrate the concept *being proper* in Context - The importance of *being proper*. The remainder of that conversation is here to demonstrate how different the understanding of a word was/is between the two cultures.

PI: "... What is the word for *gracious*? Because in English we would say that someone is being gracious when they don't want to offend and they ...

RA1: It's more like proper ... you try to be proper. [Spanish] ... so as not to offend.

W6: Because you don't want to offend the person, or for them to feel like, after having prepared the food with so much gladness, you are like...

NO!

PI: So it's to 'be *proper*,' and not *gracious*.

RA1: Yeah, cause *gracious* in Spanish means more like 'being funny.'

PI: Oh, no. I mean that's not what I mean. Yeah, so 'to be proper'...

RA1: [Spanish RA1 explained the different word concepts to W6] Right? If you are trying to be "graciosa" one understands, 'oh, she is being funny.' Right? But not in English, in English it's being proper, or to have good manners. [W6 nodded]

To confirm the variance in meaning, when W10 was asked about *pretending* in the culture, an important discussion took place about the differences between the use of some terms in English versus Spanish. In seeking her insight, the PI told a brief anecdote about another participant, without identifiers, who reported that when being polite, she was also pretending to *be dumb*. The conversation about being *gracious* then ensued.

W10: "Uh huh. Like 'oh you are very knowledgeable, thank you for your advice.' Pretending.

PI: Yes, sort of being gracious or polite?

W10: Uh huh, yes.

PI: Okay. You don't use the word 'gracious' though, do you, in Spanish?

W10: Yes ... no. Gracious in Spanish means something else. It means funny.

PI: That's what my friend told me, so I learned the hard way I can't use that word ... It's a very important word in English.

W10: Yeah. Yeah, I know what you [PI: [over-talking] It really means...]

W10: Mean - polite, well addressed, well mannered, well ... grown up, always considerate to other persons, polite ...

PI: It's a very beautiful thing. You know how God is gracious to us ... It's truly the word 'grace.'

W10: Yes. Uh huh, see it.

PI: [overtalking] but it's not in that [Spanish] language.

W10: The translation is in Spanish you say 'gracious' means all these nice qualities about that person, right?

PI: In Spanish or in English?

RA4: In Spanish. A lot of gifts, that we have, right?

W10: Wait a minute, let me see [looking at the Spanish-English dictionary] ... You say gracious, okay, you say gracious in English and gracious in English means all these fine qualities ... [PI: Yes ma'am]

W10: Okay, and then the same word translated literally in Spanish means 'somebody's funny.' [PI: Yes] [RA4: Um hmm]

W10: So, translation is that one thought ... with two words have different meanings.

PI: Yes.

W10: So, what you have to give when you translate is the equivalent?

PI: Yes, that's right. Not the exact.

W10: You cannot translate literally... [RA4: You can't]

W10: Because it loses completely the meaning?

PI: Yeah, absolutely!

W10: If you translate literally, you lose completely the meaning... Yeah, that's
the-

PI: It's the concept you have to work with, not the literal?

W10: Exactly. It is the concept with what you work, not the words literally.

It's the concept ..."

Another term that took considerable work to straighten out highlighted the profound error in understanding that could arise using common terms that had, in this case, essentially opposing meanings. When used in a sentence, the Spanish version of *convenient* meant something contradictory in English; there was no compatibility of meaning. This was also through W6; RA1 did considerable interpreting to assure accurate understanding. It was a very lengthy exchange to come to a clear understanding.

W6: [Spanish] "How am I going to think? What am I going to decide, if this or that?... What is convenient to me... [interrupted by side discussion]

RA1: [Spanish]. Yeah. ... But, before you were talking about what was more convenient. Remember, you were saying, 'I am going to decide what is more convenient for me.' What else do you think about?

W6: [Spanish] What's more convenient for me? To take care of myself.

RA1: Okay, so she was saying that she would choose what was more convenient to her.

PI: More convenient?

RA1: Yes, before deciding on something it was like, what would be convenient to her.

W6: [Spanish] It's more convenient to take care of myself, because if I don't, then this could happen, or that could happen.

RA1: So, if she doesn't take care of herself, this could happen, or something else would happen. Seeing the consequences ...

PI: Oh, I see. So, it's not just convenient 'right now,' it's how that convenience actually affects the long term?

RA1: [Spanish to W6] So, it's about what is more convenient for you, not just right now, but long term?

W6: [Spanish] Yes, all the time. *All* the time you have to think that way.

PI: So how does now affect later - essentially. Okay, so when she says convenient, ... but that it's not just 'easy/this minute,' but in the big picture of diabetes ... I'm wondering what she means by the word 'convenient.'

RA1: Convenient is what's best for her in some way.

PI: Right, but convenient often in English means ...

RA1: Easiest?

PI: Yeah, we'll say 'what's convenient for us to do right now? Which store is easiest for us to go to?' So, that's why I was asking, is she talking about the convenience of 'right this minute,' or she's ...

RA1: What is convenient for her.

PI: But for long-term?

RA1: For long term, yes. What is going to make her feel better. And not as in 'right now.'

PI: Okay. It's ... really a *long-term* choice, rather than a more immediate and that's normally what we [Americans] mean by convenient. Okay, kind of like the difference between 'gracious.'

RA1: There you go; and I realize the 'convenience' choice.

PI: Precisely. Run in quick, it's easy, it's a quick stop.

RA1: In Mexican culture, there's *no such* thing as running quick. Running ... like that. Everything takes ... [inferring everything takes time]

PI: You might want to explain to her - what we were talking about

RA1: I will. [Spanish] I am explaining to her [PI], because you are talking about what's more convenient to you, but convenient in the sense of what is more important or beneficial to you. But in English, convenient is more about what's fastest or gets done now. So, I was thinking, for example 7-Eleven, AM/PM; those are called convenient stores, and that's because you go in and out fast. So, I explained to her [PI] that in Mexico there is no such thing. In Mexico, very rarely do you go into a store and are done quickly. There is no such thing as convenient or fast.

PI: I see, and that's just a difference in the culture. That's very helpful, because it helps me understand how these decisions are made.

RA1: [Spanish] She says this is very helpful because now she understands. Because she could have written, "this lady decides according to what's faster and will get results now." And it's not like that.

PI: So, it's really more what's smart for her to do in the long term than convenient [fast].

RA1: Yes, it could be even taken up to a selfish point like what's convenient for me - not as in convenient as in fast - as more like what is the optimal and valid for me."

In the previous section on Machismo, clarification of terminology of some of the Spanish terms was provided. While not confused with English, a great deal of back and forth occurred to come to understand how the terms were being applied to the participants and about those of whom they spoke. Getting clarity for simple, common words used in both languages – with very different meanings – was not easy at times and had the process to clarify not been detailed, the outcome of understanding, especially in how W6 made her decisions, would have been clearly inaccurate. It is unknown if and when this occurred with other participants but was not identified. The same level of inaccuracy might have existed and was undiscovered.

Missing the question. A different listening style. Throughout the IVs, participants addressed the last part of the question that was put to them. Often the PI posed the primary question and gave an example or clarifying comment, which

for the English-speaking person is common; proving context. However, consistently the interviewees seemed to hear or address only the latter portion of the question, not the core of the question.

PI: “So, the first questions are really just about the information as you see yourself, so the question is ‘What is your ethnicity? What is your culture? How do you describe yourself?’

W7: Well, I’m a Christian woman, and I like be honest. I like working. So what else I can say, like, I think I’m very patient and I have a [?] with the people and I have a lot of love to give.”

Similarly, W3a (test IV) missed the primary aspect of the question about deciding on DSM and went to the latter, explanatory portion of the question.

PI: “How do you decide what to do about your diabetes? What are the kinds of things that affect how you decide and how you choose ‘I’m going to take care of my diabetes today?’

W3: First I’m going to call my doctor and see what is the best, because we just switch the medicine, and I still, I don’t think it’s the right kind of medicine, but I haven’t read that – is the medicine metformin?

PI: Yes, metformin.”

In the next case, it took three times asking the same question before W10 focused on it; she too responded to the last part of the question, not the core that was the first part of the question.

PI: “How did he diagnose you? Was it like a blood test?

W10: Yes, 2 blood tests.

PI: And did you have symptoms that made him test or one of the regular screenings?

W10: I guess the regular screening. Um hmm.

PI: And did you have any symptoms at all during that time? That once you knew the diagnosis, you said 'oh, that's why I go to the bathroom more', or 'I'm more thirsty', or 'this is why I lost weight', or ...?

W1: No, the only thing was because my father was diabetic and they he had a severe diabetes where they cut his both legs off and I was always very afraid of diabetes.

PI: So, you were afraid of it?

W1: I express him [her doctor] my concern and maybe he sent me to have these tests.

PI: Did you have any symptoms? Was it just because it was in the back of your mind 'Oh, I don't want to get it because Papa had it?' or did you start feeling ... sometimes we have little vague changes and we start thinking 'I wonder if something is going on?'

W1: It could have been. Yes.

PI: What might that have been?

W1: I became very thirsty, drink a lot of water ..."

Other exemplars above and to follow further illustrate the difficulty most participants had following a line of questioning. It was seen across ages and years of education. As could be expected, the better the English, the better the understanding of questions and concepts; but not exclusively.

The impact of education; or lack of it. W7 expressed true regret at not taking advantage of the opportunity for more education offered in the United States. She reported feeling that at almost 59, she was too old to go back to school despite the strong encouragement from her college-age son. When she returned to Mexico at age 15, having come to the United States at 14 with family but did not like it here, her grandmother tried to make her mother keep W4 out of school. She reflected on that time:

“I know for sure, I never gonna be working because... for what? I don’t need it. I have the house and everything. You know my grandma ... because I want to go to school and learn something - she told my mother ‘why you gonna let her go? Women stay in the house.’ She just wanted [me] to have fun with the boys and everything.’ So my mom she obeyed my grandma.”

Thus, when she did return to the United States at 17, continuing her education after ninth grade was not an option in her family. Reportedly, girls who finished schooling in their early teens was not an uncommon cultural pattern, especially in small towns, as inferred by various participants and was later validated by the Mexican-born Latina translator-transcriptionist. W4, in responding to inquiry about this observation said this:

PI: “How many years of school did you attend in Mexico?”

W4: Six years.

PI: That’s very common, isn’t it?

W4: Yes.”

For different reasons, M2 had his education interrupted. He had wanted to pursue education beyond his technical training and was accepted to a local college program due to his good grades at the technical school in Mexico, but his plans were interrupted when he started a family with his American wife and had to work full-time. W5 was the participant who did not problem-solve her low BG problems following very vigorous exercise every day. She reported that she ate “an apple or two egg whites” before she exercised and had taken her metformin. She tried to ‘eat right’ and not overload on carbohydrates. Post-exercise when her BG was low, she craved bread and candy, which she often ate and later regretted. She did not think of eating the desired bread before exercise so she would have enough calories for her exercise or recognize that she would not have as significant of a battle against eating a piece of bread. W5: “I know I am supposed to take care of myself, but even with all of that I still crave sweets very much ...” [Spanish] “... like more candies and more candies ... A lot, I eat bread and candies.” ... PI to RA1 to W5 [Spanish] “Maybe that’s why you have those ... cravings, because your body is telling you it needs something fast?” She saw the logic, but had not problem-solved about her recurring, daily temptations or about how to satisfy craving bread and sweets.

Some participants spoke of the solid education at all levels in Mexico and knew of many people who achieved high levels of education in their homeland. Several participants had grown children with high levels of degrees, also.

Summary of English language comprehension, use and differences.

Language differences, comprehension, variance in the use of exact terms with completely different meanings were important discoveries. This pointed to the

likelihood that these differences exist in many conversations but, likely, were/are not identified. The problem, particularly with W6, was that the very opposite of what she thought she had said was what was understood by the NHW nurse-PI. Similarly, the listening style was uniquely different and affected how questions were understood. Most often, the latter portion of a question was what participants addressed, but the primary question was at the beginning; common in English usage in the United States. Again, communication was adversely affected. While language was a larger factor than education, it was noticeable that the level of sophistication in problem-solving and sometimes in comprehension did impact both the participant's understanding and their DSM.

Access to Care. Both the type and availability of access to HC and resources contributed to the healthcare status of all participants. Each participant had access to healthcare; some of lesser quality than others. The fact that all but one of the participants [W4] had insurance at the time of the IVs had a significant beneficial impact on their overall DSM. The range of type of insurance was broad, as shown in Table 4. As seen above in Clarifying Diabetes - Routine DSM, across the board, with the exception of W2 as clarified, all other participants had SMBG testing equipment, supplies, routine lab testing for A_{1c} and FBG, regular health care visits, and most knew generally what to eat having had some level of DE. Participants were aware of the various aspects needed for positive DSM. Each was diagnosed accurately in the United States. Some were aware of others who did not have adequate access or resources.

Quality of care. Insurance coverage had a positive impact on the participants' ability to receive adequate care. As implied above, the majority, except W2 and W4, had good coverage That allowed access to the aspects of diabetes care and monitoring that was required for +DSM. Once W4 had insurance through the Affordable Care Act, as noted at the 1-year follow-up visit, the quality of her health care improved greatly. Previously, she had been going to a provider monthly for quick evaluations and medications. She did not feel that they took note of her BG or her BP readings; at least she was not aware of them writing those down and they did not ask to review her logs to see what her actual numbers were. PI: "When you go to the doctor ... do you ever take the numbers for your blood sugars [to your health visits]?" W4: "No" PI: "And they don't ask you?" W4: "Yes, they tell me...'they still like that?' ... Yeah, but they don't pay much attention." As seen in Testing above, participants often did not recall their BG numbers accurately compared to what they had recorded; thus, it could not be presumed that W4 recalled or reported all of her data accurately.

The new provider, however, did keep in close contact. W4 saw her weekly; she provided the nutritional information W4 needed to know, what and when to eat, and put her on a special diet. In the first week, she "lost 8 pounds" and had "lost 4-5 pounds every week" over the course of 2-3 months for a total of 40 pounds. This allowed her to finally get in control of her diet, the BG levels that had come down, and restraint of impulses to eat. She reported that her BG levels before the new health care regimen were in the 225-400 range; after starting the new diet her FBG levels were in the 120s. She gained control of her diabetes; she never had in the

past. She remained on metformin but was no longer using the non-insulin injectable medication that she had used daily at the time of the IV, if she remembered it. Additionally, she was being treated for low Vitamin D and possibly low Vitamin B₁₂, a co-morbid condition that, when in balance, is supportive of diabetes, BP, and cholesterol health (C. S. Hansen et al., 2017a; C. S. Hansen et al., 2017b). Two weeks after the follow up visit, she was going to find out if her cholesterol was under control.

The most likely, significant finding was the horrible pain in her feet that had severely limited her activity and quality of life one-year prior was gone! This was most startling because pain due to nerve damage from elevated BG is permanent (Mohammedi et al., 2016; Zoungas et al., 2017); but hers was gone. She felt “so much better” and was no longer fatigued. Finally, she was highly motivated “to do the right thing ... because it’s working for me” thus she was much more disciplined.

Trust relationship with HCP and respect for ‘doctor’s’ authority. In the above example, there was not a trusting relationship with the health care providers W4 saw monthly and, before insurance, she did not feel they really cared about her. They did not provide the information she needed for adequate BG control and she admitted she did not remember to ask much of them either. However, once she established rapport with the new provider who communicated interest in her and provided the education and support she needed, the relationship to the provider encouraged her and made it easier to comply with a strict dietary regimen “special vegetable and fish-only high protein, high veggie diet” eventually adding other foods but “no tortillas ... fruit or dairy.”

W1 had a long-term, close-working relationship with her doctor and other providers as well. They even had her attend a staff meeting about improving their low-cost clinic; she knew all of the workers there and called it “my clinic.” M2 felt that he benefitted a great deal from his doctor and that was part of his success.

M2: “You know something else I believe that is very helpful, to when you have the right doctor to see, which is that care means so much to be with this person.

PI: Yes.

M2: That which is the right person. Not because I’ve been going to so many places, doctors ... and I found the right person to be with and it was ...

PI: Awesome.

Wife: Yeah, the doctor, yeah.

M2: And then she [his wife] went there and actually he see both of us. I mean the doctor see both of us. And, but he’s a personal doctor. He help you so much to get well. Very confident, very confident.

PI: Confident and competent [the PI knows the physician of M2].

M2: Exactly.”

W7 talked about the importance of the relationship she had in the past with a physician from a different culture with whom she connected well and who made her feel deeply cared about. She trusted him profoundly.

W7: “You know the other doctor I had before – I had [X HC] before – that doctor he was so good, well this one too, but he [previous doctor] tried to help me a lot. He said ‘don’t do this; because remember your mom;

and after you gonna have trouble with your heart, with your kidneys, with your liver and you take a lot of medication,' he was very good.

PI: He gave you very careful guidelines.

W7: Yes, I think that doctor was ... well I never see one doctor like him ... I miss him so much because anything I have, right away he put attention, he send me 'do this exam' and he never waited. He said 'I don't want to wait for nothing.' He was Filipino."

Since physicians and other health care providers who served in physician-like roles were/are held in high esteem in the culture, it was not surprising that the first place W3a was going to go with questions about her new medication was to her physician. (Part of this exemplar was used above for a different illustration)

PI: "How do you decide what to do about your diabetes? What are the kinds of things that affect how you decide and how you choose 'I'm going to take care of my diabetes today?'

W3: First I'm going to call my doctor and see what is the best, because we just switch the medicine, and I still, I don't think it's the right kind of medicine, but I haven't read that - is the medicine metformin?

PI: Yes, metformin.

W3: And it's, but I think some kind of upset on my stomach so I'm going to go back to my doctor...

PI: Are you taking that with food?

W3: Yes, uh huh, the morning, just one in the morning."

W9, whose BG had been adequately managed on one oral med for 10 years recently found out she had to take a second type; she had not previously needed to check her BG often because it was normal each time it was checked for years. With the change to the new med, she was going to do exactly what her doctor told her to do. PI: "Will you be checking it a little bit more now that you're ...?" W9: "I'm going to have to; the doctor told me" PI: "with the new medicine, please do that." W9: "Yes, for a month I have to. They said to check it twice [daily]."

Most participants trusted their health care providers' concern and advice. They had received adequate education about their diabetes either through the provider or classes to which they had been referred. Their confidence and the positive relationships contributed to their following diabetes guidelines fairly consistently. This promoted better DSM compliance and positively impacted BG maintenance. Better daily management influenced their long-term outcomes.

Health care systems. *Problems in the Mexican Social Security health care system.* W3b told of why she did not have a confirmed diagnosis of T2D in Mexico; the reasons were related to her own apprehension (see Interactions – Response to *Discovery*) and also to serious HC system problems. She reported that in the Mexican system, the responses by HCPs to common and uncommon health problems of Mexican patients made the patients feel that they were being "put off." HCPs played down the importance of the patient's long-awaited, often all day visit indicating their concern, symptoms, or change of status, were common or not significant "...and they would say 'oh, it's normal, just a little thing on the top,'" as an example. This included someone with elevated BG. A staff would say that her BG number was

not particularly high when it was far above normal; although, by comparison, might be less severe than someone whose BG was further out-of-control.

Two undergirding governmentally-based problems were cited by W3b that kept W3a from seeking further assessment when she needed to in Mexico. First, she complained of the historical corruption in the system over many decades. Some allocated health care funds were re-routed from health care. "... Always it's been really corrupt, taking the money where is not a need in the country." This led to limited resources, lengthy waits, and poor quality services, "... there was people waiting because there was not enough equipment, enough beds." The second concern that angered W3b was the Mexican government made people who had paid their Social Security Health Care taxes feel judged, "the way that the government... looks like they have given free; and in reality [I] was paying because I had a job, and I have paid my taxes. But they [made it] look like what you were asking for ... something like charity." The long waits, being treated with disrespect, and having had her symptoms down-played contributed to her avoiding the public HC system in Mexico. For her, the many serious problems within the Mexican HC presented challenges that she never adequately negotiated around; the system was an actual barrier to her evaluation and management. It was insurmountable rather than a set of difficult obstacles. Thus, she was unwilling to go for assessment and treatment. This delayed her confirmatory diagnosis and consequently her treatment of T2D.

Both W3 and W4 were given the diagnosis of borderline in Mexico, but for different reasons, they did not receive appropriate follow-up, diagnoses, or

medication. Unfortunately, the two misdiagnoses put both at a disadvantage.

Fortunately, their eventual experience in the United States was overall positive.

Health care in the United States. The HC system in the United States facilitated adequate T2D HC for all participants. Both W4 and W3 found more ease of care in the United States and both benefitted from the consistency of care, as did all others in the study cohort. At the time of diagnosis in the United States, it was determined that W3a and W4 probably had diabetes at the time of their borderline diagnoses.

Summary of access. Fortunately, all participants eventually had good and consistent access to HC, which facilitated routine care and daily self-management. Most needs were met, promoted very good care over time, and contributed significantly to potential for healthy long-term outcomes. Although limited resources during their childhood adversely affected only two participants, it continued to have an effect on choice and self-discipline for W3 and W4; it did not have a substantial effect on the other participants. By the completion of data collection, all participants had good-to-excellent trust relationships with their HCPs, which promoted both good short- and long-term results. The experience of HC in Mexico was apparently inaccurate and burdened with internal problems. Two participants were not correctly diagnosed or treated in Mexico, but did receive adequate care in the United States.

Pre-Discovery signs and symptoms. The time between having no signs of diabetes and getting the diagnosis of diabetes has been called Pre-Discovery in this study by the researcher. This period of time from the earliest physical changes until they sought health care and received a diagnosis of diabetes varied significantly

among participants. It was often after discovery of the disease that the participants looked back and found they had had signs and symptoms that indicated the presence of T2D. Symptoms and events surrounding the actual diagnosis of diabetes is discussed in great detail in the following section, Interactions, Actions and Decision-Making, including what actions participants took at the time of their discovery of T2D.

Common pre-discovery signs and symptoms. During this pre-discovery phase when signs and symptoms began to occur and were (eventually) noticed by the participants, they might or might not have had an awareness that something was changing in them, in their health; at least not in the early stages. Usually, these changes affected the participants' sense of well-being physically, but as will be demonstrated, sometimes it affected their mental and emotional stability as well. Most participants reported having had common, expected signs and symptoms, such as frequent urination, thirst, or fatigue, but a few reported very uncommon, not-expected signs and symptoms that had occurred prior to their discovery of the diagnosis of T2D. Occasionally, interviewees attributed physical changes to other health issues, such as weight loss when using diet pills. That same participant had not identified any common signs or symptoms prior to being diagnosed with T2D.

The most common sign and/or symptom pre-discovery was fatigue; 10 of the 12 had tiredness, fatigue, bodily weariness or weakness. W10 said, "Yes, I was weak, tired." Similarly, when asked, "How did you find out?" W3a replied, "Because I was feeling sooo tired after eating." In a weary voice, W4 said "yeah, my life changed because always I feel so tired (como se dice fatiga [how do you say 'fatigue']?)." PI:

“yeah, fatigue.” W9 indicated, “uh, fatigue;” and M2 admitted “yeah, a little tired, yeah” when asked about various symptoms. Only W7 and W8 reported not having some type of fatigue.

The more commonly thought-of symptoms of frequent thirst, urination and/or hunger were the next most commonly reported signs and symptoms, done by half of the respondents. W5 had a somewhat unusual change in her urine output; she had what she described as “sticky” urine, “it felt sticky.” She did not, however, notice an increase in volume as would be expected; this was during her second pregnancy. W6 responded, “I was going to the bathroom a lot, a lot of peepee. I was drinking too much water.” M2 admitted that, when he looked back, he did have some thirst but did not think anything of it due to other more prominent symptoms, until he was diagnosed. He admitted he had a pocket full of candies all day at work.

Several people had neurologically-related symptoms such as vision changes, problems with concentration, headaches, or emotional flares. Four persons had blurred vision or visual disturbances. When asked “How did you find out?” W6 replied in Spanish, “because I started to see blurry.” W9 admitted to having blurred vision, “not for a long time, let’s say 2 to 3 months.” Three female participants experienced anger and felt desperate. W5 reported feeling “really grumpy or angry easily.” Along with reporting weight loss, W2 illustrated her feeling of desperation:

PI: “What was it like when you first found out, how did you feel? What was the beginning like?”

W2: Like I said, I didn't feel nothing, I was losing a lot of weight, because after I had my son I was big, and I was losing a lot of weight, I don't know where, I was feeling shaky and... [PI: uhmm]

W2: Yeah, and like when I have it [BG] high I feel desperate, I want to go out screaming like this [*used vibrating hands and facial expression to express feeling desperate and silent screaming*]

PI: Wow, you felt desperate, that's a terrible feeling.

W2: Yeah, I was thinking maybe because I was having problems with my husband, that was the reason I was feeling desperate. But no, it was the sugar was very high.

PI: Do you remember how high it was?

W2: One time - they gave me a machine, and it was 400, 420, yeah.

PI: It sounds like ... you said that you felt that desperate feeling because your sugar was so high, was it scary to you?

W2: Yeah, because sometimes, I had to ... I had my little baby and two girls and yelling at them all the time only for little things, and I said, 'what is wrong with me? I don't like the way I am.'

PI: So you actually didn't like yourself?

W2: No."

W1 also had experienced anger from high BG. She was reported in Context – Community – Commonality, to have told her sister with diabetes that she [W1] knew that high BG would cause anger. She recounted that scenario when her sister denied she had diabetes. W1 told her "they tell you, you have 350 - that means you have

sugar in your system!” Sister: “Well I don't have anything ... and don't tell me because I get angry.” W1 added “and she *will* get angry. And I said, ‘the sugar is making you angry, check your sugar or otherwise ...’” One-half of the women experienced having a “blurry mind” or feeling “confused” per W3a; W4 experienced dizziness and had to lay down to rest. W9 bemoaned “and I feel like confused. I said... ‘How come I can't do ...’ PI: “can't think straight?” W9: “Right. What I normally was able to do – I just couldn't concentrate...” she said shaking her head in bewilderment. W2 added “sometimes ... you not thinking right and you are mad all the time.”

Uncommon signs and symptoms of pre-discovery. It has already been reported that W7 said her only symptom was mild headaches; she denied ever having any common or to-be-expected signs or symptoms. Sometimes W5's BG was so low she started shaking and she was very grumpy or angry; she had bad headaches that hurt so badly that sometimes she could only go to bed, “I don't want anybody to bother me. My head hurts, and I don't want anything.” Her change in sexual function over the course of her diabetes was reported above. While it was more common to have had hunger, W9 reported both nausea and loss of appetite. Since these occurred following the loss of her pregnancy, she attributed them to being related to the changes her body went through when it was returning to the non-pregnant state. All but one participant, W8, had some symptoms in the period of time prior to the discovery of diabetes. It was possible her weight loss was related to her approaching diabetes, but she thought it was related to diet pills she had

used. This was the period between the emotional trauma involving her husband at a bachelor's party and the routine test that identified she had diabetes.

Demographics of disease. Table 3 illustrated that the age of onset of T2D varied from 32 - 62 years of age. The length of time that participants had diabetes ranged from only 4 years [W5] to over 26 years [W6], with the average being 15 years. Gestational diabetes affected one-half of the female participants; two of whom continued with diabetes following delivery [W2, W9] and two had a second recurrence [W1, W5]; one [W3] had been improperly diagnosed as borderline years prior to becoming pregnant.

Most participants reported having had common, expected signs and symptoms, such as fatigue, frequent thirst, or blurred vision, but a small few reported uncommon circumstances. The most common symptom was fatigue, which all but two participants reported. Several had the common 'polys,' particularly thirst and frequent urination. Even more common were broader neurologically-related signs and symptoms that occurred in the majority, including blurred vision, mental confusion and concentration difficulties, dizziness, headaches, and emotional instability, especially anger or irritability. It is understood that not all signs or symptoms were reported by participants. An important factor that interfered in the PI's and RA's understanding the symptoms reported was the across-the-board difficulty participants had reporting the sequence of events; often the history was confusing and various items in the history overlapped with other aspects. This will be evident in some of the exemplars in Discovery that follows.

Confusion in reporting sequencing of events. Other symptoms might have occurred that were not reported by these participants, as there were some who did not recall all of their symptoms years ago; a few got distracted when they talked about symptoms or related concerns and did not finish answering questions about pre-discovery findings even when asked more than once. It should be clarified that the specific symptoms M1 had prior to his diagnosis many years before were difficult for him to recall and, like most others, the sequencing of events was very difficult. He confused pre-discovery symptoms with those he had at other times, thus his pre-discovery symptoms were unknown. Some participants might not have reported all of their signs and symptoms, or like M1, might have confused pre-discovery with symptoms after the diagnosis. Confusion in reporting the timing of sequencing of events repeatedly interfered with understanding what occurred when and in relation to other factors and time. This confusion occurred in the reporting by each participant to some degree; sometimes the history was never clear despite the PI's and oftentimes RA's efforts to clarify.

Finally, it should be clear that the degree of severity of the disease during the pre-discovery phase did not appear to be related to when a participant sought interpretation of symptoms by a HCP or a diagnosis was made. Some (ex: W7, W8) had mild symptoms at the time of diagnosis, whereas the fatigue of W3 was considerable and W6 had significant symptoms by the time she sought care.

Summary of Conditions Intervening in DSM.

In general, those conditions and dynamics found to have an influence on DSM were numerous and wide ranging. They spanned deeply embedded and powerful

socio-cultural influences and expectations, such as the role of *permission* for women and the effects of *machismo* for men, to the critical necessity to *Be proper*, to the aspects of DSM that each participant needed to include to have successful DSM. Health science knowledge and understanding influenced by cultural beliefs had a notable effect. The personal characteristics of the participants, particularly social independence, *motivation*, and intra-personal qualities that facilitated development of good DSM habits, along with layered dimensions of support, were of key import. These components also enabled interviewees to deal with vital conflicts and serious life difficulties that impacted their DSM. Grasp and understanding of English and the discovery of uniquely different uses of the same term between cultures was an important finding for communication with HCPs. Finally, the adequate insurance coverage that all participants eventually facilitated access to care of the standards of good T2D care that have been set by national guidelines for persons with T2D.

A primary condition that intervened was the actual disease state of the participants prior to taking action to seek health care for signs and symptoms that had developed. During the pre-discovery phase, there were both common signs and symptoms that forecasted the arrival of a diabetes diagnosis, some unusual symptoms, one's symptoms were not recalled, and one thought she had no symptoms. The pre-discovery phase lasted varying lengths of time depending upon how the disease developed, what symptoms were noticed, what other circumstances were in their lives, and when they sought evaluation. The historical recall and ability of the participants varied in quality, report, and completeness; all had difficulty reporting the sequence of events; one was unable to report.

The following section, Interactions, Actions and Decision-Making, will establish how the decisions and actions made by the participants were affected by the influences discussed in this section as founded on the contextual findings of the culture discussed earlier in this chapter. The profound salience of *Acceptance* of the diagnosis of diabetes will be elucidated. The participants' *Negotiation* of self-management within the tight confines of cultural expectations, personal drive for the short-term satisfaction of taste, and the long-term goal of preventing the unwanted consequences of uncontrolled diabetes will demonstrate how critical were/are the daily dilemmas of battling individual diabetes self-management needs within a community-oriented culture.

Interactions, Actions and Decision-Making

The Substantive Theory

The process through which the Mexican-born T2D participants battled on a daily basis was to find balance between the short-term drive for the satisfaction of enjoying cultural food and socio-cultural-behavioral obligations were weighed against their understanding of the necessity to prevent long-term, untoward diabetes outcomes. As themes formed, there were key categories that described the theory. *Negotiation* was the actual process they underwent to fight the *battle*. *Negotiation* was necessary because, daily, there were opposing forces that caused each person with diabetes conflict.

Three forces or dynamics made *Negotiation* necessary. First, the highly community-oriented culture was strongly rule-based that meant members were expected to fulfill social obligations *to be proper* within community norms. These expectations pressed the participants routinely and had the potential, when not complied with, to negatively affect their overall standing in the society. A second force, common to all people, was the personal desire and temptation to eat delicious food. It was particularly difficult for them to resist the smell, taste and sight of colorful Mexican food. Both the requisite to follow societal norms at any given festivity and the challenge to resist eating flavorful food that had been prepared for them were short-term needs or desires - to please the hostess who had prepared food and to satisfy taste-temptations that often, had symbolic meaning and memories. The third force was an *elusive*, long-term need: diabetes required- requires one to think long-term to prevent organ damage from extended high BG or

recurring BG excursions. Thus, there was a *conflict*, a daily *battle*, between the short-term drives for personal and social satisfaction and the long-term needs to protect one's self from injury. The short-term provided immediate satisfaction and pleasure. The long-term could only bring mental satisfaction that the participant was working toward a distant, long-term goal. This was how the categories related. Each day they were faced with developing or maintaining proficiency of their DSM practices in order to have *Mastery* of their diabetes. And, once *Mastery* was attained, it had to be maintained, *Maintaining Mastery*, every day because the recurring *battles* were new each day. To gain *Mastery*, they developed numerous, creative ways to *Negotiate* with themselves and others to bargain or navigate around and through temptations, social pressure, and the fear of the consequences of failed DSM choices. The substantive theory that emerged from the data was:

*Negotiating every-day diabetes self-management decisions
about conflicts between culture, personal enjoyment, and long-term outcomes
toward mastery of type 2 diabetes by Mexican-born adults.*

Finding out about Diabetes.

Prior to performing DSM, one must first learn that one has diabetes. As conveyed in the prior section on Intervening Conditions, it was during the *Pre-discovering* phase when signs and symptoms of diabetes developed that eventually caused all but one of the participants to seek interpretation of those physical and/or mental-emotional signs. Some participants expressed that, to learn about their diabetes was a relatively quick process from when they first noticed or were

bothered by symptoms; for others, it took some time longer. As would be expected, the time between the onset of signs and symptoms heralding the presence of diabetes and diagnosis varied considerably, meaning the *Pre-discovering* phase lasted a different length of time for each participant and did not appear to consistently be dependent upon the significance or number of symptoms. Some participants had more symptoms or their symptoms were more significant at *Discovering*, but surprisingly, there was no consistent or recognizable designation. Thus, there did not appear to be a patterned relationship to the *Discovering* process. Simply said, some chose to seek health care evaluation earlier in their symptom presentation than did others. Some had more distinct symptoms, some paid more attention to changes in themselves, and others waited until they felt they *had* to go for evaluation. Many dynamics, beliefs, conditions, emotions, and personal historical factors were the determinants rather than disease severity.

As reported in the previous section, fatigue, blurred vision or mind, mental confusion, occasional headaches or anger, and irritability were common experiences. It was these and other symptoms mentioned earlier that sent people to a HCP to find out what made them feel so poorly or caused their symptoms. Rare participants (W10) went fairly quickly with the onset of symptoms because the poor outcomes of her father's unmanaged DSM *Motivated* her to start care as soon as she suspected something was wrong. Most, however, waited until symptoms were more significant and/or there were multiple symptoms. The following segment will highlight the next phase participants progressed through prior to starting DSM. These are the elements of the *Discovering* of diabetes in this cohort.

Discovery - *Discovering* Diabetes: Types, Suspecting susceptibility, Reacting to Discovering, Responding to Discovering

When participants had a high enough suspicion that something was wrong, or that they had physical or emotional changes they could not explain or that concerned them, they went to their health care provider. It was usually at that point that they were tested and found to have the diagnosis of dreaded diabetes. Any exceptions to that pattern are illustrated in exemplars following.

During the interviews, when asked the question, “How did you find out you have diabetes?” naturally, each person had his or her own story. Two primary patterns emerged. The first, as suggested in *Pre-Discovery/Before Discovering*, was an awareness or suspicion that something or some things in one’s bodily functions or appearance were changing, different, or had changed. The second was finding out through a blood test that she or he had diabetes. In the latter case, the participant thought back and realized there were actual changes that had taken or were taking place, but she or he had either not noticed the changes, had ignored them in some form, or thought they were related to something other than diabetes.

Types of *Discovering*: In pregnancy, Rapid, Gradual, and Through lab tests. There were four mechanisms of *Discovering* experienced by this cohort. One-half of the women *Discovered* they had diabetes when they were pregnant, usually in the latter or mid trimester; pregnancy-induced diabetes, also referred to gestational diabetes (GDM). Most were gradually *Discovering* what was typically experienced by newly diagnosed person with diabetes. One of the participants diagnosed at pregnancy had been misdiagnosed as borderline diabetes several years before her

pregnancies. Thus, she likely had existing T2D when she clearly developed GDM and experienced *Discovering diabetes*. Another participant had an abrupt physical change that led to rapid *Discovering*. Per the above, another had a regular doctor visit after a routine lab test exposed her unexpected diabetic status. Still another had a minor, uncommon symptom thought to be caused by a minor malady, but was confirmed on lab test to have diabetes; much to her dismay. The degree of suspicion that one was susceptible to or at risk for diabetes had an important effect on how quickly participants sought evaluation.

Discovering in pregnancy. Four of the 10 women's *my-first-time* diagnosis of diabetes was when pregnant. The insulin-controlled diabetes first identified in W1 and W5 each resolved after delivery of her child. There was a 14-year period between the recurrence of diabetes in W1 and 4 years for the younger W5. W2 and W9 did not have a disease-free period. Whereas W9 immediately began care of her diabetes upon *Discovering*, W2 used medications for only 1 year post-natal. Unfortunately, due to demanding life issues and lack of support she went for almost 12 years with no medications; she had once again sought care just prior to the interview. W3 already had a borderline diagnosis for a few years before her first pregnancy. She used insulin during both pregnancies. Shortly after the second, she finally realized she needed to use oral meds as she had tried to manage her diabetes for 7 years through exercise and diet, except for her two pregnancies. She actually considered the time when she started taking oral medications to be the time when she committed herself to being a person with diabetes; prior to that she still

considered herself borderline. Thus, 50% of the women had pregnancy-related diabetes and all eventually became full, medication-dependent T2D.

For the majority of those participants who recognized some sort of symptoms, the onset was gradual and oftentimes the symptoms could be explained by reasons other than T2D. For instance, W9 found out *after* she lost a pregnancy that she had diabetes with her early pregnancy. Nonetheless, she thought her fatigue was related to the resolving post-pregnancy changes in her body and her sadness at the loss of the unborn child. From a very different type of Discovering, W1 had what she experienced to be a very sudden onset of symptoms. Her unique story follows.

Rapid Discovering. W1 reported an abrupt change in her physical being that drove her immediately to find out what caused the rapid change. She told of having awakened one day to find that her appearance and her vision had suddenly altered.

PI: “How did you find out you had diabetes?”

W1: Oh, it’s because I woke up in the morning and my face was so skinny and I didn’t look good, and I couldn’t see good, my vision was blurry, I got scared ... So, then I went to see my doctor, and I told him what was going on, so he took a blood test, so then he says ‘it shows you are a diabetic...’ because my sugar was 350.”

Rushing on, W1 quickly added, “and I couldn’t see. I had to be close by even with my glasses on [holding her palm directly in front of her eyes]. I couldn’t see your face. I would see like a monster face - that was scary ... [shaking her head in disbelief].”

No one else reported as abrupt or dramatic of a change.

Gradual Discovering. W3's story was convoluted and at times difficult to follow. During two separate interviews, she got the symptoms from one time period confused with other time periods and her sequencing was convoluted; this happened with W4 and M1 as well and to some degree with most participants. W3 recalled fatigue as a child and had bouts of fatigue in her 20s. Following three emotional traumas (see Context – Trauma), at 27 she sought the assistance of her previous college professor, an endocrinology physiologist at a university in Mexico, who told her she was borderline, but also told her he had to “declare diabetes.” He told her to manage it with diet and exercise, which she did for a number of years. At the time of the dual diagnosis, they were using old standards (Gavin & al., 1997); had they used current standards, her BG and glucose tolerance tests would have put her in the diabetes range, not borderline (Whitley et al., 2017).

Because of lack of access and serious issues with the Mexican public HC system, she did not receive medical care there. After moving to the United States, she developed GDM during her two pregnancies and was treated with insulin. Between the two pregnancies, she apparently continued to manage her diabetes with diet and exercise; however, she did not feel well and frequently struggled with fatigue. Following the second pregnancy, she was treated and managed on oral medications, diet, and exercise. Throughout the course of her borderline status to the time of GDM, she was symptomatic but believed, or wanted to believe, that she was borderline. Sometimes she used her mother's urine test strips that always indicated she did not have diabetes. By the time of the second interview, W3 finally understood that she likely had diabetes for several years, but the outdated and

inaccurate urine testing was not sensitive enough to identify her as having diabetes. An exemplar in the prior section, Intervening Conditions – Medical knowledge, demonstrated that she avoided taking medications because of a faulty belief that her pancreas would become lazy if she used medications too soon. “And I say if I take the medicine then my pancreas will stop. Eventually maybe I gonna go on insulin.”

As previously discussed in Context – Cultural Perspective – The Effect of Trauma, W10 had gradual onset of symptoms following the trauma of emotional betrayal involving her eldest sister. Her symptoms were common: fatigue, weakness, tiredness, thirst, and frequent urination. She became suspicious of her symptoms primarily because her father had had severe untreated diabetes, discussed in Intervening – Machismo above.

M2 was warned by a physician friend in Mexico that he might have diabetes; although the symptom she suggested that might be related to T2D was unclear to both M2 and this nurse-investigator. He had no prior family history of diabetes, so he was surprised when his friend suggested this and later when he was diagnosed. The Mexican physician friend advised that he be tested, which he did soon after his return to the United States. When first tested in the United States, he did not have diabetes; however, in a short passage of time he developed symptoms. His symptoms were common to most participants.

PI: “So by the time you had the second test that confirmed it and you were starting at that point to be a little more thirsty, a little more ...

M2: Yeah, well I changed and I started to notice my body wasn't quite reacting the way it was before and I started to notice changes about myself.

PI: ... And were those ... being more thirsty, going to the bathroom more ...?

M2: Going to the bathroom.

PI: And was there any hunger ... feeling tired or changes - you felt a little tired?

M2: Yeah, a little tired, yeah.

PI: Okay. And then you were having those, a little more thirsty, a little more hungry?

M2: Yeah. Exactly."

Discovering through lab test results. As demonstrated in Context – Cultural Perspective – The Effect of Trauma, W8 had no signs or symptoms of diabetes, or any family history; later she did mention weight loss she attributed to taking diet pills before visiting Mexico. Her diabetes appeared through routine screening following a severe emotional trauma involving her husband. Also, as reported earlier, W7 did not have typical “poly” symptoms (-dipsia, -uria, -phagia; frequent thirst, urination, hunger); she had only a headache so she also was not expecting a diagnosis of T2D. Her diabetes was confirmed through laboratory studies as well.

Summary of types of discovering. GDM affected one-half of the female participants, one had it before but was inappropriately diagnosed and later avoided diagnosis (W3), two continued to have diabetes (W2, W9), and two had a recurrence in later years (W1, W5). W1's recurrence was sudden and dramatic; all others had a

more gradual onset of symptoms that sent them to their HCP. Only W8 was unaware of symptoms, except weight loss attributed to use of diet pills used before diagnosis. The awareness or suspicion of physical changes was what sent all of the others to seek health evaluations.

Suspecting susceptibility to diabetes, versus lack of perception of disease risk. It was interesting to observe that, although most of the participants, except for M2 and W8, had a family history (FH) of diabetes and some commented they even knew that diabetes was more common in Latinos, most of them did not seek healthcare sooner than they did. At least for some, there were other reasons whether they perceived the possibility that they might develop diabetes.

For example, W7's mother had diabetes over 50 years. She was warned many times by her mother and HCPs to be careful, especially because she was overweight and had a higher risk potential. Over time she had heard about common symptoms fore-telling diabetes, such as fatigue, frequent thirst and urination, change in vision or being hungry all the time. However, she had never experienced any of these common symptoms. Sounding somewhat confused, W7 shared, "I never feel *nothing* like tired or losing weight, I just have a headache, but not too much ... I still never have ... nothing. ... That's it. I never had thirsty or sometimes you go to the bathroom too much, but nothing like that." Despite the fact that she was quite overweight, had a strong, immediate FH of diabetes, because she did not suffer what she thought would be telltale signs and symptoms, her sense of T2D risk was low, much lower than was actually the case. Because she did not feel threatened, she had a low level of suspicion when she sought HC for her headaches.

On a different note, instead of looking for common diabetes signs and symptoms, W9 had thought that she had a low risk of developing T2D because she had always controlled her weight. She had determined that if a person was not overweight they would not develop T2D, because she thought everybody with T2D was overweight. Even when she had several well-known indicators for the development of diabetes, including fatigue, significant FH [her mother had dialysis-dependent T2D], and she had had three large babies over 9 pounds each, she did not see herself at risk. She even had what she thought was another indicator of menstrual irregularities, about which she had read. Because she always kept her weight in good control, she thought that would keep her from getting diabetes. She was actually at high risk for T2D, but she inaccurately perceived her risk as low.

PI: “Okay, so you actually knew a bit about it [diabetes] before you actually had the diagnosis ... Were you surprised at all that you had the diagnosis?”

W9: Yeah, because usually it’s for people who are overweight, and *I don’t understand why*. I’m not saying that I’m thin but I’m not overweight.
[laughs]

PI: You’re certainly not overweight, oh no.

W9: No, and it’s usually for people who are overweight. *I never thought* I was going to be diabetic.”

In the case above regarding W1’s sudden appearance and visual changes she had had GDM 14 years prior and had been cautioned to be careful about her diet and weight control to avoid having her diabetes return. She also had a strong family

history; her father and eventually four of five siblings and extended family members. In her own words, she was not careful. "When my daughter was born, it [GDM] went away ... then it came back when my daughter was 14. They told me it was going to come back within 10 years, but it came when she was 14. ... it was my fault because I couldn't lose the weight, if I would've lost the weight - my diabetes would be gone." Her suspicion or concern of the recurrence was low, especially when it had not returned within the 10-year forecasted warning period; but T2D did return. W5 also lost focus on the warning she received that diabetes could return after her case of GDM. Despite her strong FH she felt "ok" after a year of trying to prevent the return of diabetes, so her suspicion for risk was also inaccurately low.

M1 represented another case of low risk perception for poor health outcomes. He said he did not realize how serious his chest pains were before his heart attack, the foreboding status of his diabetes-induced toe infection, or later complicated foot infections that almost cost him loss of part of his lower limb. He reported he "just put it off;" each situation was put off until something truly threatening happened.

The situation with W10 was quite different. Due to the frightening background of her father (see Intervening - Machismo above), she went quickly for evaluation of her symptoms of which she was suspicious. She had a high level of wariness; she felt at risk. Once symptomatic, she sought care quickly.

PI: "So did you think for a little bit for a while when you were starting to first change?"

W10: No, I didn't because of my father's experience. Due to my father's experience, you know, seeing what he went through, having both his legs amputated. It made me to be very careful about it.

PI: Soon after you started seeing the changes you went? [for HC evaluation]

W10: Yes.

PI: So, you didn't deny, you didn't pretend, you didn't ignore?

W10: No, and mostly in the Mexican culture ...

PI: Yeah, talk to me about the culture.

W10: ... I think regarding men it's because they never want to go to the doctor. They say 'no, no, no nothing is wrong with me.' The macho thing.

PI: Yes, the macho thing ... 'Nothing's wrong with me.' Okay.

W10: And for the women, they always say 'well, I'll get better, I'll get better' and they are so busy with their lives that they don't have time to take care of themselves because they put the children and their family before their own health.

PI: It's that the 'family is first.' Right? [W10 Yes] Especially the children, but the family, kids first.

W10: Yes, the family ..."

A final, important exemplar was from W6 who had a family history of T2D.

Her case illustrated how one had a perception before diagnosis that one had diabetes; she did, but did not seek help at the early signs. Based on her very high BG at the time of diagnosis, it was likely that her symptoms had persisted for some time

prior to her going to see her doctor. Additionally, she was trained as a nurse in Mexico and worked for a couple of years before coming to the United States

PI: "How did you find out?"

W6: [Spanish] Because I started to see blurry.

PI: Oh, you had blurry vision.

W6: [Spanish] Yes, I went to the doctor and that's when everything came out.

PI: So, you had blurry vision and anything else, other symptoms?

W6: [Spanish] I was going to the bathroom a lot, a lot of pee-pee. I was drinking too much water.

PI: Yes. You were thirsty. Like *deve* [weakness] or *fatiga*? [motioning tiredness]

W6: *Fatiga*.

PI: Okay. So, you had fatigue. You were going pee pee a lot, you had the thirst, and then ...

W6: I lose weight.

PI: Okay. And he, what did he do? Did he check your blood, or ...?

W6: Blood ... when check the first time with them ... 600.

PI: Wow. ... did you know that you were starting to feel bad, or did it come fast? The symptoms.

W6: I went, as I started to feel this way, but I think I already had it; of course.

RA1: So, what happened?

W6: I think, so, is in my diabetes I have, but I don't know how.

RA1: She said that maybe it was ... she wasn't feeling very good, but maybe she had it before and then it just got worse.

PI: I just wanted to understand. Was she saying that - was it *after* you had the diagnosis, or *before* the diagnosis, piense [thinking] 'maybe I have something' for a while?

RA1: [Spanish to W6] So, you mean, it was before or after the diagnosis that you really thought, 'do I really have this?' Or you have already thought before that maybe ...?

W6: Well, before, I thought that maybe I had it. I thought, since I have some knowledge from nursing studies, so I thought, 'maybe I have it.'

RA1: So, before she was thinking maybe she had something because she has some knowledge of being a nurse."

Summary of suspecting susceptibility. Despite a positive FH for T2D (among all but 2 participants), W7 and W9 thought they could not get diabetes because they did not manifest certain signs of T2D, thus they thought they were protected. Their level of suspicion of risk was low, although quite false. On the other hand, W10's strong FH sent her to her physician quickly because her perception of risk was high when her father tragically lost both lower limbs as a complication of his T2D. M1 appeared almost oblivious to his multiple, serious health issues earlier in his life; he was alert to change in his maturing years and after traumatic life events. W1 and W5 did not take the warning for post-GDM seriously enough and seemed to ignore their risk until they had already developed T2D. W6's IV raised a critical question about why most of the participants waited to seek care until they

had fairly substantial, recurring, or multiple signs and symptoms of T2D and led to further inquiry about the cultural factors that might have contributed to delay.

Reacting to *Discovering diabetes* - Feeling: Fear, Sadness, Shock and disbelief, Injustice, and “Sick.” As noted above by W10, who had a high level of suspicion, some participants went to their HCP with a sense that they probably had diabetes; others were dismayed, as was the case with W9. W3 did not really seek care for a few years until she was so physically miserable she felt she had no choice following her second GDM. The range of emotion and responses to the diagnosis of diabetes varied; some people had more than one early response, such as sadness and fear (W7). Several people had fear and dread, others felt shock or disbelief, some participants asked “why me?” Still others asked “what do I need to do?”

Feeling afraid; having fear. In an exemplar above, under “Rapid *Discovering*,” W1 expressed how scared she was when her vision was distorted and she was frightened by what she saw in the mirror; she also had a significant weight loss immediately prior to her diagnosis that she had apparently not noticed as it occurred. After her diagnosis, her fear became a *Motivation* for changed lifestyle.

PI: “What did it feel like at the beginning when you first got it, it sounds like you were scared?”

W1: [with large eyes and a frightened look] “Well, yes I was scared because my face, my body just changed - completely!”

PI: ... You told us what you did after you found out, you got pretty serious about trying to change your eating habits.

W1: Yes, my eating habits because *out of nowhere* [snapping her fingers] I lost the weight. Diabetes *it eats you up!*"

M2 indicated he was afraid of having diabetes, but it was because of the change of lifestyle he foresaw rather than being fearful of consequences of diabetes as others had. When asked "What did you think and feel about having diabetes?" he hesitated, "Well, I was afraid of it, I guess... Because I guess, well my life is going to change." PI: "Yes"

M2: "Completely because of the diabetes. So, I just start to change my life in different ways, eating habits are and I was more careful with it and I start to take medicines - which I always do ...

PI: Alright, let's talk about your feelings about being afraid, because a lot of people are telling me that, that when they first find out that they think and feel afraid ... Was the major thing you were afraid of, 'oh I have to make big change in my life?' which you said, or were there other things about diabetes that you were afraid of?

M2: I was kind of, I mean actually I started to notice the changes on my body.

PI: Right

M2: You know and it's when I went to the doctor, my friend she told me that 'just be careful with the sugar, watch yourself,' and you know unfortunately we have those habits that ... eat some sweet.

PI: So, the biggest fear for you really was about changing your lifestyle?

M2: Exactly."

Similar to M2, when W8 found out she had diabetes, her response was out of concern for the changes she would need to make in her social activities; changes to her lifestyle. She was also afraid of being the first in her family with T2D. When asked how she felt about having it she replied:

W8: "Oh I felt bad! I felt bad, because they told me that you are going to have parties [limits] and this, and this ... And you don't have ... you don't have [get] to do this, you don't eat the piece of meat, you have this size to eat ...

PI: So, lots of limits ... On what you could do, or what you could eat.

W8: A lot of limits." She also added, "just I am scared to, because I only are my family diabetic ... I am the first one in my family diabetic ... That's why I am scared."

Later when asked what she thought about "oh I have diabetes?" she replied, "I am scared!" PI: "You were scared?" W8: "I am scared ... PI: "Okay, what were you afraid of Señora?" W8: "to be taking some pills. Before I never had headaches, I never take any [pills]; I never taste any pill for nothing." PI: "... except for those diet pills and you didn't like it." W8: "Yeah, that's why ... and start to taking some pill - this is my biggest [fear]." This was an example of the evasion of pills in the culture.

W9, whose mother had severe dialysis-dependent diabetes, was also afraid when she got the diagnosis over 10 years before; she was afraid of the possible consequences. Throughout the IV, she mentioned being afraid of having to be on dialysis as was her mother. As indicated above, she felt confident that she would not ever have diabetes because she was not overweight. During the interview, she

responded to the PI's question, "I'm wondering what it was like for you at the beginning?" in the following way:

W9: "Well it's hard to accept it. I was afraid.

PI: Okay, so hard to accept it and afraid.

W9: Yeah, but since my mom was diabetic for 50-some years, I knew more or less what it was, and I knew that it's something that you can control if you put your effort into it, like you know your diet and exercise ..."

PI: When you say, you were afraid, tell me about the afraid piece. What were you afraid of?

W9: Right away I thought about the side effects it has - like heart problems, palpitations, your sight - that's why.

PI: Yeah, it's scary, isn't it?

W9: It is scary."

Similarly, W7 had fear in addition to sadness. When asked how she felt when the doctor told her she had a BG of 200, she replied "No. Well ... I'm scared, I tried to be eating whatever I'm supposed to, but I don't know ..." When W10 first went to her doctor, she was suspicious that her symptoms foretold of diabetes. She expressed her fear of diabetes to her physician, "my father was diabetic and he had a severe diabetes where they cut both of his legs off and I was always very afraid of diabetes." She then had to wait for the lab tests to reveal that she indeed had it too.

Summary of Fear: Fear of changes that occurred rapidly (W1) or that made the participants feel threatened (W9, W7) because of what they had observed in their family was a fairly common reaction to Discovering. One aspect of fear was the

threat that life would change and one would have to give up some of the habits and activities s/he enjoyed (M2, W8; later W3). W8 had a common cultural fear that she had to take a pill and she was not accustomed to using medications; she was also afraid because, as the first one in her family with the disease, she had no family social knowledge of how to care for her diabetes. W10 was afraid because of her father's terrible outcomes.

Feeling sad. W7, whose mother also had dialysis-dependent diabetes, said "well, I feel sad because I know my mom suffered ... She always sick after that ... She never feel good." Later when W10 was confronted with confirmation of the diagnosis, she expressed sadness. Nevertheless, her sadness led her to have great resolve. She was determined to do whatever it took to prevent the terrible things from happening to her that happened to her father when his diabetes was unmanaged. When asked "when you first got ... the diagnosis, how did you feel? What were your..." W10 "Reactions?" PI "Yeah, and your emotion?" She stated:

W10: "Well, I was sad to learn about it.

PI: And the sadness ... tell me what that was for you?

W10: And as I said 'my Lord, I hope I don't die like my dad did without his leg', and I said, I promise myself 'I would do my best and do anything, whatever it takes to control the diabetes, being food, being exercise, whatever I need, I will do it!'

PI: So what I'm hearing is 'I was sad I had this because I know the results. I know what can happen to someone and that it is a terrible thing.' [W10 'Yes']

PI: ... I also hear you saying 'I was afraid that if I don't take care, that will happen to me.'

W10: There you go. That's it."

The two who used the term, sad, to describe one of their reactions to Discovering diabetes knew how terrible the outcome could be because of what they had witnessed first-hand in their parents. Both knew that they would have to handle their disease differently than did their parent.

Feeling shock and disbelief. W9, who was at high risk with low suspicion, clarified her complete surprise when she found out the reason she had been feeling poorly was related to T2D rather than recovering from her lost pregnancy or some other cause. She had various symptoms over the course of at least 2 to 3 months.

PI: "Did they do a blood test? Is that how you found out that you had it?"

W9: Yeah.

PI: But it was a blood test after you lost your little one?

W9: That was after. Yeah, after I lost the baby ... I don't remember exactly how long after.

PI: Okay, and do you have any idea how high your blood sugar was at that point?

W9: 3 ... in the 300s. Like 365 maybe.

RA4: 365 and 3 meals, or when fasting?

W9: No, when I found out.

PI: Oh, when you found out; so, it was probably random, okay.

W9: Right. Yeah, cause actually how I found out ... I went to my mom's 'cause she's been diabetic and I wasn't feeling well ... and I just checked my sugar and it was at 365 ... and that's what made me go to the doctor ... And, I told him that I checked it and that's when they did the test, and gave me the medicine after.

PI: Sure, well then when you say 'I didn't feel good,' what were some of the symptoms?

W9: I was nauseated, I didn't feel like eating anything ...

RA4: And which part of the day ... did 365 would ...? [as a person with diabetes RA4 was attempting to place the time of day W9 might have had this high BG number]

W9: During the day, during the day, I was at work. It was like midday, because it was my mom's birthday and we took her to a lunch and that's when I checked. I wasn't hungry and didn't feel okay, and I said 'well I'm going to check it.' And it was at 365 and I thought 'No! Maybe this is wrong 'cause I'm *not* diabetic. It shouldn't [be so high].'

PI: Yeah, you were shocked!

W9: I was shocked. And that made me go to the doctor and I told him what happened and they checked me and that's when I found out.

PI: So, you were nauseated, you had a loss of appetite ... [As reported in Pre-Discovering, she reported blurred vision, fatigue, frequent urination, feeling confused, and unable to concentrate; she had symptoms 2-3 months].

PI: ... Did you think, wonder or suspect that you had diabetes before you found out?

W9: Yeah.

PI: You did. The reason I'm asking about that... [confused because earlier W9 had said she never thought she would get diabetes] but you didn't suspect it because you were thin. You were not heavy.

W9: Yeah, yeah.

PI: ... some people have told us that sort of - in the back of their minds - they have thought 'I wonder if something is going on?' Or they've thought 'I sure hope this isn't diabetes. I don't even want to deal with that.' Or ... I'm giving you a sort of ball park idea of... [what others had said about their suspicions].

W9: Well, I knew there was something wrong with me, but I never thought that it was going to be diabetes. ... Yeah, I thought it was something else."

Because W9 did not think that she could get diabetes because of her weight control, she was shocked that diabetes was the cause of not feeling well for an extended period after having lost her pregnancy. She allowed a single sign to be her guide to suspicion instead of noting FH and other clear signs and symptoms.

Feeling a sense of injustice. "Why me?" Three participants admitted to asking "Why me?" questions. The exemplar from W6 below illustrated both her sincere question and sense of injustice at having the disease along with her resolve to do whatever she needed to "to get better."

PI: "What was it like, how did you feel when you found out?"

RA1: Como se siente ... usted ...? How did you feel emotionally when you found out?

W6: I said, 'why did I get this?' But at the same time, I'd say, 'if I have it, I have to find a way to get better'

RA1: She was saying that sometimes she would think 'why me?' and then think I'll just take care of myself with the medicine and whatever they ask me to do.

PI: Okay. Were you angry when you said to yourself, 'why me?'

W6: Sometimes.

PI: Sometimes angry. What's the word for - like for injustice, like feeling...
[asking RA1]

RA1 to W6: Justicia que porque me? [Unfair, unfair, as in 'why me?']

W6: But there are no, there are no ... There are questions, but there are no answers. [said in a tone that the situation seemed unfair... and though she has questions, she will not get answers]

W6: Porque? Why? No se.

PI: Yeah, you don't know ..."

W4 also expressed a sense of injustice when she lamented, "Why am I having this, and other people don't ...? I am not that old!" As discussed above, W9's belief that she could not get diabetes due to her weight control, despite her strong FH, left her feeling a strong sense of injustice "why *am I diabetic* if I'm not overweight? I *don't* understand." Even though W3 knew her risk, when the PI asked "Do you feel

like it's easy or hard to understand about diabetes?" she bemoaned that even though she knew *she could* have diabetes because of her strong FH, she felt the injustice - not everyone in her family got diabetes, why did she? "Well, it's easier for me but it's not easy because sometimes I feel '*why do I have that?*'"

Summary of feeling injustice: At least four of the twelve expressed a sense of injustice. That did not detour W6 or W9 from starting treatment; however, W3 did delay treatment and W4 was inconsistent. All participants had a family history, so they knew that at some level they were at risk.

"I'm sick". Feeling sick. W2 had an interesting response when asked "When you think about 'I have diabetes' what do you think of that?" she thoughtfully replied, "I think when they told me that I had diabetes ... the people get scared or they say '*I'm going to die*' (said with exaggeration). I didn't think that. I only think 'I'm sick.' That's the only thing that I said but I wasn't afraid because my mom she has diabetes, my aunt she died from diabetes, my grandma died from diabetes." Despite her observation of the serious outcomes of the disease, she did not sense a risk to herself. She took medications 1 year after her pregnancy then stopped taking them. Later, well after diagnosis, W5 came to a point where she understood the importance of diabetes care that changed her focus completely. Previously she had not taken diabetes very seriously, but due to important changes within her, she then set different priorities. She hoped to experience less loss of herself and her bodily function.

PI: "What is it like for you to have diabetes now, senora?"

RA1: [Spanish] How is it like, your life, with diabetes? [W5: Sighs] How do you feel, or how is your life as a diabetic?

W5: Right now, I am beginning to realize ... I see that it's bad. Before, I didn't...

PI: Oh really?

W5: I didn't care because I thought it was like anything else, but now I am realizing how ...

PI: So, it feels bad to you? [W5: Yes]

PI: Okay. It's a bad thing? Oh. Do you feel bad or you think this is bad? [W5: Spanish]

PI: Oh, you piense - feel bad. And why is it bad?

W5: I start to think ...

PI: Oh, you think. Yes, okay. And why is it bad Señora?

W5: You are going to make me cry. [RA1: You're going to make her cry]

W5: Can I say it in Spanish? [RA1: Can she say this in Spanish?] [PI: Yes...]

W5: [Spanish] Because before I used to be.... That's what makes me feel like little by little I am ... shutting down in everything, because I used to be very sexually active, but I am not anymore. And it makes me feel very sad that I can no longer be with my husband ...

Summary of reacting to Discovering. There were numerous reactions expressed by the participants, ranging from fear and being afraid of what they knew could be poor outcomes if they did not take care of themselves, to sadness because they had seen the results of poor or negative DSM, to shock at the diagnosis when

one had a false perception of low risk, to the sense of injustice, 'why me?!' to thinking of diabetes as an illness that if taken care of could be controlled.

Sometimes, as was the case with W5, there was a delay in understanding the risks and consequences of T2D; in her case, it was painful because of the interference in intimacy with her husband (no details given).

Responding to *Discovering* diabetes: Starting DSM right away; Delaying.

Once the participants learned of their diabetes diagnosis, they began a decision-making process, whether intentional or unintentional, about how to respond to the diagnosis of *their* diabetes. They each chose how they would respond and when. Their initial responses to *Discovering* are presented here.

Getting started on diabetes self-management right away. All five women with GDM used insulin through the latter portion of their pregnancy. W9 had been on oral medications and 30-plus minutes of exercise daily since she was diagnosed following her miscarriage 10 years ago. She had seen all of the disturbing things that happened to her mother with advanced diabetes and she was aware that diabetes could be managed. From the start, she was determined that she would maintain good control. "... I knew that it's something that you control if you put your effort to it like you know your diet and your exercise. And that's what I've been doing. I guess that's why it's under control. I haven't had any problems really." Only recently had her A_{1c} increased above 7.0. She took oral meds daily; a new type was recently added. She was faithful in daily exercise and was very careful about her diet.

Both W1 and W5 had disease-free periods after which they were both on oral medications for 8 and 4 years, respectively. Following her frightening experience

looking in the mirror, W1 made a very quick decision. During the first 2 weeks of knowing that her diabetes returned, she aggressively changed her diet and followed the directions of her physician. “So, I said ‘okay’ ‘cause I want to control my sugar, because I have glaucoma.” She practiced intentional daily DSM. As mentioned above, she had a high level of *social independence*, had no problem declining food when offered and did not feel constrained by cultural expectations to comply. As a Mexican woman, hers was an uncommon response – she had been in the United States since age 10 and her parents were born in Arizona.

Both men stopped drinking alcohol as soon as they were diagnosed. M1 did continue to use drugs to deal with physical and emotional pain. He reported struggling with severe obesity and the inability to practice adequate dietary self-control for the first 12 years of his diabetes. Despite pain, he tried to exercise and he faithfully took his medicine. One of the struggles that he faced was feeling obligated to eat what was prepared for him by his first wife and his Mexican mother; “to go along with it.” To complicate matters, his mother taught his first wife what and how to cook. Over the course of a couple of years, he eventually resolved that the only thing that would help him would be gastric bypass surgery. At first, his physician did not welcome the idea, but eventually M1 convinced him that he needed the surgery. During the normal, required wait time, he seriously intended to follow new dietary guidelines and was able to lose the required weight prior to the 2006 surgery. M1 proudly said, “you know during those 6 months, I lost 20 pounds because they wanted me to lose, and that’s what they were teaching me.” PI: “... you were beginning to change your lifestyle already.” M1: “Yes, uh-huh.” Within 6 months

postoperatively, he was off all diabetes medications. Along the way, he had other serious health problems, including a heart attack and several emotional traumas and losses as reported in *Intervening Conditions - Loss*. As his fear of more serious T2D complications arose, he became more convinced that he had to eat a lighter and healthier diet. He began to refuse food that wasn't "healthy." He finally asserted, "but then when I would put my foot [demonstrating pushing his foot down firmly], you know, say 'No, I don't want to eat that, you've got to make healthier stuff.'" At that point, his wife and mother started making healthier foods.

Despite a very long and complicated physical and mental/emotional history over the past 20-plus years, M1 had been able to remain off medications the previous 10 years. Approximately one year before the IV, he was surprised at a health care visit that his weight had crept back up to 200 pounds and his "sugar" numbers had begun to increase; he had not been checking his BG. He got serious again about weight control. Within a few months his weight went down to 189 and at the time of the IV, he had lost another 11 pounds; he weighed 178 by report. As indicated in *Intervening Conditions - Exercise*, because of his significant back pain, he had limited exercise ability. He had taken some atypical DE classes through a private organization that helped people revise and practice a very lean and healthy diet. M1 attributed the most recent weight loss to the healthier diet that his wife prepared for both of them.

As pointed out in *Reaction to Discovering - Sense of injustice*, W6 began medications right away. She had delayed seeking assessment, but once she had the diagnosis, she chose to do whatever was asked of her in order "to get better." That

included exercise, daily BG testing, quarterly A_{1c} and physician visits, and she had generally been careful with her diet. The same had been true for W10, whose father was afflicted with the disease. She habitually practiced DSM daily. M2 also started treatment of his diabetes right away. He always paid particular attention to his medications. He said they were the first thing he packed when he went anywhere, even on a day trip, “so what I do is take my medications with me and whatever I need to have, I have it ...”. W4 had been generally consistent with taking her medications from the start as well. She checked her BG regularly and went to her HCP monthly. Although surprised by her diagnosis, W7 started on medications and exercise at the time of diagnosis. W8 also started taking her meds faithfully from the start of her diagnosis. She did not like taking medication and wished she did not have to take them daily, even 20 years after she was diagnosed. At the beginning of her diabetes when she expressed her dread that she had to take pills indefinitely, she bemoaned, “Even now sometimes I feel like this ‘I have to take so many pills every day’” (see Fear above). The PI summarized, “so you really don’t like the pill part.” W8: “No, I don’t. The only thing, but I have to ...” PI: “Is there anything else that you think about when you have diabetes?” W8: “No, that’s all - I wish I didn’t have to take the pills.”

As indicated above, W2 continued on oral medications for the first year after her pregnancy because her diabetes continued; she then went 12 years with no medication or testing. The reason that she did not continue was not entirely clear. However, she did repeatedly say that she was very busy and, “I don’t have time to take care of myself” because she was a working mother who carried most of the

family's financial responsibilities. "I had to take care of the girls, go look for a job, you know? ... But right now, is different (looking at her [second] husband) as he is cooking." As a Mexican woman, she chose to be responsible for the family's needs over her own health in the interim. Since she no longer had children in the home at the time of the interview and she had *shared caring* support with and *permission* from her husband, she felt free to take care of herself again. "Like right now, he takes care of myself step-by-step what I have to do. Before I had to take care of my kids first, then the last time was me. But right now, it's me and him, he take care of me, I take care of him ...". Apparently, "the last time" referred to when she was no longer with her family and before she met her current husband; believed to be the time when she lived with her mother for a period and they practiced *shared caring*. She briefly talked about the time that she was on medication when asked how she felt, she acknowledged:

W2: "I feel different, I don't feel desperate, like I want to go like this [motions being shaken]

PI: So, you no longer felt desperate?

W2: No ... I feel better when I was on the medicine.

PI: Okay, how did you feel better?

W2: I was feeling better in my body and in my mind too because I was having a lot of problems with my husband, and was blaming that the sugar was high or low, but was only the problems that I had with my husband - he wasn't responsible.

PI: When you say, your body felt better on the medicine, what does that mean?

W2: I was big like, I was going to be 220[#]. I get down like 150. (PI: "Wow") I don't know if was the sugar or was the diet, so I don't know for the loss of the weight, because it was like this [she snapped her fingers quickly] ... It was fast, even my girls would say 'Mommy what are you doing? What are you doing?' I wasn't doing a diet I was eating the little portions of food but only when I was in the house ... I was like only vegetables and not a lot of grease."

W2 moved out of the area soon after the interview. Thus, it is unknown the results of the blood tests or if she got the medication she had hoped to get. However, she spoke with confidence that she would re-start medications and had *shared caring* support with her husband; she was very *Being motivated* to take care of herself to be able to be in a *shared caring* relationship.

Delaying medication. W5 hesitated to start medication when T2D returned 4 years after her second pregnancy. She was warned by her physician to be careful with diet and exercise so her diabetes would not return or she could stave off diabetes longer. She reported she used good self-control for about a year, then she did not use self-discipline "because I felt good" and after another 3 years, she had fatigue and "sticky" urine so went back to her doctor. He ran tests and gave her MF to take daily, along with standard cholesterol medicine and a low-dose BP medicine to protect her kidneys. She was appropriately treated for her diabetes and any co-morbid condition risks. W5 told of a 6-month period after the doctor gave her the

metformin that she did not take any medicine because she was determined to get her “sugars” down without using any medicine. She exercised vigorously every day and generally watched her diet carefully; although she admitted to a daily sweet tooth. Despite her best effort to try to control her BG without medicine, she was not able to do so. Disappointed, she took medication, continued her vigorous exercise and often learned new and healthy cooking recipes from her mother.

PI: “Okay, so this is for 4 years you used this? [holding her bottle of MF]

W5: [Spanish] Yes, and I still didn’t want to take them.

RA1/W5: She didn’t want to take them.

PI: Oh, why not?

W5: [Spanish] Because I wanted to control the diabetes by myself.

PI: Sure. So why did you choose to take them? You wanted to do it by yourself, but now you have the medicine. Why did you choose to take the medicine?

RA1: What made you? Decide ... to take the medicine? [RA speaking Spanish to W5]

W5: Oh, I can’t control it by myself, I need to take this’

RA1: What was it that told you, ‘you know what, I can’t control this by myself; I need to take the medicine?’

W5: My sugar, and ... high, high, and no lows ... *O*-kay. I’ll take it.

PI: Okay, alright. How long did you try by yourself with no medicine?

W5: Maybe 6 months.

PI: Okay, but the sugar kept going up? Were you checking your sugar?

W5: Yes.

PI: And how often did you check? Que frecuente? Every day?

W5: Every day in the morning ... after ...

RA1: She does check her BS level every day. Her sugar levels were getting higher. She tried maybe 6 months without her meds.

PI: So, after breakfast?

W5: Yes.

RA1: Before, before breakfast.

PI: Every morning before breakfast. Okay. And do you check your sugar now? Every day?

W5: Yes”

W3's unique situation impacted the start of treatment of her diabetes. During the first interview, the facts surrounding the original diagnosis were confusing. It was difficult to understand how W3 actually thought she was first diagnosed. Initially, she never felt confident about her first diagnosis in Mexico because she was told she was both borderline and “diabetic” and was instructed to manage with diet and exercise, as though she was borderline, which she preferred to be the case. During her second interview, over 4 years later, she provided more detail and demonstrated efforts to elucidate questions that remained. In addition to understanding the study questions better because she was a Research Assistant for three interviews, she also spoke better English and understood more about the difficulties of diagnosing her BG. The conversation was nonetheless, a bit convoluted (W3a = first interview; W3b = second interview):

PI: "How did you find out? How ... did you get diagnosed?"

W3a: Because I was feeling so tired after eating ... And I asked my teacher from Physiology ... And she took me to do some tests ... and I had the [calibration ?], the cure, the glucose and he says 'you passed the proof, and you're the borderline, but you are declared as diabetic.'

PI: Oh my gosh, were you surprised?

W3a: Not too strong but ... (because of her family history)

PI: '... right on the border' ... but announced that he had to diagnose it?

W3a: Uh huh ... And I started doing exercise and taking care of that with food and ... everything. [PI: Yes, so diet and exercise.]

W3a: And I didn't have any pill by then ... and I start about when I was pregnant from ... first my daughter I had to use insulin. When I was pregnant.

PI: ... so you really did have Gestational Diabetes then? [W3a nodding]

W3a: And then with my son - that's the same thing, I have to use insulin ... In my gestational, and after that is when I started.

PI: The oral medicines? [W3a: Yes ...]

PI: Okay. So, I want to make sure I understand ... but because you've been here 11-12 years ... It was when you were at the university in Mexico. The Physiology professor is the one who helped you diagnosis it. So, you were diagnosed really just before you came here to the United States, right?

W3a: Yes, but it's been 5 years when I started drinking pills because he says you can [manage the disease?] with a lot of exercise and healthy food.

PI: But, your actual diagnosis was in Mexico?

W3a: Yes. I think so...

PI: 'Cause you said it was a physiology professor ...

W3a: But he said 'you are on the border,' but when the pregnancy, that's when ...

PI: ... that's when you knew for sure. [W3a: Exactly.]

PI: Okay, I see. So the pregnancy is really where you got the diagnosis; a lot clearer specifics. [W3a: Exactly.]

PI: Okay. But you knew before then that you were 'on the border' so you really thought of yourself as ... Okay, so you were diagnosed in Mexico and then after you were already here in the States and you became pregnant, that was when it really changed and you knew for sure you had diabetes. [W3a: Exactly, but I had a problem ...]

PI: [trying to finish her thought] and had the insulin and had to take the oral medication after ... Okay, so really the thing I think you're saying -- The question is what happened after you found out? It sounds like you changed your diet and exercise.

W3a: Yeah, since more exercising and more healthy foods."

Four years and three months later, after she knew more about her own T2D and had been RA4 for three interviews and understood the study questions W3b was interviewed again to further illuminate important study constructs. It was

important to clarify other questions from the first interview, such as when and how she was diagnosed and how she responded. It also illustrated how not every patient fit the criteria for diabetes in every circumstance.

PI: “Before [at the first IV] what you told us is that ... before you knew you had diabetes, when you were in Mexico in college, you felt very tired and that you had also felt tired as a child sometimes? [W3b: Right]

PI: And then you wondered if something was wrong so you talked to your physiology teacher and she did the blood test for you? [W3b: Exactly.]

PI: And I have two questions with that. Even when I went back over this it was still a little confusing, and I think you were a little confused because she told you ‘oh, it’s confirmed, you have it – diabetes.’ But at the same time, she seemed to tell you [that you] were only borderline?

W3b: Right, because I was ...

PI: What was that about? Do you understand that better now?

W3b: Exactly, yes ... Always fasting, [I] was borderline. My blood sugar was under the limit. The higher the ... (higher than normal) but always I was borderline. [meaning that she fell into the prediabetes’ range rather than the T2D range.

PI: At fasting, okay.

W3b: So, we confirmed that I was diabetic when she did the testing, the special (explained the test). [PI: It’s called glucose tolerance.]

W3b: Exactly. She did the glucose tolerance cure and that was the method that we got to confirm that I was diabetic.

PI: Okay, so they actually did confirm it there in Mexico, but you didn't ever have any treatment?

W3b: Because he said 'you are doing fine, you are doing good with exercise ...'

PI: Oh, I see, so they said 'control it with diet and exercise;' no meds.

W3b: Exactly, because he said 'your fasting is fine, so just try to walk after eating.' but some of the times if I was on my [stress?] on my body ... always my body – has a kind of a real slow response when I have stress, when I'm on stressful circumstances. [PI: OK]

W3b: So, but the good thing always I've been doing exercise.

PI: So, when you say your body reacts to stress do you mean that your blood sugar goes up? Is that what you mean?

W3b: Right, yes. So, when [I] work - the same. So, I think I was about 27 when I was diagnosed. But I was feeling tired some of the time.

PI: Were you in college at 27?

W3b: No, I already finished. I finished college at 23, so I went, because I ... I look for him because he used to be my ... my endocrinology teacher and he was a specialist because always when I go to the clinic, always that [FBG] was normal. My fasting was under the limit, so that is why I look for him when I was about 27. I say 'I need to know for sure what's going on with me.'"

Adding somewhat to the confusion, as the informative IV unfolded, yet more information was revealed about her having not taken medication earlier. The details

of Discovering and response discussion lasted 30 or more minutes. The PI's reference to the emotional situations is in her testimonial of significant, multiple, traumas in Context – How one gets diabetes. Near the end of this portion of the IV, she expressed regret that she did not start on medicine at the beginning because at that point she realized all of her rationalizing had not been the best choice.

PI: “When you had these terrible emotional situations all very close together, at that point you had to go on to meds?”

W3b: Right, but -

PI: But you did start meds? (earlier she said she started meds after her second pregnancy)

W3b: I think so, I don't remember it.

PI: ... But I'm still wondering about when you first had the symptoms that made you go to your professor who told you *'oh yeah, you are diabetic. You failed the glucose tolerance test, so we know you're a diabetic even if you're fasting doesn't show that right now, but continue to control it with exercise and diet.'* [W3b Right]

PI: But see, that's still diabetes, even if you're not on a medicine ... But do you understand why I'm confused because you're sort of saying 'once I was on medicine I had a diagnosis of diabetes,' but he told you back here [indicating earlier on a time line] you have it. but you can control it with diet and exercise. I want to know what happened before that, so tell me this-

W3b: Yes, I never could take the medicine. [PI: What?]

W3b: I didn't take the medicine. I just tried to do more exercise."

The interviews with W3 involved long, drawn-out, multi-topic, often circular discussion that was presumed to have been clarified in the first two exemplars above about the use of medications, but new information was added that caused further delay of clarity:

PI: "So you had a couple of symptoms, you went to the professor 4 years after you graduated, he did the glucose tolerance test, you failed it meaning ... that you have diabetes, you are managing it with diet and exercise and then sometime later [W3b 'about age 28'] you had all of these traumas, right? [W3b nodding] You had the trauma being with your friend, your car was stolen, your aunt died and that was very traumatic for the whole family. So, sometime after that [while still in Mexico] you were very tired, you had weight loss, and that's when you went, must have gone, to a doctor then. And did you go to a doctor...?"

W3b: Uh huh. And weight loss was 6 months to 1 year after the big accident.

PI: So, you went to a doctor in Mexico?

W3b: Right, he used to be part of my ... how do you say social security. [PI: Right.]

W3b: So, I was kind of -- because this is a very lot of waiting [in the Mexican health system], there is a lot of wasting of time for no reason, so I was refusing to go and take [tests?]

PI: Did you know at that point it was probably diabetes that you weren't managing with diet and exercising and that it probably really was

diabetes, but you just didn't want to mess with the Mexican Health system? Or you just knew you didn't feel right and you'd lost weight and stuff like that?

[W3b told the story that she sought private care for her gall bladder; no elevated sugar was reported to her]

W3b: ... And I didn't go [??], you know being honest ... Because I didn't want to wait too long for medical visit.

PI: Right, but they [people in the Mexican health care system – per her earlier report] also play down signs and symptoms. [W3b: Right.] ... Did you understand that if you didn't get care you might have problems with your diabetes?

W3b: So, I knew about my generic – my mom ... [PI 'Genetic'] ... genetic problem, but I maybe I was so busy working and studying ... uh, having a lot of the parties, and I didn't realize that ... sometimes I would feel tired. But, because I wasn't drinking a lot of water you know? ... So, I say I know eventually I'm going to have pills, but I want the most I can hold it [keep the BG level down] with exercise, but I think that I remember still the time that I was so tired and is when I made it for sure to take the medicine. (She was in the United States)

PI: Something wasn't working.

W3b: The things I remember sometimes about being tired ... weary mind ... And I was confused and I didn't ... So yeah - I should take it since the beginning. I should take ... the medicine since the beginning."

The struggle by W3 over several years when she tried to manage her diabetes through diet and especially exercise was an excellent demonstration of various conditions that interfered with her making safer diabetes choices closer to the time of her original diagnosis. Her convoluted story revealed how difficult it was to get straight-forward answers to direct questions, how uniquely different her Mexican perspective was and experience dealt with diabetes and how the Mexican HC system issues factored into her reasoning. W3 had almost always been careful with her diet and had exercised faithfully; but she later realized she should have been on medications from the time of her first diagnosis in Mexico and certainly when she continued to feel poorly when she was living in the United States. Most interviewees did not have as much struggle as did W3.

Later in the interview, W3 was asked about a major component that had repeatedly arisen from the first interviews. That was the idea of *Accepting diabetes*. She made important contributions to understanding the veracity and importance of *Acceptance/ Accepting diabetes*. It became obvious that *Accepting diabetes* was essential for continuous, +DSM. More on her process of *Acceptance* of the diagnosis follows. It brought further understanding and lucidity to her story. There was significant variation in decisions about when to start T2D medications; the individuality of each participant's response was validated when viewed through their *Acceptance* of diabetes.

Summary of responding to Discovering diabetes. Ten of the 12 participants started on medications right away at diagnosis. The adjustment was difficult, it took time. Men stopped drinking alcohol when diagnosed and most participants started

medications. M1 had an unusual T2D and health history; he was controlling by diet due to exercise-intolerance issues and was medication-free for 10 years post gastric bypass. Although W2 did take medication for 1 year, she stopped after 1 year due to family and time constraints; there was a question what that long period of time represented to her. She had recently re-started HC evaluation and expected to begin medications and SMBG shortly. Two participants delayed starting medications. W5 tried unsuccessfully for 6 months to conquer her T2D through exercise and diet; she finally succumbed to using medications and has remained committed to medications, exercise, and was eager to modify her diet. It took several years for W3 to work through her need for medications while she tried to control her T2D through exercise and diet. Her story was convoluted and never fully clear after two IVs. The hesitancy factors follow in *Accepting* diabetes.

Acceptance - *Accepting* diabetes.

There was a difference between the 6-month delay of medication use for W5 and the several-year delay for W3 (except for insulin during pregnancy) and the 12-year hiatus from therapy by W2. This raised a question of whether they had Accepted their diagnosis as well as the others who seemed to have Accepted their diabetes sooner or with less struggle. The other participants were more successful in daily DSM so the three who delayed starting their medications might have had difficulty *Accepting* their diagnosis. The data suggested that those participants who more readily acknowledged their disease were more able to effectively manage it.

Timing of *Accepting* the diagnosis: Delaying, Promptly Accepting, Incomplete Acceptance. Study participants had one of three responses to

Acceptance of the diagnosis; this was not their response to treatment recommendations but related to their personal *receipt* of the diagnosis that contributed to or guided response to therapy recommendations. The diagnosis of T2D occurred in one of three time-frames.

Delaying Acceptance of the diagnosis. The same three participants who had a delay in starting diabetes treatment also had delay in actually *accepting* the diagnosis of diabetes for themselves. Initially, as illustrated at length above, W3 avoided *Accepting* the actual diagnosis of diabetes when she was in Mexico, but did accept the borderline diagnosis. As reported, culturally it was important to be borderline rather than to have the full diagnosis of diabetes; see Context – Importance of being borderline. The following exemplar revealed W3b’s struggle and more about why she struggled. In the same way, there were other participants who expressed a similar sense of struggle and concern about the expected loss of pleasures and lifestyle in order to accept that they had diabetes; however, they did *accept* the diagnosis and responsibility for DSM more quickly. First, W3:

PI: “Okay, I thought I knew the answer to this next question for you but, I think I didn’t. It has to do with accepting diabetes, and I know you have accepted diabetes.

W3b: Right, but it’s really hard for me.

PI: Okay, this is the question: How hard was it for you to accept that you have diabetes?

W3b: Really hard because I want to have a normal life and I have to change my definite decision that I took in order to control my illness is

because I want to be alive for my kids and my husband. But previously of this I didn't want to give up on all good things that supposed to be good for me. Even that after I would be tired or not feeling well, but because I have a lot on my mouth really good flavor and I didn't want to give up on those stuff, but now I think first I change my mind and have to see life how I want to live longer for them. Before I just want to live for today. Everybody's going to die but now I have different ... I'm taking decisions for me to help myself first.

PI: I didn't understand that last comment.

W3b: Before I used to in the morning I would wash and give them breakfast but I didn't take mine ...

PI: Oh, I see!

W3b: Um hmm. And now I'm taking decisions about control. '[name], you have diabetes!'

PI: ... So, it sounds like it actually took you a long time to choose, I mean it probably took you many years.

W3b: Right. I was really, really ...

PI: So, you didn't accept it at first - we know that because you didn't go get meds and stuff.

W3b: Right, I was really skeptical about accepting the idea about diabetes, but I'm on myself, it was really hard to accept.

PI: So, you actually took a long time ... it wasn't something serious happened, and it wasn't little by little, and it wasn't right away. It was a long time.

W3b: Right. About 5 years after ... or 6 [it was closer to 7-8 by another report] ... Basically I already knew, because I was having changes and I was reading and I was ... *the only thing for me was to accept that I needed to take the pill.*

W3b: We don't like medicine."

Earlier, in Context – Health Beliefs, regarding when the Mexican person would seek HC, she had also explained, "...we wait 'til really need it." It was later realized that her final comment at the first interview 4 years prior was about *Acceptance*. Obviously by the second IV she had *Accepted* her diabetes and felt responsible to handle it. Her rejoinder to the question, "Is there anything else you'd like to tell us or that you'd like us to know?" was profound in summarizing.

"That you can change anything in regard to diabetics. Diabetic is always in there and the only way is to accept and handled it. To accept that you have that problem and try to handle the best way that you can do because your family, you know ... Because you need to be good for your family."

As reported W2 seemed to have *Accepted* her DM diagnosis and treated it with medication for 1 year following her gestational episode. She then had a 12-year delay in returning to DSM for family reasons. At the time of the IV she had re-committed to DSM, was *sharing care* with her husband and had found *permission* through him to take care of her diabetes; prompted by a toe wound that was not

healing. Although the concept of *acceptance* was also not explored with W5, she did delay use of medication for about 6 months while she tried to control her BG with diet and exercise. She always chose care of her children and family over the care of her own diabetes. However, at the IV, her full commitment to daily DSM was evident. She indicated that, through an educational teaching following the IV, she had a new sense of self-permission; she was excited to act upon to be more consistent in her eating pattern; she knew she would feel better and have better results. This was an important indicator she *Accepted* her diabetes and embraced her DSM responsibilities.

As illustrated in the segments above, W3 delayed for several reasons and admitted that Accepting diabetes was very difficult for her because she regretted having to give up a “normal” life and the idea of “just living for today.” She had to start thinking and choosing for the long-term. Similar to W8, who did accept the diagnosis quickly, W3 did not want to have to take pills. W2 had found the support, *permission*, and time she needed for her own DSM and that supported and facilitated her *Acceptance* of diabetes and DSM. W5 had delayed medication use briefly but realized her goal to “do it on her own” did not work, so she started medications. Because she always chose her family over her own needs, when she realized she had her own *permission* to do self-care more intentionally, she was able to choose self-care as needed instead of always choosing family before herself.

Promptly Accepting the diagnosis. Eight of the 12 quickly *Accepted* their T2D and began treatment. W6 summed up the importance of diabetes in her life and her resolute *Acceptance* of diabetes when she responded to the question “what do

you think about 'I have diabetes,'" she thoughtfully responded, "My diabetes is my life." PI: "It is your life, okay." W6: "It's my life." ... PI "So, that is accepto? Is that right? It's like there is an Acceptance for it? Verdad, o no?" W6: "Si. I accept my ... I accept." She was the participant who said that, as soon as she had a diagnosis, she had to figure out what she could do to get well; in fact, she was attending DE classes at the time of the IV. Even her "Why me?" sense-of-injustice questions did not interfere with her *Accepting* her diagnosis or routinely practicing DSM that she had always been committed to doing, "I always like that ... from the start."

As reported above, when W9 was asked what did she think and feel when she found out she had diabetes she responded, "Well it's hard to accept it. I was afraid." She went on to comment about her mother having diabetes for over 50 years and she (W9) knew she could control it with good personal effort but she also knew all-too-well the serious outcomes of the disease. When asked specifically, "how hard was it for you accept it? Or were you able to accept it fairly quickly or was it something that sort of unfolded over time or...?" W9: "No, I think I accepted it quickly because I knew it was something that I can control by changing my habits, like the way I eat ..." Her social foreknowledge of T2D, in her case, made it easier for her to *Accept*, knowing that she could practice self-care. When asked, "Of all the decisions that you've made about your diabetes what has been the easiest decision for you?" W9: "Everything has been hard. It wasn't easy at first. I guess it was just the transition. It took some time to accept." She clearly had *Accepted* and had managed her BG, weight, and habits very well for over 10 years. W10 had significant insights into *Acceptance* in herself and the culture. The PI asked, "Was it hard for

you to actually *Accept* and embrace ‘I have diabetes?’ Was it hard for you, Señora?”

W10: “No, because it was part of my inheritance. The genes that you inherit.”

With far less struggle, M2 very quickly *Accepted* that he had diabetes. PI “... It doesn’t sound like it was hard for you to accept that you have diabetes? You were scared that you were going to have to make all these changes, but it sounds like you accepted it very well.” M2 nodding his head in affirmation “Oh yeah, yeah.” By inference, it was clear that several other participants also fairly readily *Accepted* their diabetic state. W1, who had the frightening face-in-the-mirror experience, began her DSM very quickly as indicated above; she was frightened by what could happen to her eyes since she already had glaucoma, “So I said ‘okay’ ‘cause I want to control my sugar, because I have glaucoma.” Initially, W4 appeared to have *Accepted* the diagnosis but had so many questions and incomplete management that she did not have BG control. At the time of the follow-up visit, she had clearly fully *Accepted* the responsibility of daily and long-term care and embraced DSM; she had started to build her life around her diabetes. W8 began immediate DSM and did not indicate lack of *Acceptance*. She hated taking pills and did not like to walk, but she did both every day, along with quarterly labs and HCP visits because she was committed to BG control. M1 had *Accepted* his diabetes at various points and most recently gave evidence of *Acceptance* through his efforts to keep his weight down so he could avoid medications and complications. He said “diabetes is about your whole life!” He was *Motivated* by the things he was looking forward to in life with his wife. A number of these participants had expressed being *Motivated* and that their *Motivation* helped to keep them on track. Only one participant was observed to be

both practicing DSM faithfully but expressed reticence about it, wishing she did not have to use medication – wishful thinking.

Some participants built their lives around their diabetes and understood it was the important focus of their lives: “It is my life,” “it is part of my inheritance,” “diabetes is your whole life!” Most participants simply *Accepted* their diabetes at diagnosis and had addressed DSM since. Others embraced it out of fear or respect for what could happen if one did not keep it in control. Some preferred not to use medications but did so because they knew they needed them.

Incompletely Accepting the diagnosis? Finally, W7 had been committed to DSM and was concerned about how her lack of sleep and worry interfered with her BG control because her numbers had risen. There was a question of whether she had fully *Accepted* her diabetes because she continued to pray for relief of or healing from T2D. She wanted to use only one or no medicines despite rising BG. While the question of *Acceptance* was not directly explored with her, she said she was both committed to manage her diabetes but also still wished she did not have it; all participants wished they did not have diabetes. Whether W7 had full *Acceptance* was in question as she did not fully embrace the use of medications despite knowing they made a difference for years in keeping her BG down.

At the time of the IVs, in all, those 10 participants who eventually *Accepted* the diagnosis of diabetes as their own (W1, W3, W4, W6, W8, W9, W10, M1, M2) were overall in good BG control. W5 had fair control and had embraced the necessity for exercise. She had found new hope (and self-permission through post-IV teaching to have better control. W2 was recently ready to re-start DSM and W7

was doing DSM, Accepted the responsibility of DSM, and had ongoing *Negotiations* with God that she was working to resolve. She was not in denial of her disease, but she was reticent to fully embrace it.

Summary of timing of the Accepting the diagnosis. Most participants *Accepted* the diagnosis quickly and began DSM promptly. Three delayed *Accepting* the diagnosis; one of those three delayed the use of medication as a primary treatment for her diabetes. One participant appeared hesitant to fully accept her diagnosis. While she addressed all of the aspects of DSM, she was *Negotiating* with God in prayer to have T2D removed or reduced. This left some question as to whether she ever fully embraced her diagnosis or was simply wishing things could be different because of her strong faith in Gods' ability to change her situation.

Cultural-based conditions that interfered with *Accepting* diabetes:
Denying, Pretending, Changing lifestyles, and Dismissing severity. Participants identified several conditions that either interfered with or delayed one's *Accepting* diabetes. All of the factors were said to be culturally-based. There were multiple comments by various participants that not everyone accepts the diagnosis of diabetes, at least not easily. Moreover, the participants were clear that just having *Accepted* diabetes at the time of diagnosis, as was the case with most participants, or along the ways illustrated above, did not guarantee consistent practice of +DSM. Continuing DSM was only partially related to one's initial response and *Acceptance*. They were clear that DSM was [is] about the daily, many times-a-day choices they made and that they would have to make; year after year. They were also clear that diabetes self-management was/is an ongoing, consistent sequence of choices that

affected/affects their BG at any given time. Thus, simply having *Accepted* one's T2D status did not guarantee successful +DSM, but it did contribute to one's success.

Denial. Denying. W9 presented a convincing argument that what she believed from the cultural standpoint was the underlying issue of why the Mexican person resisted personal *Acceptance* of diabetes. She said frankly that there was/is a common denial in order not to face the truth; one has "to believe as true what you don't want to be true." The PI posed this statement-question: "Some people kind of *pretend* that they don't notice the changes. You know they ignore the symptoms, or they deny them, or they play them down, or they just don't respond when things do change inside of them. And, I'm wondering what you think about that? ... from a cultural standpoint. What would cause some people of Mexican descent to kind of ignore or ...?"

W9: "Cause you're kind of in denial, maybe, you don't want to accept it.

PI: Okay, and why do you think that is?

W9: I guess just thinking that 'No. No,' You're in denial, you don't want to accept that you have that!

PI: But what would keep people from saying 'but I wonder what it is? and I could go and find out?'

W9: You don't want to see the doctor. *You don't want to find out the truth.*

PI: Don't want to know the truth. Okay.

W9: Even though it's best to know ... so one can get help sooner to prevent problems.

PI: So, you think the major reason that people of Mexican decent might choose not to (seek the cause of not feeling well) is so they don't have ... because they're in denial, they really don't want to face it? And is that because they're afraid of what it might be or what do you think when you ...?

W9: I think we're afraid to know the truth ... Or you don't want to know.

[laughs]

PI: So is part of that ... it's ...

W9: People just don't want to know..."

When asked "How does this interfere with making good decisions about diabetes?" W9 said with a concerned tone, "It does affect because you don't want to change your lifestyle, and it's going to affect you on the long run." Emphasizing that degree of denial, the estranged brother of W1, whose father, grandmother, and all five of his sisters had diabetes, went to the point of actually denying his membership within the family in order to avoid potentially having to find out and accept he had diabetes. When W1's father was talking about diabetes, he claimed it as his own and as being a family trait, "if you don't have diabetes, you are not my child," to which W1's brother retorted, "ok, then I'm not going to be his son; so, I won't get diabetes." He went to the extreme of moving to the other side of the country while his family-of-origin stayed in California hoping his denial and distance would prevent the disease from occurring.

Pretending. "Playing dumb". Ignoring. Being oblivious. Rationalizing. A number of participants spoke of or referenced the commonness of *pretend* or *ignore*

in the culture. M2 said frankly that a feature of his Mexican culture was to pretend. "It's in the culture to pretend, to ignore ... We grow up with it." He also illuminated that it was common in the culture not to pay attention to minor symptoms and to deal with symptoms when they did not have a choice. "I think the way people think about diabetes ... people don't pay attention ... and they ignore it ... by the time they want to take care of it, it is too late." He added they need symptoms to be more significant before they will feel that there was no other choice but to go to the doctor; when it finally grabbed their attention, it was because they "feel cruddy, and that's what makes people go get diagnosed, or go get treated." Looking further into his thoughts revealed more rationale behind the delay in seeking care, an indicator toward *Acceptance*:

PI: "Okay. ... I am wondering if you can give me some insight because some people tell us that they don't try to find out right away. When they think something's wrong ... They hold back and they don't try to find out. Why do you think that is? Why do you think people might do that? ... specifically, about people from Mexico ..."

M2: Well, I believe these people don't care about life. I guess.

PI: Oh, okay.

M2: They just think there is nothing wrong.

PI: ... but does that mean they sort of brush it off, they put it aside?

M2: Exactly.

PI: Are they denying it or they're just ignoring it?

M2: Ignoring it.

PI: Ignoring, okay. And do they sometimes actually - a few people have told me that they just pretend? ... 'No, I'm okay. And I'm just going to pretend I'm okay.' Do you think that happens very often?

M2: I believe so. Yeah, oh yeah.

PI: Okay, so you said sometimes it's b'cause they don't care about life.' Other times maybe they don't really think something is wrong. And now you're saying they kind of ignore or pretend that they're ...

M2: That they're fine."

W6 talked about how some people do not deal with diabetes, "if I don't have to deal with it, then I'm not going to deal with it," indicating that paying attention to and *Accepting* diabetes was continually put aside by some Mexican person with diabetes. W9 reminded the PI about the cultural norm that no one wanted to be different and diabetes made a person different. The PI asked curiously, "... what is this 'I don't want to stand out and be different than the group, than the community, than the culture? than the rest of what my huge family is doing?' What's that about?"

W9: "They just want to be the same."

The PI sought to clarify W7's perspective on how pretending and ignoring were possibly related to or a type of rationalizing as a way some people dealt with their diabetes. She had talked about how her mom took care of her diabetes, as did one sister. The second sister had not tended to her diabetes until their mother died from it, then her attitude started to change from having ignored it to paying attention to it. The PI inquired, "So your mom did a lot to take care of herself; one of your sisters does, the other one is sort of pretending ..."

W7: “Yeah, but now ... (she was making better choices)

PI: It’s kind of a pretending, isn’t it? Am I right, when you ignore ...?

W7: Yes.

PI: When I was talking about rationalizing, some of it’s kind of pretending, right?

W7: Yeah.

RA2: Um hmm.

PI: So, it ..., one kind of pretends that something isn’t there ...”

M2 had already explained that it was common for men in Mexico to use alcohol and how important it was for people to eat bread daily. In the following exemplar, he shared how he thought the enjoyment of both alcohol and eating bread interfered with *Acceptance* because of the changes required to manage diabetes. He thought sometimes people ignored symptoms or pretended they did not have it so that person did not have to give up too much of life and cultural enjoyment.

PI: So, what I hear ... part of what you’re saying is that people ... they don’t want to actually give up the things that they enjoy? ... You started out by answering this question ‘there’s drinking problems and people love bread’ so does that mean people are thinking ‘I’m just going to pretend that I don’t have this, or I’m going to ignore it because I don’t want to have to change? I want to keep drinking if I drink or I want to keep enjoying my bread every day.’ Is that what you’re saying?

M2: You know what it is, the way it is in Mexico is nothing else to do.

Unfortunately, we all have that mentality to be on the same pattern.

[men drinking alcohol]

PI: So, we're either going to drink or we're going to eat the pan and whatever.

M2: Well ...

PI: Oh, okay, but do you think that's why people are pretending and ignoring and just pretending things are, sort of ignoring things aren't there?

M2: Yeah, it's in the culture I guess.

PI: I ... want to understand that better.

M2: Yeah, but ... [we] grow up with it.

PI: Okay that's a good point. It's familiar.

M2: It is familiar, yeah."

M1 summarized after he said (above) that people put things off, ignore, or deny them and they pretend it is not there. When asked for more clarity, he said "you just try to hide it." PI "But why?" M1 "Why? Because you don't want people to think bad of you."

Changing lifestyles. Living to enjoy today. While the *Battle* of not wanting to change, lifestyles was mentioned by a few of the participants; both W9 and W3 clearly articulated how much of a struggle it has been for them and the population of Mexican persons with diabetes, to think about having to change their lifestyle and to

have applied their personal self-discipline on a consistent basis. It had been hard to change lifestyles.

PI: "Why do you think people don't do what they know they should do?"

W9: Like you said, maybe because they are playing dumb. Or they don't want to accept it.

PI: They don't want to accept what?

W9: That they need to change their habits.

PI: Ahh, because they have to ... and once again we're back to do they really have discipline and? Right?

W9: *It's hard work*, especially after 40 years, you have to change your lifestyle *completely*.

PI: So, part of it is that it is hard work. It's interesting because Mexican people traditionally are very hard working people [referring to physical labor].

W9: I think we are ...

PI: Yes.

W9: But that's when it comes to work ... [showed lifting something physically]

PI: That's different - than self-discipline ...?

W9: Right. But when it comes to your health, I think you just don't want to do it.

PI: And again it has to do with the amount of work [involved in changing one's behavior], right?

W9: Um hmm.”

W3 was very troubled about why people “played dumb” because she was concerned about putting off the inevitable need for good diabetes self-control. Like others, she did not have to think long about the struggle of lifestyle change required to practice +DSM. The PI posed this question, “Sometimes people pretend they don’t know the right thing to do about their diabetes. They kind of ‘play dumb.’ I mentioned that lady earlier who said, ‘well, I act like I don’t know what I’m supposed to do, but I know what I’m supposed to do.’ And I’m just wondering why some people ‘play dumb,’ or why they pretend that they don’t know something?”

W3: “Because they want to eat whatever they want to eat.

PI: Yeah, that was partly what that lady had said. Okay. So, if I pretend I don’t really know what to do then I can do what everybody else does?

W3: Uh huh, kind of like delay the situation, but they have to be serious about, delay and later, later.

PI: So, delay self-control.

W3: Uh huh.

PI: Okay, that’s great. How do you think that playing dumb can interfere with taking care of your diabetes?

W3: I think be really serious if you don’t take control of yourself when you have to, will be really hard in consequences.

PI: Please explain why you think people, why do you think people don’t do what they know they’re supposed to do?

W3: Because they want to enjoy life and think that they are the same as others and they want to not be in prevent whatever they want. They just want to enjoy today and not think about the future.

PI: So, avoid self-control.

W3: And living just for today and not think about the future.”

Dismissing severity “It’s not that serious”. M1 brought another perspective when he shared his thoughts about *pretending, ignoring, being in denial, and hiding*. He suggested another reason that people seem to ignore their symptoms is “you think there’s nothing ... It’s just a little ... [thing].” This attitude differed from denial because it was not an attempt to make less of it in one’s mind. Rather, it was an ignorance or oblivious interpretation that something serious was estimated to be less significant, a dismissing of severity. He gave the example of having ignored what he thought was a simple foot wound that became serious; he had no idea how serious it would become. He mused, “I had stepped on a nail ... After a few days, I knew something was wrong with my toe but I would go and ... nothing from that doctor. And then she started a bone graft.” Later, he indicated he did not realize that he had a serious problem going on with his foot; soon after there was discussion about amputation. That was an example of how sometimes people waited until it was too late by thinking that the problem was not all that serious, or the body will heal itself, or the problem will go away.

W3b had a similar thought. PI: “But I’m really looking for why people who are Mexican keep putting this off?” W3b: “Hoping that it will go away, the symptom will go away.” PI: “Um hmm, ‘I can sort of hope?’ And maybe they think that their body

will take care of it?" W3b: "Um hmm." Both of these contributions were very similar to what W10 had spoken of earlier, at great length; W9 had mentioned it as well.

Summary of cultural conditions that interfered with Accepting diabetes.

According to the participants, the culturally-based contributions that delayed personal *Acceptance* of diabetes were/are because the population did not/does not want to know what is true or have to believe what they do not want to believe is true about having diabetes. They were/are in denial, at times, about diabetes (W9). Many people pretend, ignore, play dumb, or rationalize because it is "in the culture to pretend, to ignore" because they "grow up with it;" thus, pretending and ignoring were/are familiar. This was a critical finding. At other times, people did not or do not pay attention. They ignore or think nothing is wrong and that "they are fine" (M2). Sometimes they honestly did not/do not think a problem or symptom is serious; they hoped it would go away or that their body would take care of it (M1). At other times, Mexican people did not want to deal with the issue (W6) or to stand out as different (W9). Ignoring symptoms and rationalizing about why "things are the way they are," were mechanisms used to pretend a symptom or a problem was not there (W7).

At times, people did not/do not want to give up an aspect of life they have enjoyed, such as drinking alcohol, which was reportedly common to men in the culture (M1, M2), or eating favorite foods, such as sweet bread (M2). Others were afraid "people will think bad of you" (M1). People also reportedly did not/do not want to give up comfortable lifestyles or have to change because change was difficult. It was easier to do physical labor than the mental work of self-discipline

(W9). The reasons for not doing what one ought to do is because they “want to eat what they want to eat,” they did not/do not want to be prevented from doing whatever they want(ed) or partaking in what others do and eat. They “just want to enjoy today” and not think about the future. They want(ed) to enjoy life and did not/do not want to make uncomfortable lifestyle changes or worry about things being too serious. Mexican people think that they are the same as others and do not want to stand out as different, but rather be the same as others (W3, W9).

Features that promoted *Accepting* the diagnosis of diabetes: Others’ experiences, *Motivation* for health, Trusting HCPs, Feeling better on medications, and the Influence of faith. Several issues have already been well-supported to promote the importance of *Accepting* diabetes, such as the fear and sadness of knowing that the disease can cause serious, sometimes irreversible complications. The benefits of the medications were very helpful as were healthy relationships with their HCPs.

Experience of others; Being motivated for health; trusting one’s HCP.

Having known others, especially family members who had suffered from diabetes, was a strong *motivator* to take care of themselves, as has been demonstrated. Being *Motivated* by love for their families, especially children, led several participants to start and maintain DSM. Having faith and trust in their HCPs was also helpful in *Accepting* their diagnosis. M2 expressed how important this was to him, “... I was started to notice the changes on my body ... you know, and it’s when I went to the doctor, my friend she told me that ‘just be careful with the sugar, watch yourself.’” She knew he liked to eat sweets and he trusted her advice to cut back on them,

which he did. W4 was first told in Mexico that she was borderline but several years later she was shown how her signs and symptoms, along with her BG, gave evidence that she had had diabetes for a long time; probably back to her first borderline diagnosis in Mexico several years prior. The PI asked, "Tell me how you found out that you had diabetes, how you were diagnosed?"

W4: "Because, I went to a doctor in Mexico.... Yeah, about 9 years ago, he told me 'you in the borderline have diabetes' ... But ... I came to when I changed doctor then I start doctor here in California. And he told me, he make exams and blood and all that. And he told me, 'you have diabetes.'

W4: ... 5 years.

PI: Five years ago. Ok and so you were diagnosed here? In the United States.

W4: It was 4 years ago, yeah, almost 4 years ago ... So, I went to the hospital, cause I had my blood pressure real high ... and one of the doctors when they called to check me in emergency ... And he told me, 'Oh no, you, you not have recently your diabetes, you had long time.' He told me ...
[showing her skin changes]

PI: Oh, because he could see the signs of it.

W4: ... 'You had long time with diabetes.' [Doctor said] ... I feel, you know, because I feel like, too tired ... and, and I get up at night, you know, go to bathroom so many, about four to five times ..."

She believed him because he was able to show her how her physical signs (e.g., skin changes) and symptoms of fatigue and urine frequency gave evidence that she had had diabetes for much longer than she had been told or knew before.

Having known people with damaging diabetes, participants who were being *Motivated* by the love of their families and desire to live a long life for their family's sakes were evidenced above as *Motivating* for DSM, which first required *Acceptance* of the disease. The relationship with a HCP who was trustworthy was helpful for some to *Accept* the diagnosis and understand it from their own perspective.

Feeling better on medications. Despite the fact that the culture does not like medications and some of the participants wished they did not have to use them, they did so anyway because the medications were helpful. When they were better on medications, they wanted to continue, even if they did not like being on the meds. W3 commented above that she knew she should have started medications from the beginning. She had fatigue on and off, sometimes significant tiredness, until she took medications regularly. M2 said proudly, "and take my medications – which I always do because they're the ones that are healing me." When asked how W2 felt when she did take medications the first year post-natal, she replied,

PI: "How did it go when you changed, when you started taking the medicine?"

W2: I feel different, I don't feel desperate like I want to go like this [*motions being shaken*]

PI: ... did you feel any different then, when you were off the medicine than when you were on it?

W2: Yeah, I feel better when I was on the medicine ... I was feeling better in my body and in my mind too ...

PI: Ok ... How did you feel better in your mind, when you took the medicine?

W2: I don't know, I was more like calm.

PI: I see, you could think more straight?

W2: Yeah, because for little thing I used to get mad, yelling at my girls, that's what I don't like ..."

W5 had not wanted to take medication, but when she could not get control with diet and exercise, she took the pills and it had been helpful.

PI: "You wanted to do it by yourself, but now you have the medicine. Why did you choose to take the medicine?

RA1: [Spanish] Decide ... to take the medicine?

W5: [Spanish] Oh, I can't control it by myself, I need to take this ... [English] My sugar, and ... high, high, and no lows ... *O-kay* I'll take it.

PI: Okay. How does the medicine help you?

W5: It lowers ... how does it help me?

PI: Yes

W5: The low ... my sugar.

PI: It lowers your sugar?

W5: Yes."

Even though the culture does not like medications, the reports by several of these participants demonstrated that when they did use medicine to treat their

diabetes, they felt better. They had fewer symptoms, weight loss, better BG control, and more family stability.

The influence of faith on Accepting diabetes. Finally, W10 shared about the effect on one's *Accepting* diabetes due to the body's ability to heal itself; for many, it was not simply *Accepting* that one had diabetes. Rather, it was equally important that when God had not healed following prayer, one had to accept it was God's will that they had diabetes. God had not removed it from them; thus, dual *Acceptance* was required – God's will *and* "I have diabetes."

PI: "Okay, so tell me why ... do you think that some of your Latin friends and family ... seem to take time to accept? Or maybe they accept a little bit at a time, or they have to wait for something grande to happen [gave an example] ... Why in the culture is it hard for some people to accept?"

W10: Because they are expecting that their own body will take care of it ...

They say 'oh, I ... 'I'll get better' ... It has to do with our religious background. [The discussion about people in the culture believing they will get better, prayer to and trust in God ensued; see Context – Faith.]

PI: But I hear ... under that I hear 'It's God's responsibility to heal me if He chooses; it's my responsibility to ask God to do that. And then it's my responsibility to accept His answer.' So, the acceptance is partly about accepting God's will, not just the scientific fact that I have diabetes? And here's all the evidence ... 'I have these symptoms. I need more than ... numbers, how I feel, ... symptoms, ... and my history - mi familia ... I

really have to know that's what God has.' Is this right? I only want to say this if it's right, Señora.

W10: It is. It is right. Yes, mi amiga."

In addition, she implied that an important aspect of *Acceptance* of diabetes was *Accepting* the responsibility to care for one's diabetes. Part of *Accepting* God's will about their diabetes was acting on that *Acceptance*, doing something about the condition in which they prayerfully or trustingly found themselves. In fact, the effect of faith on *Acceptance* of diabetes facilitated faith to accept one's DSM responsibility.

The effect of faith on Accepting the responsibility for diabetes self-management. In that same conversation, above, W10 went on to talk about the choices people make in either *Accepting* or not *Accepting* responsibility for their DSM and some of the reasons why.

PI: Some people like you accept right away. 'I have it, I have to do something about it.' That doesn't mean they don't pray. You can still pray ... 'Lord, you can still heal me from this,' but they accept right at the beginning; they get right to work, [saying] 'I have to do this, I have to do this...' And this is where I want to understand the responsibility. They feel *responsible* right at the beginning?

W10: Yeah, right away ... And they wait for a little while, praying, and hoping to be healed, and then when they see His prayers weren't heard in the way that they wanted, they accept it. And then that's when they start to either take care of themselves - some people - and some other people

they just get so busy with taking care of their families that they neglect themselves. Until it really gets bad.”

Summary of features that promoted Accepting diabetes. In all, *Being motivated* by fear and love to *Accept* diabetes and do something about it, trusting their HCPs, having functioned and felt better when taking medications, and sensing God’s will for their lives, the participants not only (eventually) *Accepted* the diagnosis but also acted on the conditions necessary to work toward +DSM. The one who grasped *Acceptance* did not simply understand “I have diabetes” but (s)he understood that “I” have to do something about it; they had daily decisions to make. *Accepting* diabetes was a primary aspect of decision-making in DSM.

Summary of Accepting diabetes. For most participants, *Accepting* the diagnosis of diabetes was not welcome but they did quickly *Accept* it and directly started DSM. Three persons delayed *Accepting* diabetes as their own, then began DSM; although one of these delayed the use of medication. Another was reticent to *Accept* T2D in total because she believed God was able to and might relieve her of diabetes. While hopeful, she had participated in DSM but resisted taking more than one metformin tablet daily and continued to pray for God’s intervention.

At the root of the culture’s reticence, participants said that Mexican people did not/do not want to know the truth because they do not want to believe they have diabetes. The personal defense mechanisms utilized were identified as denial/denying, pretending, ignoring, playing dumb, rationalizing, Fundamentally, a critical finding that was reported was that Mexican people “grow up with,” “pretending and ignoring;” it was/is “part of the culture” and they were/are familiar

with pretending and ignoring. There were also times when people did not pay attention to, ignored or thought nothing was wrong and saw that themselves as “fine” or that signs and symptoms were less serious than was the case. Other times, people did not want to deal with the matter or to appear to be unique from others. Rationalizing also was a way to believe their circumstances were satisfactory. A major reason for wanting to ignore, deny, or rationalize was in order to not have to make dreaded changes in one’s lifestyle, whether that was having to refrain from alcohol, what they enjoyed eating, or having to take medications that they dreaded. Since their daily goal was generally to “enjoy today,” having to think about the long-term and enjoy today was undesirable. They also weighted the personal expense of standing out as different from others, which was undesirable in the culture because they prefer “to be the same” as others.

All of the participants were *Being motivated* toward DSM by love for others and/or fear of the consequences of the long-term repercussions of poorly controlled BG that each one had witnessed in others. Trusting their HCPs, feeling better when they took medications, and having confidence in God’s will for their lives were other factors that helped them to *Accept* the diagnosis of T2D. Alongside *Accepting* the disease, they had to be accountable for *Accepting* the responsibility for self-care; they had to “own” that T2D was their personal responsibility. *Accepting* T2D was the foundation to successful decision-making toward +DSM. The following conditions and dynamics were the major components of decision-making for daily DSM.

Components of diabetes self-management decision-making

Numerous dynamics and issues influenced the decision-making about DSM among the study participants. Similar to the findings reported in *Acceptance*, powerful cultural influences were found to have been the most dominating force in decision-making by this cohort.

Accepting responsibility for diabetes self-management. As illustrated above, the first condition in decision-making was to have *Accepted* one's diabetes and one's responsibility for self-care. The second essential set of conditions were the well-established socio-cultural effects.

Socio-cultural influences: Pretending, Hiding, Being negligent, *Being proper, Machismo, Being in the battle.* Over the course of the interviews, as participants discussed issues that delayed *Accepting* the diagnosis of diabetes, they talked more about the influence of the cultural dynamics of *pretend, ignore, set aside, deny, and play dumb* on DSM. Cultural conditions continued to have a significant place in each aspect of the decision-making foundation. The same was true as they made decisions each day to address their DSM. Participants often employed the behaviors and concepts of pretending, ignoring, denying, and hiding diabetes. The cultural requisite of *being proper* was an overriding force, and machismo played a role as well.

Pretending, playing dumb, ignoring, denying, and putting off diabetes; and wishful thinking. Several participants revealed both the commonness of pretending, *playing dumb*, and some of the rationale behind why it was common in the culture, particularly as pertained to diabetes and being a person with T2D. The

stigma of T2D was made evident in Context. W6 set the stage when she mentioned in Spanish that she knew the pancreas makes insulin and she had been to a nutrition class the day before the IV. She went on to explain how she behaved in DE classes when she was given information she already knew; how common her response was in the culture. The RA verified the commonness of the response and expected the non-Latino PI to understand the behavior to which they referred. Regarding the class the day prior, the PI clarified, “And they talked to you about the pancreas?”

W6: “Yes, how to eat ... and I already know, so I just *play dumb*. [laughs]

PI: And what did they tell you about ... what did she say? [asked of the RA]

RA1: You know how, she said ‘well I don’t know, you know you just sit there and act stupid,’ not stupid but you know, you kind of like ...

W6: You already know how to do it, so you just *act dumb*.

RA1: You know how it works, you just ... [the Latina RA suggested the PI would know about this behavior because it was common to her as a Mexican person]

W6: Well, you already know everything you need to do, so you just *play dumb*.

RA1: So, everybody knows what they’re supposed to do but they’re not doing it, so it’s like - I don’t know if there’s a saying like that in English, when everybody knows what they’re supposed to be doing but ...

PI: Doesn’t do it?

RA1: Yeah, and then they *pretend that they don’t know how*.”

Later in the IV the reason her BG went up when on vacation was clarified:

PI: "... Okay, you understand why your sugar went high [returning to the earlier topic]

W6: Yes. [Spanish] I know. That's why I say that one *acts dumb*.

RA1: She was saying that you know what you're supposed to do but you're just like 'tone it down' or ... I don't know how to explain it to you ...

W6: It's because it's really good." [Referring to the food]

As this was the first that this concept was introduced; the NHW PI had not yet recognized the salience of the concept. The interview with W7 on this subject revealed an underlying thought process that had been initially suggested by W5 and more so by W6. Since it was complicated and the clarification was in the PI's and W7's second languages, RA2 interpreted a brief section. She helped W7 to clarify to the PI that sometimes they wanted something to be true but did not really want to believe that way, "like that." She added "People wanted to do what they wanted when they wanted." They did not want to focus on the fact of diabetes, or a symptom, and hoped that by pretending it [T2D] was not there, that it would not be there. The person who thought that way would be able to put the concern out of their mind and not worry about it. Simplified, this was pretending. W10 had said she had tried to "Brain-wash' myself to believe something' ... 'if I keep believing something I can bring it about.'" This was in regards to wanting to "think away" ever having to use insulin. She had it in her mind that she would never use insulin and believed she could "brainwash" herself into making it true. This was not called wishful thinking, but it was described similarly [see Context – Health Beliefs].

RA2: [Spanish] “You know like a rationalize, like meaning reality, like this is - we don’t want to really want to believe it but that’s what we want it to be ...

PI: ... And you see the reason this is extra important ... is the last two people ... have talked about this idea also ... the same sort of idea ...

RA2: Yeah, yeah, um hmm.

PI: ... [reflecting back her understanding] ‘oh, I really want it to be, like oh, yo quiero’ [I want], but it’s not ... but I’m not gonna pay attention, I’m not gonna focus on it ... It’s almost like - How did the other lady say it? It was kind of like she said ‘if I pretend it’s not there, maybe it won’t be there.’

W7: Okay.

PI: And so, this is proxima [close to the idea]? It’s almost like ‘I’m not going to ...’

RA2: Una la mucha attencion, like not ...

PI: That’s right! If I don’t pay attention to it ...

RA2: I won’t worry so much about it. Okay.

PI: Yes. I can kind of put it out of my mind. But is this true?

W7: Yeah. Yeah, that’s true.

Because M2 said he had tried to not hide his diabetes too often. He expressed concern that people who *play dumb* do not practice good diabetes care, they would not have taken the disease seriously enough.

PI: “Alright, okay. When you hear the words ‘oh I just *played dumb*,’ or somebody else said to you ‘I *play dumb*,’ what would that mean to you?”

M2: That they’re not serious of it.

PI: Not serious, okay.

M2: They won’t take seriously of the problem.

PI: And that’s because they’re *pretending*, or again *playing dumb*, that they don’t have diabetes or it’s not that bad and so they’re going to do whatever they want to do instead of good self-care?

M2: Exactly.

PI: ... tell me if I’m correct - what I heard was ‘if they *play dumb*, and they go along with what’s being offered and they don’t refuse the things they should refuse, then their sugars might go up and they’re not doing as good of care.’ Did I hear you correctly?

M2: Oh yeah, yeah.”

He indicated that ‘*playing dumb*’ regularly interfered with good DSM because they chose to hide their T2D instead of choosing not to eat what they should not eat. Both men had interesting responses when asked to explain, “why do you think people do not do what they know they should do?” M1 was frank. He indicated that people want “to put off” having to do what they’re supposed to do, some people procrastinated, and he felt that laziness was a major factor.

M1: “Just put it off.

PI: Okay, so we just put it off. So, we want to avoid it?

M1: Put it off.

PI: The question is 'why do we not do what we know we're supposed to do?'

M1: We procrastinate.

PI: Okay, sometimes we procrastinate. So, we put off, but isn't that kind of avoidance too?

M1: Yeah.

PI: So, why do we not do what we know we're supposed to do?

M1: Sometimes just being lazy.

PI: Lazy, okay. You think sometimes there's the social pressure? I wonder if that's connected to that feeling of being obligated [discussed earlier]. [Gave a common social example of feeling obligated] Is that part of it? I'm not putting words in your mouth, I'm asking you: Is obligation, feeling obligated, is that ...

M1: Yeah, there's that too. Not as much with my mom. [referring to her changed cooking style]

M1: Just ... I think the biggest one is lazy.

PI: Okay. Is it sometimes too, we simply want something?

M1: Yeah, I suppose."

From another perspective, M2 thought this issue was related to inadequate education.

PI: "What do you think that's about, at least culturally what's that about? [long pause] I had to put it [the question] in, but I knew it was a hard question. [all laugh]

M2: I believe this is education, a lot of people they cannot ... education.”

Hiding diabetes. W9, who reported she did not pretend or play dumb but knew people who did, and understood it from the culture, brought further insight to those concepts when she explained that at the foundation of *pretending* was the drive to *hide* that one had diabetes, which made the person different than others. The importance of *hiding* diabetes was demonstrated in Context: Community-Oriented - Social pressure to conform, Cultural norms – Role – Machismo, and Social knowledge – Stigma. Since the cultural goal for the Mexican person was/is to be the same as and not unique from others, she indicated people sometimes pretended they were not “diabetic” so they did not stand out as uncommon.

W9: “People are ... they’re just like you said, they’re ‘playing dumb.’ They’re ignoring everything.

PI: But why?

W9: Or sometimes people want to hide.

PI: Oh, I want to hear this - tell me about this.

W9: Yeah, people argue. You don’t want anybody to know that you’re diabetic, and you just pretend. ‘Just go with the flow ...’

PI: Okay, I got it. Now going with the flow. I’ve heard that sort of thing from the standpoint that people have said things like ...

W9: Just want to be part of everything.

PI: They don’t want to be different? They don’t want to stand out? Why is that?

W9: They just want to be part of what they're [others] doing, what they're eating.

RA4: Yeah, because they want to be accepted.

W9: So, you want to be part of the group. Part of whatever they [others] do."

RA4 speaking to W9: "And as you said something really important: they want to hide. They don't want to show others that they are diabetic.

W9: Um hmm.

PI: They want to hide. Okay. Not have diabetes ..."

M2 lent further perspective on why a person would hide their diabetes in a social setting.

PI: "But when you hear that people kind of play dumb, that they act like they don't know ... What about this señor ... is that a way people hide? If I go to a party and I act like ...

M2: If other people knows about your problem? That's what it is.

PI: Oh, I see, so you think that's even bigger than not caring for self?

M2: Exactly ...

PI: ... So you think that some of it might be the way people sort of hide?

M2: Yes, definitely."

In the next exemplar, M2 gave the underlying rationale for why he hid his T2D unless he knew the person. Diabetes had/has a stigma, he tried to avoid being exposed. He defended his position as a Mexican man ... "see the culture is normally, [pausing] I mean, [pausing] you can embarrass somebody I believe ... You know to say anything about it until people knows that you have it, or when [?]" PI: "Okay,

that you're embarrassed about diabetes?" M2: "Well, to, to say that I have diabetes is [?] ...". He further provided important insights on why as a man he hid his T2D, chiefly in the work setting. He felt he had to hide it because other men made fun of his health issues; even when he was trying to take care of himself. His boss did not allow him to eat when he needed to because the boss had diabetes and was orgullo (prideful) about how he handled it. Another time he was mocked when he had a seizure [See Context.] Below he described the difficulty of the male workplace.

M2: "When I have the seizure at my work, they were making fun of me. One of the guys and I was 'man, this guy's' which was very ... I didn't pay attention to it, you know, because that's the way it is. It's what you deal with ...

M2: You know, in this case I like to respect people, and unfortunately work, that's what it is. And this is what you deal with ...

M2: Well you know unfortunately work is not a place to be, discuss your issues, because they gonna ... you never know what the answer is going to be. Maybe they gonna be making fun of you."

Hiding diabetes was a common practice and expressed as a social necessity due to the stigma of the disease. Thus, people did not want to stand out as different; having diabetes made a person appear to be different from the norm and everyone wanted to be like everyone else. Some settings presented higher exposure risk, such as the work setting for men as shared by M2. Earlier, M1 had said that he did not want to share his diagnosis at work "you don't want anyone to think less of you."

“We are negligent...” Being negligent in America. An additional way that participants saw the cultural influence to avoid having to acknowledge, *accept*, or deal with T2D was rooted in being “negligent,” practicing negligence. W3b was convicted that this was a means of not taking the disease seriously and thought this ignorant practice was due to not having adequate knowledge and understanding of the disease; not being sufficiently educated and oriented to the long-term aspects.

PI: “Why do some people not try to find out sooner if something’s wrong when they have symptoms? ... is there anything else you want to say from a cultural standpoint why people would wait? Okay ... [saying what others have said people sometimes think] ‘I think something’s going on but I’ll just wait. I don’t really want to know right now, or I’m not going to go find out right now.’ Is there anything ... about why people would decide [to wait]? Because it’s a decision. They’re making ... some sort of decision at some level ... where they’re saying ‘I’m not going to go find out why I’m so tired, or why I’m peeing all the time, or why I just can’t stop eating ... but I’m still losing weight’ ... Can you say anything else from a cultural standpoint about *why* that would happen?”

W3b: In general, for the culture? [PI: Yes] ... The culture in United States has been kind of negligent.

PI: You used that word before [in an observation as a RA]. Do you mean Mexican people in, while they’re in ...

W3b: in the United States. Negligent because they don’t want ... if they are a little; and also, if they have to pay for the medicine or if they don’t want

to take the responsibility for a diet, if they aren't ready to give up on all that good stuff, they prefer 'oh, I'm gonna do exercise; I'm gonna drink a lot of water; I'm going to be careful with the food; and then I see what happens.' Do you know, I think it's missing the orientation, lack of orientation?

PI: A lack of orientation to what's true about the disease?

W3b: Right. [PI: That's interesting.] ... As you said, going back again that maybe God will cure me, or the faith, you know? Or I'm gonna do this and this ... that ... they don't want to be attached to the pill, or to go to the hospital. [PI: Or the doctor's office?]

W3b: Uh huh.

PI: So, Mexican people [with diabetes] in the U.S. are sometimes negligent? They're really not ready to give up on poor food - basically lifestyle?

[W3b: Exactly]

PI: Right, [thinking out loud what one might say] 'I just don't really want to change my lifestyle so that I will do what I have to do to take care of diabetes.'

W3b: Right ... And they don't have sometimes the money to buy medicines, to buy birth control, thermometer ...

PI: Right ... I mean 'I don't have funds for the supplies and meds etc.' - It's real. But I kind of sense ... what you were saying first is more common. I don't think it's *as* much about the resources. I think it's more about the lifestyle and what they are willing to give up. Correct?

W3b: Right.”

Similarly, W10 offered her concern about a “negligence” thread that wound through the culture as a basis of *pretending* and a means of *Negotiating* in one’s mind how to avoid having to address one’s diabetes, particularly in social settings.

PI: “Sometimes people *pretend* that they don’t know what they’re supposed to do, or that they don’t know what is the right thing for their diabetes. Some patients call this they ‘play dumb.’ Maybe they act like they don’t know what they’re supposed to do, but they do know what to do. They might go to a class and act like ... they’re just getting the information for the first time, but they know what to do. They can tell you.

W10: They ‘play dumb,’ yeah. That’s very adequate. [PI: accurate?] Yeah.

PI: So tell me what ...

W10: What causes that ... attitude?

PI: Yeah. What is that, especially from a Mexican perspective? What does it mean to you, and what do you think it’s about in the culture?

W10: I would say negligence on their part.

PI: That’s the word [the other woman (W3)] used! [Looking surprisingly at RA4] That’s the word the other woman (W3) told me.

W10: They’re very negligent with themselves. And pretend that they’re going to get well.

PI: Okay, so pretending, playing dumb. One person, maybe two told me that when they ‘play dumb,’ it’s partly like maybe they would be at a

party, or at someone's home and they want to be the English version of 'gracious.' You know, they want to be polite?

W10: Um hmm, um hmm.

PI: You know, as a simple word, and so they pretend 'oh, I'll pretend that I don't know what I'm supposed to do about my diabetes, so that I can eat what is expected of me?' Is that partly how people would 'play dumb?'

W10: Um hmm. Yeah.

PI: And that's not necessarily a negligence, it might be, but it seems like the way people *Negotiate* in their mind.

W10: It's *Negotiation* in the mind."

PI: And is that because someone is trying to be proper? Trying to do the right thing socially?

W10: Yes, definitely."

In less direct ways, others implied negligence as a general issue in the Mexican community of people with diabetes. W6 expressed frustration and implied some Mexican people with diabetes had an ignorance about diabetes that led to a negligent approach to DSM.

W6: [Spanish] "... they don't want to take care of themselves; it's all the same to them. They don't want to *Battle*, I don't know...

RA1: Sometimes people just really don't want to take care of themselves and for them it's the same - if they have diabetes or not.

W6: [Spanish] Or a lot of people just take the insulin ... They eat a lot and say, 'I'll just take the insulin'

PI: So like 'the shot is going to take care of it for me?'

RA1: Yeah. Are there people who also say, 'I am going to eat a lot and then I'll just give myself a shot?'

W6: ... Yeah. [And others-] say, 'I'll just take my pill to get better,' but ... that's not the issue I eat too much and I take my medicines.' The people thinks that 'it is better for me - I eat too much ... I take my medicine - it's okay.'

PI: You don't feel like that? You think differently than that?

W6: [Spanish] Well, yes, ... [English] I take my medicine and I know [how much] I can eat, not too much, but I take my medicine. But not like, I eat too much, too much [overeate] and take my medicine.

PI: So ... if I eat a little bit and I take my medicine I'm probably going to be okay, but if I eat a lot and I take my medicine ...

W6: Some medicine ... not too much.

PI: Oh, it doesn't help enough, it doesn't take care of the problem.... No, you're right. The medicine helps our blood sugar but it doesn't take care of all the diabetes problems."

W6 clearly had a deeper grasp of why she needed to control her BG through what and how much she ate, rather than treat BG excursions with more medication. She tried to avoid excursions because she understood the long-term risks (she had learned from the DE classes) But her understanding of the people she was referring

to was that they only thought about controlling on a day-to-day basis and seemed to lack understanding about the longer-term risks and need for daily self-discipline.

W1 expressed frustration about one of her sisters' attitudes and not taking responsibility for her own BG control. W1 believed her sister was negligent regarding self-care and was frustrated that all four of her sisters with diabetes had not taken care of their diabetes.

PI: How does the way other people around you ... who have diabetes ...?

W1: They are a pain in the butt! They don't want to listen, [W1, PI, and RA1 laugh] ... specially my sisters. That's why they cut her pinky,' 'cause she always had, always had - now she has to control it - always had it, 500, 600.

PI: Oh my gosh.

W1: ... so they took her physical, they told her that [asked if] she felt ok? and they told her [she told them] 'yes,' and she said 'why?' because she had sugar 1,000.

PI: She is really lucky to be alive ...

W1: And I go ... 'What!! Oh, [name] you could be in a coma!' ... she goes, 'Don't scare me.' 'No, I'm not scaring you, I'm telling the truth, you got to have your sugar lower than 200.' [Sister] 'Oh, I'm used to, it, I feel ok' 'I'll leave it to God.' [W1] Yeah, and she always says 'I'm God's hands.' [W1 replied] 'Yeah, but God is telling you to help yourself too. Don't leave everything just to God.' ... Yeah, we gotta be responsible for your sugar."

While this latest exemplar is about a family of essentially negligent persons with diabetes, the two exemplars preceding this make general statements about a more pervasive attitude within the culture that goes beyond pretending or ignoring diabetes or being in denial. The following segment discusses how the social requisite of being *proper* influences the decision-making about DSM.

The importance of “being proper”. Earlier, M2 said that when he was offered food by a woman he was socially required to accept it, to be proper. To the question, “What’s expected of you? Is it expected of you to at least try things?” his reply was, “if it is there” he would “have to try ... to taste,” admitting it was a clear social obligation. When asked what it meant to say “No thank you” to a woman who had prepared food and expected him to eat it, “Are you able to say ‘no thank you,’ or do you really feel that just to *be proper* and to do what is right from the culture and to not offend, it’s just important that you taste anyway?” M2 said, “Well, yeah. Taste anyway. I *cannot say ‘no.’*” He went on to stress that being socially *proper* “it’s the biggest point.”

In discussing the importance of *being proper* when making a decision about her diabetes, W10 indicated sometimes it can be an interference. PI: “And that really has to do with the properness of the people?” W10: “Um hmm.” PI: “Okay. Does that interfere with your decision-making? It probably can sometimes?” W10: “Ah, a little bit. Yeah. Sometimes.” From the perspective of W6, making decisions about what she would eat here in the United States versus Mexico or within a group of Mexican persons, it was easier in the United States for her to decline food she should not eat. PI: “You have to be a little more careful to be proper in the culture (in Mexico or

with people gathering from Mexico) ... the motivation is not to offend, so one has to do what is culturally *proper*?" "Yes."

Despite her dislike of beer and that she did not want to eat the cake people were forcing on her, W8 nonetheless took and drank some beer and ate a "little bit of a little bit" of the cake she had wanted to avoid. This decision was partly to have been proper and partly to not make social waves and to maintain her "hidden" diabetic status. She spoke mostly through RA1 interpreter.

W8: But... I don't drink beer because I don't like beer. Does everybody drink beer, and is 'oh yes ... more, I want to' [making gestures, about people offering her beer]

RA2: She is not a drinker ... but the fact that people offer her, she's not going to say 'no.'

PI: Señora, that's a good question, this has come up before - both of those (ideas). Uh, so you don't want to say 'no?' [W8: 'No']

PI: You prefer to be, like, 'proper?'

W8: Yes, like one day, the cakes, everybody, something sweet. 'Oh, just a little bit' And I eat a, just a little bit of a little bit.

RA2: Yeah, she won't say 'no.' She'll take it but she'll eat a little, little bit [W8 was agreeing in the background with RA's understanding]

W8: A little, a little, yes.

PI: ... Okay, so it's about [figuring] It's not about, 'oh I respect, I have to be proper' or 'I have to do the right thing?'

W8: Yes... No, sometimes, because, sometimes even I don't like the cake and stuff, and because all the time, um they ask me, but first I ask, what kind the cake is okay, 'what kind is it?' [*making gestures indicating the response about the kind of cake, and her saying 'no'*] 'oh, no, no, no. I don't want it. I am sick.'

W8: I am in diet! [*smiling*] ... But I eat a little bit, of everything. I eat everything, a little.

RA2: And when you were telling me about the beer ... Is it because you didn't want to tell them 'no.'

W8: Oh no, because I don't like beer.

RA2: But you still drank it, you took it still.

W8: Yes, I take it, and I drink a little bit.

So, despite not liking the beer or wanting the cake, she took both in a social gathering so as not to socially decline; which is frowned upon. Another way she chose to deal with the pressure of having to take food she did not want was to slyly get rid of her plate when the hostess was not looking.

W8: I take my plate, just a little bit, and when they ... don't see me I throw it away. And you don't feel, and you don't ... don't think, you don't ask that the people feel bad for, 'oh my food, they don't like it.'

RA2: Uh-hum

PI: Yes, they kind of take it personal, right?

W8: Yeah, you throw it away, and they say '*ohh ...*'

RA2: 'You didn't like it?' Yeah ... (agreeing as a Latina with W8's cultural experience)

PI: Okay, so she does it to be polite ... because they are annoying you.

W8: Oh, yes, it's like everybody, like the same to everybody [the hostess pushing food]

PI: And other people take it personal, and you eat a small portion, I understand."

However, as reported in Intervening Conditions earlier in this chapter, if W8 knows the person, it is easier to say "No, thank you," because they will understand, "I am sick" [she says] and not pressure her, whereas *being proper* had to do with someone being less familiar or less "safe" from gossip or being offended.

Given the potency of cultural expectations, there were some who had determined that, for their own long-term health, they must not comply with social necessities and needed to choose their own health over social pressure. As reported, W3b had been on a long journey to *Acceptance* and making +DSM choices. Deciding to choose her enduring health, she had to risk not being understood or appreciated by extended family.

PI: "There's an expectation for that man to eat at somebody else's house whatever is served to him. Correct?

W3b: Uh huh. ... Well, you can say 'no.'

PI: Okay, but what about a woman?

W3b: In my case I say 'no.'

PI: Okay, good for you. And did you always say 'no?'

W3b: Let me tell you. In your family, you have a lot of invitations for celebration. So lately one of my aunts told my mom 'she never wants to come to our celebrations,' and I said 'Mom, I cannot go to all the celebrations that we have' but I am also ...

PI: But you have them almost every week!

W3b: I know! ... previous that's common, maybe 5 years from now my son ... affect me a lot ... But right now, I told my mom ... the food that they sometimes having I can't eat that, so I cannot afford to go to all the celebrations. So, I've changed ... It's a challenge too, because you maybe if you want to challenge yourself to do the things you're supposed to do ...

PI: ... There's a lot of social pressure in the culture?

W3b: Exactly. Because they want ... to have you at their celebrations, and you say 'no thank you, I'm full.' 'Oh, just a little bit' ... They really push..."

M1 eventually refused to eat inappropriate food made by his wife and mother and insisted on healthy food. However, due to cultural requisites, it took severe health issues and a long period of time before he demanded be served healthy meals. Both of these participants weighed the risk of long-term health issues against social expectations and chose health over pleasure. While the family of M1 understood and adapted, the family of W3 still expected conformity over her health.

Effect of machismo on decision-making. W10 described the stages of machismo that she and her sister agreed their father had gone through in his complete lack of addressing his T2D as a prominent, well-read, well-respected,

business man and Mexican leader. He chose not to address his diabetes and expressed that it was his body to manage the way he wanted; no matter what anyone, even family, begged him to do.

W10: "He couldn't think straight because of the arteriosclerosis.

PI: Okay. And the more he had that from the diabetes, the more he really didn't care?

W10: Yeah. [Nodding]

PI: Okay. So, it really wasn't even denying at that point. It's still sort of ignoring it. Right?

W10: First it was orgullo [actually soberbia as earlier she had clarified 'soberbia;' this is a mis-statement per her definitions]

RA4: First it was arrogant.

PI: Yes.

RA4: And then orgullo.

PI: And then orgullo. What's the word you're using for orgullo? Is it pride?

W10: Pride. Pride.

PI: Okay. That's what I kept hearing before. And then he just ignored it. He didn't care. Is that verdad [true]?

W10: Years later, but he wasn't very old. He was 75.

PI: But is it ignored? Is that what the point was? He went from this arrogance to being sort of proud, and I'm not going to do it. And the next thing was he just ignored it.

W10: Spanish.

RA4 [translating]: Okay, 'Yes, [name -the oldest sister who was a nurse] would tell him 'do some exercise, do some exercise.'

PI: She was trying to get his brain working again.

W10: Yeah, even before and she told him 'if you do not exercise, they're going to cut your toes and you feet.' And he says 'they can cut them. I don't care. They are mine to cut.' That was his answer. 'They are mine to cut.'" [shaking her head again in dismay]

There was some evidence in M2 that the *machismo* within him would not be ruled over by someone or something and that he was always in control. Even as a younger man, he said he had learned "you know, not to be embarrassed of anything ... to face anything, yes." When asked, "Were there other things about diabetes that also you afraid of? ... So, the biggest fear for you really was about changing your lifestyle?"

M2: "Exactly.

PI: And ... you weren't as much afraid of what diabetes can do? Some people are afraid of what diabetes might do to them, but you're not saying that?

M2: You know, when I find out about it, I stopped drinking completely ... I stopped ... drinking completely. It was no more [Used his hand to indicate a complete stop]. I don't need any help for that, I'm just going to make a man and stop drinking!

PI: Okay, so you stopped your alcohol, but you weren't really afraid of diabetes?

M2: ... No, no, you know I have seen so many things come to my life that so many illness that I just ... what be afraid of? I just ...

PI: Okay.

M2: Just I have to watch myself and keep going. You know? What be afraid of?"

Despite the serious consequential outcomes of uncontrolled T2D, he claimed his concerns were about life change. Clearly they were, but he also denied concern about risks because he had dealt with so many serious health issues in life. He said he did not feel threatened by the possibility of problems with his T2D. He felt strong enough to have both applied himself to stop his alcohol use without assistance of anyone else, "I'm just going to make a man and stop drinking!" He did; successfully. When the discussion with him took place about the influence of *machismo* on the behaviors and decisions of Mexican men (See Intervening - Machismo), he was very uncomfortable when he was asked to reveal underlying motivation for macho behavior; he looked at the PI with almost disbelief at her line of questioning.

It appeared that the machismo of W2's new husband might have interfered with her getting the exercise she needed. In the past, she walked to shop, but at the IV, she worked 6- to 12-hour shifts and had no time for walking. She kept telling him they needed to walk. When she was at work, he walked as exercise for his newly-diagnosed diabetes. Because he wanted to and was "proud" to drive everywhere, when they shopped or went out to eat, he always drove, which left her with no opportunities for walking. Possibly his machismo pride to drive unintentionally interfered with her +DSM.

M1's machismo was less outwardly demonstrated by attitude, but rather his was in his oblivious approach to not recognizing how serious were his symptoms for several threatening situations. He said, "I didn't realize how serious things were." Neither male participant demonstrated the extreme machismo of soberbia (arrogance) and orgullo (pride) that were seen in W10's father; however, both missed important cues and signs in their diabetes because of their machismo-like outlook. The husband of W2 appeared to interfere with the BG control of W2.

Recognizing that diabetes self-management is daily Being in the battle.

The concept of the daily struggle being a "battle" toward +DSM that was and is intentionally fought every day was introduced by W6, who brought up several key concepts. She described how one must be willing and able to fight the "battle" between the temptation to eat good food and using proper social behavior that yielded/yields short-term pleasures, versus resisting temptation by remembering the long-term outcomes of poor control that one wants to avoid. The entire exemplar was recorded above in "We are negligent." A portion of the exemplar follows to illustrate her outlook on *Being in the battle* as she expressed frustration at those who did not really take their disease or management of their disease seriously or were looking for an easy way to avoid applying self-discipline. She expressed that they also did not realize what they were dealing with in the disease. She had learned that when she practiced self-discipline she had the key to win the daily *battle*.

W6: [Spanish] "Yes, we are going to die anyway. They don't want to take care of themselves; it's all the same to them. They don't want to battle, I don't know ... [shaking her head] ... Or a lot of people just take the

insulin ... They eat a lot and say, 'I'll just take the insulin.' And that's not good ... They say, 'I'll just take my pill to get better,' but ... that's not the issue ... their own medicine for eat too much and I take my medicine ... The people thinks that 'it is better for me -I eat too much ... I take my medicine - it's okay' ...

PI: You don't feel like that? You think differently than that?

W6: I take my medicine and I know I can eat, not too much, but I take my medicine. But not like, I eat too much, too much and take my medicine.

PI: So if I eat too much food ... if I eat a little bit and I take my medicine I'm probably going to be okay, but if I eat a lot and I take my medicine ... it doesn't take care of the problem.

PI: Am I getting that right?

RA1 and W6: Yes. Yes.

PI: ... You're absolutely right. The medicine helps our blood sugar but it doesn't take care of all the diabetes problems. You're right!

W6: The problem is *here* [pointing to her body]. The problem is in my body.
[PI 'Wow!']

W6: Right? The problem is in your body. Yes? [PI 'Yes']

W6: [Spanish] If I know my problem, and I know I have to resolve it ... but a lot of people don't think that way.

RA1: So, she knows what her disease is and she knows she has to take care of it. But she knows that a lot of people don't think that way."

W3 and W10 had comments on the challenge of the daily battle also. *Being in the battle* was a constant self-Negotiation for W10. PI: “So what’s the *Negotiating* like, cause there’s a battle there, isn’t there? Sometimes isn’t there a little battle inside?” W10: “I know ...” said with regret. W3 described it as being a conflict of her conscience; she needed to remain conscientious. Her comment regarding *Being in the battle* was:

W3: “I don’t feel any pressure [referring to social]. The only thing is dealing with ourselves to be conscious ... [conscientious]

PI: Ahhhhhh, I got it. On that whole *battle*, and the challenges.

W3: Right, yeah. The challenge to you to not be issues about having the food that you want. So, we already know, but as you say ... we do ...”

When W8 limited the amount of food at a social gathering but not the type of food, she was in a constant battle, going back and forth. “I eat whatever I eat, but sometimes I eat something that I don’t have to do [shouldn’t eat], but I just eat a little bit.” She was *Negotiating* social pressure with her diabetes needs, “should I not do it because I really don’t like it? I don’t want to increase my blood sugar but I don’t want to offend someone.” She added with a sigh, “I feel tired, taking all these medicines and having to do all this stuff for my diabetes.” Part of her fatigue was the ongoing *Being in the battle*.

A prominent feature of these participants’ decision-making was the day-in and day-out personal *battle* each had to fight through to keep temptation at bay, to be socially *proper* and because of the fear and respect of what they knew could occur if they did not keep their BG in the appropriate range. As shown, W6 was

disgusted that some persons with diabetes did not really *do battle*, but rather took extra medication as a shortcut. She felt that ignoring the long-term risks did not really deal with the internal problem of diabetes within the person. She was correct.

Summary of socio-cultural influences. *Pretending, ignoring, playing dumb, denying, putting it off* were all ways that participants said the culture, and often they themselves *hid* their unwanted T2D. Because people in the culture wanted to be the same as others and did not want to stand out – and diabetes made/makes one stand out – they did not want to draw attention to themselves. One way they did that was to act as if they did not know what to do or that they knew what to do. *Pretending* was a basic behavior of the culture that they said everyone understood/understands and did/does. Others simply *put aside* the aspect of their diabetes that they wanted to ignore. Still another reported that if one *pretended* something (T2D) was not there, then maybe it would not be there; not giving attention to it made it not present and one did not have to respond to it, one could “put it out of my mind.” This type of *wishful thinking* was a way to try to bring something about that was not there or to make something that was present not be present. The men indicated that not putting attention to it could indicate a person was not taking their T2D seriously, was procrastinating or simply being lazy; either way, not tending to one’s responsibility due to cultural practices of *hiding* and *pretending* one did not have to deal with diabetes. There was a possibility that someone with less education might be more prone to this behavior. *Hiding* diabetes was described as actually keeping the information that one had diabetes from others, not disclosing it.

Pretending, playing dumb, and ignoring were often what a person did in his or her

own mind instead of try to keep it from others. It was embarrassing to admit to having diabetes. The workplace for M2 was difficult because he was mocked for his health issues, which caused embarrassment. Both men and women sometimes hid or want to hide diabetes because they did not want to show they had diabetes; it was stigmatized in the culture.

Participants asserted the presence of an actual, negligent quality within the culture that was/is used to avoid responsibility for the life transition necessary for effective DSM. Exemplars demonstrated concern about a prevalent attitude in the culture by Mexican immigrants with T2D living in the United States that exceeded an individual *pretending, ignoring, or being in denial* about T2D. Negligence was described as an underlying contributor or source of avoiding responsibility for DSM. When W10 spoke of negligence, she indicated it was a cultural *Negotiation* to meet the criteria of social settings.

The culture placed a high value on *being proper*. This meant that not only were people to be polite and respectful, but also expected not to violate behavioral codes in social settings; these rules were followed “so as not to offend.” It was frowned upon for both genders to decline to eat what was prepared and offered; it was stricter for men who believed they could “not say ‘No.’” The social expectation was to take food prepared by a hostess, to eat at least “a little bit;” whether one liked the food or beverage. For women, it was more difficult to say “no, thank you” in Mexico than in the United States where the social rules are less strict. Both genders were able to say “no” when the person already knew of their T2D and/or was a trusted person; however, even with family, it was difficult at times for a man to

refuse food prepared for him. For both men and women, these social expectations did interfere at times with DSM decision-making. Some participants had learned the value of saying “no;” they had chosen their health over the cultural expectancies.

Machismo did effect the decisions of some men. W10’s father refused DSM due to his arrogance and pride; eventually, the CVD affected his cerebral functioning to the point that he ignored the ravages of the disease. A pride in M2 appeared to interfere with him seeing that he should have a healthy fear of the consequences of T2D. M1 repeatedly behaved in an oblivious fashion about serious health warning signs because he did not think anything serious could be wrong with him.

W6 brought definition to the concept of *Being in the battle (conflict)*, a major construct of the substantive theory. She illustrated that making decisions about and maintaining personal control of diabetes were within the individual; the effects of diabetes were also. Managing T2D was about daily self-control, not about the day-to-day “take medicine to get BG under control” because that approach allowed for recurring BG excursions. People who used medication instead of practicing self-control were considered to be persons with diabetes who did not understand the essence of the disease and were consequently at higher risk of poor outcomes.

Keeping the long-term view daily. One of the most successful features of effective decision-making and means of controlling their T2D was to stay mindful of the long-term goal of good health and prevention of consequences. They allowed short-term pleasures to have a limited influence on their day-to-day choices. Also, they were aware that they were making daily choices. Choice was intentional and admittedly, a frequent struggle; at times, it was a difficult *battle* to choose the long-

standing outcomes over more immediate gratification, as well as contend against the cultural pressures they were confronted by every day. In further discussion, the terms used will be “short-term” for more immediate or brief-lasting pleasure and “long-term” for enduring perspective on reduced diabetes consequences.

Thinking long-term. Earlier, when W6, RA1, and the PI clarified the difference in the term, convenient (see Intervening – Language), between the two cultures, W6 mentioned that her use of the term was related to long-term benefits. She went on to say that she always had to think about the long-term; it was an important part of her every day DSM; she kept the lasting view in mind.

PI: “... So, it’s not just convenient right now, it’s how that convenience actually affects the long-term?”

RA1: [Spanish to W6] So, it’s about what is more convenient for you, not just right now, but long-term?

PI: Did I get that right?

RA1: Yes.

W6: [Spanish] Yes, all the time. *All the time* you have to think that way.

PI: So ‘how does now affect later? - essentially.’ [W6 and RA1 nodded].

M2 said that he had daily choices to make for his diabetes. He correlated long-term effects with keeping his health. He added that sometimes his choice might cause some social discomfort if at times he chose what might not be popular and/or make him different.

PI: “When you make your choices each day about your diabetes –I’m getting to the idea of taste right here. When you make decisions every day about your diabetes, ‘cause you *have to choose everyday ...*

M2: Exactly.

PI: and ... I understand that you do. Do you keep in mind, are you thinking about the long-term effects?

M2: Well yeah, long-term effects, I just think that ‘I want to keep healthy.’

PI: So, you do think about long-term?

M2: Definitely.

PI: Are there things specific to a man, a Mexican man as he’s making decisions about diabetes? Not just you, but a Mexican man in general.

M2: You gotta think about what to have or not to have. We can’t say ‘it’s going to offend you’ [referring to worry about what the other person might think].

PI: Yes, right.

M2: You know? And you’re going to feel the difference. [feel at times like he stood out]

PI: You really do keep the long-term in mind.” [M2 nodding].

W9 stressed the importance of keeping the long-term in mind every day and agreed with other participants that choices have a cumulative effect in the long run. When the PI inquired, “Okay, when you make choices that affect your diabetes it sounds like you are thinking about the long-term effects. You really kind of always have that in front of you, don’t you?”

W9: "Yes.

PI: I mean like every day?

W9: Every day, yes.

PI: You know the people who I have talked to, who have been the most successful, that's been true for them. They keep in mind that they're having to think about the ongoing, long-term effects; that every choice they make contributes to their long-term. And they make a choice that's heavier on the long-term, and less on the short-term ['I really want it!']. Does that make sense?

W9: Yes.

RA4: Yeah!

PI: So you weigh the long-term against the moment's pleasure? I know I'm kinda putting words in your mouth, but I feel like that's what you're saying. Right?

W9: Yes."

W10 also spoke of the importance of thinking long-term, keeping the long-term needs and goal in mind every day. She enjoyed simple pleasures in very limited or infrequent doses.

PI: Okay, so when you make choices that affect your diabetes, do you think about the long-term effects?

W10: Yes, definitely.

PI: You're always thinking about the long-term?

W10: Oh, yes, the long-term.

PI: And it affects some of your choices now?

W10: Yes, like eating sweets. My ice cream that I miss so much ...

PI: So you might limit eating your sweets?

W10: Yes.”

Several participants said that every day they had to keep the long-term view of T2D and DSM in perspective. They knew they needed to have a persisting outlook that meant they had to choose foods and activities - daily – all day - that prevented or delayed consequences and untoward outcomes of inadequately controlled BG. They alone had to make intentional choices; this mindset had to be with them all the time. The commitment to “keep healthy” had to be their goal. Every day, each one had to choose to let short-term pleasures and tastes go in place of lasting health choices. To fight the *battle*, they had to keep the long-term in mind.

Remembering the outcomes of uncontrolled diabetes. A salient aspect of keeping the long-term view was to remain mindful of the outcomes of uncontrolled diabetes. As made evident throughout this chapter, each participant both knew and observed someone who had suffered the consequences of inadequate, inconsistent, and/or failed daily BG control over an extended period. W10, whose father’s machismo soberbia [arrogance] and orgulloso [prideful] about his diabetes, agreed when the PI commented, “I’m thinking that one of the other things that affects how you choose is that you never forget the situation. It’s always sort of close to your mind; the situation with your father.” W10: “Oh yes, ever so present. It’s ever so present ...”. The mothers of both W7 and W9 had advanced T2D and suffered through dialysis-dependent months at the end of their lives. Both participants were

driven to not repeat their mothers' fate. M1 had personally been threatened with the loss of a lower limb in the days when he was not taking care of his T2D and knew people who had suffered that end. The sister of M2's daughter-in-law had lost a lower extremity to T2D; the result of -DSM. People on both sides of M2's families had lost limbs and/or vision. W1 experienced the threat of vision loss at the beginning of her uncontrolled diabetes and knew people who had had organ failure. Both W4 and W5 have known people who went blind. W8 was afraid of loss of independence, possibly being put into a convalescent facility if a family could not take care of her; W1 preferred to die than to lose her legs and independent function; and W5 dreaded the thought of her children leading her around.

Keeping the outcomes of uncontrolled diabetes in mind on a regular basis was an important aspect of keeping one's long-term goals in mind; knowing others who had not kept the lasting outcomes in view was useful. Considering the poor outcomes of others helped the interviewees remain focused on the long-term.

One dimension that made *Being in the battle* everyday easier and helped them to keep their goal toward the long-term was the degree of *social independence* each possessed. The more comfortable the participant was with her- or himself to *battle* against daily cultural constraints, the more successful (s)he was in doing *battle* with her- or himself and resisting cultural pressures. *Social independence* was less of an issue for men than women in the culture, although it played a role.

Social independence. *Social independence* was an important concept present in the first IV. W1 was fiercely independent in her thinking and approach to diabetes. She did not let anyone influence how she approached her DSM and did not

care if they liked her answers socially. W1 "... because I know what I have to eat, and not to eat. If I eat at my house and I go visit her and she is having dinner, they offer me something, 'No thank you, I already ate' and I take my medication, I have to wait." W9 had been emotionally wounded by her mother's suffering through many health issues; the worst of which was dialysis for ESRD. The participant determined that nothing was going to get in the way of her +DSM. She was clearly *socially independent*. M1 eventually developed that also as has been illustrated. An interesting finding that varied from the cultural norm was when W9 was asked if, from a cultural perspective, she got *flak*' for being socially independent? She replied,

W9: "The people, they're persistent.

PI: Yes, they are.

W9: They tell you 'come on, it's not gonna hurt. Come on, try it.' It depends on the person, like in my situation, even if they keep telling me ...

PI: No, you're not going to 'cause you're socially independent.

W9: Yeah, I'm not going to do it.

PI: But do you get flak from that?

W9: No.

PI: People eventually say 'that's just the way she is.' ... they eventually accept it anyway?

W9: Yeah, uh huh. Same thing like with the drinking. I've never. I don't drink. I've never done it. And let's say I'm around people that say 'come on, just one. It's not gonna hurt you.' I say 'No', and I think they learn that I'm not gonna do it, and they stop doing it. [stop pestering her]

PI: And they just know that about you.

W9: Yeah, 'she's not gonna do it.'

PI: They get it after a while ... So even though there's this worry for other people than yourself about being different, the reality is that culturally people will eventually accept you anyway, even if ... [she was different] so, people are uncomfortable being different, but it's not always because people don't accept them. Is that right?

W9: That's right, no."

While the culture dictated conformity, her experience was that people accepted her choice not to conform. In fact, those who usually pestered her to do what she did not want to do eventually left her alone when they realized she would not conform or comply with their pestering. She was accepted despite her difference from the expected norm. Beyond their tolerant acceptance, later she shared that she actually enjoyed the respect and admiration of people who observed her making independent choices to manage her diabetes. PI: "What do your family and friends say about your diabetes?"

W9: "They really don't say very much. My family tells me just to 'be careful,' 'cause 'don't end up like my mom.' Friends, not really. They don't say anything. Actually, they have mentioned that I have it under control, that it's good, that they really don't see very - too many people the way (she manages) ... I mean I tell them and I check what I eat, so they know more or less. They admire me for that.

PI: ... They really seem to be very respectful. Okay, so actually that's a positive thing for you. It's interesting because your social independence ... Some people are afraid of that 'cause they don't want to be different, yet people admire someone like yourself who has good balance and you are so socially independent. It's interesting ... The very thing that people are afraid of [being rejected for being different or speaking up for themselves] - your story is different than that. Okay, so it makes you feel good and it doesn't seem to interfere in any way." [W9 nodded]

As reported above, W3 had a slow *Acceptance* of her diabetic status and having to "take a pill" for treatment. But, after she *Accepted* her T2D, she continued over a several-year period to be reluctant to go against cultural/family expectations when she and her family attended all extended family events. Although, shortly before the second IV, W3b had a personal reckoning and had found the needed *social independence* to resist cultural pressure to meet the expectations of extended family and other cultural pressures. The PI addressed the *social independence* of previous IVs with other participants when she served as RA. When asked "What is required for a woman to be *socially independent*, to do what she wants to do whether others understand or not, for her to take care of her diabetes?" W3b recounted that, although she was *socially independent* by the second IV, it was only in the previous 5 months that she had changed her attitude. She realized she needed to be well and alive for the sake of her family. Referring to the prior time, she said,

W3b: "I was kind of reluctant.

PI: ... And so, what interferes with a woman being independent? And it sounds like you were feeling obligated, that you had to serve others first, before you felt free? Now, cause now you feel free.

W3b: Right ... I was myself second place ...

PI: Right, so the interference was that your value was 'I have to serve my family first.' Okay. And that actually did interfere?

W3b: Right.

PI: Okay, do you think that the way you [will] make your decisions (in the future) will be pretty similar? I think my sense is that now that you're feeling more independent

W3b: Right. Yes."

W6 had a number of dynamics that affected how she made day-to-day decisions; however, when asked the question, she had a *socially-independent* response. Her mindset was that if she needed to make a decision she simply did so.

PI: "What kinds of things affect how you decide? How you choose?

W6: How is it? ... Affect me?

RA1: [Spanish] Yes, what things affect you that lead you to make a decision?

For example, I want to do this [gesturing]. What am I thinking before, that lead me to decide to do this? And it's the same with you and your diabetes. What things are you thinking or saying that prompt you to make a decision?

PI: How to make a decision? . . . What do I think? No, well, normal. I just make a decision. If I need to do something, I do it.

RA1: So she says that when she has to do something, she just does it.”

Another example of her *social independence* was her willingness to use insulin when others around her warned her not to use it because of its dangers and the strong social stigma against it. She had started using it and her doctor or his office called daily to find out her SMBG, so her insulin dose was adjusted daily until her BG stayed in a normal and safe range.

W6: “Insulin? Well, I don’t use insulin. [Confusing because she had just started to use insulin]

PI: Okay, but nobody talked to you about the changes and about the pancreas?

W6: Oh yes, they told me about insulin; that it was dangerous, and that I shouldn’t take it.

RA1: This is what other people would tell her about insulin, not to take it because it was very dangerous.”

Both women and men had to learn culturally how to be *socially independent* in their community-oriented culture and family groups. For W3 and M1 it was a longer process; for W1 and W9 they were assertive from early on and did what they had to do whether supported or not; they had both spent part of their childhood in the independent American culture. Ironically, W9 reported being regarded because of how she self-managed; an exception to the cultural core values of everyone “being the same” as she described the culture. W6 simply did what she had to do when there was something she had to do, including having started the dreaded insulin.

Lacking resources. Both W9 and W3 expressed concern that one type of circumstance that interfered with people taking responsibility for their DSM was a factor outside of themselves; lack of resources.

Financial matters. W9 added a compounding issue that, if lack of resources played a role in avoiding DSM in the Mexican person with diabetes or diabetes-like symptoms, they might use self-care remedies at home.

W9: "People, especially Mexicans, they don't have medical insurance.

PI: Aahhhh. So maybe ...

W9: I've had it. I mean I've been having it since I started working, but sometimes that's the problem. You think you can just take home remedies and it's going to solve the problem."

W3b concurred, she said that sometimes people pretended because they did not have the money for diabetes or other HC. She believed still others were afraid of legal exposure. Those effected might pretend to "save face," especially if there were no resources for HC.

PI: "After somebody has diabetes, why do some people pretend that they don't know that they have changes or symptoms or they ignore them or deny them or set them aside when the change happens? I just wonder what your insight is from the culture standpoint. They know they have diabetes and they've been treating it in one way or another, but they kind of pretend or ignore, again they just don't do anything about it.

W3b: I think because they don't have the money.

PI: Okay, so sometimes it's the money.

W3b: Um hmm. They are really struggling with the daily business ...

PI: What other things do you think causes that?

W3b: Being afraid of the legal ...”

Above, the story of W4 getting insurance between PI visits and the stark improvement she made after she had insurance and had received the nutritional guidance she needed is recorded in Intervening Conditions – Access to Care. Her example supported the concerns voiced by W9 and W3 in this segment.

Food scarcity in childhood. Two participants admitted to having had food scarcity as children. During the IV with W4, she told of how significant of an impact not being able to have enough food and the kind of foods that she wanted in childhood affected her choices as an adult person with diabetes. She was the fourth of 11 children and only her father worked. Two uncles ate with her family, meaning there were 15 people at the table daily and no school meals were provided. They all slept together in one bedroom, “we raised up real poor family ...”

W4: “My mom had to make like the eggs, scrambled, with chile salsa and all that, and I want two eggs, you know with the yoke, two eggs... and my mom said “no because you have to ...” [PI: Yeah, share with everyone] and I never get [laughs]

W4: ... And I see my mom and she never ask, you know, she was so pride, and she never asked the neighbors for nothing. [PI: Yes] And she make the oatmeal for us and she don’t have no milk ... And she gave us, and I said ‘oh no, I don’t want it like that” (chuckles). I never eat because I want the real thing (laughs), with ... milk ... and always I like that ... and

they make pancakes, I say 'no.' I wanted the Aunt Jemima box ... and my mom buy the Aunt Jemima box but she put a little flour.

PI: To stretch it.

W4: Yeah. I said 'no, I want my pancakes from Aunt Jemima only ... and I want the real thing [laughs]."

She told the story of when she was 17 and the family came to the United States for the first time to work in the fields. Her mother kept all the money they made because there were many things the family needed in Mexico. Her aunt told her mom to share W4's portion with her as a young woman, but she never got any of that money. She did not have her own money until she was working, and then it was hers to spend on whatever she wanted.

W4: "... When I started working even I was in the house, I spend my money and buy things; what I want. And my mom said 'you supposed to save,' and I said 'what I save? I want that, I want that [pointing her finger in various directions] ... what I want – *it was mine.*'

PI: Um hm. Well there was some part of you that really felt a little bit deprived, right?

W4: Uh huh."

She explained that her deprived state affected her in two important ways as an adult. Most importantly, the deprivation significantly impacted her DSM discipline. She remembered her aunt told her, "you eat whatever you want to eat because you healthy now, you young, you eat ..." Later she thought, "Wait, because

I'm now old[er] and I can eat; I have the money to eat now all I can eat. And probably that thing there ..." [referring to her self-control over food].

PI: "Have you thought about that ... maybe one of the reasons that you just eat anyway [W4 'Uh huh'] or eat more than you need to is because you didn't have it before?"

W4: Uh-huh, always I want something.

PI: ... just enjoying the food you have whether you are supposed to or not [W4: Yeah - nodded] because you couldn't before ... Do you think that has anything to do in the back of your mind ... with why it's hard to be disciplined now?"

W4: Yeah, yeah, there's a lot of lacking to discipline."

The second way she was affected was "we could never have shoes." She said "I buy new shoes all the time." Sometimes she even bought duplicates of ones she did not recall she had already bought. One sister overfed her children at every meal and as adults, W4 said of them, "the girls are fat now" and the sister's defense was constantly, "I always hungry in my house" referring to their impoverished youth. A friend of W4's always chews chewing gum because her family could never afford it; she cannot get enough of it.

W3 came from a rather poor family of seven children. Her father was the only income producer. She told of many meals that she looked back and realized they mostly had carbohydrates, sometimes very sugary ones, and often lacked balanced meals. She too thought deprivation affected her delay of starting diabetes care and practice of self-denial in eating.

PI: "So you would get some calories but not the nutrition you needed. So, you were actually short [on adequate nutrition].

W3: My childhood was like that and I would love combination of good balance. We used to drink a lot of milk but before bed with a conchita – sweet pan, really sweet, that's our dinner. A glass of milk.

PI: Which is a great protein

W3: Yes, but always with conchita.

PI: Your blood sugar shot right up.

W3: Right. And before, so I think when my mom knew that she had diabetic, then she start doing more vegetables. But I remember my childhood was really missing balanced meals. Lack of balance of what you eat.

PI: Do you feel like that had any ... see - I immediately go to thinking, 'I wonder if that's one of the reasons when you found out you had diabetes, and you were finally eating whatever you wanted. Do you think that had any reason why you didn't go to take care of your diabetes sooner?

W3: Yes, because I remember, I was thinking really hard about pizza and it was really expensive to have pizza for everyone - 12. It was new, the restaurants was brand new in Mexico, so when I came here I loved to have pizza, but I never eat too much but it was one of the things that affected me to have bad choices in regards to my illness. Because after that I was feeling sick or heavy or sleeping and then I should not have eaten it.

PI: So it actually did sort of interfere with you.

W3: Yes.”

W3 had already mentioned her concerns of families who do not have adequate income for healthcare and understood that lack of funds could impact the choices people made for food. She gave an example of the people she used to supervise; they would often have only enough money for ramen for dinner every night at work – it was all they had and she understood the nutritional challenges, especially because she knew some of them had diabetes and had to eat on time. “So, they go with the cheapest - maybe canned food or maruchan pasta, they used to take those kind of food to our job because they didn’t have any more money.”

Although only two participants reported the personal effects of insufficient resources in their youth as having had an effect on their adult diabetes decision-making, it was nevertheless compelling to observe and important to report. In all, there were many components to decision-making, beginning with the need to accept the disease and then accept the responsibility to care for the disease. The well-established socio-cultural influences, especially pretending, playing dumb, ignoring, denying, and the necessity of *being proper* were potent; machismo played a role for men. The importance of keeping the long-term perspective of diabetes and DSM to prevent untoward outcomes, recognizing that the *battle* for balance is daily, and that the more *social independence* they could be, the easier it was to do the daily *battle*. For a few, lack of resources affected both *Accepting diabetes* and food choices.

Summarizing the Conflict: More about *Being in the Battle*. As the findings suggest, positive DSM was an all-day, every-day *battle*, a struggle between food

temptations common to most people, the frustrating dietary limitations of the person with diabetes, and strong cultural temptations of the taste of good food, family responsibilities, and social requisites to abide by powerful and culturally-embedded norms and expectations. As shown, there were many aspects to the decision-making of the participants' DSM. Whether they were *Negotiating* with themselves, rationalizing, setting limits to have "a little bit," using extra medication, doing more exercising, eating less the following day, denying, pretending, ignoring, or avoiding certain foods, they were seeking to find a comfortable balance between cultural and diabetes-related forces. They felt the innate cultural stigma of diabetes; it complicated their *battles*, especially in social settings. At times, they were very creative in how they balanced the short-term with the long-term. The following segment illustrates how they made their decisions.

Negotiating. How They Made Their Decisions About Diabetes Self-Management

The dominating decision-making mechanism for each participant was *Negotiating* what they thought at the time was the best decision for them given all of the conditions, pulling them in different directions for various personal, relational, and cultural reasons. There were many ways of *Negotiating*; some of which have been discussed above: hiding, pretending, ignoring, setting aside, and denying.

Types of *Negotiating*: With one's self; Rationalizing; Limiting self; For taste, smell, meaning; and Using extra medications. Through the course of IVs, participants repeatedly described a sundry of methods and behaviors that allowed them to navigate through the *battle* of wants, needs, shoulds, and should-nots in their recurring daily efforts to practice +DSM, at least somewhat. They bargained,

reasoned, exchanged with themselves and others as they made their decisions about what to eat, how much, when, why, and with whom. These *Negotiations* were confirmed by several later participants and the process was evident in the transcripts of the earlier IVs. The most common *Negotiation* was with one's self. Rationalization was an important variation. Similar to what has been discussed previously, they also limited themselves by choosing "a little bit." They *Negotiated/* were *Negotiating* for taste, smell, and memories that were important; some were *Negotiating* by use of extra medications to manage at-the-time elevated BG.

Negotiating with one's self. When exploring the concept of *Negotiation* with W10, she clarified that *Negotiating* was based on one pretending not to know what to do in a social setting, "playing dumb" as a way of *Negotiating* in one's mind between social expectations *to be proper*, not wanting to stand out as different, and one's diabetes choices.

PI: "... so they pretend 'oh, I'll pretend that I don't know what I'm supposed to do about my diabetes, so that I can eat what is expected of me?' Is that partly how people would 'play dumb?'

W10: Um hmm. Yeah.

PI: ... but it seems like the way people *Negotiate* in their mind.

W10: It's *Negotiation* in the mind.

PI: And is that because someone is trying to be proper? Trying to do the right thing socially?

W10: Yes, definitely.

PI: And it is a social expectation, right?

W10: Um hmm.”

The PI sought to learn more about *Negotiation* as a means of managing BG from W10. She summarized her self-*Negotiation* after she enjoyed an entire ice cream one day.

PI: “Tell me in summary how do you *Negotiate* with yourself about diabetes?

W10: Well like I said, if I eat sweets then I try not to eat sweets. Okay I have my ice cream. So, next day I try to cut off sugar completely so that I balance it.

PI: So, you’ll be real high [BG] one day, and a lot lower the next day, and hopefully a little more even after that.

W10: Yes. That’s how I more or less *Negotiate* and try to eat less food, make smaller portions - which is pretty hard for me - but I try and that’s just about it. And I try to do my exercises. I say ‘move it, move it, move it!’ And I push myself.”

W10 went on to explain how she approached getting her BG back to the normal range without checking her BG before or after the ice cream.

PI: “Okay. If the next day you check, let’s say it’s 170, or whatever, would you do anything different that day to help get your sugar under control?

W10: Yes,

PI: Tell me what you would do after you enjoyed your ice cream or your chocolate from Mexico.

W10: Just cut everything sweet out of my diet. ... And a little bit less food.

Less bread ... Other carbohydrates I would cut down.

PI: So that's how you help yourself get back under control? [W10 Yes]

PI: And does that work very well for you? [W10 Yes, very well]

PI: You know what I think that is? I finally have been figuring out that's when people are *Negotiating* with themselves. And I wonder what you think of that idea.

W10: Um hmm. Um hmm!

PI: You're sort of *Negotiating*: I had that, now I'm going to have less of this.
Is it *Negotiating*?

W10: Yes."

When examining *Negotiation* with M2, he explained how he had to maintain being proper, avoid being rude, and not offend another at all costs. He stressed how, even though he had significant social pressure, still "*you have a choice*," he said about the foods he felt obligated to eat. Thus, it was important to *Negotiate*/be *Negotiating* with himself to address his elevated BG that occurred following his social courtesies. He did several things to get his BG down, including fluids, exercise, and subsequent meal portion adjustments.

PI: "And when you're deciding what to do, or what to eat, and you're out someplace ... what I'm hearing from people is that they do a little bit of *Negotiating*, they kind of bargain with themselves. 'Well today I'll eat a little of this and I won't have that ...' They *Negotiate* a little bit and ... as

a Mexican man who's a diabetic, I really want to know what that looks like.

M2: You know in this case we thought it was safe eat the same, we always agree with the [?] we made ...

PI: Okay. You always agree with the food offered?

M2: Yeah, and we try not to make any sugary stuff ... To be the proper step. If I rely on this too much sugar, I won't eat.

PI: But let's say we're in that situation where this lovely Mexican woman has prepared food and to be socially proper and not to be rude, you cannot say 'no' [earlier he had clarified this at length]. So, you end up eating ... you taste a little here, you taste a little there because you are obligated socially ... Do you *Negotiate* later with how you're going to control your blood sugar?

M2: Yeah, definitely.

PI: So, you might eat differently or something? What would you do?

M2: Yeah, well first of all, drink a lot of water. And take a walk. ... To bring the sugar down.

PI: Perfect. If people just understood how easy that is!

RA4: Yes.

PI: ... Okay. And if you're at that same party, where you've had to say 'yes', do you actually *Negotiate* with certain foods?

M2: Oh yeah, you have to. *You have a choice ...*

PI: So, what does that look like when you have to be the one to *Negotiate* with yourself? [example given by RA4]

M2: ... I may not [eat] the big amounts of food.

PI: So, you're going to eat small ...

M2: Yes, smaller amounts.

RA4: In case that you want to try one more, do you *Negotiate* with yourself and say 'Oh, I will go biking', or [PI: Yeah, that's a great example]

M2: Yeah, yeah, I always do ... I always exercise. When I have break into some sugar or tamales, I do what I have to do to bring the sugar down. Cause I don't want the sugar to stay in me."

W9 admitted to *Negotiating* with herself as a means of balancing her desire to satisfy taste urges and control her BG. She practiced using her will power and she did it so consistently that she was successful with urge control.

PI: "What kinds of things affect how you decide, or how you choose? ...early, you said '*I have to choose every day.*' You said something like that. 'Sometimes I really want to eat these things ... but I just have to ... I have to keep ...'

W9: Oh, yeah. Well I try not to ... I crave but I just eat a little bit.

PI: So, the way you choose - literally, is to limit yourself?

W9: Um hmm. I limit myself, yes.

PI: So, does that satisfy you?

W9: Yes. I'm happy.

PI: You think 'oh I love carrot cake,' so you have a little bit and you go 'I'm just going to enjoy this little bit of carrot cake...?'

W9: Yeah. And if I taste it and get the little piece, I don't want to do it more. I know that's enough. I have, I guess the will power to STOP!

PI: Right. But you also get a chance to satisfy?

W9: Yeah.

PI: So, you're kind of - this is a different word - but it's almost like you're sort of *Negotiating* with yourself. 'I want this ...'

W9: But I can only eat so much! [laughs]

PI: Is that right? You kind of *Negotiate* with yourself?

W9: With myself, yes. If you put it that way, yes. With myself.

PI: ... Cause that's what it sounds like ... you say 'I want that, I can't have it, but I really want to satisfy myself ...

W9: I'm just going to have 'a little bit.'

PI: So I'm just going to have 'a little bit' and because you do that consistently, you really are satisfied ... That's awesome!"

W1 had the most interesting methodology for *Negotiating* with herself to keep her BG under control and still found a way to eat intensely sweet desserts on a frequent basis. In discussing her increasing A_{1c}, which had jumped 0.3% in 3 months, she seemed to quickly know the cause and she already had a remedy.

W1: "That's 3 months back it was 6.0 and this time I got a .3 [6.3] because I ate some chocolates. I eat some raisins with chocolates. I cannot stop eating my sweets. If I want to eat something sweet, I check my sugar.

PI: So if your sugar is high do you still eat the sweet?

W1: No, I drink a lot of water. The water will get it down. 3, 5, 6 cups, 8 oz.
you will urinate the sugar.”

Later, when commenting on how she had advised her newly-diagnosed friend about how to “manage her sugar” W1 said,

W1: “... and I told her ... in between those 4 hours [of eating] you wanna drink 2 or 3 cups of water, between. The water helps you a lot.

PI: It sounds like it; you've mentioned it a few times now.

W1: Yes, water helps you a lot ... It helps because when you go to the restroom urinate you ... the water cleans your system so the water goes down. For me. [tapping her upper chest with both hands]

PI: You mentioned the sugar, right? The water helps the sugar ... is that what you told me?

W1: Yeah, if you drink a lot of water the ... when you urinate, the sugar goes out too.”

She went on to talk about her sweet tooth and how she *Negotiated/* had been *Negotiating* to eat chosen treats.

W1: “... oh, I eat a whole bar of chocolate!

PI: Oh [laughs surprisingly]

W1: Oh yes, I go to the market just to go get me a pound of raisins with chocolate, and I'll eat at one sit.

PI: But you check your sugar first?

W1: Yes

PI: And if your sugar is ok ...

W1: Then I'll eat it! Yes. I'll skip what you can say my snack, and that will be my snack, I give myself a reward.

PI: I see yeah, I think that is very interesting.

W1: That's the key, is to check your sugar, that's the key...

PI: So, when it comes to the kinds of things of how you decide, how you actually choose... It sounds like you said that its your blood sugar, am I right? Is there anything else that helps you choose what you do ...?

W1: No.

PI: Ok, because it sounds like if your blood sugar is not good, even if you want the chocolate bar you don't eat it.

W1: No, I won't and if I want to eat it, because [BG] is too high and I have to drink maybe 5 [8] oz. of water, a lot of water, and then I'll check it. And it's gonna be a 100, 96 sometimes it's 80, so I'm good, then, I can eat the whole chocolate.

PI: She's got it down to a system [said to RA1]

W1: Yes, yes."

These exemplars demonstrated how participants with overall, well-managed diabetes with A_{1c}'s in the 6-7 range actually bargained with themselves in order to have the sweet desserts they desired or they fulfilled social criteria when they ate "a little bit" of several non-diabetic foods in social settings. Reducing what one ate the next day and cutting out sweets and carbohydrates was the primary method, as was the all-important exercise. Increasing their water intake in order to flush out excess

sugar from their system was a very important method to get their BG down fairly quickly. While W10 did not concern herself with her BG at the time she ate her beloved ice cream, W1 focused on testing her BG and drinking water until she got her BG down to what she considered a low enough level that she could indulge in a full chocolate bar or pound of chocolate-covered raisins. One might consider this later method an aspect of rationalization.

Rationalizing as a means of Negotiating. Sometimes participants *Negotiated/were Negotiating* by rationalizing in their mind that the consequences of short-term enjoyment either would not be all that significant or, in the past, had not been all that significant, or that they might do this “only once” or “not very often.” W10 helped bring some clarity to this form of *Negotiating*.

PI: “And it goes with ... this *Negotiating* piece but part of it is there sort of seems to be a rationale. The people sort of rationalize - ‘if I do this, I can do that’, or ‘if I do more of this, I’ll do less of that’ ... And they think, and ‘it’s not really going to [do X].’ I’m only doing this once, ‘or ‘the last time I did it my sugar didn’t go up very much ...’ They sort of rationalize that it’s okay to eat something or eat more of it. And I just wonder if you find yourself doing that?”

W10: Yes. Yes, yes.

PI: It’s not just *Negotiating* ...

W10: No, it’s different.

PI: So how do you go about rationalizing?”

W10: Well, I like, I try to eat less, and that's very hard for me because I'm a very good eater.

PI: Meaning that if you overeat, or you eat something you shouldn't ideally eat as a diabetic, is that what you mean? So, you say 'I'm going to eat the Mexican chocolate,' ... 'or I'm going to have more of this' ... or do you mean you eat less of other food? ... what do you mean by 'eat less'?

W10: Eat less of the food that I like, like the chocolate, I eat less.

PI: That's when you eat 'a little bit.'

W10: Yes. Like, I like the jam. I got the sugar free strawberry jam. It was so terrible, so I threw it away and what I do is from the little packages in the restaurant, I open one and take little portions ... From that square, I make four servings.

PI: Oh, so it's a *tiny* bit, but you get to taste it.

W10: Very little, but I get to taste it. Just taste it!"

W7 found herself rationalizing on some days and had a hard time resisting. She indicated the battle she had when she pretended that it was "ok" to eat some foods she wanted; other times she had less *battle*.

W7: "But sometimes you feel like you want something and you can't wait, like you can't do it because you say 'ah, well maybe I eat a little bit or this piece of cake is not going to kill me, it's not gonna be ...' It's hard sometimes. It happens to me sometimes."

PI: But it sounds like you're saying 'I kind of rationalize ... explain to ourselves... I'm gonna pretend this is not so big of a thing. I *pretend* it's

like this big [motioning a small portion with her hands] and not THIS BIG of a thing' [motioning a very large portion] ... 'I want THIS!' [the food item]

W7: That's why you know like you eat a lot of stuff. It's good because the taste is good, but *it's no good for you*.

PI: ... we sort of ... rationalize, 'This is more important to me. The taste is more important,' or 'it's not gonna kill me, it's not a big thing.' I'm going to do what I WANT to do!

W7: Yeah, and then some days it's like any culture I think, sometimes you feel like you [must] eat and sometimes you feel you can stay out of the food."

Rationalizing was a way participants bargained by making the food they wanted seem to have less caloric value or risk than it actually had. By reasoning that reduced frequency or amount would have little to no impact was how they were *Negotiating*, by thinking that they could indulge when they actually should not have. W7 wisely added that sometimes temptation won and she felt she had to eat something she should not, whereas other times she did not have the *battle* to "stay out of the food."

Choosing to limit one's self; eat "a little bit". Practicing self-discipline. W9, similar to some of the other participants, developed self-discipline over the years. Although she occasionally indulged in a sweet, she practiced eating just "a little bit." It had allowed her to satisfy her cravings but did little harm to her BG and long-term diabetes health; she had rare excursions.

PI: "What kinds of things affect how you decide, or how you choose? ...
earlier, you said 'I have to choose every day.' ... 'Sometimes I really want
to eat these things ... but I just have to ... I have to keep ...'

W9: Oh, yeah. Well I try not to ... I crave but I just eat 'a little bit.'

PI: So, the way you choose - literally, is to limit yourself?

W9: Um hmm. I limit myself, yes.

PI: So, does that satisfy you?

W9: Yes. I'm happy.

PI: You think 'oh I love carrot cake,' so you have 'a little bit' and you go 'I'm
just going to enjoy this little bit of carrot cake?'

W9: Yeah. And if I taste it and get the little piece, I don't want to do it more. I
know that's enough. I have, I guess the will power to STOP!

PI: Right. But you also get a chance to satisfy? [W9: Yeah]

PI: So you're kind of - this is a different word - but it's almost like you're
sort of *Negotiating* with yourself. I want this ...

W9: But I can only eat so much! [laughs]

PI: Is that right? You kind of *Negotiate* with yourself?

W9: With myself, yes. If you put it that way, yes. With myself.

PI: ... 'Cause that what it sounds like ... you say 'I want that, I can't have it,
but I really want to satisfy myself ...'

W9: 'I'm just going to have a little bit.'

PI: So 'I'm just going to have a little bit' and because you do that
consistently, you really are satisfied. ... That's awesome!"

W4 admitted that she too has “a little bit.” “I sometimes I eat a little teaspoon; but, you’re not supposed to eat that.” From the start of her diabetes, W6 had practiced self-discipline. In this excerpt, she provided more insights into why she chose to eat “a little bit.”

RA1: [Spanish] So your motivation when you make that decision is that you don’t want to offend people. You want to have good manners and be proper, right?

W6: [Spanish] Yes, so as not to offend the person who is sharing her food with me, very gladly.

RA1: So, she does not offend somebody that she [cook who made the food] wants to share with her (W6).

W6: [Spanish] I don’t eat much, but I do eat a little bit, because it’s good food, but even with that little bit, my sugar goes up.

RA1: She says with that little bit [to eat], she *accepts* her sugar does go up too ...

W6: ... I like cakes a lot but I eat just ‘a little bit.’

PI: Okay. But she takes tastes. She samples ...”

Usually “a little bit” is for self-control. In the case of W6, she also needed less to feel full so she chose to eat only “a little bit.” W8 ate “a little bit of a little bit.” Many exemplars above have testified to most participants setting personal limits on the amount they eat of various foods by eating ‘a little bit;’ often the conscientious person with diabetes did this is for self-control; equally often it was for social courtesies.

Negotiating for taste, smell, connection to meaningful memories and BG.

Referring to how nurturing food has been and that how she used only one quarter of a sugar-sweetened jelly packet on her toast allowed her to enjoy flavor she liked, the PI commented, “Oh, so it’s a tiny bit, but you get to taste it?”

W10: “Very little, but I get to taste it. Just taste it!

PI: Okay, so that’s one of the reasons why people *Negotiate* and have a hard time resisting. It’s because you want to be transported, so to speak. You want to have that nurturing, comforting feeling that taste brings. [‘Like when your mother caresses you with food’ she shared earlier]

W10: If it comes to your mouth. Your taste comes back to your mouth! Your mouth waters!

PI: Is that right? [Musing] But it makes it harder to resist?

W10: *Yes.*

PI: Because you’re not just resisting, ‘oh, I like the taste of this special food,’ or more of it. You’re really wanting for those moments actually have more than the experience of the food. You want the emotional experience that comes with it?

W10: *Yes, the taste and the smell.”*

Later she affirmed the importance of taste, how food affects her emotions and the importance of eating in the presence of others:

PI: “... you’ve talked about this a little ... things that affect actually how you decide? How you choose? What are the things that affect ...?”

W10: Yes. Flavors.

PI: Flavor! See, we're back to taste! [laughs]

W10: Um hmm.

PI: That's an excellent insight! Because that determines if you sometimes are going to *Negotiate* with yourself, that you're going to eat something that you might not have eaten.

W10: Yes, uh huh.

PI: So flavors, part of it, how you feel is another – you know feeling good or not feeling good.

W10: Being with people. Company. Just about it.”

Also, related to taste, W8 talked about *Negotiating* when she prepared a meal, *Negotiating* her cooking recipes.

W8: “You know what, I, I make the receipt, recipe whatever ... the recipe, whatever they say, okay ... In the book. [PI “Yes”] And I say, ‘Oh I am going to change a little bit - this one and this one [ingredients]’

PI: Okay, so sometimes the ingredients change.

W8: Because I don't like the ingredients, I change a little bit. You know what, I don't eat tortilla because I know that even if I eat one tortilla or two tortillas is when the, my sugar going up.”

M1's complicated health history and sometimes mental state due to heavy medications often led to incomplete answers or faded into other topics. He too, though, usually chose “a little bit” as a way of *Negotiating* to get to taste and eat what he wanted.

PI: Tell me how you decide what to do about your diabetes.

M1: How do I decide? Actually, what you're going to put in your mouth?

PI: I'm asking is that part of it, that sometimes we just simply *want something* more than we want the other?

M1: I ... so ... I'll eat something that I'm not supposed to, but just 'a little bit.'

PI: Right, just a little bit.

M1: Like if I want a donut, I'll cut it in half and give her half and I ...

PI: Right ...

RA3: I think it has to do with the fact that if you totally restrain yourself completely from doing what you're not supposed to do, it gets depressing. And so, you try to live maybe as normal as possible. So, you eat a little bit, you...

PI to M1: Oh, does that seem right? [M1: Yeah, um hmm]

PI: Okay. So, when we restrain ourselves too much, [do] we feel deprived? Is that what you're saying? [RA4: Deprived and depressed!]

PI to M1: But does that make sense to you?

M1: Yeah, it makes sense.

PI: So we feel deprived and ...

M1: Yeah, well that's one of my things why ... well not only that. Grief and ...

PI: Pardon me sir?

M1: Like when my daughter was sick, I was so tired. We used to sleep in her room with the recliner and she [his deceased wife] had to take care of the suctioning and all that ... Oxygen and ...

PI: Oh yes. So, some of that is kind of a fatigue, and some of it is depression, the depression piece has something that goes with it. Part of it is the depression that goes with it?

M1 Depression. I still see a counselor ...

Some felt the need to *Negotiate/be Negotiating* what they ate based on powerful taste/smell-emotional connections. They indicated that the importance of the taste of food was not just momentary satisfaction but was a connection to something more personally important. From a more pragmatic standpoint, W8 was one who made changes to her recipes in order to use ingredients that tasted good but caused less of an increase in her BG. M1 used a practical "I give her half" option.

Using extra medication as a means of Negotiation. Several participants spoke of taking extra medication or observing others did so as a means of dealing with elevated BG, especially after a social gathering where they had eaten too much and/or the wrong foods. M2 took extra medication.

M2: "... When I have break into some sugar or tamales, I do what I have to do to bring the sugar down. 'Cause I don't want the sugar to stay in me.

PI: You just brought up something really important. So sometimes you actually are going to take another pill, right?

M2: Yeah. ... After meals, I take a pill for sure.

PI: But did you just say that sometimes you'll take an extra one?

M2: So ... One and a-half of it.

PI: I got it. Another 1/2 pill.

M2: Yeah, 1 ½ of it. Glipizide. To lower my sugar."

Similarly, W3b has used extra medication in the past as a means of BG control after socializing. Contrasting was W6, whose exemplar is below.

PI: “But I’m still trying to find out if there’s anything else we need to talk about in terms of the *battle*, the day-to-day *battle*. Because what these other ladies are telling me is for some people they go to the party and they just say ‘well I’ll just get myself some extra insulin when I get home. Oh, I already took 1,000 of the metformin and another 1,000 with dinner, but I’ll take an extra 500 when I get home. Do you follow what I’m saying?

W3b: Right, when I used to go having celebrations I was dealing [Negotiating] with myself: Okay, I already eat the cake and the jelly, and I’ll have an extra 1/2 of the pill, just to prevent that I not ...

PI: and I see that as a *Negotiation*. That’s when somebody is *Negotiating*. [digital recorder problem]

W3b: We were talking about sometimes when I eat more than I expected, I take an extra pill, especially for celebrations.

PI: Um hmm. So, that is something that you do sometimes? I think that’s a kind of *Negotiation*, where we sort of say to ourselves ‘well I ate this, I’m going to *Negotiate* that.’ Does that make sense to you?

W3b: Right.

PI: But you’re saying that you do that only once in a while. The point that some of these people have made to me is that they observe people doing that every day. They just use more insulin or they take an extra

pill regularly – often as a way to *manage* their blood sugar instead of practice self-discipline. And I wonder if you’ve seen that?

W3b: No, I haven’t.”

In talking about her current situation in which she limited her time and frequency at celebrations, W3b addressed how she more sensibly took her medications if her BG was running high, but not as a means of *Negotiation*.

W3: “So always I have 500 mg [referring to MF] and then if I feel right, 500 mg in the evening. If I feel that I will be high, then I take the 1,000 mg.

PI: Yeah, exactly, and it may be that when your [BG] number is a little higher you have to do some of that. But to me that’s when you would use it. When you need it, not on a daily basis.

W3: Um hmm. I completely agree with you.”

W1 was recorded above as occasionally taking an extra pill if her BG was elevated, although she usually used water to “flush out the sugar.” Above, in *Recognizing that DSM is daily Being in the battle*, W6 shared her concern that some people simply gave themselves extra insulin or pills to kept their BG under control instead of practicing self-control of what, when, and how much they ate.

W6: [Spanish] ... They say, “I’ll just take my pill to get better”, but ... that’s not the issue ... their own medicine for eat too much and I take my medicine ... The people thinks that ‘it is better for me -I eat too much... I take my medicine - it’s okay.’” [She shook her head in disbelief at this approach and lack of discipline]

Negotiating with medication was done in one of two ways. On occasion, participants utilized extra medication when they had over-eaten, such as when they had to comply socially with eating things they should not have eaten. They took a little extra medication to reduce their sugar level into a healthier range or prevented it from going up too much. Some participants reported knowing people who actually *managed* their BG on a frequent basis with the use of extra medication rather than the application of self-discipline. It was considered short-sited by most participants because the long-term protection needs were not balanced, rather it served only for immediate BG adjustment. For those who practiced self-control and sought to keep their BG regulated by using self-discipline, they frowned on the short-sited approach. Overall, the participants understood that particular short-term remedy was not effective diabetes self-management.

Summary of Negotiating. As a result of the significant *battle* between the need for a balance between the short-term enjoyment of food and the influence of social norms with long-term DSM goals to prevent complications caused when a person with diabetes does not consistently control their BG, the participants were faced every day with having to make choices. They had to choose between the powerful long-term needs and pressing short-term demands and personal wants. On their own, each understood the underlying, ingrained social pressures and expectations; women in particular knew they had role expectancies that they wanted to fulfill. As already mentioned, a man had to “be a man;” they had cultural standards to meet as well. It became clear that the way they brought balance between these important opposing forces was that they bargained with themselves

and others with whom they dealt. They did so in order to balance their physical needs and interests, behaved properly so as 'not offend' anyone, and kept their BG under control as much as possible so they would not have long-term complications – of which they were all afraid to some degree.

Negotiation/Negotiating was the primary form of decision-making in the day-to-day choices participants used to navigate through the short-term social pressures and personal temptations against the need to protect themselves from the long-term cumulative damages. Pretending, ignoring, hiding, 'putting aside,' and rationalizing the use of extra medications were commonly used by participants and other Mexican people with diabetes whom they knew. Only occasionally was extra medication taken. Some mechanisms to regain fairly quick control of high BG included ways to limit food intake in the next day or two, exercise, and ingesting water. Ultimately, each one *Negotiated* or was *Negotiating* with her or himself to have both the short-term satisfaction to taste and smell of delicious Mexican food with efforts to respect cultural expectations and the essential long-term goal of keeping BG low so as to avoid T2D complications.

Preferences about diabetes self-management: Personal choice, Choosing role and family. Another important approach to decision-making was the simple choice about "what do I prefer?" Participants expressed various ways in which they chose or made their preferences; sometimes it was a personal preference involving only one's self. At other times, it involved one's responsibilities and one's role for the sake of others – consistent with the cultural values.

Personal choice. A primary approach W8 took to choose what she ate was by preference. She spoke at length about how she used preference as a primary decision-guide. Routinely, she compared items such as food, drink, even clothing to determine which of the options or choices was the one she preferred. Here she illustrated how she chose what she wanted to eat, even if only “a little bit” over what might be a healthier choice in a larger portion.

PI: “Right, it’s the one you care for the most.

W8: Oh yes, the most.

PI: It’s what you *want* to eat.

W8: Uhuhm

PI: Okay, but it’s the one ... you choose, the way you choose...

W8 It’s the same the eat ... look it: I prefer the, I saw the two plates and I prefer to eat a little bit the other one that my plate, the other one.

PI: Yes, [you’re saying] ‘better to have a little bit of what I want... than a lot of what I don’t like.’

W8: Yes, that’s right.

PI: This is very helpful, and that’s how you choose, you choose what you like the most.

W8: The most. Of course, I prefer to eat, a little bit, right? ... ‘I’m not being stubborn, I’m just choosing what I prefer.’ [PI: ‘Of course’]”

This same approach was taken by W1, who was recorded above in ‘*Negotiating with one’s self*’ of this section to have her preferred food/sweet. If she wanted the whole candy bar, she drank water sufficient to bring down her BG so

that she could have what she wanted; and she did. Ironically, she was comfortable with high-sugar candy but avoided sweeter vegetables. [*Pointing at the vegetable tray brought by the PI*] W1 said, "I don't eat carrots." PI: "Ok" RA: "Yeah, because they are sweet" W1: "Because they have a lot of sugar." However, she sought to balance those *sweet* drives with a healthier diet, PI: "...so the other side of the questions is... 'What are the kinds of things that helps you take care of your sugar, of your diabetes...?'" W1: "Eating ... the right foods that I have to eat ... small portions." Also, from a healthier choice outlook, W5 generally had very healthy meals - when she ate. She was the 40-year-old who did 90 minutes of vigorous exercise daily but ate too little before she exercised. That led to intense *sweet* cravings through the day due to her low BG that she often could not resist. Her good choices follow:

PI: "How do you take care of your diabetes, señora? What do you do? Do you take your medicine? [W5: Yes]

PI: And anything else? Do you do any special food, or ...

W5: ... salad, and juice, green juice.

PI: And you make it yourself?

W5: Yes. [Spanish] With Kale, ginger, other Spanish ingredients

RA1: She takes three [glasses] a day.

W5: Chicken, salmon ... Tortillas,

PI: And how many señora?

W5: One or two a day."

W2, who had just returned to DSM, had chosen to avoid greasy and other unhealthy foods as the new diet method she shared with her husband who cooked for them.

PI: “What are the things that help you take care of yourself?”

W2: Like taking the medicine, not eating a lot of grease, a lot of junk food ... before I was drinking a lot of soda, now drinking water or juice.

PI: So avoiding food that isn’t good for you.

W2: Yeah.”

Participants demonstrated various approaches to eating their preferred foods. In the case of W1 and W5, this meant eating candies and sweets often, generally in balance with healthy meals. W8, like the others, chose “a little bit” of her preferred foods as her primary mechanism for choice. Also, W2 tried to avoid unhealthy foods altogether.

Choosing role and family. True-to-form, W6 made an interesting contribution that illustrated how the role of mother, even to children in their 40’s, took priority over her own need for exercise. Moreover, despite her physical changes, she was not able to tell them she needed to exercise when they came home wanting something from her.

PI: “What gets in the way, what interferes with her doing what’s right?”

[RA1 translated]

W6: [Spanish] Hmm, well, like I said, I haven’t felt the strength. I say, I am going to do it [exercise], but it’s not the only thing that interferes.

Sometimes, I wake up early and somebody comes for lunch, then the other, and another, and, well, I don't go.

RA1: [Translated into English (fairly accurately)]

PI: So, others may interfere with her plans to take care of herself?

RA1: [Spanish] So maybe other people are not letting you, not as if they won't let you, but for example, you said there are people that just show up in your house.

W6: [Spanish] Yes, my kids, because they want to eat.

RA1: Her kids go eat at home - still. [PI: They what?]

W6: [Spanish] They want to be fed. [laughs] [PI: Oh, they come to eat at home. Okay.]

RA1: So, that sometimes interferes.

W6: Sometimes, it does. [nodding with a "well yeah" tone]

RA1: Sometimes, it interferes with your plans to go to Zumba, or take your medicine.

W6: No! Not with the medicine. It doesn't interfere at all with that.

PI: Mostly with the exercise ... And is this similar ... cultural ... in your culture, you can't say to the kids 'Oh sorry, I have to go to Zumba.' It's necessary as the mama to prepare the food and be there when they eat?

RA1: [Spanish] For example, is it part of the culture, is it easy for you, or is it difficult to say to your children ... well, the 40-something year old kids! ... [RA1 & PI laugh] Is it easy for you to tell them ... 'You know what

guys, see you later. I am going to my Zumba class' Or do you like to cook for them, be with them and watch them eat?

W6: [Spanish]Well, I like it, but they come over, and say 'Mommy, I am hungry' and what am I supposed to say? [RA1 translated]

PI: ... What [other] kinds of things or people affect how you decide what to do?' [To RA1 'You could ask her if she has anything to add to that']

RA1: [Spanish] For example, you were saying that when you don't feel well, and your kids come over to have breakfast, and you can't go to Zumba class. Do you think that, at that moment, it's affecting you that your kids show up at home to eat?

W6: No, no.

RA1: [Spanish] She doesn't think her kids affect the way she chooses for her diabetes. I was asking ... [interrupted]

W6: No, I say, 'poor kids, they are hungry' [laughs]."

She did not recognize that by not choosing her own needs over the wants and comfort of her children that they were actually interfering with her +DSM. She was undergoing some physical changes and had only recently started on insulin and was not feeling well.

Summary of preferences about diabetes self-management. As was reported earlier, in the past, W2 chose her young family for years, which was a more immediate and a culturally-responsible priority. At the time of the IV, without her children to care for, she was able to choose her own DSM and *shared caring* with her husband. The discussion on W3b's evolution to social independence demonstrated

how, when she fulfilled her role as mother in the past, she always chose her maternal role before self-care; thus she had often lacked balanced BGs. The same was true of W5 who had learned post-IV that she needed to eat differently before exercise and when she was hungry, busy driving her kids to various locations. Both had learned that their diabetes and DSM suffered when they chose their highly-valued maternal role over their health.

No matter the age of the children, those mother-participants who chose their children's needs consistently before their own diabetic needs had more difficulty with their BG. When the mother chose her diabetes needs, she reportedly felt and functioned better within the home.

Observing others. Learning from + DSM. Learning from -DSM. Thus far, it has been clear that each of these participants had social knowledge about diabetes, much of which had been gathered through their own observations of family, relatives, friends, and others who had inadequately, poorly, inconsistently, or ignored their DSM. Each participant was afraid of the possible outcomes for unmanaged BG and was *Being motivated* toward +DSM. However, several of them had positive models to observe, learn from, and by whom to be encouraged. Below are exemplars supporting what they had observed and learned from others who had either +DSM or -DSM. Some shared about both. These observations contributed to their decision-making about their own DSM.

Learning from +DSM. W3 commented about her family's contributions to her T2D practices at both IVs. W3a was the original interview; W3b was after she served as RA.

PI: “How do these other people take care of their diabetes? ... So how do those other people, your other family and friends, how do they take care of their diabetes?”

W3a: My mom is really doing that. She’s about 45 years being a diabetic and my uncle [his story is told in *Learning from -DSM* below]. My mother is really good on that.

PI: So, she kinda set the example.

W3a: She is really strong what not to eat.

PI: Wow, and how is she doing?

W3a: She’s doing good.

PI: ... about your mom. You said that what she does about her diabetes is she’s careful about what she eats. Is there anything else that your mom, or sister or uncles do about their diabetes?

W3a: My mom, she always on a regular basis takes a walk. About 30 minutes. My sister sometimes does the same as me, sometimes not because we have to work, both.

PI: How does what your mother, sisters, uncles do ‘affecta Usted’ affect what you do?

W3a: Oh, okay I want to do the same things that my mom does. I want to follow her taking good care of me. And my sister sometimes tells me what to do. We are the same. We are really good on food [helping each other].

W3b: My mom is really strong. She's strong about diet. She can see somebody eating cake and she will won't eat ..." [She added – remembering about her mother with diabetes] I remember myself in my childhood. I remember that we ate really good cake. 'Mom, I don't want to go in [leave the party] until they serve the cake' and they really was chicken but it was a jelly form of chicken with the eggs. Oh, it looks really [tempting/good] and they were doing home-made. Delicious. She said 'No. We *are leaving.*' Now I think that because of her diabetes. Right?"

The daughter of W1 had a 2-year history of diabetes. She purchased healthier types of foods than many college students bought and shared her ideas with her mother. W2 also learned from her mother with diabetes. At one point, they had lived together as adults and that was the first time W2 worked alongside another in mutual diabetes support, *sharing care*.

PI: "Alright. So [Name] have you learned anything else from people, like did your mom do anything to take care of her diabetes?"

W2: Yeah, she start with diet, a lot of diet, the way she used to cook, she changed her habit of cooking ... Yeah, she was using a lot of oil, she start using olive oil."

Similarly, W5 had family with diabetes and several of them took care of their disease. She too had learned from her family.

PI: "Now the two brothers who take care ... How do they take care? What do they do?"

W5: [Spanish] RA1: They exercise, and no candy or bread. [all laughs]

PI: When you see your mom cook good, does that help you?

W5: Yes.

PI: How does that help you?

W5: [Spanish] RA1: She observes what she's serving him [her dad], how much, and she does the same at her house... And then I give her ideas.

PI: So, you learned about the diet and the exercise from your mom and your brothers?

W5: Um hmm.

PI: Okay. And do you exercise also, senora?

W5: Yes. [She went on to describe her daily 90-minute intense workout.]

W10 found encouragement in observing friends, two from whom she had learned more specific ways to manage her BG. They served as a type of feedback guide about her own DSM.

PI: "... either your nieces or your two friends, the way they take care of their diabetes ... Do they take care of their diabetes?

W10: Um hmm. They do.

PI: They do, interesting. And I'm wondering if you've learned anything from watching them? ... And it can be a negative or a positive.

W10: From one of them their eating habits.

PI: And they are good eating habits?

W10: Um hmm. Good eating habits.

PI: And that sets an example for you or it encourages you or it teaches you? What's it do?

W10: It encourages me.

PI: ... Is anything they do, not just a good example that encourages you, but actually sort of shows you another way that is helpful, that you can adapt into your own life?

W10: Um hmm.

PI: What would be one example of that?

W10: Measuring the amounts.

PI: Ahhh, amounts of food. Okay. Like they may say 'I should only have a half a cup of this' and they actually measure it instead of saying 'oh this looks like it.'

W10: Um hmm

PI: So how does the way all 4 of these people – your two nieces and two friends – how does the way they take care - actually affect how you take care?

W10: It gives me a good feedback.

PI: Hmm. And does that mean like 'I know like they're doing x, and it's helping them, so when I do that I expect it's going to help. Is that what you mean by feedback?

W10: Yes. um hmm

PI: So, you're sort of literally seeing the benefits?

W10: Yes"

Learning from -DSM. W2 observed her husband's uncle succumb to alcohol problems that harmed his T2D. She indicated the problem was related to alcohol, but she learned an important lesson from observing him; she actually re-started diabetes care because of what she had witnessed.

PI: "So you've learned when you watched them and how they deal with their diabetes you learn from them - almost what not to do.

W2: Like my ex-husband's uncle, he used to run. One time we went to see him he was already in the wheelchair, how you say ... because he has ... I don't know something happened to his feet that he had to go to the hospital and then they cut his thumb.

PI: 'toe.'

W2: His toe, and then the rest of the feet, only from the knee to the bottom and then. They cut it, and then the last time I saw him, he had no leg.

PI: What did he do or not do with his diabetes that you learned from?

W2: He was drinking. He wasn't taking his medicine.

PI: Is that one of the reasons you went to the doctor so you could find out about getting more medicine again?

W2: Yeah ... yeah because the other day I had an ingrown nail - it cannot [did not] go away, so I said 'I don't want my finger to be cut off.'

PI: It seems like you also ... that the two of you [indicating her husband and W2] help each other, and ... it seems like, as you have watched the other people in your family you have that idea in your mind, that you don't want to do what they are doing.

W2': I don't want to be the way they were.

PI: So, you are *motivated* to be different.

W2: Yeah."

W6 had other people to observe, but she did not want to learn from them because she took better care of herself than they did of themselves. They were not good role-models.

PI: "But are there other people that you have known with diabetes who have taken care of their diabetes, done good like you are doing ... that helps you to do good too?"

W6: [Spanish] Like ... other people? [RA1: Yes, like someone you may know]

W6: I know people who have diabetes, but ...

RA1: [Spanish] But do they take care of themselves in a way that you say, 'oh I am going to do what Chabelita is doing?'

W6: [Spanish] No ... they don't take care of themselves.

RA1: No, the people she knows, they don't take care of their diabetes.

PI: Okay. So, you haven't really learned from other people how to do it?

W6: [Spanish] No. If I learn from other people as ...I ... better not!

RA1: If she starts learning from other people she's just gonna learn about things [that aren't good habits], so she'd rather not."

W3a: "... my uncle he just passed away. He was not taking really good care about himself." PI: "So diabetes is part of why he died? W3a: "Yes, he was 63 years old. Something like that." Unfortunately, one of W5's brothers denied he had diabetes, so he ignored his symptoms. W5: "And one brother, no. [Spanish]

Sometimes he shows up to 400, before breakfast.” RA1: “One, the one that doesn’t take care of himself sometimes he has it up to 400 while fasting.” She does not use him as a positive example as she does the others in her family (mother, father, two brothers) who do practice +DSM. W1 had seen several people with consequences from -DSM. Earlier recordings of two different sisters were offered above. This was her witness about a third sister who had denied she had diabetes and therefore never *Accepted* her DSM responsibility until this unfortunate situation:

PI: “... you were going to say something else about your sister ...

W1: 92 pounds - no teeth, pure bones...

PI: That's really scary

W1: And I told her ‘oh my God’ my daughter said, ‘Mom, relax,’ I said ‘ok.’ She won’t walk, she couldn’t even ... she was so weak on her legs, that it was just like rubber ...

PI: Oh my ...

W1: Really bad ... so she ended up going to the doctor, she started gaining a little bit with time, she said, ‘I’m gonna check my sugar now...’”

W7 observed her mother take fairly good care of her T2D and lived into her ninth decade of life. She had observed close family members and friends take care and not take care of their diabetes. The summary comment by the PI about W7 having observed her mother was, “And then, it sounds to me like what you learned from watching your mother is that it’s very important to take care of yourself so that you don’t have to have dialysis or something like that.” W7 exclaimed, “No. I don’t want to. Believe me, because I know what to end, is the end.” It has been previously

recorded that W9 watched her mother suffer many poor outcomes from not taking care of her T2D. She was the participant who practiced Fatalism of Enjoyment (see Context in this chapter), preferring to enjoy her short-term food pleasures rather than be concerned about the *battle* for long-term health knowing she was going to die anyway. W10 always had the awareness of the horrible outcome of her father's full failure to address DSM. She, too, was very *Motivated* for +DSM.

Summary of observing others. Several of the participants benefitted from their experience of watching others who practiced -DSM. Observing the negative behavior had *Motivated* W1, W3, W5, W7, W9, and W10. The negative experience of W2's husband's uncle was the actual prompt she needed to get back into diabetes care. W6 did not have good examples around her, so she ignored -DSM in order to practice +DSM. In all, observing others poor or absent DSM attempts and positively addressing DSM led to participants in the cohort having learned from what they observed; this benefitted their DSM.

Practicing one's habit: Planning ahead, Avoiding, Keeping regular care. For both men in the study, it made a difference when they got out of the habit of checking their BG every morning. Over a period of months, both of them had a salient increase in their A_{1c} and M1 had gained over 25 pounds, threatening his ability to stay off of medications for the first time in 10 years. M2 was advised by his "doctor" that he needed to take a second type of diabetes medicine because the original was no longer adequate. It was difficult to secure a clear answer from him about what his daily habits or routine were, but he clearly knew the components and did them with the exception of only checking his BG when he felt it was high.

M2: “Be active! ... Take your medications, they help you. Check yourself your sugar.

PI: And do you do that every day?

M2: I do it myself and I notice myself when my sugar level is up because I better watch! I better watch that because unfortunately we have so many bad habits [sweets] that can break you away from it.

M2: You know, once I came to see the doctor and my numbers was very bad ... was very bad! ... And I got kind of disappointed in myself. And 3 months later I told the doctor ‘I gotta take care of it.’ and I went back and the numbers changed so back ...” [He had regained control.]

Again, W6 likely had the clearest description of the importance of having and practicing her DSM habits. Since she developed T2D years ago, she had told the RA that she “kept on living as normal and started doing whatever the doctor asked” her to do about her T2D. She added diabetes to her life as a wife and mother. The PI inquired about her routine being an actual habit.

PI: “So is part of this a habit, like she said in the beginning a minute ago. You said, ‘I do what I’m supposed to do, I just do it!’ Is part of that a habit? She ... over 26 years she knows what to do so she does it. She’s in a routine every morning: she gets up, she doesn’t like to prick her finger; she pricks her finger; she takes her medicine; she eats her food. So, is some of that she has developed a good habit of just doing what she’s supposed to do? [Asking the RA to inquire in Spanish]

RA1: [Spanish] So, for example, you have, and correct me if I am wrong

W6: [Spanish] The habit.

RA1: The habit that if I have to do this, I'll do it. It's not about whether you want it or not. Like when you have to prick your finger every day, you could easily say, 'nah, I feel lazy ...'

W6: Yes. I don't want to, but it's a habit of what I have to do.

RA1: Um hum, so you are used to doing things that you know are *convenient* [Mexican use of the term meaning *better for long-term gain*] to you, even though you don't like them.

W6: Even if I don't like them. I have to do them.

RA1: So, yeah, she's just doing stuff she necessarily doesn't want to do but she knows that she has to do them. She has a strong sense of duty, I think. Is that ..."

W9 had been very consistent in her DSM except she had such *normal* BG for so long that she did not need to check those until just prior to the IV; she had started checking twice daily. "I think I *Accepted* it [T2D] quickly because I knew it was something that I can control by changing my habits, like the way I eat. And that's what I've done." W3 had to do a battle every day with her BG until she *Accepted* T2D and developed a routine way to take care of her disease. She had removed the *battle* from her home that had made her DSM habits easier.

PI: "Do you feel like you do a daily *battle* for yourself in your own home?"

W3b: If I'm at my house, no.

PI: Okay, so you just have your routine and

W3b: Right.

PI: It's not a battle day to day. Is that correct?

W3b: If I was working ... I used to be out of control ... If I'm at home, cooking my food ...

PI: But what I'm saying is you don't feel like you're battling to stay on track with diabetes every day?

W3b: No, because when I'm cooking for myself, when I have taken my pills ... when I go up hiking ..." [she hiked every morning in nearby hills]

W10 was a very organized and regimented woman who stayed active. She had a set schedule to keep her diabetes habits consistent. She managed her diabetes well. With a regular routine, it was easier for her to include each important aspect of her DSM.

PI: Do you have a routine or a habit every day? Are there certain things that you do in a certain order or that you do in your day that helps you with your diabetes? ...

W10: Yes, well I just really get up and we have a tablespoon of olive oil for our liver. And then chop half of garlic which we chop real well, but in order to get it through we put 1/2 cup of water with 1/2 cup of lemon and agave...

PI: Okay. And you do this every morning? Is this like a cleanser?

W10: Yes. We always do it, every day. Take us time, but ...

PI: And do you do this before you check your blood sugar?

W10: No. First I take the blood sugar, and after I start doing this.

PI: ... Okay so the first thing you get up, the second thing you check the blood sugar.

W10: Yeah. That's it ... Then I have my ... malt that I put oats that I have roasted previously, I put almonds, walnuts, raisins, cranberries and raspberries ... And then at 11:30 we have lunch ...

PI: So, that's your breakfast?

W10: That's breakfast ... It's about before 8:00.

PI: Okay, so 11:30 makes lots of sense that you would have lunch ... You don't have to tell me exactly what you have for lunch but what sort of things do you have?

W10: Soup, salad is basic for us ... and beans ... Very important. Every day beans. One way or the other.

PI: So, you go out and you do your exercise?

W10: I'm all day out. I leave home quarter to eight, and return around 5 or 6:00. That's when I ... and in between I'm busy at the Senior Center doing this or that classes, playing cards ... Then I come home and between 6:00 and 7:00 I have dinner. Usually soup. I love soup ... I always make our soup from scratch. And then salad. I eat a lot of salad. And some meat, not much. Fish, chicken those are my ... and pork."

While W2 had not yet developed a repertoire for her day because she did not have a glucometer, medications, and had not worked exercise into her schedule, she nevertheless understood the importance of having good eating habits for DSM. She reflected,

“... but you know, sometimes we are Mexican and we have to do some changes on the food - so I was. I really don't like the taste, like vegetables, but now I like it, because I can take care of myself, but before, no, I don't like it. You have to change your eating habit.”

Having a routine for their DSM habits made it easier for them to know at any point what their BG and helped with discipline of eating well, getting exercise, and keeping their “sugars” within a safe range. A common thread was *doing what they had to do*.

Planning ahead. When W3 was interviewed the second time after serving as RA, she shared her solution to a common but unhealthy practice by many people of “grabbing something fast” to eat and not tending to the diabetic diet. She had only healthy food choices at home for herself and her family, thus she had no significant temptations in her home. During the discussion about the *self-battle* and self-discipline, she contributed the following insights:

PI: “... Do you think the idea that's been presented to me ... that some people just don't want to do the personal *self-battle* of having to fight them self to be self-disciplined on a day to day basis? Your temptation is when you're at a party ... because you don't have your temptation at home.

W3b: No.

PI: But some people do and they're coming home from work and they think 'well I want some French fries,' so they drive through ...

W3b: You know [PI], it's because you don't have the food waiting. It's because when we are hungry we will eat whatever we have in front.

PI: That's an excellent suggestion.

W3b: It's because we don't ... when you're hungry - you'll eat whatever you have in hand. You don't want to come and cook and ... [PI: Oh, you hardly can, it's crazy]

W3b: Yes, because you already are hungry.

PI: Oh, yeah, sometimes you just *have* to eat something. So, the solution is people need food ready, so when they're hungry they will ...

W3b: They will have healthier choices.

PI: But if I could make just a quick comment to that about healthier choices - you can decide to ... choose that higher fat, higher calorie stuff, or drive through and get a chicken salad. So even if I don't have it ready at home I can still make the choice outside.

W3b: Right."

She made sure she always had the right foods at home and built part of her day around preparing healthy meals for family so there were always diabetes-appropriate foods for her and her family. In contrast, the struggle that W4 had at the IV (first visit) was that she did not always have the foods she should have or have them prepared. Resources were not the issue.

W4: "But sometimes, uh, [unintelligible] I don't have, I can buy, you know vegetables and all that ... I can eat, umm ... There is not a problem with that.

PI: Yeah, it doesn't sound like it.

W4: But, uh, I have to get disciplined in that, that's all because I am not ..."

The question about how she decided what to do about her diabetes and what kinds of things affected how she decided, how she chose what to do about her diabetes, and what things went into her decision, the PI acknowledged, "Part of it you said was your self-discipline. That sounded like it was especially hard when you're hungry. Is that true?"

W4: "[laughs]. Yeah, yeah. I forget everything [laughs].

PI: When it does matter, right? [W4: Uh huh]

PI: So you're not disciplined when you're hungry. [W4: Laughs]

W4: Yeah, yeah, there's a lot of lacking to discipline."

W5 indicated that she did not always have the right foods ready either. M2 had said above that he always had his medications with him; whenever he left the area he packed his meds first. W3b also talked about pre-evaluating a social setting so she knew what time she and her family should go to an event. She decided to leave the gathering before the cake came out because she had the most difficulty with her self-control at celebrations around the tasty foods and sweets. W3b: "So I used to go really late and coming back ..." PI: "Sooner, and leave before it was over." W3b: "Yes. Even before the cake!" She was one of the participants who described in detail the importance of the taste and smell of Mexican food. She had to avoid the temptation, so she avoided the cake [see Avoidance]. W7 also thought ahead about what foods would be available so she could better resist temptation and conflict; if she determined ahead of time what she would eat, she had better self-control.

Avoiding. W1 had developed a way of keeping herself busy so she avoided the common location snack-traps in the home. Because she was disabled from work, she was in her home most of the time.

PI: “Is there anything else to tell about your diabetes?”

W1: Well you want to stay away from the kitchen that is one thing, and TV, kitchen and TV, because once you are watching TV you're constantly eating snacks all the time. So, I stopped making piñatas, I do scrapbooking...I sew, I try to keep myself busy, because I don't want to be just laying down.

PI: So actually, that's another thing that helps you, it's your distractions, you give yourself things to do ... well, isn't it, activities, that distract, that keep you busy?

RA1: Hobbies

W1: You have to have hobbies, not just go walk, I do the walking, but...

In additions to planning ahead for situations that caused her to lose self-control of her eating practices, W3 had developed a way to avoid her biggest temptation.

W3b: “And then coming maybe 2 hours, I'm not staying longer ... because we have also that kind of characteristic - Mexican or Latin people they go 3:00 - 10:00 [p.m.] and I don't like that at all ... So, I used to go really late and coming back ...

PI: Sooner, and leave before it was over.

W3b: Yes. Even before the cake!

PI: It helps you to avoid?

W3b: Yes, and I'm not having the difficulty for sweets.

PI: You really have to *battle* to avoid them?

W3b: Uh huh! For really good dessert, you know you see a kind of cookie ... if they cook it, they bake, it's homemade, it's when I have a lot of trouble.

PI: Resisting. So, your self-control is really primarily avoiding?

W3b: Right

PI: Okay, and it works for you because you're able to exert the self-control before the food is there. But once it's there, it's harder?

W3b: Right. Because I think I'm kind of anxious myself, I need to be active ...

PI: Okay. That's very helpful. So ... were you going to say anything about yourself in terms of the *battle*?

W3b: No, that my *battle* is the sweets."

She summarized saying "... the food that they sometimes having I can't eat that, so I cannot afford to go to all the celebrations," she simply avoids many of them. Earlier it was recorded that M2's family was very careful about what they brought to the home or had around him. They participated in helping, or causing him to avoid sweets, even on special occasions.

PI: "So what are the other things that motivate you to take care of yourself?

You said that one thing is your sons inspire you. And does that mean you want to be here and be healthy for them?

M2: Yeah and they want me to be healthy also. Because when it comes to a birthday, they don't want me to have a piece of cake whatsoever! 'No, dad! You're not eating that!'

PI: So, they watch out for you.

M2: Yeah, they bring me those cakes with no sugar at all."

W4 had similar family experiences when they restricted some foods it helped her to avoid or reduce the amount and frequency of eating what she should not.

PI: "What type, what things or people affect you in the way you make your decisions about how to take care of your diabetes?"

RA1: Could we use like a sample answer? [Spanish] ... like other people have said like their husband doesn't like the way she cooks or they're having a lot of parties and she eats whatever's there, or children or their job, those things affect how they take care of their diabetes.

W4: No.

PI: How does what they say help you? How does what they say, 'oh, no, no mom' don't eat that?'

W4: Well, they don't allow me because I want it but, ok I don't eat it.

PI: Once again it's the discipline that kind of reminds you. Right?

W4: You're right, yes, because I want it, but I want a little piece.

PI: So it helps you."

These were four examples of how participants avoided eating sweets or snacks that were problematic for their BG. There were other participants whose families were helpful; some of those are in exemplars in other chapter segments.

Choosing to keep regular health care and laboratory test appointments.

In Intervening conditions, the consistency of the participants in attending health care visits and having gone to the laboratory for quarterly A_{1c} testing was documented. Because these are actions the participants took, based on their decisions to do so, these acts, including SMBG levels, are an important aspect of how they made decisions and practiced DSM.

Summary of practicing one's habit. Having the right foods on hand at home was important to self-control, especially when a participant was hungry. Planning ahead for social events, either the timing of when cakes and desserts were brought out, what hours to attend, or planning on what one would eat or not eat prior to an event also helped with better self-control. Staying out of the kitchen and off of the television, having hobbies to occupy one's time were helpful ways to avoid snacks. Going for routine HC visits and lab testing provided a level of accountability.

The influence of stress on decision-making. More than one-half of the participants reported that they did not have stress in their lives at the time of the IVs; however, they had experienced it earlier in life when working and raising a family. The following two excerpts address the effect of stress on their diabetes decision-making.

PI: "I'm wondering how stress influences or affects how you make decisions about diabetes?"

W9: Stress affects your diabetes.

PI: Yeah. How does it affect how you make decisions?

W9: I think it does affect everybody when you're under stress and to make a decision.

PI: Yes, so how does it affect just making decisions about diabetes? Does stress affect or influence how you make your decisions about diabetes?

W9: I think it does.

PI: And how does it affect you in how you make your decisions?

W9: It's hard ... How does it affect my decision? We might do the wrong thing.

PI: ... Okay, a quick example might be, like you might eat more? You might be stressed ...

W9: Probably the exercise, cause when you're under stress you just don't want to do anything ... I think it affects overall in everything. Even relationships are work."

Initially, W6 said she did not have stress in her life, but she did admit that she preferred not to make decisions about her diabetes when stressed because she was not clear-minded. She had an effective approach to decision-making when stressed, however infrequent that might have been.

PI: "Okay. How you make your decisions?

W6: [Spanish] How I make my decisions? I think about what I am going to do. If this is convenient ...

PI: The stress doesn't affect how she makes them?

RA1: “So, then, being stressed when you have to make a decision, does it affects you? Or you say, no. Or only when you are calmed can you make decisions?”

W6: [Spanish] No, it doesn’t affect me. I think things first, because if I get stressed, I can’t think.

RA1: She can’t think straight when she’s stressed. So, she calms down. So, she doesn’t ... She avoids *deciding* when she’s stressed.

PI: Oh, I see. So usually when you feel stress, you say ‘I’m not going to decide now?’

W6: Um hmm.

PI: Alright. Do you have that often with diabetes? Stress and you have to decide about your diabetes and you have stress. Is frequent? Do you have that frequently Señora?

W6: [Spanish] Frequent stress? [RA1: Spanish. Um hmm]

PI: When you have to *decide*.

RA1: [Spanish] When you have to decide something about your diabetes?

W6: No. [Spanish] Well, I have to decide what I am going to do.

RA1: She has to do what she has to do. [all laugh]

W6: Of course! [all laugh] what else am I going to do?

RA1: You’ve got to do, what you’ve got to do!

W6: [Spanish] If I have to do it, I have to do it.”

W6 did not make decisions when she had infrequent stress because she lacked clarity and W9 believed stress impacted her diabetes and decision-making.

Previously, W3 and W7 asserted how stress consistently increased their BGs; both indicated it affected their decision-making as well. The latter's BG and A_{1c} had been slowly climbing in the environment of her stress and worry. When asked how W2 planned to make decisions about her diabetes in the future, she spoke to the stress as an important factor. W2: "Decisions for good, to be better with your health and to, not to get a lot of stress, you don't have to have a lot of stress, if you don't have to care of yourself." PI: "You don't have to have stress, if you take care of yourself you won't be stressed." W2 nodded. Stress was noted to have an effect on participant's decision-making and their diabetes in general; it was attributed as a cause of T2D.

The influence of faith and being positive on decision-making. When dealing with her stress (see above), W7 turned to God and asked for help for what she needed. "And I say 'oh God, give me the strength.' You know but I try to change my life. I have to because I tell you like 2 weeks ago I say 'no, that's it.' I have to change more like try to rest and I don't know why I can't sleep late, and I have to [get more sleep]." With less control of her BG she knew she had to make different decisions about how she handled her stress and she needed God's intervention to do that. In the previous section on *Context – Influence of Faith in God and Intervening Conditions – Spiritual beliefs*, the idea of Wishful Thinking had been presented; not that God would not answer prayer, but that her wishing-in-prayer might have interfered with full *Acceptance* (see *Accepting diabetes* above). She hoped that her diabetes would go away or her symptoms would be reduced or that she would need less medication. Her faith and relationship to God were genuine and open. Her faith

helped her day-to-day, especially in light of the daily unresolved grief she had at the loss of her older son a decade prior.

When W4 had health issues, she asked for God's healing and saw the result. At the 1-year follow-up visit when she showed remarkable improvement in her DSM through the new HCP, she commented on God having answered her prayers to help her get well. She was seeing significant improvement and was very hopeful it would continue. From a unique perspective, M2 talked about faith being a force that gave him the ability to have positive thinking that was helping to heal his diabetes. His focus was more on faith and thinking positively than on the intervention of God.

PI: "... And then some people also say that they feel like God will heal them, particularly if they pray about it, and so I'm wondering what your thoughts are on that.

M2: My thoughts on that is that, what has been helping me a lot is faith.

PI: Okay, so faith has played an important role?

M2: Faith is playing my role and I believe faith is really controlling mind wise to think positive in a lot of things.

PI: ... So to helps [you] think positive ...

M2: But the faith is what always keep me sharp. Of course, medications I take, it's what's been healing me.

PI: Yes ... You're not excluding the medicines. [M2: 'Oh no, no']

PI: But you're saying that an important part of how you manage your diabetes is maintaining your faith and I think I also heard you say that ...

RA4: Being positive?

PI: Yes, that's what I was going to say. It sort of teaches, helps you to be positive?

M2: Exactly."

Finally, when asked if there were things besides her sister that helped her with her diabetes, W10 warmly replied, "Well, I would say praying." Whether faith in God or faith as an empowering force, better decisions were made for some participants.

W3 elucidated the ongoing contradiction she saw/sees culturally in which the Mexican person with diabetes did not/does not take responsibility for their part of DSM but rather hopes and prays that God will heal them or magically make the calories disappear. She illustrated how a person goes to a lot of celebrations and forgets about diet, somehow hoping God would magically take care of the problem of having diabetes. Instead of continuing to have personal responsibility, she said the person with diabetes "leaves everything to God" but lacked cooperation with God (e.g., not doing his or her part in the *battle*).

PI: "There's really an underlying confidence that God's involved in every day, right?

W3b: Um hmm ... sometimes there are things that need to be done in order for God to act ... it's not magic.

PI: That's a very good point. Not magic! But what you're sort of saying is that some people kind of treat it like it is? [W3b: Right]

PI: [Recounted the extended explanation about God and faith by W10 that she attended as RA – See *Context – Influence of faith*] ... she said

'eventually if they feel like He doesn't answer then they just accept His will that for some unknown reason, He's chosen not to heal them of their diabetes. And they accept that.' But some of these other people are not as accepting, that God's not changing things.

W3b: Right. [W3b explained her observation of the two-sided contradiction of many Mexican people with diabetes.] We ... have reunions and to have good food, so on one side you're asking God [to heal or change one's health status], but on the other side you're ... It's we don't take care the way that we supposed to take care of it [T2D]. *We leave everything to God sometimes.*

PI: Oh my, okay.

W3b: So, what - God is on one side, and the other side ... But ... *you forget about the diet*, because you [think] 'oh, on Sunday will be somebody's birthday,' so you cook and you have everything, cake and jelly and ... [PI: Bread!]

W3b: ... a lot of food. So, God is on one side but on the other side we are not being really cooperating [with god by doing our part]."

For some participants, faith in God or faith that empowered had a role in their DSM through simple prayer and trust. For others, they hoped for God to rectify what they wanted. W3b expressed her ongoing concern that there was an enduring and culturally-embedded issue within the Mexican community of people with diabetes. She was troubled that some in the culture did not take responsibility for their part of DSM and hoped magically that God would intervene and take care of it,

heal it or keep their BG low after having attended a social gathering where a lot of food and sweets were served.

Summary to Interactions, Actions and Decision-Making

Participants traversed through various stages in their journey toward DSM. The *Pre-Discovering* phase was between the time they first had symptoms and the time of *Discovering* they had diabetes – demonstrated in Intervening Conditions. *Discovering* diabetes occurred in four different fashions: during pregnancy (half of the women), rapidly (one), gradually (five plus the one who had misdiagnosed T2D prior to pregnancy), and through laboratory testing (one after a routine blood test, and one after feeling ill with thought-to-be non-diabetic symptoms). Although all but two had a family history of diabetes, even those with a strong family history were sometimes surprised at their diagnoses. Only one had a high suspicion level and went quickly to her physician. The overall delay in seeking HC to identify the cause of their symptoms prompted exploration. The reaction to *Discovering* their diagnosis fell into the five categories with some participants having more than one reaction. These included fear, sadness, shock or disbelief, a sense of injustice, and feeling sick. Those who had a low suspicion of risk were more surprised or felt more injustice. Once the discovery was made, participants either responded to the need for DSM by getting started right away –about three-quarters of the participants – or delayed onset of medication. This specifically involved two interviewees.

Acceptance of the personal diagnosis of diabetes was found to be a critical factor in developing positive DSM habits. Two participants delayed *Accepting* their diagnosis; one of those was protracted. The majority quickly *Accepted* their illness;

there was question about the delay of full *Acceptance* by one. There were features that both interfered with and promoted *Accepting* diabetes. Strong cultural influences interfered: *denying, pretending, playing dumb, ignoring, being oblivious*, the threat to change of lifestyles, and not taking the diagnosis seriously. The features that promoted *Acceptance* of the diagnosis were being acutely aware of the experience of others (with poor outcomes), *Being motivated* for health, feeling and behaving better on medications, the influence of faith on *Accepting* diabetes, and the resulting effect of faith on *Accepting* the responsibility for DSM.

Once *Acceptance* was established, at least in part, various components of decision-making about DSM were evidenced. Again, the profoundly potent socio-cultural influences mentioned above and *hiding* diabetes played important roles; *wishful thinking* was also observed. The dominance of the importance of *Being proper* and the struggle to learn to say “no” became evident. The influence of *machismo* was noted to have an important impact on decision-making in some men. It became clear that those who kept the long-term perspective about diabetes, on a daily basis by remembering the outcomes of uncontrolled T2D, made *Being in the battle* daily easier to struggle through DSM. *Social independence* from the socio-cultural influences contributed to being successful in keeping the long-term view. Four participants expressed concern about lack of resources in the larger population and two experienced food scarcity in childhood; one severely. This impacted the decision-making of those two participants. It became clear that the need for +DSM was an all day, every day *battle* between food temptations, dietary limitations, strong cultural taste temptations; family responsibilities and roles; and

strong, embedded cultural norms and expectations. These were the forces that propelled and inhibited the participants to make decisions about their DSM.

How they made their decisions was primarily done through various forms of *Negotiating*. They were *Negotiating* with themselves, rationalizing, and choosing to eat *a little bit* of what was offered, even if they did not want it or knew it would raise their BG; it was important not to offend the one who prepared and offered. Taste, smell, and social connections were involved; the use of extra medication was a means of *Negotiation* for some. Others made their decisions through their preference – personal choice or their role and needs of their family as the lens through which they chose. Observing others was important for all of them since they had all witnessed the results of -DSM. Some learned from observing +DSM behaviors actions and attitudes, some learned from observing -DSM. Developing and practicing a habit of DSM through planning ahead or avoidance contributed to the way some made their decisions. Stress was found to have an influence on decision-making and faith had an impact for some. These findings support the over-all substantive theory.

The final segment of this chapter will address the consequences of the decisions made by this participant cohort. Particular attention will be paid to the outcome of various levels of *Mastery of/Mastering* diabetes through DSM.

Consequences of How They Addressed DSM

Since the general goal of DSM expressed by these participants was to avoid the dangerous potential consequences of the disease as long as possible, each was attempting some degree of +DSM. This included W2 who restarted care two weeks prior to the IV and was *sharing care* with her husband. As demonstrated, there were many dynamics, conditions, and factors that influenced the participants' decision-making. The ever-powerful sociocultural influences had particularly strong impact, often offering fierce challenges to and interference with long-term goals for BG control. *Accepting* the diagnosis and responsibility for DSM and T2D outcomes played an important role in T2D decision-making; the sooner *Acceptance* was reached, the more resolve they had to focus on the goal and the more effective was their DSM. Participants were then equipped for *Being in the battle* between social expectations, personal dietary enjoyment, and trying to balance these with the necessity of long-term control; the battle was all-day, every day. Each one of them had various creative ways of *Negotiating* socio-cultural and personal dynamics against long-term needs. Ultimately, those participants who navigated consistently through the cultural maze and resisted temptation most often actually reached a balanced posture of *Mastering* DSM.

The Substantive Theory

*Negotiating every-day diabetes self-management decisions
about conflicts between culture, personal enjoyment, and long-term outcomes
toward mastery of type 2 diabetes by Mexican-born adults.*

Socio-Cultural Influences

Throughout this investigation, the prevalence and potency of socio-cultural influences were obvious. The cultural influences were the most salient for decision-making in this cohort of Mexican-born immigrants with T2D living in the United States. The dynamics that had the most impact were *Being proper* and feeling compelled to eat *a little bit* at each of the many social gatherings that everyone in the culture was expected to attend. They were ever-mindful of their social duty to respect the hostess by eating the food she had prepared. As they felt obligated to comply with cultural expectations, they often over consumed food and beverages they should not have had; this increased their BG in the short-term, although it did satisfy cultural requisites and their desire for aromatic, tasty food. But, they understood that in the long-term they were at a higher risk of the unhealthy results linked with frequently elevated B. Ultimately, the risk was that socio-cultural priorities often took precedence over DSM needs and one's long-term goals.

Being proper; and eating a little bit. Earlier in this chapter, evidence demonstrated the quintessential importance of *Being proper*. Being both respectful and polite were shown to be principal cultural expectations of *Being proper*. Showing respect was *being socially proper*; it was critical when it came to eating food prepared by another. RA1 translated for W6 that "*Being proper ... is to have good manners.*" One was expected to *be proper* "so as not to offend." W6 admitted that she often had to have *a little bit* to show respect. She also said that sometimes she *could* say "no" when in the United States; however, she *could not* say "no" in Mexico. When she visited her cancer-stricken sister for an extended time, her A1c

went from 7.6 to 8.9. They dined out eating tasty, authentic Mexican food whenever her sister wanted; she could not say “no” to her ill sister. She knew why her BG was elevated and *Accepted* it would be higher “I accept my sugar is high.” Eating to *be proper* had negative consequences for her short- and long-term. Both W8 and M2 described the importance of *Being proper* when the other person was less well known to them. There was some reduction in social pressure when they were more familiar with the hostess, leading to fewer social etiquette restrictions. Also, if the hostess knew of their diabetic status, there was less expectation to follow social norms; however, due to the social stigma of diabetes, they did not readily disclose their diagnosis. As reported earlier, they worried about the long-term BG risks.

Negotiating Being proper. Participants had to find creative ways to *Negotiate* eating foods that they were either tempted to eat or were socially-obligated to eat in order to *Be proper*. If they did not negotiate, their BG would have remained high from eating excessively or eating inappropriate foods. Eating *a little bit* was a primary mechanism of *Negotiating*: drinking water and exercising were key as well. In whatever manner, they were *Negotiating* that they were aware that their “sugar” would “go up” following a social gathering. M2 responded to the PI’s clarification of what he described as his absolute obligation at a festivity hosted by another. In *Interactions – How they made – Negotiating with one’s self*, the PI inquired about how he might negotiate control of his BG after having several tastes of *a little bit* at a social event. He strongly agreed he would negotiate his BG control.

M2: Yeah, well first of all, drink a lot of water. And take a walk ... To bring the sugar down ... I may not [eat] the big amounts of food.

PI: So, you're going to eat small ...

M2: Yeah ... When I have break into some sugar or tamales, I do what I have to do to bring the sugar down. 'Cause I don't want the sugar to stay in me."

W8 commonly took both food and drink at gatherings because she did not want to offend anyone; not being different was of high value to her. She noted that when she ate foods at gatherings or drank just *a little* beer, her BG went up. She was an unfortunate example of how her drive for *Being proper* led to elevated BG.

W8: I take one drink and I say, I don't take another one because I feel [gesturing that she feels dizzy with the drink] ... And when I take beer - I don't like beer, but sometimes I want to - somebody told me, 'drink a beer' and... [they told her] 'I take one beer and nothing happen.'

PI: ... This is what I understood, is that when you have one or two drinks of alcohol ... you sometimes feel a little funny in your head but your sugar doesn't go up too much.

W8: No, no, no, they [the BG] ... It's the other way around.

RA2: Uhuh, what she is trying to say is that she feels that when she does drink either one or two beers ... She feels, 'Hey, I know this is wrong for me...' [PI: Yes] But I am still going to take it, and then she does the blood test and she knows she is coming to the doctor ... [W8 Uhuhm] ... She drinks one zip [sip]; the blood sugar is like, all over the place.

PI: So, the beer in particular does increase the blood sugar, even though the people told you 'no!'

RA2: Uhuhm, and the food is more damaging ... Yeah, she just feels that, you know, maybe the portions that she is eating ... it's more than ... [W8: Yes] Cause, if it's one zip [sip] of beer ... Her blood sugar will go high."

W10 had said earlier that *Being proper* could sometimes interfere with her decision-making. Typically, she practiced +DSM intentionally, but in some settings, she too felt the need to show respect to the hostess which impeded her BG control. M1 also indicated that he struggled with *Being proper* with his own family. He had to learn to tell his wife and mother that he would not eat the food they prepared unless they made healthier meals for his diabetes, cardiac issues, and weight. Once he gaining the courage to "put my [his] foot down," he had much better BG control.

Frequent social gatherings. Frequent collective events were difficult to avoid in this very social, community-oriented culture that congregated regularly around tasty and desirous Mexican food with tastes, smells, and colors that were difficult to decline or avoid. Everyone was expected to attend all of the eating functions. To not attend was considered to be improper and socially rude to the hostess who had invited the person or family; it caused social conflict. That was why W3b's aunt was annoyed at W3 and expressed her hurt through W3's mother. The aunt was offended that W3b's family was not attending many of the family celebrations; when they did attend, it was for a limited time and they left before the cake was brought out. W3b knew her *Battle* was with sweets at gatherings, so she limited the frequency and length of time they attended. She had safeguarded her home and avoided the struggle when in public settings. PI: "Your temptation is when you're at a party ... because you don't have your temptation at home?" W3b: "No. ...

And in my case, I'm really good how you say ... sweet?" PI: "Sweet tooth?" W3b: "Sweet tooth." In the past, she had decided to accept the long-term consequences of T2D as a result of her poor self-control at the many celebrations they attended. She struggled with her BG and her conscience was troubled "when I used to go having celebrations I was dealing with myself: 'okay, I already eat the cake and the jelly, and I'll have an extra 1/2 of the pill, just to prevent that I not ... [have high BG]." PI: "and I see that as a *Negotiation*; that's when somebody is *Negotiating*." [W3b nodding].

Consequences of *pretending, ignoring, denying, being negligent and hiding*. In earlier sections of this chapter, it was established that the participants believed there was a cultural tendency to *pretend*: "we were raised with it ... it's in the culture to pretend" (M2; confirmed by W3b, W6 - W10). The two most salient consequences of *pretending, hiding, ignoring, and denying* were delayed diagnosis and poor diabetes choices in social settings. First, these reportedly common, cultural responses delayed identification of the diagnosis of T2D. As demonstrated in the section *Decision-making*, most participants had symptoms for a period before they sought out a HCP to identify the cause. These cultural behaviors interfered with seeking care that delayed management of their T2D. In the case of W3b and the sisters of W1, medications should have been started sooner, but their denying and ignoring impeded a clear diagnosis and effective treatment. Secondly, the tendency to *pretend* that they did not have T2D led to compromised decision-making when *hiding* their diagnosis in social and work settings. As T2D was (is) a stigmatized disease, they reported they did not want to be identified as unhealthy or different in social settings. In conjunction with their efforts toward *being proper*, they ate foods

and drank beverages that were not healthy or proportionate to what they knew they should have consumed, even only *a little bit*, as it caused BG excursions.

In the DE class of which W6 said that she had *played dumb* by *pretending* that she did not already know the information that was being taught, she indicated she did not learn anything new because she “already knew everything” and dutifully practiced DSM. The risk of *playing dumb* was that she might *be ignoring* helpful class information. She implied she had not learned new, clarifying information or insights into how to adjust her DSM as she only had recently started using insulin. Her culturally-entrenched habit of *pretending* via *playing dumb*, as she called it, might not have profited her progressive diabetic condition. Her more advanced disease status was the reason her physician sent her to DE classes; he intended that she might learn new ways to approach her new diabetes-related situation.

“People want to do what they want when they want,” said W7. Several participants avoided attending to a symptom or the disease as a whole [see *Interactions - Discovering and Accepting diabetes*]. When they were *ignoring* or *setting aside* their symptoms, it increased their risk for less-well-controlled BG. The highest risk was *ignoring* the need for long-term protection from elevated BG that they were afraid would lead to permanent organ damage (Zoungas et al., 2017) as they had seen happen to others. They each said they knew that organ damage would occur in those who did not control their BG over time; they knew people for whom that was true. So, each time they *pretended*, *ignored*, or *denied* a symptom or rationalized “just this once,” “I almost never do this,” or repeated the cultural mantra “it won’t hurt,”. They knew they increased the potential for long-term

consequences. An example was W10's idea that she could "brain-wash myself to believe something." She believed she would be able to think away or wish away any need for exogenous insulin use in her future "I resolve to never do it!" Ironically, she feared the loss of BG control that he had and she lamented his refusal to do what he needed to do to prevent poor outcomes; yet she was willing to do the same by *denying* the need for insulin and *pretending* she would never need it.

The cultural value that "everyone is the same" (W3b, W7, W9), that they "want to be like everyone else," (W9) was a significant challenge for most participants since they did not want to stand out as different. Only W1 and W9 were not concerned about this cultural pressure; both spent a few years of their childhood in the American individualistic culture. Both expressed that they were not concerned about what others thought and that they did not *hide* their diabetes from others; many knew of their T2D. W9 was the participant respected for making wise diabetes choices. On the other hand, prior to leaving W1's home, the PI noted the smell of cigarette smoke in her bathroom. There was not an opportunity to inquire about her smoking, It is unknown if there is an association with *denying* or *pretending*. All of the others indicated that they *pretended, ignored, hid, put aside, or denied* their diabetes in social settings and only disclosed to those whom they trusted. W8 shared, [Spanish] "Well, depends on the person, if it's someone you trust, you tell them, 'I don't want any, no thank you' right? Or if it's someone they know you are sick, they'll know that it's bad for you or something like that, right?" [translated by RA2]. M2 shared from a Mexican man's point of view.

M2: “When I have the seizure at my work, they were making fun of me. One of the guys - and I was ‘man, this guy’s’ which was very ... I didn’t pay attention to it, you know, because that’s the way it is. It’s what you deal with [in a man’s workplace]. You never know basically ...

PI: And that person you never trust.

M2: Exactly ... so, you never discuss problems with.”

Social Independence. *Social independence* refers to being free to make choices about what is best for one’s self instead of what the culture and community expects. As documented in *Interactions – Response to Discovery*, in general, those participants who were culturally more comfortable resisting persistent cultural expectations and more able to place their long-term diabetes needs above meeting social demands had better on-going success of DSM (W1, W3b, W9, W10). The participant who chose +DSM for herself knew that when done consistently could lead to long term benefits of BG control that they all expressed they desired (Palta et al., 2017). That was the goal of W1. She first demonstrated *social independence* in her approach to T2D. She refused to allow anyone to dissuade how she approached her DSM; nor did she care how they responded in social settings. She was the participant reporting that, if she was offered food but it is not the right time to eat, she would politely decline.

The experience W9 shared was intriguing. Due to her fear of what befell her mother, she made choices socially to not *pretend* or *hide*, “I don’t do that,” promoting her long-term goal to avoid poor outcomes. She denied getting “flak” from others about taking a firm stand and said with satisfaction that once people knew that she

would stand her ground and not eat the food or drink the alcohol that was pushed on her, they eventually left her alone, “and I think they learn that I’m not gonna do it, and they stop doing it. ‘... She’s not gonna do it.’”

PI: They get it after a while ... So even though there’s this worry for other people than yourself about being different, the reality is that culturally people will eventually accept you anyway, even if ... so, people are uncomfortable being different, but it’s not always because people don’t accept them. Is that, right?

W9: That’s right. No.”

She also shared that others had noticed that she was careful about what she ate and respected her for standing her ground. “Actually, they have mentioned that I have it [T2D] under control, that it’s good, that they really don’t see very - too many people the way ... [she managed her T2D]. I mean I tell them and I check what I eat, so they know more or less. They admire me for that.”

An interesting consequence of her *social independence* was that when she stood her ground, no matter the degree of pressure or social expectations applied, others eventually understood. Even though her culture taught her that she would not be accepted if she was different, that had not been her experience. Culturally, she had been accepted anyway. She had maintained an A_{1c} below 7% for 10 years. She attributed the stress of worry about what could happen to her – as it did to her mother - if her BG increased, as the cause of the recent A_{1c} increase to 7.2% with no changes in her DSM. Her consistent *social independence* resulted in both +DSM and being respected within her cultural group.

In contrast, W6 had *social independence* traits and generally practiced +DSM with two notable exceptions; *Being proper* and her role as mother [see Role below]. She introduced the essential concept of *Being proper*. She practiced *Being proper*, meaning she often had *a little bit* in social settings, more in Mexico than the United States, but was careful to *be proper* and “not to offend.” Due to having *a little bit* fairly often, at times, she ate excess sweets or too much food, although she ate only small portions because she “fill up fast.” She had had diabetes for over 26 years; as a result of her excursions and the natural advancement of the disease, over the months prior to the IV, she had lost most pancreatic function and her BG/A_{1c} had worsened. Thus, she was started on insulin injections. W3 had recently developed a sense of *social independence* when she found a level of personal *permission* to care for her diabetes in the midst of her role as mother.

PI: “You’re socially independent. You are taking care of yourself.

W3b: Yes, but I’m starting just recently, maybe 3 to 5 months ago, but before I was kind of reluctant.

PI: What’s required for a woman to be socially independent, to do what she wants to do whether others understand or not, for her to take care of her diabetes? What changed in you ...?

W3b: For my family. I want to take care of my children.

PI: Okay, so you realized ‘if I don’t take care of myself I’m not gonna be here, so I have to take care of myself so I can ...’

W3b: Right.”

In contrast, W8 did not demonstrate *social independence* and preferred to blend in with other women in her culture. Generally, she had good BG control and practiced consistent +DSM. The risk she took was twofold. First, as reported above, any amount of beer caused a BG excursion. She attended frequent gatherings and did not decline food or beverage unless W8 knew the hostess well and felt safe with her knowing W8's T2D status. Thus, she frequently had BG excursions that she knew were not good for her BG control; she accepted her BG went up so that she "had no troubles with anybody".

Summary of socio-cultural influences on addressing DSM. While multiple social factors were at play, the all-important requisite of *Being proper* in social settings and therefore having to eat *a little bit* of what the hostess prepared were demonstrated to be cultural expectations and practices. Showing respect for the hostess, "so as not to offend" was required social behavior. These expressions of etiquette interfered with both men and women being able to set personal limits on the types and amounts of foods that they ate at social gatherings; it was particularly difficult for men as they were required to always "at least taste" (M1). For those who had developed adequate *social independence*, it was easier to make safer BG choices; it was possible to be respected for one to make wise personal DSM choices. When M1 developed *social independence*, he was able to "put my [his] foot down" by refusing to eat unhealthy food; his family changed their cooking methods and the types of foods they prepared.

Since the participants' community-oriented culture was highly social with frequent gatherings and celebrations, they were expected to attend. As T2D had a

social strong stigma attached to it, it was common for the participants to *hide* the diagnosis unless the hostess or others already knew about it; this was less common. '*Pretending*' was ingrained in the culture, therefore to *ignore*, '*put aside*,' and *deny* the presence of diabetes was a common practice. *Pretending, ignoring, or denying* their diabetes in social settings led them to practice social etiquette; this meant they ate too much and the wrong things too often. This had a negative effect on their DSM and interfered regularly with their long-term goals of maintaining stable BG control to prevent unwanted organ consequences; BG excursions contributed to long-term accumulated damage even when not notable on A_{1c}. However, those participants who had developed social independence were more consistently able to decline foods they should not eat. This benefited them and helped toward their long-term goals of positive DSM.

Roles. The unique cultural role distinctions between the Mexican male and female participants were evident in this study. *Machismo* had both positive and negative effects on the male participants, but the negative influences were more common. The *machismo* effect influenced men to *hide* their diabetes more than women. It also contributed to some men misusing alcohol and led to poor outcomes. Women on the other hand required *permission* at various levels and from various sources in order to adequately tend to their DSM. There were positive and negative aspects of the maternal role as well.

Machismo. The influence of *machismo* often led to -DSM results if "there is a lot of machismo in there," as M2 asserted about the attitude of some men. For the father of W10, it resulted in terrible outcomes. Alternatively, when not in excess, as

was the case with M1 and M2, it did not interfere significantly with their DSM; in fact, it was a helpful component because it gave them the courage to stop alcohol use. Either way, because the underlying cultural expectation was that the man should be “strong,” as W3 explained, “Instead of show weakness, they are acting more macho ... because they don’t want to ...” PI: “So they may act macho basically, to cover up?” W3b: “Right.” PI: “To cover up their vulnerability?” W3: “Right.”

Positive DSM outcomes of machismo. Both of the male participants stopped using alcohol as soon as they were diagnosed with T2D, benefitting them both. One of the first things they did when they learned they had diabetes was to stop drinking. Both had seen the poor effects of excess alcohol on male relatives who had diabetes and had not stopped drinking. They were aware that alcohol worsened one’s diabetic state (Monterrosa, Haffner, Stern, & Hazuda, 1995; PAHO, 2012; Pérez-Escamilla & Putnik, 2007). M1 spoke of this twice in his IV, “Yeah, I stopped drinking right away. I still did the drugs, but not more alcohol.” Prior to his diagnosis, M2’s drinking was fairly heavy and he developed seizures, thought to be partly alcohol-induced. At least two events were attributed to alcohol; one caused a coma as confirmed by his wife. Referring to his *Discovering* of T2D, the PI asked, “Were you drinking at the time?” M2: “Yeah, I think so ... yeah [said a bit sheepishly, avoiding eye contact with his wife at the other end of the table]. Due to his inner *machismo*, when he wanted to stop drinking, he applied his macho willpower to illustrate that he could stop drinking without assistance from anyone else. He proudly shared how his *machismo* had helped him. “You know, when I find out about it [T2D], I stopped drinking completely ... I stopped. It was no more [used his

hand to indicate a complete stop]. I don't need any help for that, *'I'm just going to make a man and stop drinking!'*" Both of the men's ability to promptly stop drinking made their sojourn with T2D less complicated. In the long-term, the choice to stop alcohol use lessened damages that might possibly have occurred had they not stopped (WHO, 2014).

Negative DSM outcomes of machismo. The most striking finding implicating *machismo* was related to W10's father. Even when his oldest daughter, a nurse, told him "if you do not exercise, they're going to cut your toes and you feet." He declared with soberbia (arrogance) and orgullo (pride), "they can cut them. I don't care. They are mine to cut" [W10]. As a result of this neglect and his *machismo* attitude, he lost both of his legs to uncontrolled T2D. Similarly, M2 reported that when he asked to have a break at work to have a snack, his supervisor, who was much younger, refused the request and with orgulloso (acting in pride) declared that he too had diabetes, implying if he could postpone his diabetic needs then the subordinate, M2, would have to wait also. "It's not time. But, you know what? I'm diabetic too. *I'm diabetic.*" However, when the supervisor's wound did not heal after surgery due to his prolonged, uncontrolled diabetes, the man was dead within 1 year. Although M1's *machismo* showed less orgullo, his *machismo* might have contributed to his oblivious approach to the severity of his symptoms. He said, "I didn't realize how serious things were." As a Mexican man who believed his body could heal itself, he behaved as though he did not think there was anything wrong with him. He did not worry about his toe or foot infections, chest pain that led to a heart attack, and other serious maladies. His *machismo* interfered in identifying health issues.

Negative influence of machismo on hiding. Both male and female participants agreed that both men and women tended to *hide* diabetes in social settings because of the cultural stigma of T2D. They also agreed that, culturally, there was more ‘macho’ social compulsion for men than women. The abbreviated excerpt below from M2 supported this assertion:

PI: “One of the things that I’d like to hear from you as a man is that some people think that it’s more likely that men are going to hide it [T2D] than women. What do you think would be more likely - from a culture standpoint ... for a man ... or a woman in a party setting ... to not admit she or he had diabetes?”

M2: I believe it is a man; the man is more common.

PI: That’s what I’ve heard more often. And tell me why in the culture ...?

M2: Why men? I have no idea. I say it depends I guess [?]

PI: Well ... I’ve had a couple of people talk to me specifically about orgullo and also soberbia. Sort of the arrogance and the pride-end of the man’s person. ... and I wonder what you think of that as man? ...

M2: [silence]. [Looking intently at PI with a serious and questioning look on his face; questioning how to respond – prompting her to say:]

PI: That’s a hard question, I understand for a non-Hispanic woman to ask a Mexican man ... So please, I hope you’re not offended by that ... [Gave reasoning] ... So ... if you think it would be more likely that a man might hide his diabetes than a woman – at a party or a fiesta – do you think it would have anything to do with orgullo or soberbia?

M2: I guess so [laughs nervously]. I guess so. Yeah ...

PI: Why do you think that? From ... from the culture standpoint?

M2: One of the reasons I believe this that when you mentioned that kind of ... see the culture is normally [pausing]. I mean [pausing; then quickly adding:] you can embarrass somebody I believe. [PI: Oh, okay]

M2: You know to say anything about it until people knows that you have it, or when [?]

PI: Okay, that you're embarrassed about diabetes?

M2: Well, to, to say that I have diabetes is [?]

PI: Yes, embarrassed to, to say, unless you have to ...

M2: Exactly, unless is a person that knows I have it, then that's fine."

He went on to say that he would taste what was offered. In this case, M2 did not choose to decline food he should not eat. He felt that, as a man, he was compelled to eat food that was prepared whether it might be harmful to his T2D and to prevent others from seeing his diabetes. Each time he did this, he was aware that this culturally-necessary compromise raised his BG and potentially had long-term cumulative effects. That was why he did exercise right away to reduce his BG.

Negative influence of alcohol. The prevalence of alcohol use by men in the culture was reported in Context and Interactions. It was illustrated that it was/is common and some men do not want to give it up, even if they have diabetes. In contrast to M1 and M2 who did stop drinking alcohol when they were first diagnosed with T2D, the relatives with diabetes of W3 and W2 continued to drink with poor outcomes. The uncle of W2's ex-husband had been a runner but gradually

lost an entire lower limb because he used alcohol and did not practice DSM. She said with regret, "Then the last time I saw him, he had no leg." PI: "What did he do or not do with his diabetes that you learned from?" W2: "He was drinking. He was not taking his medicine." He had died from diabetes sometime prior to the IV. W3 sadly reflected, "... my uncle he just passed away. He was not taking really good care about himself ... He always said he could stop [drinking alcohol] anytime he wanted, but he didn't." [said in a somewhat sad tone] PI: "So diabetes is part of why he died?" W3a: "Yes, he was 63 years old. Something like that." Possibly, neither uncle had a long-term protection perspective. They might not have understood the relationship of alcohol to T2D, possibly they chose short-term pleasure and the familiar cultural commonness of men using alcohol. The undesirable outcomes of excessive alcohol use in these latter two examples demonstrated the damage that could happen with alcohol, particularly in the person with diabetes.

It was possible that *machismo* might have had a more negative affect on those men who allowed soberbia (arrogance) and orgullo (pride) to interfere with DSM, such as the father of W10. Due to the need for some people to hide diabetes, the macho element placed more social pressure on those men to blend into social settings rather than potentially reveal their diagnosis by declining to consume food or beverages that would make their diabetes worse. *Machismo* reportedly interfered with the DSM of some men. Fortunately, the two male study participants channeled their *machismo* to help them stop drinking when they were first diagnosed with diabetes, providing better long-term protection than if they had continued to drink.

Permission. For many of the female participants, their unique need for cultural *permission* to care for themselves was documented earlier in this chapter [see Intervening – Social – Permission]. W10 explained that the cultural training in the rules-based and role-oriented society placed a woman in a position to choose family needs first. M2 substantiated that the role for women, culturally, was to choose family needs over her own while the male participants did not encounter this conflict. Women who had *permission* were more consistent in DSM (W1, W3b, W6 - W10). Those who did not have or had not had whatever-type of *permission* they needed were not consistently as successful (W2, W4, W5) until they gained the *permission* they needed. Ultimately, the most salient *permission* was when the woman gave her own self *permission* to care for her needs before the needs of the family (W3b, W5). This generally led to the potential for improved BG levels. In the case of W3b, her A_{1c} went back down to 6.0% from 6.6%.

Positive DSM benefits of permission. Those participants who had personal *permission* and/or *permission* from husband, family, and/or God to practice DSM every day were more successful in managing their BG according their reported BG and A_{1c}. W1 was a prime example; she simply did not care what others thought and chose to routinely take care of herself with no concern for offending others. As a widow, she did not have family constraints; in fact, she was motivated to +DSM for the sake of her college-age daughter.

PI: “ ...Does the way they [family and neighbors] take care of their diabetes, affect, any ...?”

W1: No, it doesn't affect me because ... I know what I have to eat, and not to eat. If I eat at my house and I go visit her and she is having dinner, they offer me something [she demonstrated] 'No thank you. I already ate, and I take [took] my medication, I have to wait.'"

Due to her strict adherence to her DSM commitments, she had maintained an A_{1c} of 6.0% or lower for a long time. Only recently had it gone up to 6.3 because she had eaten intense chocolate sweets after flushing her system of sugar via water intake to lower her BG to what she thought was a safe level before she indulged. On the other hand, W2 went a dozen years without T2D care. Only shortly prior to the IV had she chosen to seek care of her T2D when she felt she had *permission* from her new husband; she would not have gone to the doctor without his support.

PI: "... and then recently ... you returned to the doctor for medicine ... now, with him [her husband] using his insulin, did that help you to think, 'oh I should do the medicine, too?' So, did that help you motivate also? [W2: Yeah]

PI: If he didn't take the medicine, do you think you would have gone back to the doctor to take the medicine?

W2: No, because like I told you I was feeling good, and then I had my ingrown nail and I was feeling bad. I said 'why is that?' and he told me 'maybe because you are not taking medicine, maybe because your sugar is high ...'"

While W2's BG was not yet under control, she expected it would be when she started medications; she anticipated that would be in the following week. W9 felt

she needed no one's *permission*, only her own and she had had excellent BG control for 10 years; her first increase came only a few weeks before the IV; she attributed that to stress. W10 was single and had been married years before to an American who gave her full independence, even when he thought she did not need it from him; but culturally she did. W6 and W8 had good control; they had excellent support from their husbands and personal *permission* to practice +DSM. W3b had gained personal *permission* more recently and her sugars were in better control because she was eating on time instead of going hungry and feeling poorly. When the PI acknowledged that she was taking care of herself, she corrected the viewpoint about her independence:

W3: "Yes, but I'm starting - just recently ... 5 months ago, but before I was kind of reluctant.

PI: ... And so, what interferes with a woman being independent? And it sounds like you were feeling obligated that you had to serve others first, before you felt free; 'cause now you feel free.

W3: Right, but when I was working, I was hiking and I will eat whatever I had and then start working because I wanted to give them [the family what they needed]. And then we will sit everybody together, but I was really hungry and I was myself second place because I wanted to cook first ...

PI: Right, so the interference was that your value was 'I have to serve my family first' ... and that actually did interfere [with her diabetes]?

W3: Right."

Negative outcomes of needing permission. Findings from W3's IV above illustrated how her lack of personal *permission* for DSM interfered with her diabetes care and BG. Due to family obligations, W5 indicated their needs were unending. "My problem is that sometimes I am busy and I always put priority in doing things for my kids or prepare their food, and it's always one thing or another, and I always leave myself for last. Then I feel tired because I didn't eat at the times I was supposed to." Her BG suffered; she had reported her FBG ran around 150. When she was hungry, she often grabbed candy then felt terrible later. At times, she went to bed with a severe headache. As a person with diabetes, it became clear that she needed to make her needs a priority in order to be effective for the family.

W5: "Yes. I *have* to do something for myself ... in the same way that I exercise
I need to start doing something for myself first ...

PI: So, if you ... [practice the advice given by the PI following the IV] Señora,
it's a possibility you'll feel a little better. And then you practice that ...
every day. [RA1 to W5: interpreted]

W5: I promise you I will. I will now. I know I have to do it."

Positive consequences of the maternal role. As suggests above in *Positive DSM benefits of permission*, an important outcome of the struggle by W3 was when she learned to choose to take care of her T2D and to be more consistent in her DSM. Ironically, although she had strong commitment to her family and put them first, as she had learned the cultural values, she did not take care of her T2D and therefore put herself at risk. She realized her ongoing decision to put herself second, "I was myself second place," resulted in putting her family at even greater risk. Because she

feared in the “back of her mind” that she might die early from diabetes, “sometimes I afraid I might die earlier because of diabetes” and was afraid to leave her children motherless, she came to believe she had to take care of herself in order to be available and well for her family, particularly her children. She not only gained *permission* to more routinely place her diabetes needs first that had been resulting in more consistent BG, she also felt better; she had ultimately chosen her family as her priority again, but had included her own health in that equation.

Negative consequences of the maternal role. As stated, the maternal role for female participants placed them in frequent dilemmas that affected their family and their diabetes. The challenges faced by W5 were reported above. Often, when W6 chose to cook meals for her adult children when they came after work or on days when friends made unplanned visits, she did not go to the gym so she missed her daily exercise. She did not recognize that her inability to exercise because of her children’s requests for her to make them food interfered with her DSM. Her care of them did affect her long-term well-being because she missed many days of exercise. Her BG was not controlled as she had just started on insulin. Those many days of accumulated BG from lack of exercise had the potential to lead to further consequences. During the years that W2 did not address DSM, she had to put her young family first. The long-term results of 12 years of no therapy are unknown, but did impact wound healing just prior to the IV.

The identification of *permission* for personal DSM in women was an exceptional finding. The majority of women participants had a need for personal *permission* to make their DSM a priority, particularly over immediate family needs.

Once women had a sense of *permission* from their husbands, families, God, and ultimately themselves, they were more consistent in addressing DSM needs on a regular basis. This benefited their BG in the short-term and facilitated much better long-term control. They felt better, they performed better, and their BG level short- and long-term were better. Their maternal role was highly regarded in their culture as holding the family together, keeping the family first. Ideally, once the participants decided to be healthy for their families, they were better able to take care of their diabetes, potentially making them healthier for the long-term.

Summary of roles. The uniqueness of the distinction of roles between men and women in the culture was evident in this study. Women required *permission* at various levels, from various sources in order to feel free to adequately tend to their DSM. Despite the limited number of men interviewed, the many contributions by the female participants about the effect of *machismo* on the men in their lives led to substantial data about *machismo*. Role findings of *machismo* had both positive and negative effects on the Mexican man. Positive effects of *machismo* were evidenced by M2 and M1 when they applied personal strength to stop their *Pre-Discovery* frequent use of alcohol after their T2D diagnoses. Both consistently remained off of alcohol. There are long-term benefits for persons with T2D to avoid alcohol.

Acceptance/Accepting diabetes.

Ultimately, all of the participants were *Accepting* of the diagnosis of diabetes and *Accepted* the responsibility for daily DSM. Each of them made progress toward or generally maintained good BG control for +DSM with the exception of W2 as discussed. An important preliminary factor was whether and to what degree one

was suspicious that (s)he was at risk for the disease. Those who perceived the possibility of the disease went for health care more quickly than those who did not. The disadvantages of not *Accepting* the diagnosis are summarized below as are the advantages for *Accepting* diabetes. In either case, *Accepting* the responsibility for daily DSM was an important aspect of *Accepting* the disease. The example of W10's father, who reportedly *Accepted* the disease and his responsibility for the outcomes of the disease but *not* the responsibility to take care of it. [see *Roles – Negative DSM outcomes of machismo*; also, *Interactions – Effects on decision-making*] This suggested the necessity to *Accept* responsibility for one's self care and disease outcomes in *Accepting* one's disease status.

Perception of the risk of developing diabetes. As evidenced, 10 of the 12 participants had a known family history of diabetes and they all knew that genetics played a role in developing this disease. W10 was particularly concerned because of the severity of her father's disease; when she had distinct symptoms, she was suspicious she might have diabetes because her perception of risk was high. She quickly *Accepted* the diagnosis and started treatment, which she continued. W7 and W9 had very strong family histories of diabetes and watched their mother suffer dialysis. Each of them was looking for a specific sign to indicate they would be at risk. Because they did not see the specific evidence for the disease for which they observed, they felt their risk was low. Thus, their lack of suspicion was inaccurate and misleading. W7 actually practiced risky behavior; given her overweight status and warnings from her mother and healthcare providers, she overindulged in eating high glycemic sweets (5-7 oranges per day for 2 weeks). She only sought healthcare

for minor atypical headaches. W9 blamed her recent pregnancy state as the cause; she delayed seeking HC thinking the cause of her symptoms were due to something besides T2D. Both did *Accept* their disease and began DSM, although at the time of the IV, it was in question whether W7 had fully *Accepted/was Accepting* her diagnosis because, as she reported about her prayerful pleadings, she was *Negotiating* with God.

Neither W1 nor W5 heeded the warnings of their physicians who told them they were at risk for recurrence of their diabetes following the pregnancies. After about a year, they made no efforts to avoid habits that contributed to the development of T2D; but they both did. They did not perceive their physicians' caution combined with strong family histories as being signs of risk. Because they both "felt fine," they hoped they would not get it. They ignored what they had been told and what they knew about the genetics of T2D. They practiced what W3b called "wishful thinking." W6 had a number of symptoms for an extended period of time, along with a family history of T2D and was trained as a nurse. Despite her Pre-Discovery knowledge and training, she was at risk. She had even suspected or wondered if her symptoms might be from T2D. Nevertheless, she delayed seeking assessment. She ignored her symptoms or pretended they were not there until she had no choice but to seek care. M2 had been forewarned by a physician friend in Mexico that he might have T2D. His first test was negative; however, even with the warning of his physician friend whom he trusted, he delayed going for the second analysis until he had a number of physical changes. At that point, he also had reason to believe he was at risk for T2D but he had low suspicion during his symptoms. W8,

with no family history and no diabetes-specific symptoms, neither had a suspicion of risk nor a perception of illness; however, she had been told she had prediabetes.

Both W3 and W4 had been misdiagnosed in Mexico. W3 did not attend to increasing symptoms despite knowing she was at high risk and being declared “diabetic”. W4 also went several years after receiving her “borderline” status. With her family history, prior borderline diagnosis, and worsening symptoms, she might have had a higher sense of suspicion. She went 10 years from the borderline assessment until a clear diagnosis, despite many physical changes in between.

Actual risk for individual participants did not correspond to the level of suspected risk or the participants’ perception that they were candidates for T2D. Only W10’s perceived sense of risk equaled her suspicion as to the cause of her symptoms. W8 did not perceive risk nor suspect symptoms because her only symptom, weight loss, was thought to be due to the diet pills she took; also, she had no family history. Several participants who by family history should have had a stronger perception of risk had a low suspicion of the cause of their symptoms. In their case, factors other than suspicion of risk led them to seek HC evaluation. The low perception of risk did not have a significant impact on *Accepting* diabetes, although it had an important impact on the delay to seek assessment and the initiation of treatment. Each excursion was met by lack of attention to control.

Disadvantages of not *Accepting* diabetes. The extended situation involving W3 took a number of years to come to *Acceptance* of her T2D diagnosis; it is recorded in *Interactions – Response to Discovery – Delaying medication*, and *Acceptance – Delayed*. For several reasons, she had difficulty *Accepting T2D*. The

problem began with a mixed diagnosis, “you are borderline” *and* “you are declared diabetic.” This was followed by major HC delays, frustrations with inefficiencies in the Mexican HC system, and outdated diagnostic criteria, all of which interfered with her use of the Mexican system. She expressed a sense of injustice, “why me?” and was sad knowing she was genetically at risk. As a highly social person who loved the taste and smell of food, her regrets about the extent of self-denial required to manage T2D and her childhood food scarcity interfered with her need for lifestyle changes. She avoided medications for as long as she could and, true to her culture, she hated the idea of having to take a pill. For a time, diet and exercise were generally sufficient. She finally was *Accepting of* her diagnosis following her second pregnancy because severe fatigue from inefficiently-utilized BG was too much for her; diet and exercise were clearly no longer working. From that point, she had sincere regret that she had not started medications from the beginning. She essentially struggled with her nonmedicated, diabetic-state for almost 10 years and, regretfully, realized she had put both her long-term health and the overall well-being of her family at risk.

The long-term results of the 12-year delay in W2 accepting diabetes is unknown as she was just restarting HC treatments at the time of the IV and moved out-of-state shortly thereafter. There were personal reasons for not seeking care, family responsibilities and financial issues left her no time for healthcare and she lacked the necessary support. Apparently, she only practiced dietary restrictions during the times she was *sharing care*. At the time of the IV, W2 was *sharing care* with her husband with recently-diagnosed diabetes and had fared-well through a

healthy diet when she lived for a time with her mother with diabetes who was conscientious of what she cooked. W2 reported that she sought HC because an ingrown toenail would not heal. Having witnessed her ex-husband's uncle eventually lose a lower limb from not taking his medication (and excess alcohol use), she was frightened the same could happen to her "I don't want to lose my thumb". This fear had *motivated* her toward DSM; her husband's *shared caring* support had given her *permission* to seek care. It is unknown what damage might have existed at the time of the IV, but according to the literature, to have gone for 12 years with little efforts toward DSM, the likelihood that vascular changes have occurred and the risk for long-term macro- and microvascular changes were more likely (Chatterjee et al., 2017; Collier et al., 2011; Phillips et al., 2014; Pilon, Bailey, Montgomery, & Bakker, 2011).

All of the participants knew people who had not fully *Accepted* their diabetic status and had witnessed loss of limbs, blindness, kidney failure leading to dialysis, and the death of loved ones from uncontrolled T2D, the root of which might have been lack of *Accepting* the diagnosis and responsibility for DSM; but not always. W10 and her sister said that their father did *Accept* his diabetes, he did not deny it, but for potent *machismo* reasons (soberbia, orgulloso), he chose not to treat it even with simple exercise. They did not believe that *Acceptance* was his issue. W10 clarified that while *Acceptance* for her also included *Accepting* responsibility for DSM, she believed that her father did *Accept* the diagnosis and responsibility for the outcomes, but not the responsibility for DSM. The outcome was his slow demise.

Regarding W1's brother [see *Interactions – Acceptance – Conditions that interfered*], who denounced being his father's son and moved 3,000 miles away hoping to avoid developing diabetes, it was unknown whether he made intentional dietary and weight choices to reduce his risk of developing dT2D, ever developed symptoms, and if so, whether he acknowledged the symptoms, *Accepted* them, or started DSM. In any case, according to W1, he detached himself from the family hoping that distance would keep him disease-free. This tactic did not help W9.

Benefits of *Accepting* diabetes. The majority of participants readily were *Accepting* of the diagnosis as demonstrated in *Interactions – Accepting diabetes*. They began medication treatment, changed their diet, initiated exercise, SMBG, had quarterly lab tests, and routine HC visits. Those with comorbidities at the time of diagnosis either continued treatment (e.g., M2 had seizures and sleep apnea) or received additional treatment. W5 was on cholesterol-lowering medication. She did not know if it was because she had high cholesterol but might have been the commonly-prescribed adjuvant treatment for T2D. W9 urged that others who might be a risk or were symptomatic ought to take action sooner to prevent complications; this would be the benefit of early DM diagnosis. Most had maintained their BG/A_{1c} in a very good-to-acceptable range and most did not report signs or symptoms indicating possible complications of the disease, other than W6 who had needed to start insulin. W4 was an exception. She had always *Accepted* her diabetes, but had poor dietary guidance; previously, she had not had consistent DSM. She wanted nutritional assistance, "then I can do it myself because I have learned what to deal with my eating." Food scarcity as a child had an impact on her choices before she

received sound nutritional guidance from a nutrition-oriented physician when she acquired insurance, as learned at the follow-up visit. She had lost 40 pounds and no longer had lower extremities peripheral neuropathy that had severely limited her activity; she embraced DSM. After over 26 years of T2D, W6's disease progression to insulin use was helping to safely adjust her BG back into control with fewer excursions. M1 who had not been on medication during the 10 years post gastric-bypass was again controlling his BG and weight loss effectively with careful dieting.

W5 had a brief delay, not in *Accepting* her disease, but in *Accepting* the use of medication. However, following 6-months of hard personal efforts, she realized she could not control her diabetes with diet and exercise; she consented to medication and had continued to use it. Once W3 fully *Accepted* her diabetes diagnosis, she began medications and was committed to all aspects of +DSM. With the exception of a period of high stress when she was working and managing the care of her family, her BG was well-maintained with an A_{1c} in the low 6 range. At the time of the IV, W2 was expecting to re-start medications and knew she needed to monitor her BG; she wanted her husband to plan walks around her narrow schedule.

Summary of *Accepting* diabetes. The perception of risk was not consistent with the actual risk for most participants. The overall low suspicion of risk delayed the assessment of most of their symptoms. The delay in assessment led to delay in the onset of treatment for the majority. Similarly, the delay in *Accepting* the diagnosis and thus the delay in the *Accepting* responsibility for management of the disease also postponed the assessment of health for W2 and W3. The same was true for at least two close family members of W1 and W10. The eventual *Acceptance* of

the diagnosis of T2D and of daily DSM occurred in all 12 participants. Probably the most important benefits of *Accepting* diabetes and *Accepting* the responsibility for DSM was that they were better equipped to *Be in the daily battle* required in the struggle among short-term enjoyment of food, social pressures, and the need to keep the long-term health view in mind. It was evident that those who had been fully *Accepting* of the disease and the responsibility were more consistent in the *daily battle*.

Addressing Diabetes Self-Management.

In the everyday need to make DSM decisions, participants struggled with a three-way conflict between social requisites, particularly *Being proper*, their own temptations and preferences for the tastes and smells of good Mexican food that brought short-term enjoyment, against the necessity of careful daily BG control in order to protect against long-term damaging consequences of inconsistent or poorly controlled T2D. Every day, their being in control or close to being in control brought them closer to their long-term goal of avoiding or reducing dreaded T2D outcomes. On the other hand, every day that their decisions allowed or fostered an excursion of BG increased their risk for long-term damage. Some of them understood this better than others, but all of them understood the outcome potentials. The most common way that they made their decisions, as demonstrated in *Interactions – How they made their decisions*, was through various mechanisms of *Negotiation*.

Being in the battle. The essential cause of their daily conflict was to keep the long-term goal in mind, which provided no gratification, while they wrestled with daily temptations to eat tasty flavorsome Mexican food and maneuvered through

cultural expectancies in social settings. The latter two aspects were short-term pleasure and communal niceties that had to be balanced with an unseen longstanding goal. W6 was gently adamant that thinking long-term was the only way to approach DSM. When the PI clarified W6's use of the term "convenient" was not about the current moment, but long-term, W6's stated with conviction, [Spanish] "Yes, all the time. *All the time* you have to think that way." M2 also emphasized "*I have a choice*" ... W9 stressed "*I have to choose every day.*"

Decision-making involved setting priorities; focusing on the long-term.

There were occasions when the participants did not have to struggle. For instance, W3b shared that she had only healthy food in her home and she avoided social gatherings as often as possible where she would have social pressure and temptation. She commented, "If I'm at a party then I forget." Thus, she avoided exposure to festivities that did not serve the kind of food she could eat, including those with her extended family. There were many days when she did not have to *Be in the battle* because she had already made food and activity decisions with the goal of long-term protection in mind. W9 made daily choices based on the long-term goal she kept in front of her every day. She intentionally limited the options she allowed herself to be exposed to in social and work settings. Her daily priority was to protect herself long-term. Both participants repeatedly chose the long-term goal over short-term enjoyment and chose their health in times and places when they had to *Be in the battle*. W3 had good control in the A_{1c} 6% range. For the first time in 10 years, W9 was above 7% - attributed to stress. W6 suggested that if one lived in the present with only "now" in mind, one did not have a broad perspective of DSM and

thought “I’m just going to take a pill” to manage the immediate high BG; one that would in the long run not lead to good control. Thus, those who had an enduring plan to work around their BG had more success (W1, W3b, W6, W9, W10, M1, M2).

+DSM habits, self-control and willpower for *Being in the battle daily.*

Developing consistent habits of +DSM had overall short-term and long-term benefits. Those participants who had developed daily routines around their diabetic needs and took care meeting those needs consistently had overall less conflict with the temptations and struggles to manage BG while waging the everyday battle among temptation, social pressures, and long-term benefits. There were distinct advantages to having good habits and equally clear disadvantages to not maintaining good habits. Simply because someone had good habits at one time did not ensure that they would always have a consistent routine. Maintaining a good habit proved to require a great deal of effort.

Advantages of having good DSM habits. Those who developed a habit of having the correct food available and/or prepared at home were able to resist the temptation to grab fast food or less-than-healthy meals. W3b: “It’s because you don’t have the food waiting.” PI; “So, the solution is people need food ready, so when they’re hungry they will ...” W3b: “have healthier choices.” Both W3 and W10 had healthy foods available at home and did most of their own cooking. Some participants learned from and developed good habits alongside family members with T2D (W5, W1, W3). Being influenced by the positive practices of others, they developed better habits that benefitted each one in the short-term and cumulatively could benefit the long-term. For example, once W4 developed +DSM eating habits

and gained BG control, her neuropathy ceased. As that was an uncommon outcome (Pop-Busui et al., 2017), the evidence for her transformation was strong with benefits both in the short-term and potentially the long-term as previously documented. W9 was disciplined about meal portions, what she allowed herself to eat, and daily exercise. *'I have to choose every day.'* ... *'Sometimes I really want to eat these things ... but I just have to ... I have to keep ...'* [indicating resolve] This practice of restraining herself through self-control limited her need to *Be in the battle* within herself.

Adopting the habit of planning which celebrations to attend, how much time to attend, and which ones to avoid was a healthy habit W3b had developed for her family. She knew that if she chose to eat something she should not, it led to her feeling anxious. Whenever she had anxiety, it significantly increased her tendency to put something into her mouth that she should not eat, which led to the sense that she was spiraling out of control; one wrong bite led to more. Her BG increased and she felt she had lost another *battle*. Once out of the routine of going to all family events, her anxiety level diminished and she gained control through her +DSM habits. She no longer struggled with not going to all social events; it was a victory.

Each participant who applied her or his self-control strengthened the habits that improved DSM practices. These behaviors promoted better control in the long-run. Those who had habitual exercise (W3, W5, W7, W8, W9, W10, M2) overall had been able to maintain fairly consistent BSBG, except during times of stress, not eating regularly, or getting out of the habit of checking BG. Likewise, keeping track of BG helped them have a good sense of control, as W10 acknowledged. As reported

earlier, it was important and a good habit to write down their BG results because they did not consistently recall what their BG had been.

Disadvantages of not having good DSM habits. A disadvantage of pretending, hiding, or ignoring aspects of their T2D put some at risk for getting out of the habit of +DSM. For example, when the male participants ate what they should not in order to avoid social discomfort, they were intentionally not practicing +DSM. Just as keeping track of their SMBG reinforced good habits and promoted self-accountability, when both men got out of the habit of daily SMBG, their BG gradually went up. M2's physician threatened him with adding another medication, which M2 rejected; he got back into better eating habits and SMBG more often. M1 gained considerable excess weight that put him at risk of having to go back on medication. When he re-started daily SMBG and changed his out-of-the-diabetic-habit diet back to a healthy diet, he lost and continued to lose excess weight. His weight had always been the determinant in whether he controlled his T2D with diet or required medications post gastric bypass.

Poor or inconsistent habits interfered with the DSM of W4 prior to getting the nutritional guidance she needed. She was inconsistent when she performed SMBG, ate, or exercised. Some days she did not remember to give herself daily non-insulin injection at the same time of day. Neither did she practice purchasing nor preparing diabetic food stuffs even though she had the means. She did not have good habits of +DSM and experienced high BG, sometimes into the 400s; she consequently suffered from neuropathy. Once she established daily habits of careful dietary intake and routine SMBG along with her medications, she lost weight and the

neuropathy resolved. W5 had excellent exercise and medication habits but was inconsistent in eating meals on time. The same had been true for W3a; when she worked, and struggled to balance work and family needs with her T2D, the latter suffered. Both experienced periods of low BG when they felt poorly, were hungry, and in the case of W5, she ate sweets for pleasure and a quick BG surge. Both had higher-than-desired BG. Once W3 got into better routine of eating when hungry instead of placing family first, her BG improved. W5 learned during the post-IV how she might do similarly and hoped that improved habits would benefit her too.

In sum, most had some degree of routine and habit. Maintaining consistency of the habit was an ongoing challenge for some, less for others. Those who were conscientious of their long-term goals on a daily basis were more consistent over time. Alternatively, those who did not develop or inconsistently practiced effective DSM habits experienced sporadic and/or frequently elevated BG and ultimately experienced less long-term BG control. Fortunately, despite the ongoing *battle* to maintain good habits, most practiced fairly consistent habits most of the time and some did so impeccably – except for insertions of cultural *Being proper* and eating *a little bit* did at times compromise the long-term.

Mastering Diabetes and Diabetes Self-Management

The participants did not use the term *mastery* or *mastering* diabetes. The concept emerged from the data as it became clear that there were varying degrees of DSM skill and commitment. *Mastery* was effectively how they were addressing DSM, navigating through daily *Being in the battle* to balance short-term requisites and desires with long-term needs for protection from feared organ damage. It was a

function of being *Motivated*, confident, and often having the benefit of adequate support. These conditions were adequately in place and led to varying levels of *Mastering* DSM in all but W2, who had just returned to diabetes care. The sooner the participant *Accepted* the diagnosis and responsibility for DSM and developed suitable *Negotiating* skills with long-term goals in mind, the sooner and more effective (s)he was at *Mastering* management of T2D.

Growing in the practice of good, +DSM included *Mastering* daily impulses, social pressures, expectations, conflicts, and roles expectations in various situations while developing personal *permission* for *social independence*. An important aspect of *Mastering* T2D was confidence that one could be successful, had self-assurance to make consistently correct decisions, and the determination or willpower to face and overcome constant temptations. Success bred further confidence in +DSM performance, as demonstrated earlier. Thus, DSM began to serve as a lifestyle that facilitated consistency in DSM. W6 said “diabetes is my life” and M1 exclaimed “diabetes is about your whole life.” Successful and consistent *Mastering of* DSM improved BG in the short-term that more often resulted in ongoing BG control with the promise of long-term control (Ramal et al., 2012) for participants. As the previous statement implied, there was variance, at least for some, in the degree of *Mastering* they maintained. It was not enough to achieve *Mastery*, they had to be actively *Mastering* T2D every day. Some participants were overall successful in sustaining a high level of *Mastering*, others had generally good *Mastery* and had chosen effective ways of *Negotiating* that facilitated what they felt was a safe “range” of BG management to preserve an acceptable A_{1c} with most daily BGs in the

preferred range (Chamberlain et al., 2016), but had some compromise that potentially could negatively influence their long-term outcomes (Chamberlain et al., 2017) – of whom all were aware. There were some who were sporadic; they had periods of DSM laxity that resulted in their BG and/or weight being at risk. Participants knew of others who completely failed DSM and suffered the outcomes of constant, poorly controlled BG.

Consistent *Mastering*; keeping the long-term view. W9 had been highly fastidious and successful in mastering DSM because of her recollection of how her mother had suffered. W9's stress and worry about developing advanced T2D caused a slight increase in her A_{1c} BG after 10 years of excellent DSM founded on daily vigorous exercise; she continued to keep herself slim. At 53, she set herself up in the first decade to have well-controlled BG for an extended period.

Once W3b gained *social independence* and personal *permission* to choose care of her T2D first, rather than always “be second” to the family, she mastered all aspects of DSM and excelled at them with rare compromise. She limited her exposure to festivities where she knew she would succumb to temptation. Her husband assisted her in limiting her choices when they did go to celebrations. She had only healthy choices of food in her home and prepared food daily so she was not tempted to have to stop and pick up a fast meal. She hiked an hour every morning. The regret she had for having lost several years of consistent DSM served as a motivation to not lose more valuable time; she wanted to be healthy for her family.

W10 had readily *Accepted* her diabetes diagnosis because of her suspicion about her symptoms due to her father's devastating disease. She began DSM

immediately and had almost 8 years of *Mastering*. At the time of the IV, she had been ill with a long-term virus from which she was recovering. Both her and her sister's attention to her diet had helped her BG while ill. She knew she needed to return to full exercise as she had done throughout her T2D history. It was likely she would return to full control since she had been successful before the illness. She had only one important fault, which was her declared refusal to ever use insulin and her plan to "brainwash" herself into never having to use exogenous insulin. However, depending upon how long she might live and her overall health, there remained a possibility that at some time in the future she might need to use it. To refuse it was to put herself at risk of having increasingly high BG that she could not control with diet, exercise, and oral or other injectable medications. Up to the time of the IV, she had successful DSM with short- and long-term benefits.

When M1 re-committed to attentive DSM, changed his diet, and restarted daily SMBG, he reclaimed successful DSM. Although he was unable to exercise due to chronic back pain, he was *Mastering DSM* that resulted in steady weight loss. He lost 11 pounds twice, successively, within a few months. He also controlled his BG again. With this success, he recognized his self-discipline led to +DSM control, was *Mastering T2D*, and had warded off having to re-start T2D medications.

The historical factors of W4's story is found below in Poor *Mastery*. As has been documented, once she obtained health insurance through the Affordable Care Act, she gained new HCP support and the nutritional guidance she needed. She complied with a rigid diet and quickly lost 40 pounds in about 3 months, her neuropathy resolved, to which she attributed God's answer to her prayers "from the

prayers". It is unknown if she knew how very unusual an occurrence (Mayo-Clinic, 2015b) was her experience. She was no longer restricted to her home and overall felt empowered, supported, understood, and much healthier. Her BG returned to the near normal or pre-diabetes FBG range on most days. She followed the guidance of her new physician whom she saw often, had grown in confidence, and was reaching her DSM goals at the follow-up visit.

Successful while compromising. Despite the unusual water-sugar flushing technique of W1, she had maintained an A_{1c} in the 6% range, remained trim, and was generally consistent in other aspects of DSM, except exercise due to her back injury. She had the mental fortitude of *social independence* and had essentially *Mastered* DSM; however, often compromised her long-term success because of the frequent rapid excursions in BG when she ate chocolate-covered raisins or a whole candy bar at one time. Her A_{1c} had increased prior to the IV. She recognized that because she managed her BG in the short-term, in order to satisfy her "need to have sweet" (after each meal), "I'm a 'sweet' person," that her A_{1c} had gone up. Unfortunately, she had inaccurate health science knowledge based on outdated information (Gavin & al., 1997) that limited her understanding about how her disease progressed. Thus, it appeared that she was unaware that she might not be able to continue her water-flushing practice to reach a desired BG level in order to eat a whole candy bar or the apple pie she bought the morning of the IV and left on the counter at eye level to the PI.

W6 mastered DSM years prior and built her life around her T2D. Her mental outlook from the day she was diagnosed was that she would "do whatever I need to

do to get well.” She had two weak points in her *Mastering* pallet. First, her role as mother to her adult children who still expected her to cook for them anytime they went to her house; thus, she frequently missed needed exercise. She declined to set limits with them and instead thought, “oh, poor kids, they’re hungry.” Secondly, due to her great respect for cultural norms, at times she felt socially compelled to eat *a little bit* more than she should. In both of these forms of *Negotiation*, she did not consistently practice *Mastering* that she knew and was capable of doing every day. Although she had *Mastery* of all DSM skills and worked most days toward *Mastering* T2D, her BG recently crept up and she started using insulin. After 26 years of T2D, she was thought to have pancreatic failure. It was possible that her compromised *Mastery* via recurring BG excursions had contributed to or might have hastened her disease progression.

W8 had faithfully practiced DSM since she unexpectedly learned of her diagnosis 20 years prior. The primary *battle* for her easy-going nature was her refusal to make anyone around her or herself uncomfortable by declining food or drink she should not have; she did, however, refuse to stand out as different. Having *a little bit* and choosing what “I prefer” were weaker points in her DSM. These practices commonly interfered with her overall *Mastering*. Similar to a few others, she allowed cultural dynamics to overshadow her long-term T2D needs. In the long-term, she knew she risked a cumulative effect of her frequent BG excursions so remained diligent in her (disliked) daily exercise regimen.

W7 had also mastered DSM and was consistent in all aspects although she continued *Negotiating* with God to relieve her of having to take medication and

possibly of her T2D. She was successful at diet, exercise, SMBG, quarterly health care visits, and laboratory tests. Sadly, due to the stress of her worry, grief, and lack of sleep, her BG had gradually increased. She desired to only have to take “one pill ... or maybe nothing;” it added to her unease and appeared to cause a hesitancy to fully embrace her long-term T2D. She had deep respect and feared what T2D could cause as her mother had T2D for over 50 years and used insulin for 30 years. Similar to W10, who might someday require insulin, W7’s reluctance to take a single pill might have interfered with fully *Accepting* the path of her T2D and maintaining *Mastery*.

W5 struggled with *permission*, therefore the inconsistent times and amounts she ate and weakness to avoid sweet candies and bread were her primary inconsistencies along with her maternal-role focus. She had *Mastered* several aspects of DSM and once she *Accepted* that she had to take medication, she had been faithful to her DSM. Her role as mother to two young children interfered most days with the timing of her meals and she had difficulty getting adequate calories before her daily rigorous exercise. After the IV, suggestions by the PI about the timing and amount of food to eat before exercise had *Motivated* her with new confidence that she could choose to take care of herself. She was empowered to fully *Master* all aspects of DSM; she had effective *shared caring* with her mother.

For years, W3a had delayed *Accepting* her diagnosis and was intent on holding onto her borderline diagnosis. Her childhood food deprivation interfered with her *Accepting* the limitations of a diabetic diet. She had routinely put her family’s needs before her own. Her BG were often low from not eating or high from grabbing something to eat when hungry. Thus, her BGs were irregular. She was

often not stable for the short-term, which compromised her long-term. The greatest compromise was going 7-10 years managing with diet and exercise only when she should have been on medications; a mistake she realized after years of struggling with fatigue. She did not have *permission* inside of herself for full DSM. Once she resolved her priority to be healthy for her family and available in the long-term for her children, her DSM changed (see *Consistent Mastery* above).

Despite significant physical and emotional/psychological health issues, including gastric-bypass, heart attack, near limb-amputation, drug addiction, recurring loss, and severe, unresolved grief, M1 kept his weight off and controlled his T2D without medications for several years. Within the year prior to the IV, however, he wandered from his previously-successful *Mastering* of DSM, put on significant weight and stopped SMBG; he did not realize he was losing control of his T2D. A fright at his doctor's office stimulated his return to consistent DSM. His eventual success is told in *Successful* above.

Similarly, M2 generally had good *Mastering* of DSM. In the previous year, he too relaxed his vigilance and routinely enjoyed more of his favorite foods, especially sweets. Following a lab test when his A_{1c} level was high and his quarterly FBG was clearly not controlled on his single oral T2D medicine, his doctor advised him to start an additional medication. Due to the cultural preference of fewer or no medicines, the stigma of the disease, and his own *machismo*, he vigorously declined and applied himself to practicing +DSM daily. Unlike M1 who re-started daily SMBG, M2 only checked when he thought he was symptomatic, "when I feel my body changing", referring to his BG being above his normal readings. In a conversation

about the natural progression of the disease, that he and his wife had with the PI following the IV, he reported being unaware of physiologic changes due to loss of pancreatic function over time. He was unaware that he could not indefinitely depend upon his current practices being sufficient to track BG elevations. Thus, the potential for an eventual lack of close connection of how he simply “felt” to his true BG meant that in the future he was at risk of less-symptomatic elevations in his BG (Pop-Busui et al., 2017). Because he was monitored quarterly by his physician through lab testing, he would learn if he tended to run higher than he presumed. He otherwise had returned to overall successful DSM with attention to exercise and had maintained healthy A_{1c} levels to that point.

Poor Mastering of DSM. W4 was lacking in several aspects of DSM at the time of the IV; however, she was *Motivated* to learn correct nutritional information and menu options. Despite her monthly clinic visits, there was a disconnect between her and her HCPs. She developed peripheral neuropathy and increasingly was limited in her activities to the point of being almost house-bound at age 62 years of age; she could no longer do regular exercise. Due to fears of side effects from the neurologic medications, she did not take them. Her BG ran high and was often out of control, at times reaching 400, although she was very hungry. Sometimes she did not eat at that point because the high BG numbers frightened her. When she felt famished, she ate without control and whatever she could find. It was a vicious cycle. At the heart of her battle she believed that if she had nutritional guidance to know what to eat, when, and how much, that she would be able to gain control. She had personal self-efficacious qualities but lacked the DSM knowledge she needed.

The food scarcity aspect of her childhood in which she was hungry every day impacted her adult T2D choices. Once she finally had any kind of food to eat at any time, it was difficult to apply self-restraint. She had poor *Mastering* and limited personal or HCP support. (See Consistent *Mastering* for the remainder of her story.)

Early in M1's T2D history, he had *Been in the battle* daily was for several years with insufficient self-control when eating, lacked regular exercise, and was morbidly obese. It should be clarified that, during the IV it sounded like this was the case; however, the confusing, convoluted history left some uncertainty. He previously had felt socially obligated to eat foods prepared for him even when unhealthy for him. He suffered serious health issues and multiple heart-breaking losses. Before his gastric bypass surgery, either 10 or 20 years prior, he reported that he had limited self-control. He pushed his doctor to consent to the surgery and proved he could change his dietary habits; and he did. After the surgery, he was off of his medications within 6-months and had not needed them.

Failure of *Mastering* DSM. The case of the prominent, talented, Mexican father of W10 has been detailed above. Being from an older generation of Mexican men who were reportedly more *machismo* in nature (M2, W3b, W9) and belonged to an often-ineffective Mexican HC system, he might have held more traditional health beliefs that furthered his resistance to any type of personal effort to address DSM. In any case, he refused even minimal exercise for the circulation in his legs despite family pleadings. His soberbia (arrogance) and orgulloso (prideful) reportedly prevented any DSM. He lost both legs, reportedly (by W10) suffered comorbid "arteriosclerosis" and succumbed to diabetes-related death. The alcoholic uncle of

W2's ex-husband and W3's uncle both also suffered lower limb loss and eventually died when they were unable to control their alcohol use.

The sisters of W1 *ignored* or *pretended* that they did not have diabetes even when one had a BG of 350 and the other had an almost-un-survivable BG of 1,000. Until they were frightened by their symptoms, both had not addressed DSM. One lost all of her teeth by 51 years of age. All of the participants knew people who had gone blind or been on dialysis. The mother of W9 preferred to enjoy eating whatever she liked "because I will die anyway" and suffered many complications and co-morbid conditions because she chose to enjoy food over the battle for DSM. Although, she lived to be 86 years, she had an agonizing end that terrified her daughter with diabetes into strict DSM. All of these people failed *Mastery* of DSM.

In summary, despite fluctuations in BG control over the years, most participants were *Mastering* +DSM and each of them knew what they needed to do as an individual to return to good T2D DSM habits. Each one had experienced a time when they did not have as tight of control, even if brief, and sometimes that was due to circumstantial stress outside of their control. All 12 were committed to +DSM habits and all had skills for successfully *Mastering* T2D, including W2 who had had a year of success prior to being off medications for the past dozen years. She knew the benefits and wanted to return to successful DSM.

Summary of Study Findings.

Many dynamics, conditions, and aspects of life influenced how these Mexican-born, adult immigrant participants *Negotiated* the every-day DSM decisions of conflicts (*battles*) between cultural requisites, personal enjoyment, and

long-term outcomes toward *Mastering* T2D. Supported, socio-cultural dynamics, norms, and expectations had the most significant impact on personal decision-making and behavior. In the culture, social etiquette required one to *be proper* and respectful so “as not to offend,”; one was expected to at least try *a little bit*. Thus, it was difficult for participants to decline; in fact, a man, “cannot say ‘no’”. It was difficult for participants to avoid social gatherings because, as a community-oriented society, the social expectation was that everyone and their family attend all festivities; those who did not stood out and suffered social disapproval. To stand out in this collective culture was neither desirous nor comfortable. The stigma of diabetes made the participant with diabetes appear more vulnerable, “weaker” so they tended to *hide* their T2D or *pretend* they did not have it so they could blend in with others. *Pretending* was deeply rooted in the culture; people grew up with it. Rather than decline food that was unhealthy and risk acknowledgement of their diabetes, they tasted *a little bit*, sometimes many times over. The result was short-term excursions of one’s BG that risked poor diabetes outcomes due to increased long-term BG; particularly given the frequency of social events.

A second important factor was the participants’ temptation to enjoy the desirous smells, flavors, and appearance of Mexican food. They wanted to taste various dishes and beverages; many foods had added social and family meaning. Even at home, it took *socially-independent-courage* for a man to decline food made for him or for him to ask that healthier foods to be prepared (M1).

Socio-culturally, the distinct roles of men and women played into their decision-making. *Machismo* in men both interfered with DSM and benefited men. As

a strength, male participants were able to do whatever they set their mind to do, such as abruptly stopping the use of alcohol at the diagnosis of T2D, as was the case with M1 and M2. Unfortunately, *machismo* had more negative outcomes especially when it interfered with *Accepting* responsibility for T2D and DSM, as with the father of W10. For some participants' family members (W2 and W3), the *macho* attitude toward alcohol led to male alcoholic-diabetic demise. *Machismo* contributed to the exaggeration of men *hiding* their T2D. They reported that a man could not fulfill his role as "strong;" he would be perceived as weak because diabetes was socially-perceived as a key vulnerability. Contrarily, the need for some women to have *permission* to address their DSM had both +DSM and -DSM outcomes. When a female participant did not have personal *permission*, despite *permission* from husband, family, and God, she was less likely to be successful in DSM. Once self-*permission* was achieved, her overall T2D picture improved because she had internal *permission* to choose self-care rather than always be "second" to family. The same was true with the maternal role. Those women who allowed the maternal role to interfere in their DSM had more short-term T2D inconsistencies and were at greater long-term risk. However, once the maternal role was seen as a *Motivation* for +DSM for the family's sake, she had BG improvements, and both the participant and her family benefitted.

Accepting the diagnosis of T2D was a key aspect of the participants' *Accepting* responsibility for all aspects of DSM and DSM outcomes. Those who delayed *Acceptance* of their diagnosis tended to withhold full commitment from DSM (W2, W3, W5). The perception of whether the participant might be at risk for T2D was inaccurate in some participants (W7, W9 M2). Once participants had symptoms,

their suspicion of illness was equally inaccurate (W1, W3, W5, W6). Only W10 was accurate in her level of perception of risk and suspicion of illness due to her father's situation. Those nine who *Accepted* their T2D diagnosis quickly also began DSM straightaway. The decisions to delay management versus act quickly affected short-term BG, emotional lability, affected family, and the cumulative long-term BG affects, respectively. In due course, all participants *Accepted* their T2D and the responsibility for DSM, including outcomes of DSM. In the case of W10's father, she believed he had *Accepted* his diagnosis, but *machismo* qualities interfered in his *Accepting* responsibility for DSM; he did *Accept* outcomes of his refusal to participate in DSM. Because he *orguloso* (behaved proudly) and rejected DSM, this recurring choice led to his demise; it was unknown if he fully *Accepted* his diagnosis.

DSM, on a day-to-day basis, was a battle for these participants. Repeatedly, they had to resist temptations for savory food at frequent social events and sometimes in the home. They confronted cultural conflicts with the urge to satisfy social requisites and expectations. They had to balance their struggles every day, several times a day, with keeping the long-term goal of preventing the consequences of poorly controlled BG from occurring. They simply had to keep the long-term in mind, all day, every day. Participants had to set priorities; they were more successful with DSM when they had a plan in mind before they left their homes for social events. As they developed habits of +DSM, they included practicing self-control and utilized their willpower to reduce the daily *battle*. There were many benefits for participants who developed good habits; most had done so. The disadvantages of not having good habits was recurring risk to short-term BG

elevation that increased risks to long-term control. Some had discouragement when they did not practice good self-control (W3, W4) and the battle was a bigger conflict.

Every IV revealed the importance of *Being motivated* to achieve +DSM. The two major aspects of *Being motivated* were love of other (W2, M1, M2) particularly children (W1, W3, W5, W6, W8), and secondly, fear of the consequences of poor T2D outcomes (W7, W4, W9, W10). *Being motivated* by either of these was strong in some participants. The consequences of strong motivation for decision-making toward long-term protection resulted in +DSM and generally well-controlled BG. *Being motivated* from within by something of dear importance to each of the participants resulted in their having +DSM that increased the possibility of long-term beneficial outcomes (A. Fortmann et al., 2015).

The *battle* (theory construct is *conflict*) was also addressed more easily for those with support, particularly *social support* and *shared caring* with others. W1, W2, W3, W5, W6, W8, W10, and both men had family members who supported and often shared in their diabetes care. This was an important way participants were able to fight the daily *battles*. Both W9 and W4 did not have as much support, but both had strong internal drives toward success. *Spiritual support* has already been identified as an important source of strength and resolve toward *Acceptance*.

The primary mechanism of decision-making in-the-moment were processes of *Negotiating*. Individuals utilized tasting *a little bit* and psycho-social mechanisms of *pretending, denying, putting aside, and rationalizing*, as previously described. When *pretending* was used in *Negotiating* with themselves, there were increased risks of essentially *ignoring* the impact of eating what they should not eat or too

much of it because their BG went up. Due to the stigma of T2D, it was common for them to *hide* their diagnosis, thus, they partook of foods they should not have eaten. They had all developed ways to *Negotiate* (e.g., navigate around over-eating in social settings, due to social pressures, at home). They utilized exercise, drinking a lot of water, and reduced their intake or skipped sweets and carbohydrates in following days. Exercise after excess caloric intake was especially helpful because it decreased their BG more quickly. The risk of modified intake in following days was that BG more gradually returned to normal, but the excursion might have caused harm in the long-run depending upon the frequency of their BG elevations. Most did not use extra medication regularly as a means of day-to-day management of elevated BG and did not approve of those who did; they knew the importance of keeping the long-term in mind rather than simply making short-term adjustments. They knew they needed to avoid stress, worry, and discouragement or grief because these raised their BG. Those who employed faith benefitted overall. There was a risk of thinking of prayer as magic, to have wishful thinking toward God; some knew Mexican people with T2D who did not apply self-discipline because they used prayer as “magic.”

The important accomplishment of having *Accepted* T2D and responsibility of DSM and having developed effective means of *Negotiating* social requisites, personal temptations, and all-important long-term protection goals was to achieve ongoing success in DSM; *Mastering* of diabetes through *Mastering* DSM. All 11 who had been practicing DSM prior to their IVs also had been successful for long periods; most at the time of the IV or follow-up (W2 had 1-year of beneficial experience in the past).

Four levels of *Mastering* DSM were identified. Some had attained more than one level of *Mastering* DSM. There were five participants, nearly one-half (W9, W3b, W4, W10, M1), who achieved consistent *Mastering*. Curiously, illustrating the movement between levels, three (W3, W4, M1) had experienced poor or compromised *Mastery* previously. Just over one-half (W1, W3a, W5, W6, W7, W8, M2) were *Mastering* DSM most of the time but had some degree of compromise that interfered with either short- and/or long-term outcomes; thus, they had the skills for *Mastering* T2D but did not always apply their best efforts. Two of the 12 (W4, M1) practiced poor *Mastery* for an extended period of time. Fortunately, they both had circumstantial changes that facilitated true *Mastering* of DSM, showed progress, and long-term protection. Most participants knew people who had failed at *Mastering* DSM; at least some of them did not address DSM, such as the father of W10. There was actual failure that led to loss of limb, vision, organ function, and death.

Even those who had recent increases in BG (W9, W7, W6) had developed the overall DSM skills and had the long-term goals in front of them. The effects on BG by the stresses in life and the decline of pancreatic insulin production had negative effects; those issues were being addressed or the participants were aware they needed to address their stress more effectively because of the long-term risks.

Access to care was available to all. Most had healthy or effective relationships with HCPs. The negative effects of childhood food scarcity had been quelled and there were no remaining HC system obstacles. The inquiry into antecedent factors in Mexico that might have contributed to emigration from Mexico did not appear to have a bearing on the decision-making or DSM habits of the participants. Several

came as a result of their parents' decisions and some of those had to do with sociological and economic factors; had their parents been investigated, possibly the response to pre-emigration questions would have been different.

The Substantive Theory

In summary, the substantive theory flows from the major factors that influenced decision-making by this cohort of Mexican-born immigrants with T2D: (a) powerful cultural requisites, (b) the personal desire to enjoy delicious Mexican food and to have immediate satisfaction while doing what everyone else is doing, and (c) the long-term need to maintain one's BG and avoid spikes or excursions that increased the risk of dreaded, long-term complications. There was a daily sense of *Being in the battle*, having conflict between these social, pleasure, and science-based forces. The goal was *Mastery* of DSM which equated, over time, to be *Mastering* of type 2 diabetes by the Mexican-born immigrant adults living in the United States.

The substantive theory is:

***Negotiating every-day diabetes self-management decisions
about conflicts between culture, personal enjoyment, and long-term outcomes
toward mastering of type 2 diabetes by Mexican-born adults.***

Serendipitous Findings.

Serendipitous, general findings included important difficulties in either understanding and reporting time sequences or keeping historical facts and sequencing in order. As has been demonstrated in numerous segments, there were difficulties obtaining historical data and understanding it in relation to other aspects

of symptoms and disease care. Each participant had difficulty with sequencing recall and clarity. This handicapped some data collection and had potential for significant errors between participants and HCPs. Similarly, important language issues arose and, without PI exploration, would not have been identified; some terms have opposing or very different usage and understanding in the two languages. For example, the term, *conveniente*, had opposing meaning. In Spanish, it referred to making the best choice for the long-term/choosing what is best for the individual decider, while in English it meant short-term and expedient choices. *Gracioso* in Spanish meant “funny” but in English, it was about being courteous, kind, polite, forgiving, and/or well-mannered. The concern was about understanding common terms used by both cultures that could be easily misunderstood among the participant, Latina RA, and PI. The ramification is the potential to misunderstand or accidentally offend others from the different culture.

Finally, one of the most important findings of the study was that these participants did not understand their knowledge gap between knowing they needed to practice DSM to avoid untoward effects and their ongoing efforts for *Mastering* DSM; control of short- and long-term BG. They simply did not know or understand that, due to the *progressive loss of insulin* production, no matter how well or faithfully they addressed DSM, they were at risk of eventually losing production of their own insulin and might have to use culturally-dreaded exogenous insulin to prevent the long-term consequences they each feared and worked so hard to avoid.

The final chapter will discuss how key study findings and the constructs of the theory that emerged from the data fits within or relates to existing literature.

Gaps in the literature, and how this initial substantive theory might address those gaps will also be addressed. Evidence will be provided to support study constructs.

Chapter 5

Discussion

Socio-Cultural Context

The Substantive Theory

Negotiating every-day diabetes self-management decisions about conflicts between culture, personal enjoyment, and long-term outcomes toward mastering of type 2 diabetes by Mexican-born adults.

Overview of Chapter

This chapter will summarize the most critical aspects of the substantive theory and those dynamics that had that most influence on the every-day *Negotiating* decision-making by Mexican-born immigrant adults with T2D as they sought to gain and maintain *Mastery* of their T2D through DSM. The substantive theory will be presented as situated in the current literature with discussion on how the theory advances understanding of decision-making in T2D. The implications for practice, research, and education will also be discussed. An overall summary of the study will conclude the chapter.

From the rich data of this intriguing study arose a set of constructs that explained the process of decision-making that the Mexican-born immigrants with T2D sojourned toward in *Mastering* DSM. *Mastering* was found not to be something achieved once and easily maintained; it was an all-day daily struggle of *Being in the battle* in order to choose effective DSM and had to be addressed throughout each day. The culture was collectivist, oriented toward community. Fixed roles, embedded values, and social identity often collided with delicious, tempting food.

These values and yearnings were at odds with the long-term need to maintain a steady, within-normal-limits BG level with little variation (Chamberlain et al., 2016). They were aware that insulin therapy was always a distant possibility; that was almost as frightening as the long-term risks of losing limbs, vision, or being on dialysis. The stigma of T2D worsened the situation because one could not appeal to others to understand that (s)he should not indulge in eating specially-made foods. To do so would expose the *sick* status of the person. Therefore, with the social pressure to comply with cultural expectations aside the relentless attractiveness of food and pleasure of indulgence, the conflict of *Being in the battle*, led to pressure to eat what one ought not to eat. The risk for accumulative loss of long-term function was once again present. At times, the *battle* was more often lost than won unless one's self-efficacy, strength of willpower and willingness to assert *social independence* overshadowed the pressing need to comply with one's collectivist-cultural expectations.

Community-Oriented Collectivist Culture

Prior to starting the research study, it was understood by the PI, who *had* worked for many years with the largely Mexican, H/L population in the clinical setting, that the cultural influences on the Mexican-born person with T2D would be significant. However, the pervasive impact of cultural and ethnic identity, cultural values, societal norms, expectations, obligations, roles, influences, beliefs, and experiences was truly underestimated in breadth, depth, and ramifications. In previous chapters, it was demonstrated that the H/L cultures are community-

oriented and collectivist in nature and substantiated in the literature. The following discussion delineates study findings in this literature.

Community-orientation. The salience of a community-orientation over an individualist mindset was powerfully observed throughout the study. From the early IVs, the primary constructs of the study began to emerge; clearly some identified concepts had to be further explored. This ongoing discussion lent important insight into understanding how compelling the perspective of the collective culture was - and how one fit into that culture. The distinct difference of the H/L culture from the dominant American culture was appreciated. In the American culture, one tends to think of the individual first and generally supports choice for the person before the group. Contrastingly, the underlying Mexican cultural-focus was on the communal, the cultural group as a whole, not individualistic in nature; this was clearly evident in nearly every participant IV. In this community-focused, Latin society, group membership and commitments as a group follower are more expected than among NHW Americans (Schwartz, Galliher, & Domenech Rodríguez, 2011). Study participants living in the United States for many years and routinely exposed to the highly-individualistic American culture retained a strong community-oriented outlook and approach to life (Jeong Jin et al., 2008).

Collectivism. Utilizing the nonpolitical, non-socialist definition of collectivism is helpful in understanding the phenomenon of putting the community before the individual as this was a recurring theme for several participants and reported by others as an essential element of their culture. Collectivism stresses the

salience of the family and community over the personal gains of an individual (Collectivism, 2016). Throughout the study, there was evidence of a collectivist outlook across participants who are consistently making choices that allowed them to participate in group functions without exposing their T2D. The concern for gossip against them served as an underlying boundary against standing out as different. These study findings correspond with the Chang (2015) study of how Latino and Asian college students utilized social support. The primary concern of the Latino students was to maintain group harmony. They were concerned that if they disrupted unity by revealing their needs they would be judged by the group. The three Mexican immigrant participants who had lived part of their childhood in the United States and were exposed in their youth to the individualistic American culture had the least tendency toward a collective mindset; they did not care what others said.

Cultural identity and ethnic identity. The concept of ethnic identity distinguished itself as participants discussed aspects of the culture that each one related to and to which individuals felt connected. They all took pride in their identity as Mexican, Mexican-American, Latino(a) or Hispanica(o) [see Table 1]. Much of their cultural socialization happened in their families. Various participants spoke of aspects of life that they had been taught and observed, ranging from learning about pretending behavior, playing dumb, ignoring what one did not want to contend with socially, observing how people they knew failed to manage their T2D, and the benefits of spiritual coping (Alamilla et al., 2016). A salient aspect of their cultural and ethnic identity was how they appeared to others; including how

they were viewed as belonging to the cultural group (Juang & Syed, 2010; Umaña-Taylor, Zeiders, & Updegraff, 2013). The participants who were more independently-minded and made choices for their own or their family's welfare met with friction by those who expected more conformity from them.

Cultural Values: Familismo, Respeto, Role-based and Rule-based society. As with any culture, as the values and morals of the culture become internalized, these gradually help to define primary characteristics of the culture and those who make it up. The external influence - including what each one has been exposed to, taught to think, and believes - becomes the internalized values and beliefs that contribute to the essence of each person. Cultural values undergird a culture, acting as a mainstay to the society of persons living within the culture, and these values serve as a type of guide for beliefs that influence and direct behavior (Choi, 2001; Johnson, Carroll, Fulda, Cardarelli, & Cardarelli, 2010). Traditional Latino cultural values practiced by the Mexican-American community include values of Familismo, Respeto, Religiosidad, and Traditional Gender Roles (Morgan Consoli & Llamas, 2013). *Familismo* is valuable, indicating close family relations that expand beyond the nuclear family to the extended family over the lifespan, including a wide assortment of "horizontal and vertical relationships" (Kao & An, 2012, p. 112). It is manifested by loyalty, reciprocity - the core reciprocal value of mutuality, shared by all in relationship, and solidarity (Dillon, De La Rosa, Sastre, & Ibañez, 2013; Kao & An, 2012). Once internalized values are demonstrated as an internal dynamism within each societal member, previously it had been an external force that gradually worked its influence. This enculturation of values occurs primarily at the level of the

family, within the home (Chávez-Reyes, 2010; Gamble & Modry-Mandell, 2008) as is the case in most cultures. Through the development of values occurring within the family, the individual also learns that it is the family that will take precedence in one's own beliefs and values (Calderón-Tena, Knight, & Carlo, 2011).

Familismo - Family comes first. For the typical Mexican family, it is understood that at the core to these cultural values, the family is the first priority. Dillon et al. (2013) reported that, for Latinos, la familia or the family is considered the primary, and sometimes only, resource for help, strength, direction, and encouragement for each family member. Typically, the family is central, "family centeredness" (Baig, Benitez, Quinn, & Burnet, 2015, p. 100), and often serves as the shield from various types of threats ranging from health to the honor and dignity of the family (Dillon et al., 2013). Dillon et al also asserted that, since the family was a unit and the concerns of the family unit were placed at highest value above each individual, it followed culturally that the concept of family was seen as an extension of the self. This commitment to family solidarity included efforts to avoid all forms of confrontation or opposition (Sotomayor-Peterson, Figueredo, Christensen, & Taylor, 2012).

As reasoned earlier, the value of cultural identity, that community/culture as a whole takes precedence over the individual parts, it flows conceptually that focus on family precedes the singular. On the day-to-day basis, the family is the immediate community that has priority over the individual because the whole of the family is more important than the individuals who comprise it. "... You grow up a certain way that you always think the family's first than anything else" (M2). There is great

cultural strength in the family. Traditional Latino values have been found to predict resilience (Gamble & Modry-Mandell, 2008; Morgan Consoli & Llamas, 2013).

Of collective importance, it is essential to benefit the family, the community first. Thus, it is routine for persons of Mexican heritage to avoid standing out so that they minimize distracting from or lessening the whole. Reciprocally though, the reduction of self naturally does occur, even if unintentionally. This has important ramifications for the person with diabetes as decisions about most DSM are done by the individual on a day-to-day and choice-by-choice basis. This brings an interesting dilemma. If the whole is functionally more important than individuals who make it up, then individuals who choose the individual-self risk reducing the value of the group or standing out with personal needs that, to some extent, violate the value of family /community. One might think, "If I'm not independently important, then choices that I make for me are not as important as choices for the community or family. Thus, I should choose family over self..." One does not want to appear as being more important than anybody else because the whole then becomes devalued. Choosing one's self risks reduces the value of the group and interferes with conformity. Once again, having to choose the corporate over the needs of the individual is a true and recurring challenge for the person with diabetes and this conflict, often a true dilemma was shown to conflict with DSM choices, for both women and men. It placed some women at a considerable disadvantage for DSM because they had to choose family, children, and spouses before they could choose their own needs as a person with diabetes.

Respeto – Respect. Being Proper. Respect for authority. One of the dominant themes identified in this study was the absolute importance of *Being proper, of showing respect* for other, in both settings of authority and in general regard with deference to others. Often in IVs, a participant referred to *Being proper* or not to be rude, and some spoke of the importance of showing respect with dignity. The Spanish term *Respeto* was never used; however, it was clear that what was being described was to show respect to others. Similar to the literature describing *respeto*, respect, was/is to be shown to all people, particularly to those who are older and/or in authority, and can be various family members, especially “male figures in authoritarian atmospheres” (Morgan Consoli & Llamas, 2013, p. 618). *Respeto* restrains negative attitudes and discouragement and seeks harmonious relationships with others. Because close, social relationships are an important aspect of the social culture, *respeto* shows regard for family and especially elders; it emphasizes the value of family (Ashida et al., 2010). Chavez-Reyes expands the discussion of *respeto*. Children are raised to be respectful members of their family and society at large, to show respect, and dignidad, dignity, to other members of one’s family and society indicating that a primary lesson of lower-class children is the import of dignidad and *respeto*. This sometimes includes “addressing parents in the Usted, formal voice” (Chávez-Reyes, 2010, p. 505). Similarly, an important aspect of relating to others, according to a clinician working with the population, is the “element of formality in Hispanic interactions, especially when older persons are involved” (Kemp, 2005, p. 4) and that verbal and non-verbal interactions are to be respectful in nature.

As important and considerate as respeto and dignidad are to the internal communications within the culture, this social expectation to defer to others, particularly elders, those in authority, and family presents a complicating dynamic to the Mexican person with diabetes. As was illustrated in Chapter 4 Context, when an older family member gives advice or passes down decades-old health information and methods, the person receiving that information has an obligation to accept it and act on it so as not to be disrespectful. Ashida et al (2010) confirmed both the advantages and disadvantages as family health information is disseminated within a family. While it provides a context of health and health promotion, it can easily cause a conflict for the person with diabetes. Once again, to comply with the cultural standards places the person with diabetes at short and long-term risk. When the elder recommends to the person with diabetes that she should mix and drink pineapple, cactus, and agave every morning as some sort of health concoction, the person with diabetes is immediately in a quandary or dilemma. No matter what the person with T2D chooses to do, (s)he or he will be making an inappropriate choice. The person with T2D cannot drink the concoction if (s)he wants to have BG control on any given day. Yet, to not follow the advice is not respectful of the elder's recommendation. It is not appropriate to try to teach the elder that the younger person with T2D has better information since that advice has been passed down for generations. At the beginning of the day, the person with diabetes already has a difficult choice to make.

Role-based and Rule-based society. The before-study anticipated roles for both men and women repeatedly were demonstrated and clarified, affecting how

one both viewed her or his T2D and responded to demands, needs, and expectancies of those around. Society is the environment or the community surrounding persons (Identity, 2016) including a people that have developed patterns and ways of relating, with shared traditions and institutions. Much of the function of this society is fulfilling one's role or roles in relationship to and within the culture. In the Mexican culture, a customary approach to roles is learned early. Girls observe their mothers, grandmothers, older sisters, aunts, cousins, and other females in the society in order to learn what is expected of a girl to be woman. Likewise, boys observe their fathers, grandfathers, other male family members, neighbors, and other men around them to learn how a boy should behave, think, and respond as he becomes a man. Beginning these observations and responding to verbal instructions at a young age means the role becomes ingrained in one's youth (Morgan Consoli & Llamas, 2013); this is an active enculturation (Fisher et al., 2000). Through this process of observation and the practice of the appropriate role, one's consequential identity develops. There is a validation process in this as well – one is becoming who she or he is culturally designed to become and contributes to the collective continuation of the family, the community, and the overall culture. The resultant positive feedback adds further support to the continued development of individuals in these corporate functioning roles.

Thus, there are social expectations and societal rules with which each one is expected to comply. As with other aspects of the culture discussed above, the social rules and obligations are learned early and reinforced in most aspects of the culture – home, social gatherings, the workplace, common public arenas, and toward

authority. They are meant to guide the functioning of society and provide structure for the overall good. However, the disadvantage is that cultural requirements can be extreme or demanding and can place a person in a true dilemma having to choose cultural mandates against legal and/or ethical requisites. Such was the case with W10 when, as the younger sister, she was requested, that is required, by her eldest sister to do something that put W10 in legal jeopardy and an ethical dilemma. She felt constrained by powerful cultural rules to obey her sister, but in so doing she was at great risk legally. What was worse for her was the ethical dilemma of knowing she was choosing to do what was wrong and she violated her own conscience. Although, she was able to rectify the legal matter, the dilemma placed her in such personal conflict - she was emotionally betrayed and traumatized - that T2D developed within a few months of those devastating events. She obeyed her cultural rules, but she violated ethical and legal boundaries and never had full resolution; she had only poor outcomes and the knowledge that she had been obedient. The relationship was permanently damaged. When role and rules surpass ethical and legal norms, the rules no longer serve well as a socio-cultural guide.

While *familismo* was credited with having the most influence, traditional gender roles contributed to resiliency (Morgan Consoli & Llamas, 2013). According to the participants in another study that looked at gender-role, indigenous cultural expectations suggest that care of and feeding the family was the role of women and, not unexpectedly, the male's role was to provide for the family's financial or material needs (Cuy Castellanos et al., 2013). An interesting study examined work-family conflict in Latino immigrants and the implications for health. One aspect they

studied, related to this current study, was the effect on women of dual roles of working outside the home and managing their families. They determined women did have more work-related health outcomes due to job demands than did men (Grzywacz et al., 2007). One of three themes in an international, systematic review of studies of ethnic minorities identified barriers to self-care related to gender roles. Men had a tendency to concentrate on the physical effects of T2D. Women, on the other hand, discussed more general concerns about having a poorer health status. Gender influenced how they perceived support as well. Men reported having strong support of their families, but women expressed feeling unsupported (Majeed-Ariss, Jackson, Knapp, & Cheater, 2015).

An important, recent study examined related issues to the current study, including the meaning of adults having T2D, how they coped, problems they confronted, and strategies used to manage their disease daily (J. Li, Drury, & Taylor, 2014). Similarly, they found that the women were challenged by their multi-caregiving roles which were complicated by trying to manage their T2D at the same time. They found that women were emotionally and mentally challenged, and they needed support from others, including spiritual support. They took personal responsibility for their own T2D and felt it was important to maintain their autonomy. The parallels to this study are intriguing. In the current study, some women faced the emotional and mental challenges of life's responsibilities and tending to their T2D, although women who were retired in this study did not have the same conflicts as those with children and those in the Li et al. study. The need for and evidence of the benefits of support in the current study were relevant to all

participants except one; another with limited social support had spiritual support. Four of the 10 in the current study reported spiritual support as well. Because each participant had *Accepted* their diagnosis of T2D, they also took personal responsibility for their DSM, as did those in the Li study. Autonomy was less of felt-concern to participants in the current study; however, each participant did function independently. An additional role-related finding was that, despite the women's commitment to self-care, they often placed their family's needs above their own (J. Li et al., 2014), and like the findings in this current study, they also suffered ineffective DSM when they chose family needs over their own T2D needs.

Cultural Characteristics

A distinguishing feature of the participants' Latin culture was the quality of not being in a hurry most of the time, living in the now. During one of the IVs, multiple aspects of the culture in general were discussed. The female participant went into considerable depth discussing the factors that contribute most to decision-making for the Mexican-born person with diabetes. The IV with her was profound, as were several others that followed because of the large inter-connected, underlying, aspects of the culture that came to light. During part of the discussion, the participant, the RA, and the PI were clarifying the term *convenient*, discovering that the Spanish and the American English definitions are markedly different from one another; having no similarity. [This will be discussed in detail in the Intervening section under Language Differences.] What emerged from that discussion, relevant to cultural characteristics were the stark differences culturally in the attitude and speed with which persons in each respective culture are accustomed to living. In the

smaller Mexican towns in particular, there were no businesses into which one could walk, grab an item of desire, pay for it, and walk out quickly in a moment's time. Presently, the possibility exists in the larger metropolitan areas. The RA who lived all of her life in Mexico, except during the previous 2 years, exclaimed in laughter "Nothing is quick in Mexico!" to which the participant laughed, shook her head in agreement and said, "NO!"

The culture and the meaning of food, taste and smell. From prior observation of the culture by the PI over the course of many years, it was understood that food played an important role in the social aspect of Mexican culture. As the study progressed, however, more had to be explored about the actual meaning of food because it became clear that food and eating were not simply the central focus for socializing and enjoyment, although these were clearly essential to the socialization aspect of culture. The sensation of food was more than taste or meaning as was summarized by an articulate participant in Chapter 4. Her English was good, she is well-educated, and she had given a great deal of thought to the line of interview questioning while serving as RA. In her final interview, major constructs of the study were further solidified with helpful detail that elucidated a number of well-developed and saturated constructs and concepts. She discussed the context, indicating the importance of food, an aspect of which was the immediacy of it through its appearance, "about the way food looks and what food represents in the culture makes it have a really strong pull" (W3). Those participants who discussed food found symbolism and emotional-psyche connection of food in the Mexican culture are deeply experienced. Consequently, the ramifications for the

person with diabetes are much clearer as a result of this study. An interesting study in New York City examined consumption of traditional staples used by Latinas and found that nostalgia played an important role. Over time, the Latinas tended to consume foods in higher caloric value and progressively abandoned fresh fruits and vegetables. Authors recommended that HCPs should consider barriers that interfere with Latinas being engaged in healthier lifestyle, particularly healthy foods, when living in the United States (Viladrich & Tagliaferro, 2016). The nostalgia aspect paralleled findings in the current study where participants reported that some foods were more meaningful despite the fact that their nutritional value was compromised by higher calories and glycemic-increasing qualities; the participants preferred them because they had a “strong pull.” Some participants had reported that the diet in Mexico was healthier with less starch, grease, artificial ingredients and sugar; the Mexican diet has protective features such as high fiber (Jones et al., 1997). They either had felt poorly or gained weight on the American diet. This is consistent with results by Sharkey, Johnson, and Dean (2011) who found that American-born Latinas had a higher consumption of fast food and high sugary beverages than Mexican-born Latinas.

Cultural perspective on T2D; stigma; and insulin. In the course of seeking to learn what sort of information each participant had about T2D, it eventually became clear that there were two types of knowledge about the disease. The first was social knowledge, the cultural standard of knowing about T2D, what people learned from observing those who had it, how others around them responded to people with diabetes, what they were told about T2D by people who had it and by

those who had known others with it, and what was told in the community. The second kind of knowledge, part of what the study sought to learn, was the participants' level and degree of health-science knowledge of T2D. During one of the analysis meetings with a member of the PI's dissertation committee, the PI became concerned that there was a limited understanding in people with diabetes, as noted in the participants, in particular about the progressive nature of the disease (i.e., progressive loss of pancreatic insulin-producing function). Not one of the 12 participants had any understanding of this concept. However, the committee member suggested that these individuals "know a lot about diabetes from what they've learned from others." Both of these perspectives were true and well-substantiated in this study. What came to light in this discussion was the salience of the cultural social knowledge. It led to the question, "if one lives more 'in the now,' maybe one simply does not think or does not know how to think 'progressively?'" Thus, the importance for HCPs to understand the variance between cultural social knowledge and patients' understanding of broad, health care facts was important to know. From the standpoint of future application of study findings, this was one of the most important outcomes of the study.

Diabetes is a stigmatized disorder in many cultures (Bock, 2012). Within the H/L culture, T2D is a stigmatized condition (Hanson & Kerkhoff, 2007; J. Li et al., 2014; Weiler & Crist, 2009) outside the culture, the H/L with T2D is stigmatized with illness, access, language issues, and structural barriers (Hanson & Kerkhoff, 2007). In the study of older women coping with T2D, stigma was an issue; some participants experienced a threat to their sense of identity. They perceived that

“others no longer saw them as a person, but rather they saw them as the disease of diabetes” (J. Li et al., 2014, p. 128). Weiler and Crist (2009) explored the sociocultural influences and social context related to migrant Latino adults living with T2D in Arizona, where the “meta-theme of self-management in a social environment emerged” (p. 285). The four major themes included family cohesion, social stigma of disease, social expectations/perception of “illness,” and disease knowledge and understanding, all of which were influenced by the social context. All of these were likewise identified in the current study. Similar to this current study, participants in Weiler and Crist’s (2009) study reported that the social perception within the culture was that people with T2D were sick and identified a social stigmatization encompassing T2D. Even more, some participants in the Weiler and Crist study reported being emotionally devastated when they were diagnosed. One said “In my Hispanic culture I’ve seen it all the time, that anybody that had T2D was just about the worst thing that there was, nothing compared to it, not seizures, not hypertension, nothing. Diabetes was a horrible monster; you were worthless if you had diabetes” (p. 289).

Due to the advancing nature of the disease, the actual progressive loss of pancreatic insulin production over time, despite how well one maintains one’s BGs day-to-day and hour-by-hour, it is almost guaranteed that the person with T2D if she or he lives long enough will exhaust their ability to produce endogenous insulin (Balkau et al., 2015). Consequently, there is a genuine possibility that (s)he will need to use exogenous insulin. However, insulin, even more than T2D, is taboo in the culture. The ongoing recommendation by “the people” in the culture, is that insulin

“is bad” and “you die when you start to use it” (W3). This fear of possibly having to use insulin sometime in their lives is frightening; and not only to Latinos (Bahrman et al., 2014; Miller & Powell, 2014). Thus, when participants refused to consider the future need to use it, such as was the case for at least three, there is a risk of *wishful* thinking or *ignoring* of facts about the benefits of exogenous insulin. These common cultural approaches put one at risk of potentially *denying* her or his need for or refusing the thing that could prevent the dreaded outcomes they had witnessed others suffer (Nam et al., 2014; Petrak et al., 2007).

The importance of being *borderline*; the importance of taking *only one medicine*. Numerous times during the IVs participants indicated that their goal was to need the fewest number of medications possible and *never* to need or use insulin. It became clear it was important to be *borderline*, to not actually have T2D and to hold off the diagnosis for as long as possible. In this appearance-based Latino culture in which T2D is a stigma and because of what T2D represents, the more medicines one takes indicate that the state of one’s T2D is worse than one cares to admit and, than one is able to control on one’s own accord. Despite the participants knowing that this serious illness represents risks to vital organs, the desire to not have the stigma of T2D or to only have a mild case of the disease was strongly preferred (Bock, 2012; M. C. Hansen & Cabassa, 2012; Weiler & Crist, 2009). Based on the cultural stigmatization of T2D, it follows that it was important to the Latino to stay on the edge of the precipice, as so many Mexican persons do, rather than fall into the dreaded abyss of T2D.

Summary of the Context of the Study

The Mexican culture is a highly communal culture and has a community-orientation. Being collectivist in nature, each member views her or himself as a partner first of the community, particularly the family. The view of self as individual is not a tenet of the society, thus, social rules and roles function around the community (e.g., family, group) not the individual. However, each individual is important, not for the sake of the one, but for the sake of the whole. Each has their place and is expected to fulfill their role and duties for the benefit of the whole. The family, *familismo*, is the core cultural unit. All decisions should benefit and consider first the needs of the family; it represents the culture. Cultural identity provides a sense of *belonging* and ethnic identity provides a sense of identity with which one identifies as part of the whole. Other primary cultural values are *respeto*, respect for each other person and authority, and is the core to '*Being Proper*;' how one demonstrates regard for others in this more formal culture. Each person has given roles and is expected to fulfill those roles always within the context of the rules of society. While rules and roles provide substance and structure to the culture, sometimes they take precedence over the needs of others, over ethical choices, and/or over legalities. When not in balance, they affect choices about DSM or the health of the person with T2D.

Food is critical to the society, a central focus for gathering, and has meaning in and of itself. Food is important to culture, period. However, the sight, smell, and taste of Mexican food is not only pleasurable, it has meaning and provokes important memories and family values. Latinas work hard to prepare meals and it is

expected that everyone will at least have *a little bit*. This causes small and not-so-small conflicts for the person with T2D who both wants to eat the savory food, but knows (s)he should not, even though (s)he is socially obligated. This is clearly the accepted cultural standard. By accepting a small amount or eating *a little bit*, one is bargaining, or *Negotiating*, as one neither has to refuse what is offered, which can offend the hostess, nor expose one's diabetic status. This does affect BG; but it is not possible especially for men to say "no" because they will "offend," a cultural taboo. This presents a true dilemma for the person with diabetes because if (s)he eats what should not be eaten, his or her BG goes up risking cumulative LT poor outcomes. If these individuals do not eat what is offered, they violate cultural rules and values, risk offending others, risk standing out as different than others, and risk exposing their stigmatized disease. One tries to remain in the borderline category as long as possible so as to avoid being seen as sick or losing one's identity and being known as the person with diabetes, a status that is wholly undesirable.

Influencing Conditions

The goal of diabetes care is for the individual with T2D to self-manage her or his daily BG as close to the established normal non-diabetes serum range as possible. Participants understood the primary DSM components expected of them and were aware of general goals. The major aspects of DSM were well-described by participants; some did not understand the A_{1c} test. In general, they were practicing the behaviors necessary for successful T2D outcomes and most were within desired ranges, although not always. Some comprehended the rationale behind the recommendations that serve as a guide to achieve good BG control, the hallmark of safe DSM. Exemplars from each guideline demonstrated how participants addressed/attempted to accomplish the health science-based goals of DSM through routine activities.

Participants understood that damage occurs to one's organs in the presence of recurring and/or prolonged elevated BG levels and that over time DSM facilitates the fewest and least serious changes from occurring. They recognized that healthy functioning of organ structures and tissues were core to good health, the extent and quality of one's life, and that they needed to avoid frightening, unpleasant, and other life-altering consequences. Although they did not like some aspects of successful DSM, they knew they needed to practice it to prevent irreversible organ system changes that led to decreased quality of life, loss of organ function, and eventual diabetes-caused death. All participants had known/observed others suffer serious consequences of poorly-managed BG.

Participants understood that HCPs, family, friends, and associates can provide support, guidance, education, boundaries, and reminders. Also, supporters could purchase and prepare appropriate foods and beverages, come alongside them in decision-making, exercise, or routine laboratory analysis. However, it was ultimately their sole responsibility as the person with T2D to accomplish daily management of their own condition through BG control. Essentially, they knew that only they can manage their T2D. Each one understood, sometimes painfully, that the ultimate goal is consistent, routine, and habitual control of their BG. This required them to supervise their daily BG to maintain the normal range, assure that they exercise to best utilize their BG, make wise meal-by-meal, snack-by-snack, and beverage choices, and for all but two, use of medication. Thus, the repetitious and wearisome, often monotonous decisions they made on the hour-by-hour, day-by-day, week-by-week, month-by-month, and year-by-year basis determined whether and how quickly undesirable, elevated BG-related changes occur. Each one sincerely desired to extend and protect their overall health and life quality.

The literature on influencing conditions and dynamics.

There were a multitude of intervening conditions and dynamics that impacted decision-making including: (a) all facets of DSM (Ashida et al., 2010; Bagnasco et al., 2014; Chamberlain et al., 2016; Schulman-Green et al., 2012; Schulman-Green et al., 2016); (b) important social and cultural expectations and influences, particularly roles of both genders (Barnes et al., 1998; Davis & Liang, 2015; Marvan, Quiros, Lopez-Vazquez, & Ehrenzweig, 2012), and the critical need to at least taste *a little bit* as essential to *Being proper* (Jeong Jin et al., 2008; Morgan

Consoli & Llamas, 2013); (c) health beliefs, cultural myths and often-inaccurate health-science knowledge (S. A. Brown et al., 2007; Lemley & Spies, 2015); (d) personal characteristics, particularly *being socially independence* and personal effectiveness, also known as *self-efficacy* and *internal locus of control* (Flores, 2004; Liu, 2012; Peyrot & Rubin, 1994; Ramal et al., 2012; R.-H. Wang et al., 2016); (e) conflict in aspects of life such as stress, worry, anxiety, grief, loss, unresolved grief, distress, discouragement, sadness, and depression (Cabassa et al., 2008; A. L. Fortmann, Gallo, Walker, & Philis-Tsimikas, 2010; Gallo et al., 2014); (f) unrelenting temptation with significant impact; and (g) various forms of support through social networks and family, *sharing care* between person with T2Ds and those who participate directly in DSM, and spiritual support (August & Sorkin, 2011b; Davidson et al., 2015; Gleeson-Kreig, Bernal, & Woolley, 2002; Hu et al., 2013; Skolarus et al., 2012). These conditions and dynamics were invaluable to most participants.

Aspects that interfered with or served as barriers to DSM were examined also (Collier et al., 2011; McCloskey & Flenniken, 2010). They included: (a) the language barrier of speaking English as a second language; (b) low HL that hindered with learning and behavioral response to DSM (Broome, 2012; S. H. Kim & Lee, 2016; Sarkar et al., 2011; Swavely et al., 2014); (c) distinct cultural-language differences in the meaning of the identical words that could have profound impact on understanding between a patient and HCP; and (d) education level and its effect on comprehension and communication (Menke et al., 2015; Tovar & Clark, 2015).

It was suspected that pre-immigration, emigration-antecedent factors might affect DSM decisions by participants in this current study. They included: (a) socio-cultural religious concerns, (b) geopolitical dominance by the ruling elite, (c) serious economic issues and poverty, and (d) environmental and ecological damage; they are described in Chapter 2 Literature Review – Mexican-born Immigrants – Reason for emigration. *How* these might influence emigration or how life in Mexico may have influenced DSM was unknown. Nevertheless, as interviewing proceeded, it became clear that those factors were not reported to influence the decision-making of DSM. The majority had left Mexico a few years prior to the onset of diabetes. They described their lives, eating habits, and responsibilities as different than in the United States and unrelated to their diabetes, with the exception of the two participants with borderline diagnoses in Mexico. Some of them referenced decisions made by their parents to move their family to the United States were related to economics and or education and others referenced the same as their own choice; corruption as a cause of emigrating was identified by one.

The fact that all participants had access to care and eventually had health care provision was significant as was the trust level between them and their HCPs (Davidson et al., 2015; Gonzalez et al., 2013; Mainous et al., 2007; Nath, 2007; Strain et al., 2014). Health care systems issues particularly impacted those who had not been accurately diagnosed in Mexico; one had less effective care in the United States (Coffman, Shobe, & O'Connell, 2008; Jennifer B. Hunter et al., 2003). The *Pre-Discovery* status of the participants before *Discovering* that they had T2D was an important period. In all, the most impactful was their level of *Being motivated* and

the sources of *Being motivated*. In this section, *Motivation/Being motivated* will be examined per the current literature.

Motivation.

In preparation for the study, the concepts *influence* and *affect* were the primary factors to be explored in the IVs. Both influence (*influencia*) and affect (*afectar*) were understood to be external forces that would come to bear on DSM decision-making in the Mexican émigrés. During the first IV, however, W1 spoke as though she had *internal Motivation* for practicing DSM, as recorded in Chapter 4 Results – Intervening – Motivation. It became clear that *Motivation was/is* a response from *within* the individual. *Being motivated* developed into a powerful construct that affected choices by all of the participants. *Motivation was/is* founded on personal, familial, and cultural values. Through analysis and co-analysis, it was recognized that *Motivation/Being motivated* alone was not sufficient to bring about change; some participants identified *being motivated* but that did not prompt +DSM behavior. One needed conviction in order to have *Motivation*. *Motivation* could be circumstantial. The situation might be such that one was *Motivated* in the context of a given moment. Those who were *Motivated* to learn and apply DSM wanted to be healthy to live longer. The *Motivation* had to be adequate and sufficiently meaningful to promote +DSM or positive behavior change. Participants described both internal and external *Motivating* forces; the literature supported both as well.

Adequate Motivation is required and helps to create behavior change.

Other chronic illnesses that depend upon self-care (SC) are faced with similar *Motivational*, self-efficacious, and other dimensions of SC. In a study about asthma

SC (ASC) authors hypothesized that asthma patients' *Motivation* to change SC behavior was driven by how they understood their illness, the strength of their beliefs about how important it was to change their ASC behavior, their level of self-confidence that they would be able to change their ASC behavior, and their emotional response to asthma and treating it. Authors found that participants "Reasoned *Motivation*," (Denford, Campbell, Frost, & Greaves, 2013, p. 1419) a combination of confidence in their ability to change (self-efficacy) their ASC and how much importance they placed on changing their behavior. Similar to the current Mexican DSM study, *Motivation* alone was not adequate to change behavior due to other intervening conditions. An example was the patient who did not use his medication because he did not believe he really had asthma; this was similar to how the delay in accepting T2D by participants in the Mexican DSM study led to delay practicing DSM. The authors revised the model to include both the understanding of the illness and affective response, as these influenced the patients' *Motivation* to alter their ASC actions. They also determined that the delivery of how to do SC (comparable to DSME) was equally important as the content.

A DSM-related study also found *Motivation* to be an important factor in behavior change. Five factors that influenced initiation of a DSM program related to dietary changes were examined, one of which was *Motivation*. Support, knowledge, empowerment, and relationship shift also impacted the adjustment made in the amount of food that participants ate (Murphy et al., 2011). Findings on internal and external motivation are presented next.

Internal – autonomous – *Motivation/Being motivated.* An important aspect of internal *Motivation* is one's interest in one's own welfare (Nouwen et al., 2011). In the current study, this involved love and respect for one's self. These factors served as positive motivators, propelling the participants toward +DSM for preservation and protection of self. Other internal *Motivators* were experiencing physical change, such as fatigue or neuropathy, blurred vision, and seeing changes in one's BG numbers (e.g., SMBG, A_{1c}). Also, when the participants experienced a personal threat, it promoted striving for self-preservation; having fear provoked behavior change to +DSM. Even being discouraged had the potential to stimulate self-preservation through +DSM.

Studies that attended to internal *Motivation* in SC supported several findings of the current study. For example, Nouwen et al. (2011) evaluated constructs from social-cognitive theory and self-determination on dietary outcomes and T2D control. Dietary SC had a longitudinal association with self-efficacy and *autonomous motivation* (e.g., the *internal motivation to do what is best for the self*) but not with the controlled motivation that has to do with external expectancies. Thus, those who were motivated from within and had more self-efficacy had better dietary control. This finding corresponds to the Mexican Immigrant study as the same was true for several participants.

A similar study also examined the relationship of autonomous *Motivation* and DSM behaviors. Subjects completed multiple surveys on DSM, health literacy, social support, health, and self-efficacy. Again, *autonomous motivation* was the single variable with a marked association to maintaining diet and SMBG testing. That

cohort of 77 non-Hispanics did not exercise regularly, including those with sufficient HL (Shigaki et al., 2010). Similar to the current Mexican Immigrant study, the Tanenbaum et al. (2015) investigation found that fear of complications served as a strong motivator that led to changed behavior. An aspect of their conviction came in *ah-ha* moments when participants' BG was high and they saw they needed to change. In a study that looked at a different chronic illness, rheumatoid arthritis (RA), researchers found that those subjects who believed strongly that physical activity could help to manage RA had an elevated level of *Motivation* to participate in physical endeavors and a higher level of actual physical activity (Ehrlich-Jones et al., 2011).

Motivation does not necessarily remain internal or external; it can traverse from one form of *Motivation* to another. For example, one may have internal *Motivation* based on the fear for one's self, especially if one has had a personal brush with death or loss of limb, one may be more motivated to +DSM. Negative modeling may be stronger than positive modeling due to fear of consequences, "I'm scared to death," but out of concern for others, such as children, one's *Motivation* may refocus to an external *Motivation* – *being* motivated by forces outside of one's self. Once one learns about and internalizes DSM to practice +DSM habits, it is easier to focus outside of the self. At some point, one is able to start focusing on others outside of self for one's *Motivation* toward +DSM. One moves from initial internal self-preservation *Motivation* to external concerns for others. One may understand based on a level of knowledge affected by *Accepting* T2D [see Chapter 5 - Decision-making].

External motivators. *Motivation* from outside of oneself can also come from a multitude of sources. Those who have personally observed the suffering of others, particularly loved one(s), are motivated toward +DSM; it is a strong motivator, not for fear for self alone, but the burden it causes others. On the other hand, the love of other(s) was one of the two strongest motivators in the Mexican Immigrant study. Not wanting to be a burden to family members or embarrassment at loss of independence were external motivators. Temptation is a powerful *motivator*, particularly when the focus is satisfaction of enjoying the food. Temptation and willpower are linked to *Motivation*. Depending upon the response, it can lead to +DSM or -DSM. Temptation to eat good Mexican food creates conflict because it is “difficult to have really good *Motivation* if it tastes so good!” Another external motivator was trying to avoid conflict, “I don’t want to have any problems with anyone.”

An interesting study evaluated the *Motivational* effects of interpersonal engaging emotions in Mexican and Euro-American college students. Briefly, the Mexican students were most motivated by relational factors such as *simpatia* and *personalismo*. When they felt interpersonal engagement, they performed better on testing; the opposite was true when they experienced negative or disengaging emotions. The Euro-Americans were not affected by engagement or disengagement (Savani, Alvarez, Mesquita, & Markus, 2013). Tapping into the relational aspects of Mexican persons has a higher likelihood of *motivating* them toward goals.

A fascinating cultural phenomenon was observed in some female Mexican immigrant participants when they were *Being motivated* by the value of love for

their children, to choose care of self *before* care of others. The relational value of love rose higher in importance than the cultural value of placing family first. The latter, the cultural value and practice of *family first*, involved the cultural requisite to *place* the family first, an expected obedient/socio-cultural obligation. Except in the case of *Being motivated* by love, it was not about a woman, the mother, practicing the social norm of placing the family first because the social norm allowed her *not* to take responsibility for DSM; rather, the social norm required the woman to choose family above DSM. In this case, she would not choose herself because it would appear selfish to choose herself over her family. on the other hand, when the woman was sufficiently, *socially independent* to *choose* to take care of herself in order to care for her family, she was vicariously able to benefit the object of her love – her children. In choosing herself (i.e., her SC/DSM) to be well for the sake of her family, the result was that she chose the long-term well-being of her children and her family. Her choice was not selfishly for herself; although it benefitted her health greatly. This ironically, puts *Being motivated* outside of self, outside of autonomous *motivation* and places it back into family, into the heart of community. Because the *Motivation* was love of other, not selfish love and not blind obedience to cultural requisites, *Being motivated* by the love of other was a higher value.

Summary of Motivation/Being Motivated. *Motivation* was a dominant force in DSM decision-making by the participants in this study. They were aware of many facets that affected DSM and decision-making. The inquiry about *Motivation* was participant-generated; it was evident from the first IVs that *Motivation/Being motivated* was an internal factor that drove participants to SC. *Motivation* was

driven by both internal forces, such as fear of the consequences of uncontrolled BG, and externally driven by concerns outside of the participant, such as love for family or not wanting to be a burden. Studies support both autonomous-internal and the external *Motivational* forces. The most interesting was when internal *Motivation* switched to external for the sake of love of children. The participant(s) behaved similarly to when they obeyed cultural rules of choosing family, but the *Motivation* was exclusively for love of other. Thus, the focus of the mother was back on the family but for the purpose of love of family, not for serving cultural rules and roles that required family first

Decision-Making, Interactions and Actions

Diabetes is primarily managed through activities requiring self-management. DE based on the Western biophysical model teaches DSM to prevent long-term complications of hyperglycemia. Persons from Mexico have a unique, culturally-based mental model of disease that contributes to how they self-manage the disease, particularly how they make decisions about DSM. There remains a need for HCPs to understand the factors that influence the processes of DSM decision-making in the immigrant to be able to teach DSME more effectively. A gap exists in knowledge and understanding between HCPs and Mexican immigrants about T2D as neither group truly understands the other's perspective (Hatcher & Whittemore, 2007; McSweeney et al., 1997; Poss et al., 2003).

Multiple aspects go into the complex process of decision-making, the stages of which have not been well understood. Cultural and contextual influences were potent persuading factors on DSM of émigrés from Mexico with T2D. The assumption has been that, if HCPs better understood the decision-making process and influencing factors, they will be better equipped to intervene in the decision process from the perspective of the immigrant and teach improved DSM behaviors. The findings of this study may assist HCPs to more effectively intervene in DSM decision-making in this population and result in reduced complications while promoting improved quality of life.

Many dynamics, conditions, and aspects of life influenced how participants *Negotiated* the every-day DSM decisions about conflicts between culture, personal enjoyment, and long-term outcomes of T2D by these Mexican-born adult

participants. Reported socio-cultural dynamics, norms, and expectations had the most impact on personal decision-making and behavior. Social etiquette required one to attend social gatherings and to try at least *a little bit*, making it difficult for participants to decline food. Mexican food appeared attractive, smelled aromatic, tasted delicious, and had familial meaning. There was a strong temptation to taste many things, some were not appropriate for T2D. As a collective society where “everyone wants to be the same,” to decline food exposed the person as different. Type 2 diabetes was a stigmatized disease that made the person appear vulnerable. Thus, it was difficult for the participants to decline food as it could reveal or acknowledge their T2D. Pretending was reportedly ingrained in the culture.

Successfully managing or failing to manage diabetes required some form of decision-making, albeit intentionally or haphazardly. It simply was how one addressed one’s own DSM. The term, management, did not directly imply efforts to control T2D or suggest success. Each person with T2D had choices to make about diabetes. Thus, how one performed DSM was related to recurring choice and resources, not simply whether (s)he attempted to keep BG under control. This distinction became clear during the IVs; participants were making choices all the time, no matter how they applied or did not apply efforts for control.

Pre-Decision-Making

Prior to actual decision-making, other important steps in the decision-making process took place. Transcript analysis revealed that decision-making began before one *discovered* that (s)he actually had T2D. Participants were clearly making decisions to either seek assessment of their symptoms or to postpone assessment.

This period was referred to by the PI as the *Pre-Discovery/Pre-Discovering* diabetes phase; they were making decisions about how to respond to changes in their health. When the participants *Discovered* they had T2D, they were in the *Discovering* diabetes stage. On the journey to *Mastering* DSM, they had to *Negotiate* the stage of *Acceptance*, to be *Accepting* of the diagnosis, because this had a significant influence on the effectiveness of and willingness to consistently practice DSM. As they made decisions, they were *Negotiating* between the short-term socio-cultural and personal pleasure forces and *Being in the battle* to maintain illusive, long-term BG goals. Each time they decided in favor of BG control for the short-term, they promoted long-term control . The more often they chose the long-term goal, the more they were *Mastering* DSM; they were *Mastering* their T2D.

Prior to *Discovering* one had diabetes, one could choose to look at and respond to perceived risks, signs, symptoms, and warnings or choose not to do so. One could opt to employ behaviors and thinking processes that refuted evidence or suspicion. As demonstrated in Chapter 4 Interaction, Actions and Decision-making, when the participants *Discovered* they had T2D, some reported that they had been more suspicious than others. The former had a perceived risk of developing T2D.

Perceived Risk

Per the results in Chapter 4, there was often a negative relationship between disease risk and the level of suspicion in the participants before *Discovering* diabetes. Latinos in the Ashida et al. (2010) study who had a higher degree of perceived risk for high cholesterol also had a higher level of intent to be tested. Similarly, the Latina in the current study who had a high perception of T2D risk,

because of her father's illness, had testing earlier than the others. Perhaps the delay in seeking care by some was avoidance behavior (e.g., pretending, denying, ignoring) similar to one participant's conviction, "if you do not acknowledge it, you do not have to deal with it." One study conducted in a dental office sought to detect a difference between oral blood and finger-stick blood at diagnosing T2D. Oral blood was found of equal determinant strength in A_{1c} accuracy. Nearly one-half of the study participants had an A_{1c} in the T2D or pre-T2D range. Relevant to the current study, most of the Hispanic women reported they were unaware of their diabetes risk (Strauss et al., 2015). Swedish researchers reported it was critical for adults to perceive the seriousness of their T2D in order to begin DSM (Audulv et al., 2012). Another study hypothesized that subjects whose family members had leg amputations would be more likely to do foot care. To the contrary, these researchers discovered that subjects did less foot care (Scollan-Koliopoulos, Walker, & Bleich, 2010). Fortunately, the participants in the current study whose families suffered the most were also the most aggressive in DSM. For some, it was difficult admitting their risk for fear of long-term consequences, the stigma of the disease, appearing different, and was a reason why they did not want to *Accept* the diagnosis of diabetes and/or the responsibility of DSM.

In sum, perceived risk and suspicion that health changes might indicate T2D was an initial facet to *Discovering* T2D. How rapidly one sought assessment aided in the diagnosis and the speed with which DSM could begin. As reported, a number of studies have been conducted indicating that, like the participants of the current study, people misinterpret changes in their health. While some participants were

aware of the risks, others had a higher level of intention to undergo diagnostic tests. However, having some suspicion of T2D symptoms or risk of T2D was helpful in *accepting* the T2D diagnosis.

Acceptance/Accepting Diabetes

The importance of *Acceptance/Accepting diabetes*. According to the participants in the current study, *Acceptance of/Accepting* the diagnosis of T2D was critical to DSM. The participants used *Negotiation* to make their decision (discussion below), but the key to recognizing their DSM responsibilities, to actually managing their T2D, was *Accepting* their diagnosis; this was the essential gateway to effective DSM. Following *Pre-Discovering* and *Discovering*, *Acceptance* was the next step toward successful DSM. An important insight was that, to *Accept* diabetes meant “you have to believe what you do not want to be true.” This was difficult for some, more monumental for others; it took time to internalize the truth and develop a sense of conviction. Another participant summarized, “*Accepting* is *soooo* difficult,” it required acknowledging and assuming the disease as one’s own. Similar to the current study, one participant from a study by Paterson, Thorne, Crawford, and Tarko (1999) was reported to have said, “I have diabetes ... I’m not going to let it rule over me” (p. 789). The primary focus of their research was the transformation of one’s mental perspective on his or her own self. For that transformation to occur, they needed to find balance. This was also seen in the current study. Interestingly, Paterson et al. defined balance as “an *Acceptance* of the inevitability of changes in living with diabetes and a commitment to live as well as possible within the constraints of the disease” (p. 789). A German study identified that those subjects

who scored lower on acceptance of their T2D diagnosis had impaired DSM and BG control. They also had a higher A_{1c}, diabetes distress, more symptoms of depression, and were less effective in coping, eating a healthy diet, exercising, and adhering to medication use (Lin, Katon, Von Korff, Rutter, & al., 2004; Schmitt et al., 2014).

Other studies have identified *Acceptance/Accepting diabetes* as a primary factor to a healthier outlook on chronic disease. One European study examined the presence of meaning, the search for meaning, and the role of these two concepts on the well-being of patients with chronic illness. The 481 subjects completed instruments measuring meaning in life, life satisfaction, optimism, and *Acceptance*. Researchers hypothesized that both the presence of and search for meaning in life related to measures of well-being. *Acceptance* of chronic disease was measured on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) using a single item "I have *Accepted* my chronic disease." The results of cluster analysis revealed that those who found meaning in life reported higher levels of well-being and *Acceptance* of their chronic disease (Dezutter et al., 2013). Rather poignantly, when the concept of *Acceptance* of diabetes arose in the current study, W6 described *Accepting* her disease. The PI clarified, "you *Accept* your diabetes?" the participant nodded, "I *accept* it" She had accepted her T2D from the day of diagnosis and required little adjustment time. In contrast, another took years to arrive at *Accepting* diabetes. The European group summarized that meaningfulness in life might be related to *Acceptance* of the chronically ill person's condition as well as to their well-being. Their findings also support the importance of *Acceptance* in the current study as a

step in the process of decision-making. *Acceptance/Accepting* diabetes served as a key to embracing their disease and consequently for the responsibility for DSM.

Another study looked at helplessness, *Acceptance*, and perceived benefits in patients with chronic diseases (i.e., rheumatoid arthritis, multiple sclerosis). Noteworthy outcomes were negative correlations between Helplessness and *Acceptance*, whereas there were moderately positive correlations between *Acceptance* and perceived benefits. *Acceptance* had a fairly strong relationship to better psychological health, less neuroticism, and more optimism. Perchance, the same sort of optimism and strong mental health found in participants in the current study would have been similar. *Acceptance* was also related to improved physical health. Previous studies have utilized a different conceptualization of *Acceptance*, seen as resignation rather than “the perceived ability to live with and master the aversive consequences of the disease” (Evers et al., 2001, p. 1033). The current study found *Acceptance* to have a similar perspective to the Evers study; it was about embracing the truth of one’s diagnosis. This allowed the participants to internalize, to make it their own however painful or fearful.

In an international, systematic review of 57 studies of ethnic minorities, researchers sought to understand barriers to self-care from the perspective of patients rather than providers. They identified three major, descriptive themes. The first related to personal identity, one’s emotional response to being diagnosed and having to live with T2D. It comprised self-confidence concerns about how to fulfill their roles in life; feeling overwhelmed, depressed, anxious, in denial or frustrated and angry about the complexities of daily DSM; and becoming resigned or being

pessimistic. For some, having T2D was an assault on their identity. The second theme related to *Acceptance* of their T2D. Very similar to the current study, participants who accepted their T2D were empowered to accomplish DSM, tended to embrace their changing identity as a person with T2D, and accepted the need to manage their health status, that is, accepted responsibility for DSM. Others were disoriented by the identity change and rejected their diagnosis. The result was a loss of self-confidence in their ability to follow through with DSM changes. Some persons so rejected their diagnosis that they felt their own bodies had betrayed them. Sometimes these strong tendencies persuasions affected whether or not immigrants sought HC (Majeed-Ariss et al., 2015). This may be reflected in the current study as pretending, putting off, or ignoring bodily changes.

One intriguing study compared the models of DSM across the Pacific; one model was developed by Shimizu in Japan, the other model by Canadians Paterson and Thorne. The Canadians saw *Acceptance* accomplished early in the T2D experience recognizing that the disease would remain, whereas the Japanese model demonstrated a process that was never completely fulfilled, “not an end in itself” (Shimizu & Paterson, 2007, p. 355). The current study identified aspects of both cross-Pacific models. The Mexican immigrants, like their North American counterparts, arrived at a point of *Accepting* diabetes; however, like the Japanese, *Being in the battle* daily meant the H/L participants had to routinely struggle for *Accepting* diabetes. Whenever they relaxed their vigilance, they risked not being fully *Accepting*; they relaxed their grip on the long-term goal.

The layers of *Acceptance*. In comprehending the salient connection between *Acceptance/Accepting* T2D and *Mastery* of DSM in this study, clearly one must also *Accept* responsibility for DSM. However, a third factor emerged as well – *Accepting* responsibility for the *outcomes* of DSM. One *Accepts* the disease and must perform DSM in order to control the disease. Because of the long-term component of T2D and the enduring goals of DSM in order to protect one’s self from damage, one must *Accept* the potential outcomes of the disease. When one keeps the long-term in mind, (s)he is *Accepting* the possibility of untoward effects. Thus, *Acceptance* of T2D is layered and triangular.

One aspect of enfolding diabetes into one’s life is the need to possess adequate knowledge and understanding in order to have *Acceptance*. W5 explained how she painfully came to comprehend that diabetes was “not just an illness, but a serious disease ... it is bad to have.” Until she understood the seriousness of the disease, she did not embrace it as fully and she lived with the consequences. Another reason participants had a difficult time *Accepting* the diagnosis of the disease was because they might have been overwhelmed by the volume of information and degree of personal responsibility. Observably, some did not want to give up their pre-diabetic lifestyle and appeared overwhelmed by even bits of information. As for her sisters, W1 often snapped directions and listed information that they seemed unable to retain for future access. Possibly their social obligations outweighed their need to *Accept* the responsibilities or they may have had long-term fear of poor diabetes outcomes. For years, both sisters could not *Accept* all three dimensions of *Acceptance* and act upon them.

Accepting responsibility for DSM and the outcomes. Participants who stressed the importance of *Accepting* the diagnosis as early as possible, recommended others to start sooner on medication and apply other aspects of DSM in order to avert the onset of unwanted consequences. Those who truly understood what it meant to have T2D knew that “I have diabetes” and also understood that “I have to do something about it.” This message was offered by several participants. The Icelandic study on mastering diabetes reported that one participant was angry with the doctor for telling the truth about her or his diabetes status. Resigned, (s)he finally had to accept the truth; to not do so would be to “let diabetes take over and win ... and kill you earlier than otherwise. The choice is mine” (Ingadottir & Halldorsdottir, 2008, p. 612). However, at times one simply did not want to know about the disease, instead eating sweets and sodas “like normal people” (p. 612). The Icelandic and Mexican ethnicities are unique from one another and illustrate that race and ethnicity did not define the struggle or *battle* for DSM against the desire to be normal as these comments and sentiments so closely mirror those of participants in the current study.

In the participants’ hierarchical and community-oriented cultural where the group often makes decisions, the individual is groomed to depend upon someone else giving direction, to be responsible, and to make decisions (Chang, 2015). Consequently, there are social risks to *Accepting* diabetes, especially in the case of women. Either gender can *hide* one’s responsibilities in the group. When an individual *Accepts* the disease, and adopts responsible DSM, it can interfere with cultural norms making it difficult for the T2D to self-problem-solve, more so than in

the looser-structured society of individual independence with fewer socio-cultural risks. This conflict was evident in the IVs, particularly W8 who acquiesced routinely in social settings to whatever anyone tried to give her. The social risk for her was great and that social pressure overrode other options. Alternatively, W1 and W9 took full responsibility and would not allow social pressure to derail their strict DSM. Overall, the role of personal responsibility was essential to +DSM but was particularly challenging within the culture because the group ought to supersede self-choice. Ultimately, if one was to cope, one had to *Accept*.

Relationship to coping. According to the literature, one aspect of *Acceptance* is *Coping*. Several studies reported how persons with chronic illness, often more debilitating than T2D, learned to cope (APA, Bourdeau, & Walters, 2013; K. Jackson, 2014). One critical study examined the meaning of T2D and how older women coped with their disease. Coping was defined as “the methods that a person undertakes to deal with stressors” (J. Li et al., 2014, p. 127) and this study evaluated how women reacted to and managed the vast array of stress factors and ongoing adjustments made with diabetes. They foresaw coping strategies as either problem-focused (e.g., management of stressors) or emotion-focused (e.g., emotion regulation). Coping was examined in day-to-day DSM modifications. Researchers queried how coping might affect management outcomes – successful or not – in adapting to life with T2D. They asserted that the better one adapted/was able to cope, the better the outcomes; less successful coping led to anxiety. They identified four aggregate findings: Life with T2D was emotionally and mentally challenging, support facilitated coping, women saw and *Accepted* DSM responsibilities, and

maintaining autonomy was important (J. Li et al.). Three of these findings were also identified in the current study; the autonomy finding resembled *being socially independent*.

Another aspect of the coping literature is founded in works that identify the final stage of grief as *Acceptance*; clearly for some chronic illnesses, there is ongoing grief and loss of function (APA et al., 2013; Telford, Kralik, & Koch, 2006). Grief stages are similar to the emotions through which participants in the current study sojourned; however, they did not discuss grief related to diabetes at length. They had stressors and other grief-causing life events, but grief focused on their disease was not a common or ongoing theme. They might have been in denial as evidenced by cultural behavioral and thinking patterns; denial was a recurring process in the culture, but not expressed solely as grief. Bargaining was a type of *Negotiating*, their primary, daily, decision-making process. Bargaining was the original thematic term explored, but later emerged as *Negotiating*. Bargaining or *Negotiating* was an ongoing process; nevertheless, it was not limited to grief. Some were sad when they learned of their diagnosis and before *Accepting* it (Risi, 2014), but it was not described to the depth of heartache found in much of the chronic illness literature (APA et al.). While none of them wanted diabetes, they did not present as living in a continual state of sadness. Ultimately, most did not convey depression or grief, no one expressed feeling anger, and some stated “I’ll do it my way,” but that could have been *machismo* or unidentified anger.

Summary of *Acceptance/Accepting* diabetes. *Accepting* their diagnosis of T2D was the beginning of *Acceptance* of the whole disease. Truly *Accepting* diabetes

as an aspect of the self, meant that one understood or was willing to assume the disease burden as comprehended at the time of *Acceptance*. One had to admit to the dreaded, stigmatized disease. For the Latino person, this might be difficult and unwanted, even if one perceived the risk. The more one has to accommodate the constraints of T2D, the more one came to understand the gravity and breadth of the disease. W5 lamented, “it isn’t something I just have ... it’s a disease.” After *Accepting* the diagnosis, one must also *Accept* the responsibility for self-care by adjusting one’s life focus to T2D. Maintaining that focus and not being discouraged took time and intention. As W9 reflected “it’s hard at 40 to have your life change” and have “to focus on diabetes. It’s hard.” Finally, one had to *Accept* the outcomes for self-management choices as well as the disease; however, effort alone could not guarantee desirable outcomes. The hope of reducing long-term sequelae was more likely for those who practiced +DSM.

The literature supported the necessity of *Acceptance/Accepting* diabetes, at times as a simple stepping-stone unlike the current study. Not all cultures had the degree of stigma found in the Mexican culture. According to the literature, *Acceptance* was difficult in all cultures. For some study participants, *Acceptance* facilitated meaning and meaningfulness to the diagnosis in their lives. This was not a categorical trend in the current study, but was a consistent theme across the literature. The relationship of *Acceptance* to coping was strong in the literature, particularly for chronic diseases that caused broader handicaps over the course of illness, not only in the long-term. Grief over one’s disorder has long been an aspect of coming to *Acceptance* for a chronic illness. Although not a common finding in the

current study, there were some who expressed sadness; none of them wanted to have diabetes. They all had or were in the process of (W7) full *Acceptance*.

Acceptance/Accepting diabetes, as discussed above, has been identified in studies as an important influence on the decision-making process.

Decision-Making

One of the most important findings of this study was the identification of the actual *process* of decision-making, what occurred when Mexican immigrants with T2D made decisions about DSM and how they considered DSM choices. In the current study, decision-making was primarily accomplished through various means of *Negotiating* with one's self and one's culture; it was an ongoing process, all-day, every day. The stages of decision-making have been identified and named for their functioning properties (i.e., *Pre-Discovering*, *Discovering diabetes*, *Accepting diabetes*, *Negotiating*, *Mastering*).

Decision-making in the literature. In contrast to the current study, most previous studies have identified influencing factors, such as motivation, affect, self-efficacy, and family input (Al-Ali & Haddad, 2004; Dijkstra et al., 2008; McCaul et al., 2005; Strohschein et al., 2011); all of which supported findings of the current study. Some studies have identified stages but had not *identified* or named the *process* of the stages. For example, Laidsaar-Powell et al. (2016) elucidated stages in the decision-making process: (a) *pre-consultation preparation* (b) *information exchange*; (c) *deliberation*; (d) *the decision*; and (e) *post-decision deliberation*. While these stages delineated the steps, the steps did not describe the *process* of deliberation or the decision; also, the outcome of the decision has not been identified. It was unclear

whether the person gained mastery, designed an escape route, or resolved the conflict. The staging was helpful as a guide for the clinician, but did not clarify the psychosocial processes that the patient undertook. Similarly, Pierce (1993) identified five behavioral variations in making a choice: (a) *perceived salience*, (b) *decision conflict*, (c) *information seeking*, (d) *risk awareness*, and (e) *deliberation*, which led to different *decision styles* and incorporated important decision-making steps. What was missing was the actual method or means of deciding and how outcomes were addressed. Others have described various types of decision makers (Petersen et al., 2000). The work by the Thorne, Paterson, and Russell research group identified processes and stressed the salience of decision-making as grounded in the every-day, complex, socio-cultural context of people's lives. They urged HCPs to consider how the patient constructed her or his idea of the problem, including their goals and expectations (Paterson et al., 2001; Thorne et al., 2003). Their study outcomes had implications for and supported the current study.

A doctoral study by Garris (2002) was similar to current study examined T2D in the Midwest and the health decision-making process of persons who were newly-diagnosed, defined as within the past 6 months. Three interviews occurred over 6 months to identify the factors that influenced the 21 participants' choices about lifestyle changes related to their diabetes. The author identified four categories of influence, parallel the current study: (a) the degree of emotional upheaval and imbalance in life with T2D (*stress facets*); (b) various degrees and types of knowledge about their illness included factual knowledge (*health-science knowledge*), emotional, and experiential knowledge (*social knowledge*); (c) the

different perception of power that participants felt over their disease that the author termed self-agency (a type of *self-efficacy*); and (d) the degree of inspiration and sense of purpose to make change (*degree of Being motivated*).

An important Swedish study had similar findings to the current study. They describe a turning point in the process from pre-diagnosis (*Pre-Discovery*) to adaptation (adjusting to diabetes). That junction was where one's emotional self and real-life experience were said to merge with DSM, similar to *Acceptance*. The phases were similar to the current study: suspicion of illness, discovery/diagnosis, learning about the disease, and negotiating around illness to deciding about DSM (Hörnsten, Jutterström, Auduly, & Lundman, 2011) .

Findings from the multi-state Ethnicity, Needs, and Decisions of Women (ENDOW) Project explored the attitudes about hysterectomy in Texas. It revealed that Hispanic women were willing to discuss concerns with their physicians, husbands, mothers, and close female friends (Groff et al., 2000). The sense of community, sharing ideas, and decisions was consistent with the community-oriented culture; however, participants in the current study chose to limit the shared information because of fear of gossip, being judged, or standing out as different.

An interesting correlation to the current study involved Canadian women who sought emergency treatment of possible cardiac conditions. The primary concerns for both groups of women were their role and relationships as mothers, daughters, and wives; these relationships took precedence over their own health concerns. The Canadians resisted interference with their schedules, activities, and

relationships, referred to as the most common “way of knowing” (Turris, 2009, p. 5). Likewise, the H/L used social and health-science knowledge to interpret symptoms and their meaning. The similarity in decision-making conditions between women in both studies was their concern about the effect their decision to seek care might have on their families.

Being in the battle. The *Battle* was the critical point of decision-making, the conflict one encounters in a dilemma. One must weigh the cost of yielding cultural lifestyle, social expectations, and comfort or pleasure against the serious but illusive and obscure, long-term health risks of T2D. Each option was undesirable and had unwanted consequences. The struggle was between the anticipated loss in equally undesirable choices; essentially, a dilemma (Dandry Aiken, 2004; Dilemma, 2016). Whatever the choice, the individual lost as one had to give up cultural enjoyment, unexposed identity, risk offending others, or gamble with the cumulative long-term damage from inconsistent BG. These challenges were not isolated events, but commonly, multiple daily occurrences.

The conflict among willpower, knowing what one ought to do, and temptation was the battle of *Negotiating* hour-by-hour temptations and frustrations. Conflict could be pivotal in decision-making as each choice had potential for struggle and could tip the balance between short-term/more immediate and long-term challenges. Resolving the conflict was achieved by *Negotiating* through the discomfort of the conflict. Successful use of one’s willpower, determination, and resolution to overcome temptation could lead to +DSM, including the development of positive habits. When one controlled the environment, such as W3 avoiding

festivities and having only healthy food choices in her home, one exerted self-control to avoid temptation. This reduced the conflict and eliminated the battle, possibly the dilemmas. However, when willpower succumbed to temptation, it could lead to -DSM; as occurred at times with all the participants. Having *a little bit* was part of the decision-making process. When one made good decisions with beneficial consequences or outcomes, it affirmed good decision-making and facilitated or empowered one to continue to make better decisions. The short-term response, “I’m just going to eat *a little bit*” solved the short-term dilemma but had a long-term impact. One was required to maintain long-term DSM goals to prevent complications.

In the current study, various levels of *Mastering* diabetes through DSM were the outcomes of the decisions that were made. How participants applied *Mastery* also influenced their decision-making. When they practiced consistent *Mastering*, they wanted to continue +DSM; when they practiced poor *Mastering*, they were *Motivated* to practice +DSM in order to improve their outcomes.

The concept of self-care decision-making was more complex than a patient merely learning about the care of a disease and taking steps to conform to expected self-management behaviors, i.e., decision-making among the participants was more than learning about T2D and applying DSM. This complexity paralleled the author-clinician’s experience of attempting to medically-manage patients’ diabetes and teach self-care, then recognizing there were more unknown factors and conditions involved. This insight led to the research question that drove the current study.

Negotiating. Making a Decision

Negotiating came after *Acceptance* and became a part of the participants' self-care management. One wanted what one wanted to eat, but also wanted to manage one's disease. It was not about choosing the right food, it was the ability to choose what they wanted and then find a way to get it. The short-term gain the participant who drank excess water to indulge in sweets received was pleasure as she attempted to gain long-term protection. Because her A_{1c} had increased using this approach, it was possible that this particular practice would not continue to work. Because she faithfully had quarterly A_{1c}'s drawn, she had an opportunity to see if her *Negotiation* mechanism worked as well as it had in the past. Due to the progressive nature of the loss of insulin production and the high BG excursions, there was a possibility she would have different outcomes in the future.

Other participants asserted that when a Mexican person with T2D pretended they would get well or minimize the problem (e.g., after splurging), that person was being negligent about their DSM. A few saw that behavior as an interference in +DSM because the person ignored what (s)he should have known was best in the long-term. Those participants acknowledged that individual as risking her/his overall and enduring health.

A somewhat safer form of *Negotiation* might have been the *a little bit* approach that almost all of the participants reported; several said they were genuinely satisfied with just to taste. The frequency of this approach would have bearing on the long-term outcomes. As exercise was an essential method for utilizing excess BG, those who chose to increase their exercise after splurging as

well as those who exercised on a regular basis were more likely to get their BG back in control more quickly. Pretending, ignoring, putting aside, and hiding were not only used to keep one's diabetic status private, but were also important mechanisms of *Negotiation*. Even when there was no social pressure, the participants made decisions about what they would eat. They employed several psychological approaches. If they wanted an extra tamale, they hid a second helping from a spouse, ignored the advice family members, or rationalized their decision, "I have not had an extra helping of tamale in quite some time." They rationalized any negative effects, particularly long-term problems from their poor choice. Because they had consistently well-controlled BG, this general approach to *Negotiation* worked adequately for them. The key was that, because they were conscientious about the long-term concerns of T2D and set some limits for themselves about the frequency and amounts they ate, they were able to keep a relatively good balance in the *battle* to keep their BG under control.

Eventually when one *pretends, ignores, puts aside, or denies* the likelihood of harsh outcomes or complications of T2D, those choices have long-term effects. If one *denies* there is a conflict, *pretends* not to be in conflict, or *pretends* one is going to get well, playing dumb is a barrier. Thus, the nature of *Negotiating* included flexibility and adaptability. Part of having adequate flexibility is managing stress. A risk of excessive flexibility is to risk the loss of boundaries and habits of +DSM choices. Conversely, insufficient flexibility and rigidity interferes with weighing various aspects and limits *Negotiation*.

Rationalization is a subset of *Negotiating*. *Pretending* may be a component of rationalization. *Negotiating* played a major role in decision-making. To rationalize, one could say, "I'm going to go ahead and eat it anyway. I have to pretend that what I will eat is not going to affect me." This is a case of *wishful thinking* as rationale. Rationalization could also be used to justify sub-optimal DSM. In many cases, rationalization was the means justifying a negative DSM choice, to get what they want and know they should not have. While the overall *Negotiation* process generally worked for them, there remained important long-term risks. Participants fought with elevated A_{1c} and wrestled it back under control. They resisted eating more sweets, increased accountability with more frequent SMBG testing or did more exercise. Participants who had mild A_{1c} increases shortly before their IVs had to examine how their future with T2D would unfold. Another risk they identified was their use of denial or pretending, rather than negotiating, to avoid conflict between the short-term and long-term. Martinez (2002) also found that patients who tended to use what she termed "avoidant coping" mechanisms of "denial, self-distraction and behavioral disengagement" (p. 560) were less likely to see advantages to genetic testing for BRCA1 and BRCA2 mutations at genetic risk to develop breast or ovarian cancer. This avoidant coping is a fitting term for some of the behavioral practices of participants in the current study. *Negotiation* of diabetes and DSM was identified in prior studies, some had similar usage of the term to the current study and others from a unique position. The Icelandic group found participants *Negotiating* with themselves when they were unable to adhere to +DSM, although this term was not used in the Icelandic study. As in the current study, the desire to

do right competed with a wish that everything could be normal, i.e. Wishful Thinking, and those participants gave into temptation. Because they did not manage as they desired, they expressed feelings of guilt. The current study reported very little guilt, possibly because they could *rationalize* that they were *being proper* when they strayed. A way to *Negotiating* when the Icelanders had good control was to periodically reward themselves with “good food.” This resembled the reward of chocolate for some like the majority who had *a little bit*. An interesting aspect of the Icelandic *negotiations* was that, if they thought their desires were good and would improve life, they did not feel a struggle was worth it; their struggle was comparable to *Being in the battle*. Thus, they *Negotiated* a way to control BG such as increasing exercise (Ingadottir & Halldorsdottir, 2008). This was the same remedy as used by several participants in the current study; both sets of participants made their own rules. A final finding in the Icelandic study was that they stayed true to their method of *Negotiation* and found meaning in their T2D, whereas in the current study, only one-quarter of the participants gave adequate reflection to indicate they possibly found meaningfulness in the diagnosis. Based on the studies above in *Acceptance*, finding meaning in having diabetes might be a common theme in many studies (Dezutter et al., 2013; J. Li et al., 2014); it did not emerge as a finding in this study.

Similar to the Icelandic and current studies, a Canadian study found participants with T2D practiced calculated-cheating when they did not follow guidelines. They also tried to balance medications and exercise for BG control while cheating on their diets. Similar to the other ethnic studies, all Canadian participants admitted to making conscious decisions to ignore or disregard lifestyle practices at

times when they chose to eat more or the wrong foods at special events; this resembled the Mexican participants when on vacation. Canadians described those specific times as their way to “maintain your sanity” (Thorne et al., 2003, p. 1345).

Two unique studies from Sweden looked at different aspects of *Negotiating* management of T2D. A 3-year descriptive, qualitative study of middle-class Swedes examined how DSM was integrated into everyday life. They found four phases: (a) seeking effective DSM strategies, (b) considering cost/benefits of strategies, (c) creating routines and action plans, and (d) negotiating DSM into life situations. In *Negotiation*, they sought to balance life goals, illness control and living a meaningful life (Audulv et al., 2012); the same long-term goals as the participants of this study. As the Swedes prioritized and adapted DSM strategies to fit particular situations, the Latino cohort of this study undertook short-term maneuvering. The Swedes also took stock of the benefits of DSM versus the negative effects. While the Latino group could likely have done the same, they did not report it specifically related to their individual lives as did the Swedes; rather, it was related to the socio-cultural aspects of the collective community. The Latino participants calculated the cost of not being the same, concern for offending the hostess, or not showing respect to others. They considered the stigma of T2D, their roles and responsibilities, and how to resist the temptation of savory, meaningful Mexican food. The more individualistic Swedes *Negotiated* how DSM could fit into their lives and ways to accommodate DSM. They, too, used creative strategies, developed routines, and *Negotiated* details in practice. Also, similar to other studies, they found over the 3-year study that participants individually *Negotiated* from within to find balance between life goals and ways to

integrate DSM into their lives (Audulv et al.). As the participants in this study gained *Mastery*, they did so similarly to the Swedes, but with more community focus.

The goal of another Swedish study was to describe the process of illness integration and self-management among people with T2D. They described integration of illness as a developmental process that referred to the emotional and real-life aspects of being ill. It was a rubric concept that “describes the process that a person undergoes in living with a chronic disease, from pre-diagnosis to adaptation to illness as a natural part of life” (Hörnsten et al., 2011, p. 42). The stages were listed above in Decision-making with Negotiating around illness to deciding about DSM as the final stage. Perceived risk, disease severity, one’s emotional response, goals, and perceptions about what might be the outcomes of DSM were processed. Interestingly, they concluded that illness integration and DSM happen concurrently. At times, as was the case in the current study, participants found DSM to be essential and doable. The authors found that participants did better with DSM but it added stress to life. They described *Acceptance* as a *turning point* after which participants partook in DSM while finding a balance to care for the disease/their health, and to find meaning in life. They summarized, “negotiation and adaptation of daily life and lifestyle were required to manage the disease, to achieve control over an altered life situation” (Hörnsten et al., 2011, p. 44) and identified social rejection due to stigma that resulted in lower self-esteem. Similar to the current study, those Icelanders who had not reached the turning point, not *Accepted* the diabetes diagnosis, continued to struggle with emotions, *Negotiating* between being ill and being well.

Summary of Decision-Making, *Being in the Battle* and *Negotiating*

Decision-making is an ongoing process; understanding it will continue to evolve. Participants in this study and others wanted to be in control, to not be controlled by diabetes; they were *Motivated*. Most decision-making literature did not adequately describe the actual *process*; most identify steps and/or influencing factors. Some research has called for the inclusion of cultural dynamics and contextual influences; however, rarely was culture seen so poignantly as in the present study. Motivation also influenced decision-making. Ultimately, *Being in the battle* was the critical point of decision-making for Mexican-born persons with T2D in this study. At times, the battle was a skirmish, at other times it was a true dilemma, but nearly always there was struggle; only rarely was there no conflict. Thus, one had to be effective at *Negotiating* through the conflicts, become proficient in navigating through *battles*, and learn to discern through dilemmas how to have peace with one's self after two or more poor choices.

Negotiation followed *Acceptance* that generally followed perceived risk and *Discovery*. *Negotiation* was essentially finding a way to choose what the participants wanted and then finding a way to get that. There were various degrees of *Negotiation* in the culture. The participants faced many choices: cooperate in this rules- and role-based community- and family-oriented society; succumb to one's own temptations to eat attractive, flavorful food/beverages; and battle for the unseen long-term. Some participants made simple, limited choices and others *Negotiated* to get over a hurdle. For some, more navigating was needed to get around an obstacle, either something they desired or social requisite. Sometimes

there were barriers to +DSM. To *pretend, ignore, put aside, or hide* facilitated them in keeping their diabetes diagnosis unexposed. Eventually, their choices affected future outcomes. Most study participants reached a fairly good balance while *Being in the battle* over cultural requisites, a desire to taste, and unseen LT goals that they generally kept in mind, “always gonna be thinking about that.”

Part of the balance was to maintain adequate flexibility to adapt to situations, especially socially. Too much flexibility could undermine boundaries and personal decisions about what one would and would not do. Rationalizing could disrupt the participants’ commitment to +DSM and put them at risk of not achieving full *Acceptance* of diabetes as their disease, the responsibility for DSM, and outcomes of their decisions. This had the potential to destabilize the foundation of decision-making. Fortunately, little destabilizing was observed among the participants in this study, but they told stories about others for whom over-rationalizing led to untoward outcomes and death.

As for *Negotiation*, other populations also reported difficulty with maintaining self-care of chronic illness. A type of wishful thinking was observed in some studies and was founded on a lack of *Acceptance* of the disorder. Other studies demonstrated similar negotiating techniques, such as, “do more exercise tomorrow.” In explaining why other participants did what they wanted to do, it was attributed to the event or celebration as a higher priority or to act normal to “maintain your sanity” (Thorne et al., 2003, p. 1345). The basis of negotiation was to choose what one preferred most and work around it. As mentioned in the *Acceptance* summary, meaningfulness was a common finding in studies, often as part of *Accepting* diabetes

and working within the confines of self-care. Typically, this was related to individuals finding meaning for themselves. Since the study participants viewed themselves as part of the whole, finding individual meaning did not carry the same value. It was about that person addressing her or his DSM and making those choices fit around others; the meaning was not about the self.

Ultimately, *Negotiation* was the day-to-day technique used to bring a balance to the three competing dynamics that the participants had with T2D. They used various approaches; some were safer over the long-term than others; they described how they made peace with social, personal, and health risk issues. Their *Negotiations* indicated various levels of *Mastery* or *Mastering* of their DSM. The different levels of *Mastery* each had, or had the potential for, long-term consequences. Those could either be more closely reflective of +DSM or the results of -DSM. The following section discusses those outcomes and projected outcomes according to the previously presented literature on long-term diabetes consequences.

Consequences

Mastery/Mastering Diabetes

The *Mastery/Mastering of diabetes* through DSM allowed the participants' willpower to overcome recurring temptation. An important aspect of *Mastery/Mastering diabetes* was habitually practicing +DSM. Without adequate willpower, they tended to give into temptation rather than choose long-term organ protection. The more +DSM became a lifestyle, the more confident they became and the less conflict over declining unhealthy choices. Practicing *Mastery* of +DSM resulted in less fear of poor outcomes and fewer opportunities for weakened willpower to triumph while *Being in the battle* daily. Growing in the practice of +DSM included gaining *Mastery* over daily temptations, social pressures, expectations, and role conflict in various situations and settings while they developed personal *permission* for *Being socially independent*. *Mastery* of T2D has been previously identified by other investigators and will be discussed.

Mastery/Mastering diabetes in the literature. *Mastery* is defined as "the extent to which one regards one's life-chances as being under one's own control" (Pearlin & Schooler, 1978, p. 5). *Mastery/Mastering diabetes* requires an internal sense of capacity to complete tasks in spite of difficult challenges as well as understand or gain insight into how to face them. It is related to coping with various sorts and degrees of stress and overcome or navigate obstacles in life. *Mastery* exceeds having skill alone to complete tasks and is more than doing tasks well (Paterson et al., 1999; Raaijmakers et al., 2014). *Mastery/ Mastering diabetes* requires recurrent application of skill through one's general self-efficacy

(Scherbaum, Cohen-Charash, & Kern, 2006; Weisskirch, 2013). In order to gain *Mastery*, one has to apply an aspect of one's self to action; *Mastering* does *not* occur passively. Likewise, one must apply knowledge in order for change to occur, for *Mastery* to develop; this leads to beneficial decision-making. One needs to act on *Discovery* knowledge in order to grow and progress in *Mastering* (Schipper & Abma, 2011). With application, one gains more understanding and becomes better able to make effective decisions for disease management. *Mastering* T2D is related to important concepts identified in this study, specifically *self-efficacy (S-E)*.

Self-efficacy and general self-efficacy. A San Francisco research group clarified distinctions between *S-E* and *Mastery*, recognizing the two as inter-related. They described *Mastery* as “global control beliefs” (Skaff, Mullan, Fisher, & Chesla, 2003, p. 295) with a broad perspective about the ability to be successful and affect factors in one's life. *S-E* as a construct denotes the individual self-perceives her or his abilities to be effective, behave competently, use coping skills, and affect the outcomes of chosen behaviors. There is an internal confidence that one can accomplish well what one needs to do (Strauser, 1995). Originally, specific *S-E*, also called task- or regimen-specific (Nothwehr, 2008; Rapley & Fruin, 1999), related to a group of domain-specific beliefs about one's own abilities to take specific actions toward a particular task (e.g., complete daily SMBG, DSM activities). The actions would benefit expected outcomes (Bandura, 1997). For example, *S-E* has been reported as a predictor of persons with T2D adhering to medication regimens (Aljaseem et al., 2001; Flores, 2004; Nam et al., 2014). Traditional, task, or regimen-specific *S-E* skills were noted throughout this study. A broader sense of being able to

accomplish the many facets of T2D care was evident to some degree in all participants, including managing all aspects of DSM in a positive direction.

General self-efficacy (GSE) theory, however, proposed a more general level of functioning where one was confident in one's ability to cope and succeed in a broader range of demands, including those more challenging or stressful in nature (Luszczynska, Scholz, & Schwarzer, 2005b; Tong & Song, 2004). Lorig, Ritter, and Gonzalez (2003) found that Latinas with chronic illness benefitted psychologically through *GSE*. A Chinese study found that *GSE* had a positive relationship to both physical and mental well-being (Oi-ling, Chang-qin, & Spector, 2007). As a construct, *GSE* has been validated and several tools are available for evaluating *GSE* in study subjects (Bosscher & Smit, 1998; G. Chen, Gully, & Eden, 2001; Luszczynska et al., 2005b; Rimm & Jerusalem, 1999).

It was intriguing to see how various participants possessed and displayed what appeared to be *GSE* about their T2D. At the root of *GSE* was a self-confidence that when one applied oneself, (s)he was capable of succeeding and could control factors to reduce poor health outcomes (Scherbaum et al., 2006). At a deeper level, the individual valued both one's self and one's personal health. Early in the IVs, a foundation was laid for querying the importance of participants' personal characteristics that led to successful +DSM. This ranged from self-discipline and willpower to the level of *S-E* and sense of self-responsibility. Ultimately in a community-oriented culture, the degree of *independence* (i.e., *Being socially independent*) from social and role pressures could determine how one applied her or himself to the responsibly of care for one's diabetic status. The PI, RAs, and

Committee Member assisting in analysis all noted that those participants who had a personal sense of being valued by others demonstrated more consistent effort toward +DSM; being valued and supported increased self-confidence.

Mastery/Mastering diabetes in other cultures. Self-management has cultural components that have been demonstrated in many studies, including this one; cultural components influence decision-making (Shimizu & Paterson, 2007). The study by Shimizu in Japan and Paterson in Canada compared and contrasted DSM models appropriate to each culture. Uniqueness was elucidated. An essential, foundational factor different between the two cultures was that Japanese individuals defined themselves from an interdependent cultural context. The goal in relationships with important others was to reach and maintain harmony as well as to share experiences, including with the HCP. This was an important aspect of how Japanese people with T2D saw themselves as managers of DSM; not to control and be independent as was seen in the Canadian cohort.

The qualitative Icelandic study on the *Essential Structure of Mastering Diabetes* (Ingadottir & Halldorsdottir, 2008) examined the structure of *Mastering T2D* from the patient's point-of-view and the consequences of not adhering to a multifaceted DSM routine. They found that the degree to which T2D controlled participants' lives varied from full control and making peace with the disease, to fighting constantly with DM, to ignoring it, which, as seen in the current study, led to loss of control. Authors identified four progressive categories: (a) knowledge, understanding, and experience; this included learning DSM skills and thinking ahead about diabetic choices. The Icelanders were found to have a higher level of health-

science (called “medical”) knowledge than their Mexican counterparts in the current study. For the latter, this category would enfold social and health-science knowledge and empiric knowledge, such as participants in the current study used when they felt they needed SMBG testing. A second category was (b) fighting fear in the search for safety. In the current study, there was an equivalent fear of long-term complications; being afraid to *Accept* the truth of T2D. Both nationalities had success and failure with *Accepting T2D*. The Icelanders feared hypoglycemia; this was rarely an issue for the Latino cohort. The third category was (c) dealing with conflicting desires. The current study exposed actual dilemmas in which the Latino *battled* daily conflicts; Icelanders struggled between the desire to do what was right for the long-term and the desire to be *normal* (i.e., to not have T2D). Participants in both cultures wanted to be known as *being the same* as others in their culture. Both cohorts also struggled against constant temptations. The struggle for balance was constant in both cohorts and entailed values, preferences, personality, moral strengths and weaknesses, ever-changing social situations, successes, failures, and how well they applied themselves to DSM. The fourth was (d) freedom or constraint, and was the final category identified in the Icelandic study. The researchers found a search for balance between strictly adhering to recommended DSM and a sense of autonomy to make their own decisions; to self-determine. This category was less recognizable in the current study. As a collectivist society, it was not important to be autonomous unless one was a man in whom “*machismo* was strong in there.” Instead of being individualistic, as were the Icelanders, the Mexican immigrants of the current study who attained and practiced *Being socially independent* exhibited a

type of autonomy when they made their own decisions. The goal was *not* to be autonomous, but rather to avoid being subsumed by cultural values that did not support the person's long-term T2D needs. Thus, balancing was found among the participants in the current study as they intentionally continued to think about the long-term risks while living and negotiating day-to-day.

The Canadian research group examined the *transformation* process that patients with T1DM sojourned when enfolding diabetes into their lives as an *aspect* of their person rather than defining themselves first as being a person with diabetes. They saw themselves becoming *experts* in their own DSM. Ultimately, the process “added meaning” to their lives; similar to several other studies cited above (Dezutter et al., 2013; Hörnsten et al., 2011; Ingadottir & Halldorsdottir, 2008; J. Li et al., 2014; Thorne et al., 2003), they were “changed” in the experience (Paterson et al., 1999, p. 790) and gained a “sense of self, meaning, and mastery” (p. 786). As much of the literature on T1DM is unique from T2D due to important distinctions about each underlying disease, most T1DM literature was not appropriate to include. Due to the recurring theme of *finding meaning* in T2D and the conceptual relationship to the *Mastery* of DSM this article was included.

A recent mid-range theory of DSM *Mastery* was recently published (Fearon-Lynch & Stover, 2015) and developed out of concern for the stressful response to T2D due to the complex nature of DSM; some respond more effectively than do others. It is a synthesis of the Theory of Mastery that addresses the psychological aspects of the stress response and the Organismic Integrations Theory, a sub-theory of *Motivation* to “promote self-determined behaviors” (p. 330), to deal with life

challenges. The authors argued that the union of the two theories offered practical ways nursing might intervene using theory to assist patients who need more *Motivating* or needed assistance determining what might be interfering with progress toward *Mastery*. They rightly asserted that *Motivation* needed to be initiated prior to reaching *Mastery* and that *Mastery* was never actually attained, at least not maintained by most. The major draw-back to the relevance of the theory to this current study was that it did not address cultural factors. The irony was that the authors cited an important Dutch study (Raaijmakers et al., 2014) conducted in a different culture whose authors accentuated the importance of cultural differences. The newly published theory speaks to the mainstream American culture with focus on stress surrounding DSM. The current study participants often reported stress; sometimes it was significant. However, most of the stress was not directly T2D- or DSM-related. The theory authors refer to “crises” of diagnosis but this was found to be limited among the current study participants, perhaps because T2D was *comun*, common, in the Mexican culture. Receiving the diagnosis was less traumatic than for people who were naïve to the disorder. Although they acknowledged fluctuations and the context-driven nature of *Mastery of diabetes*, other life factors were not addressed (e.g., potency of support, role-factors, cultural expectations). Also missing was the essence of why people did *not* engage in DSM. This calls into question whether the authors approached *Mastery* from the perspective of motivation being a cognitive function, whereas in the Latino culture, motivations are more about culture, affect, and beliefs.

The Dutch study (Raaijmakers et al., 2014) assessed the association between the *Mastery/Mastering diabetes* of T2D patients and how they perceived support for autonomy, DSM skills, and health-related quality of life (HRQOL). The Dutch subjects reported a fairly low sense of *Mastery*. Not surprisingly, those patients who had a higher sense of *Mastery* perceived a marked degree of autonomy support (perceived support of their autonomy) and had higher scores for DSM and HRQOL. Their results on educational levels was consistent with prior studies; a lower sense of *Mastery/Mastering diabetes* was seen in patients with lower education. In the current study, that level of education factored into the participants' understanding of DSM, limiting conversation with providers and the PI at times. For the Dutch, *Mastery/Mastering diabetes* had an important relationship to how patients perceived support for their autonomy from HCPs, their DSM, and HRQOL. The authors summarized that, if a strong sense of mastery increased a diabetic's self-motivation to cope better with their disease, interventions should be so directed. Generally, these studies supported the value to identify *Mastery/Mastering diabetes* through DSM as a study outcome. While the number of studies was limited, their value in supporting the findings of the current study does offer a degree of validation.

Summary of *Mastery/Mastering diabetes*. *Mastery/Mastering diabetes* is having control over aspects of one's life, necessary for continuous +DSM.

Mastery/Mastering diabetes is founded on *Acceptance* of the disease, responsibility for DSM, and disease outcomes. In the Mexican émigré, it functions through various methods of *Negotiation* influenced by cultural values, expectations, and roles.

Mastery/Mastering diabetes requires one's willpower to overcome temptation. Each

effective choice has the potential to strengthen future choices, making decision-making potentially easier with each success. *Mastery/Mastering diabetes* is pliable, readily changing over time, and depends upon the choices, practices, and needs of the person with T2D. The better the habitual practices of DSM, the more consistent the DSM, the steadier the diabetic's BG is— a primary goal of +DSM. There are varying levels of *Mastering diabetes* application ranging from consistent practice, to success with compromise, to poor *Mastery/Mastering diabetes*. Some choose to ignore the requirements of DSM and the result was more than failure of self-management, it resulted in failure of organ function and, eventually, death. Thus, consistent practice of DSM components best facilitated successful DSM and long-term protection.

Self-Efficacy is a significant component to one's confidence to execute *Mastering diabetes* and the knowledge that one can maintain it. GSE encompasses knowing one is capable of completing all required tasks and make correct decisions. *Mastery/ Mastering diabetes* was seen in various other cultures and, like other constructs in the substantive theory, are determinants of how people apply themselves to self-care. The recently-published work on *DSM* mid-range theory was not applicable to the Latino population under study because no cultural aspects, affect, or beliefs were included. The aspect of *Mastery/ Mastering diabetes* that most represented this Mexican-diabetic study were the cultural requisites that affected all aspects of decision-making in Mexican-born émigrés with T2D.

Summary of the Substantive Theory

This study demonstrated the powerful influences that socio-cultural values, expectant rules of society, role, and other cultural aspects have had on every-day DSM decisions and actions. Many personal factors, types of *Motivation*, aspects of support, levels of education, health literacy, and comprehension impacted choice. Choices were made all day by the Mexican immigrants with T2D. The more practiced the participants were at wise decisions, applying willpower, and resisting temptation, the more likely they were able to routinely make decisions that promoted health. Prior to making choices, the current study participants had to *Accept* their diabetes, responsibility for DSM, and for DSM/disease outcomes. Then they could *Negotiate* other major factors that affected their long-term health.

There were three fundamental and naturally-opposing forces at work that placed the participants in a quandary about their many choices. First, the potent, embedded, socio-cultural expectations, rules, and values required the Mexican immigrant with T2D to eat food that was prepared for him or her by another. Declining was generally not an option because, culturally, to do so was offensive. It also drew attention to the one who declined, making her or him different than others - that was culturally undesirable because it was important "to be the same" as others in the culture. Since T2D is a stigmatized disease, the participants wanted to hide or ignore its presence when in the social gatherings that were frequent in this highly-social, community-oriented culture - everyone was expected to attend all social events and participate. Thus, unless the hostess already knew of the participants' diabetic status, they would not readily reveal their diabetic status. It

was much easier and less complicated to simply taste *a little bit*, which maintained *Being proper*. There was an immediacy to this dimension because it occurred at the moment the hostess observed whether her food was being eaten by everyone.

The second competing dynamic (construct) was the temptation to eat aromatic, scrumptious, and attractive food; the food smelled, looked, and tasted delicious. One was drawn in and wanted to taste many different dishes and desserts; however, they knew they should *not* eat or drink it. The participants enjoyed their food very much and it was common to be tempted. Occasionally, a particular food was memory-provoking, making that food meaningful, delicious, and particularly enjoyable. Quickly or soon, one wanted to satisfy the temptation and the desire for the pleasure of tasting and experiencing meaningful memories. The culture supported the tendency to *live in the now*, not in the future; this directly violated one's long-term BG goals.

The final dimension of the triangular conflict was the illusive, long-term poor diabetic outcomes from historically and repeatedly not controlling BG well. Since BG needed to remain as near to normal as long and often as possible to prevent damage (Okada et al., 2013), each occurrence of a spike (an excursion) or prolonged elevation was a risk for damage; this could be cumulative (Nalysnyk et al., 2010). Thus, participants struggled *Being in the battle* between these important forces, particularly long-term needs that one could not see in the present. Each choice moved the person with diabetes toward the future. One had an opportunity with each decision to sustain +DSM *Mastery/Mastering diabetes* or to return to positive diabetes self-management. The Substantive Theory:

*Negotiating every-day diabetes self-management decisions
about conflicts between culture, personal enjoyment, and long-term outcomes
toward mastery of type 2 diabetes by Mexican-born adults.*

Recommendations

Implications for Practice, Education, and Further Research

The study question originated in the clinical setting of the researcher serving in the role of Nurse Practitioner (NP). Prior to the study, it was evident to the NP-turned-investigator that there were unique, core-cultural values and mental model distinctions between the Mexican-born immigrant clientele and the NHW clinician; details of these unique differences were identified in earlier chapters. From experience, efforts by the NP to offer DE often did not result in beneficial lifestyle changes in the H/L. It became increasingly clear that the NP and colleagues were lacking understanding about the decision-making influences in the H/L culture regarding T2D. Published research on this issue was also missing. Results from this study may offer a glimpse into ways clinicians may assist in providing care to this widespread clinical population. This final section of the Discussion offers recommendations for practice, education, and future research.

Recommendations for Practice

Five recommendations for enhancement in the clinical setting were identified. These include (a) understanding and improving values-based communication, (b) appreciating English language communication effects, (c) the necessity of teaching clientele about progressive pancreatic function changes, (d) providing recurrent monitoring of glycemic status and processes of care, apprising clientele on risk status for pre-T2D/T2D, and (e) how to assist clientele in *Negotiating DSM*.

Values-based communication differences. The uniqueness in cultures between the Mexican immigrant and the Non-H/L HCP are founded on core values differences. Mexican immigrants with T2D were raised in a collectivist, community-oriented culture where in the person places family and community before her or himself (Chang, 2015; Ruby et al., 2012). This is in contrast to a Non-H/L HCP descendant of an individualistic culture in which (s)he is free to choose her or himself before others (Shkodriani & Gibbons, 1995). As demonstrated in Chapter 4, the differences in language, understanding, and expectations often have a critical impact on communication between the two cultures. It is the intersection of these distinct differences that understanding between the HCP and patient may unknowingly or unintentionally break down. The problem for the HCP from the dominant American culture is that (s)he is expecting the conversation with the Mexican-born patient to be based on the host culture's individualistic core value of candor when exchanging information to determine what is accurate situationally for that patient (Ruby et al., 2012). Conflicting with that is the patient's rule-based, collectivist social norm expecting patients to defer their opinion in order to show respect for elders and those in authority (i.e., the HCP). The patient may also choose to hide or ignore symptoms. The individualist-oriented HCP at times does not recognize that the H/L patient is culturally-committed to practicing cultural expectations and roles; to choose corporate values over individual desires. While honesty is valued, showing respect and maintaining cultural values take precedence. In the H/L role-based culture, for one to violate these social norms and values is to break a cultural obligation that may show disrespect or individualism. This

difference of values-based positions does not readily facilitate a common ground for having frank discussions between patient and HCP. As the Anglo mind has a more individualistic perspective, the HCP who is not aware or mindful of these value differences risks clarity about the patient's situation or the extent of the information exchanged. The HCP who is aware of the unique differences in explanatory models between the Mexican immigrant patient and Non-H/L HCP can incorporate the patient's perspective and to assist him or her toward more effective DSM. Thus, it is recommended that HCPs be cautious about preconceived ideas about the perspectives or lenses of persons from other cultures. If one has a perception and there is a conversation with the patient, *one needs to clarify* that perception with the patient. Simply using the same words does not equate to shared meanings or understanding. An important question for providers would be to ask, "What does that mean for you?" One must keep *context* in mind.

Secondarily, there are conceptual, definitional differences, including the meaning of personal responsibility. While responsibility is essential to successful +DSM, to the H/L it may be of less importance culturally because one's choice must support family, corporate, community, and cultural values; the collectivist value surpasses the individual(ist). The American culture values responsibility; as a culture, people are respected for their responsibly and that respect is defined by independence (Livaudais et al., 2010). The H/L may define responsibility by being faithful to the family and culture (Morgan Consoli & Llamas, 2013). Along with language issues, the HCP must keep cultural perspective in mind (Ackerson, 2007; Cooper et al., 2003).

Health care providers should acknowledge potential conflicts between patients' socio-cultural-family matters and DSM. Due to the family-orientation of the population and degree of family involvement in decision-making, DSM *shared caring*, and DE, it is essential to include the family in both formal and informal DE and HC visits (Chesla et al., 2003). Based on these differences in values, it may appear to the HCP that a conflict exists, but to the patient, (s)he may have clear priorities: socio-cultural and family needs will likely be addressed first. The HCP's expectations for the patient's DSM will often exceed the patient's personal DSM as well as movement between those goals to meet both needs. Health care providers should recognize that family will often be the choice for overall balance; those needs should be factored into DE and DSM (Davidson et al., 2015; Domian, 2001; Gleeson-Kreig et al., 2002; Hu et al., 2013; Hu et al., 2014; Ramal et al., 2012; Rodriguez Le Sage, 1999; Rogers, 2010). Similarly, when HCPs assess the patient's explanatory illness model and clarify patient/family misconceptions developing a more patient-specific plan that includes their health beliefs, such as *susto*, cultural and herbal remedies; cognitive and emotional needs, including diabetes distress or depression status; and level of health literacy and education, will likely will be more effective (Barron et al., 2004; Fowler, Kirschner, Van Kuiken, & Baas, 2007; Hatcher & Whittemore, 2007; Lemley & Spies, 2015).

The ADA recommends effective ways to avert communication issues by keeping discussions focused on the patient. They advise HCPs to use active listening, elicit beliefs and preferences, assess the literacy and numeracy capabilities, and potential or existing barriers as well as co-planning with patients and families about

realistic goals so they will commit to the plan. Life factors that impact activities and choices, such as work, responsibilities, cultural beliefs, needs, and other medical conditions and needs are to be incorporated. Including the family helps to empower patients in most situations (ADA, 2017c; Ramal et al., 2012). Also, HCPs should keep in mind that acculturation may not be associated with glycemic control, thus HCPs should be careful not to assume that poor control is directly related to acculturation for H/L with T2D (S. E. Ross et al., 2011). Assumptions by HCPs, in fact, can contribute to not performing at the level expected of them.

English language communication and health literacy issues. Another salient issue in the practice setting is comprehension and communication, specifically English-language usage. With Spanish as their first language, immigrants' grasp of the English language and how well they acculturated to individualistic expectations were noted in the current study cohort; this may affect others in the same population. Despite the PI having worked in clinical settings with this population for over three decades, the factors related to language, knowledge, and understanding were found to be even stronger contributors to how participants grasped and implemented diabetes-related material than had been anticipated. On the other hand, one aspect of this could have to do with limited education. Misinformation, even for those who were well-educated interfered with gathering, integrating, and executing information; this is health literacy (HL). While HL was not studied in this cohort, it may be an aspect of the difficulty in responding to questions directly; possibly the difficulty of sequencing may have some relation to lower HL (Nath, 2007; Schillinger et al., 2004). Since the participants fit criteria commonly-

seen in those with lower HL, it could have been a component. Coffman et al. (2012) recommended that interventions promoting HL skills could improve symptom interpretation in Hispanic-Americans that might promote better use of HC services. Another post-intervention recommendation was for the use of plain language and tools that were easily manipulated as well as strategies to encourage change of behavior (Coffman, Ferguson, Steinman, Talbot, & Dunbar-Jacob, 2013; Sarkar et al., 2010).

Likewise, since participants were inclined to keep education and concepts simple, they often tended to take a heuristics approach of “getting back to the simple bottom line” (Broadstock & Michie, 2000; Tversky & Kahneman, 1974, p. 1124; Yu et al., 2014). Often, H/L employed an intuitive-type of decision-making that could result in reasonable choices. Nevertheless, in some instances, intuition could direct patients to choices that did not serve their best interests (Redelmeier et al., 1993). Patients sometimes addressed both safety and danger categorically; they undervalued the importance of “partial risk reduction” (p. 72) and could be influenced by the way they understood how a problem was framed. This was noted repeatedly in the current study. Fischer and De Vries (2008) described the process as being integrated when, based on the evaluation of previous behaviors, the person used the past to predict the future, including behavior. This made decision-making a limited effort and could lead to an inaccurate evaluation of actions and subsequent results.

Over the past two decades, HC delivery has changed with more complex diseases and pressures to provide care rapidly to even more patients. Justifiably,

providers may lack adequate time needed to develop beneficial relationships with patients. Weak relations exist for other reasons as well; providers are rushed; one may miss the innuendos or not take the time to clarify with a patient, or worse, assume the words and message mean the same to the Hispanic as to the non-Hispanic. Examples found in this study included the unique differences in meaning and usage of the words *gracious* and *convenient*. Thus, the HCPs could miss important cues or points of clarity. Without seeking clarity, the message might cause offense and interfere with confidence between the HCP and patient; trust could be eroded. The lesson learned in this study was how essential it was to routinely clarify meaning of and use of terms. Language interference could lead to lack of information or understanding. If patients do not understand certain aspects, they cannot make good decisions about what they do not know. For example, the HCP may give clear instructions about checking BG post-prandial (after a meal); however, it needs to be clear that the SMBG is performed at 2-hours (2hpp). Currently education may not be reaching some H/L patients. If they understand the instruction "after a meal," but not "2-hours after a meal," they will not know to SMBG at 2hpp. It is essential to distill information down to what is manageable and avoid complexity that requires higher abstraction using the English language. It may place the H/L patient at a disadvantage, meanwhile the HCP believes (s)he has provided the information accurately. Also important is the need to clarify the chronology of events; as best as one is able.

Bartol's (2012) recommendations for practice specifically addressed the role of the NP. He recommended that, through *Motivational* interviewing, NPs look for

means to improve the treatment experience of T2D through education and to *Motivate* them to make beneficial lifestyle changes that helped them remain committed to treatments tailored to their individual needs and expectations. In addition, always include cultural aspects.

Teaching pancreatic function. One important finding in the study was the apparent ignorance of participants about the progressive loss of pancreatic production of insulin. Many participants understood this, but thought there was an indefinite plateau rather than a gradual decline in those with genetically-predisposed T2D not related to modifiable risk factors such as obesity (Poveda et al., 2015; Winnier et al., 2015).

As established, early BG control prolongs pancreatic function. If HCPs wait for evidence of significantly increased insulin resistance and/or signs of lessening pancreatic insulin production, the message to the patient can be “this is what eventually happens in diabetes, you have to have more medicine - or even insulin.” This can be a crushing defeat to the H/L person with T2D. As with the current study participants, when patients who have been stable and successfully managed on a T2D regimen and DSM starts to have physiologic changes with increases in SMBG and A_{1c}, they may think “I’m doing the same thing I have for years, but it’s not working anymore!” This may cause undo consternation. The patient may well understand the outcome risks of progressive T2D, but not why they do not have control indefinitely. This health-science knowledge void must be addressed by HCPs much earlier in T2D care, not when there may be irreversible change.

Recommendations from the literature. Robertson (2012) supported DSME when urging NPs and other HCPs to begin DE early, it “can lay the foundation for treatment throughout the disease continuum” (p. 212); Cordisco and Broccoli (2015) advised formal DSME, not solely offered by busy HCPs. Providing adequate, culturally-based DE from the time of diagnosis has been strongly recommended (Lorig et al., 1999; Lorig, Ritter, Dost, et al., 2008; Lorig et al., 2003; Tanenbaum et al., 2015; Zeh et al., 2012). Good quality DE literature and decision-making aids that offer culturally sensitive information can reduce knowledge and communication gaps as well as help discern patient preferences (Davidson et al., 2015).

Researchers from the CREDIT study supported an earlier start of insulin (Balkau et al., 2015). In their study, when A_{1c} was measured at the onset of insulin therapy, they found it had the most predictive strength for later A_{1c} after they accounted for other variables. The team suggested initiating insulin therapy sooner may improve BG target control; if the A_{1c} was lower at the beginning, it would stay lower throughout the course of the disease. Fleury-Milfort (2008) agreed with early start, “insulin is the only hypoglycemic agent with unlimited potential to lower blood glucose” (p. 295). Likewise, an important aspect of success in reaching patients with psychological insulin resistance (PIR) has been healthy patient-provider relationships that were directly linked to reducing PIR. Intervention programs aimed at improving S-E of T2D were suggested because relationships between patients and providers are necessary to reduce PIR (Nam et al., 2014). Miller and Thomas (2014) suggested that HCPs take time to educate patients themselves about insulin therapy and injection options or send patients to a

diabetes educator who will teach them. Given the time constraints of HCP's in today's practices and the expertise of diabetes educators, the latter would be the most efficient and effective means to build a support team for the patient who requires the onset of insulin. Ultimately, after systematically assessing insulin therapy barriers, designing culturally-sensitive, individualized treatment plans, and informing patients early that insulin is a *normal* functioning hormone that might help them, over time, may overcome the fear and negative attitudes. This could lead to the initiation of insulin therapy sooner and improved treatment adherence, thereby leading to a higher quality of life (Bahrmann et al., 2014) as well as improved provider-patient relations.

To summarize, recommendations for HCPs to improve T2D care to H/L should include a variety of approaches, adequate and periodic DE that will facilitate growth in skills, problem-solving, confidence, and self-efficacy. Support should be ongoing, integrated into routine care. The lifestyle, roles, responsibilities and demands of family and work, eating patterns, physical activity options, personal priorities, co-morbidities, cultural perspectives, and values should be included in planning and assessment (ADA, 2014a; Cusi & Ocampo, 2011; Ramal et al., 2012).

Recommendations by the author. The results of the current study and working with this population for over 30 years, the author is convinced about the need to start early in DE with a gentle introduction normalizing references to the progressive nature of diabetes, specifically gradual loss of pancreatic function and the reality of insulin resistance. Equally important is to periodically reinforce insulin and pancreatic function as a normal part of clinical visit discussion; that there is a

possibility of an eventual need for increased medications and possibly exogenous insulin in the long-term. Also, it is critical to stress the importance of early control and how consistent control prolongs pancreatic insulin production, sometimes indefinitely. Beginning the conversation earlier rather than bringing up the need for more medications or the use of insulin when other options fail provides motivation for +DSM while normalizing possible medication adjustments in the future.

Teaching is not simply providing accurate information for patients by helping them understand the progressive nature of diabetes. It is necessary to make connections with patients so they understand that the HCP is connecting with their ideas. In one example, if the patient believed that stress caused diabetes, there is value in “meeting her or him at that point,” helping the patient *from* that point rather than trying to correct the belief system. Clearly, the approach to change what people believe without first connecting to their mental perspective has not been effective and has contributed to the gap experienced currently in clinical practice. The information patients receive needs to make sense to them in order to consider unfolding it into their thinking. For example, if the person is convinced T2D is solely related to weight, as was the case with one current study participant, there is wisdom in working with him from that perspective because it makes sense to him and no harm is likely to come to him because of that belief. In helping him to look at weight gain, his gauge for being more cautious, exercising or other factors may be involved. If he is *Motivated*, help him to move forward. Likewise, if stress is seen as the cause of or a contributor to T2D, help the person deal better with stress so it becomes or feels less of a contributing factor and distractor. Helping H/L patients to

understand how stress exacerbates or possibly creates another set of problems for their T2D may encourage them to want to resolve or reduce it. The HCP can help the patient see how(s)he can decrease stress in order to improve health.

When dealing with different cultures, it is important to try to appreciate the patient's mental model so that the HCP can help it make sense to them. This can be used as a building block for other points of education. If they are not grasping a concept or instruction, then they are less likely to enfold it or learn how to work with the information they need.

Recurrent monitoring and apprising clients of current risk status. As previously demonstrated, H/Ls are often disadvantaged, have less access to care and processes of care (eye exam, renal status, A_{1c}), more often are unaware of their glycemic risks for pre-T2D and T2D, and do not receive DE/DSME (Gonzalez et al., 2013; Mainous et al., 2007; Morales, Lara, Kington, Valdez, & Escarce, 2002; Strauss, 2014). Thus, in addition to providing and/or referring patients for culturally-appropriate DE/DSME (R. Chen et al., 2014; Haas et al., 2014), it is essential to provide recurrent monitoring of glycemic status (FBG, A_{1c}). Those with either diagnosis should have annual assessment of processes of care (renal function [serum and urine testing], annual eye exams) to evaluate for microvascular changes (Egan, 2017; Nápoles et al., 2009). It is the HCPs responsibility to inform clientele on test outcomes considering HL needs, assess their beliefs and perceived risks for pre-T2D/T2D; discuss actual health-science based risk status for disease, and to assess and discuss BG goal status, how to attain or maintain control, and the signs and symptoms to observe (Ackerson, 2007; Coronado et al., 2007; Freedman, Kouri,

West, & Keating, 2015; Maty & Tippens, 2011; Rizvi & Sanders, 2006; Yanez et al., 2012). Assisting patients through difficult life struggles, identification of stress and depression offers important support (Kasteleyn et al., 2015; R.-H. Wang et al., 2016).

The literature is replete with recommendations for making each encounter and diabetes care plan patient-centered as this benefits the patient and improves satisfaction and trust in the HCP-patient relationship; evidence of sensitivity to patient/family cultural needs and beliefs promote success (Berrios-Rivera et al., 2006; Nápoles et al., 2009; Robertson, 2012; Saba et al., 2006; Schillinger, Handley, Wang, & Hammer, 2009; Searight & Gafford, 2005). An example of the beneficial influence of the HCP (NP) assisting in tight control was sustained improvement of A1c by 1.5% over 1-year when patients received teaching on T2D and DSM (Melaku-Abbera & Smith, 2017). Others have stressed the importance of including social support in shared decision-making in HC settings (Gleeson-Kreig et al., 2002; L. T. Lee, Bowen, Mosley, & Turner, 2017; Ramal et al., 2012).

Monitoring of medication status, when specific medications are taken/used; timing of SMBG, assuring FBG and 2hpp are appropriately timed; actual physical activity and frequency; how they *Negotiate* DSM conflicts; and compliance with specialty referrals and diagnostic testing are important HCP roles (Castillo et al., 2010; R. Chen et al., 2014; Tanenbaum et al., 2015). Special attention should be paid to elders (Federman et al., 2014).

Identifying and supporting *Negotiating* DSM. The most important outcome of this study was identifying the mechanism of decision-making: *Negotiation/Negotiating diabetes*. The immigrants *Negotiated* through cultural

requisites, a personal drive for pleasure, and long-term needs for stable BG. They did not appear to know that they were *Negotiating* until the question was posed for their clarification and validation as the construct developed. Once presented, they understood that *Negotiating* was an important process they validated. They were aware of all three influencing forces and felt the demands of culture, pull of temptation, and knew they alone could control their long-term BG and diabetes outcomes. Based on experience discussing these issues with them, it is possible that similar conversations can occur with others in the clinical setting.

Recommendations from the literature. As the HCP acknowledges her or his understanding of these influences on decision-making, both validating the reality and importance of the conditions that cultural understanding has been shown to improve communication (Schillinger et al., 2002; Schillinger et al., 2009; Strain et al., 2014). M. C. Hansen and Cabassa (2012) urged providers to assess for psychological barriers to self-reliance, such as stigma, structural obstacles, language barriers, competing family and health needs, to look for ways to collaborate with people with T2D who are depressed and to include their support network. Likewise, Barnes and Lu (2012) recommended that HCPs understand what are barriers and what facilitates BP control from the perspective of the patient. The same is true for T2D. The Swedish study (Hörnsten et al., 2011) that identified *Negotiation* as the final stage of the ongoing process of integrating self-management into one's life identified that *illness integration* develops in tandem with one's DSM integration process. At times, one has a turning point seeing DSM as necessary and achievable; this parallels *Acceptance and GS-E*. They advised HCPs to assist patients with "integration

trajectory” (p. 41), a type of anticipatory guidance that aids people with integrating T2D into life which helps with integration of DSM.

Numerous studies counseled on keeping physically active (ADA, 2017d; Buchholz & Edmunds, 2017; Siomos, Andreoni, Buchholz, & Dickins, 2017) and others have stressed the value of social support, particularly by family (Domian, 2001; Gleeson-Kreig et al., 2002; Komar-Samardzija, Braun, Keithley, & Quinn, 2012; Ramal et al., 2012). In the family-centered culture of the H/L an important role for the HCP is assessment of adequate and effective support, level of self-efficacy and/or barriers that interfere with healthy +DSM choices (Komar-Samardzija et al., 2012; Ramal et al., 2012). In all, NPs and other HCPs can educate regarding the benefits of controlling diabetes and motivate patients to be active participants in their own DSM (Bartol, 2012).

Recommendations from the author. Initiating conversations for problem-solving with patients can help them understand and practice how to reduce situational temptations, work around cultural expectations, and keep the long-term goals in mind. Participants in the current study demonstrated how they had problem-solved this conflict for themselves. In addition to family support, and sometimes eating restrictions, they chose ahead of time which celebrations to attend, how long to stay, to eat only diabetes-appropriate food in their homes, and prepared it to be readily available to eat. If there was no choice other than a drive-thru meal, they chose foods that were diabetes-friendly rather than typical, high cholesterol and high calorie fast foods. Patients could also buy ready-made salads and healthy sandwiches or wraps to keep in the refrigerator for a meal away from

home; the same was true for purchasing nut/dried fruit snacks that were healthy, quick, and easy-to-carry. Helping patients to see that there are simple and inexpensive solutions to common practices might help them *Negotiate* food and situational obstacles. Since identifying these study results, the NP-researcher has successfully applied these suggestions with patients in clinical practice with enthusiastic reception as they have welcomed new ideas.

Health care providers can also encourage patients to discuss their goals with their families to increase the willingness of families to “leave before the cake comes out.” Once patients know that HCPs understand socio-cultural pressures and the stigma of T2D in the culture, the two might be able to problem-solve ways to decline food or beverages with less offense to the hostess. If not, encouraging vigorous exercise and steady diabetes-dietary practices may be of help. The dialogue between the patient and the clinician needs to be open, non-confrontational, respectful to the patient and culture, and allow *permission* to the patient to explore options.

Reminding them that *they have the control all day, every day to choose* their long-term health may be the *Motivating* and “*permission giving*” that was observed in the current study. Helping women to understand that, when they choose their short- and long-term T2D needs over their family, such as eating on time, they will actually be choosing the health and welfare of the family as the patient will be healthier, may live longer, and may be less of a burden on their families; all concerns expressed by the current participants. Providers need to utilize *Motivating influences relevant* to the patient. If love is the primary motivator, motivate with love. If fear is a more meaningful motivator, offer suggestions that motivate through fear. For instance,

discussing fear-raising concerns such as potential dialysis with the mother whose sole *Motivation* is love of other, teaching self-preservation of herself for the sake of her family will be a more effective motivator; fear is not the correct tactic, as several participants indicated. Contrarily, the person motivated by fear of dialysis because (s)he observed her/his parent suffer on dialysis may be much less likely to respond to motivational teaching on “you want to be here for your family”, particularly if (s)he has already said (s)he is not concerned about anyone but herself not suffering. The sooner and more consistent these conversations occur, the more possible that patients will improve awareness and control in *Negotiating* their everyday conflicts in DSM decision-making.

Recommendations for Future Research

This study deserves replication with a larger sample size that includes more men. Participants who do not have access or only limited access to care should be interviewed. Stricter efforts to recruit participants who “speak some English” would be beneficial with more consistency in “mostly English” volunteers. A certified interpreter should serve as the Research Assistant at all interviews, not merely a Spanish-speaking person who is able to translate the generalities of what was said by the participant. If Spanish is used during an interview, participants should be stopped after brief statements for direct interpretation to the PI to allow for more in-depth exploration and clarification as needed. The transcriber will also need to be a certified translator so that no comments or descriptions in Spanish go without direct translation onto the transcripts. Some interview items could be deleted or question segments reduced to a single information-gathering stem. Other questions

could quickly focus on study constructs. Funding would be necessary due to the significant costs of transcription.

Ideally, gathering more data on this question could be done in Spanish; however, the benefits of a non-H/L investigator would allow for exploration of concepts familiar to the culture but not to the investigator. Individuals from within any culture do not have full perspective of their own culture that allows for comparison, to distinguish innuendos and unique dimensions of one's culture because (s)he sees what is normal or *comun* ("common", per W9). People also self-explain their own cultural phenomena, relationships, and genesis. A person may not be able to fully appreciate a comun feature because it is not unique to her or him, but is outstanding to the investigative person. Thus, the Mexican person cannot necessarily perceive cultural features distinctively in the same way that the non-Mexican can see these characteristics as unique, and vice versa. In numerous IVs, a behavior, belief, or value was so culturally-ingrained that participants were unable to explain beyond "it's the way it is" "... the way everybody is raised", or the RA "oh you know... ohh, I don't know how to explain it." With further probing, features of the culture became clearer at times, but in other instances, participants were unable to see or, at times, unwilling to evaluate or discuss the characteristic the PI sought to understand. When one is exploring cultural factors and dimensions, there are occasions that one literally cannot see the facts clearly about one's self or one's culture. Through this aspect of inquiry, it became more important for a NHW to investigate important Mexican-cultural roots. Exploration by a non-H/L would permit deeper exploration of concepts and constructs as they would be contrasted

by a different cultural perspective that would help to identify conditions and influences that might go unnoticed or be accepted as “normal” by a same-culture investigator. Participants would be required to explain cultural phenomena rather than expect the same-culture investigator to know what the participant might be explaining. Another option that might be beneficial would be a paired non-H/L and H/L investigator team. The salient findings in the following chapter will demonstrate the characteristics, conditions, factors, and cultural features identified in IVs with the Mexican immigrant participants with T2D.

Recommendations for Education

A third role the investigator has had over the past three decades has been as an educator of nurses and advanced practice nurses. For educators of all HC disciplines, the findings of this current study have the potential to benefit future-generation clinicians. All professionals working with this population would be advised to help students understand the pervasive differences between the collectivist society and the individualist values of the American culture into which the immigrant and their offspring function. Decision-making is based on different values, mental models, and motivation for choice. Negotiation may be a broader mechanism of decision-making than for this small Mexican immigrant cohort. Simply being fluent in English does not imply that the individual is fully acclimated, acculturated, or that their approach to making decisions, evaluating their options, interest in, or ability to apply different decision-making criteria is accessible to them. Not enough can be stressed regarding the significance of cultural influences

on this population. All HC educators and students would be well-advised to hold the importance of culture at the forefront of all interactions with the population.

The Substantive Theory

Negotiating every-day diabetes self-management decisions about conflicts between culture, personal enjoyment, and long-term outcomes toward Mastery of type 2 diabetes by Mexican-born adults.

Limitations

Limitations of this study fall into four categories. First, there were serious issues with time sequencing reported by participants that interfered with accurate data collection. The second set of conditions were sample-related limitations. The third related to Spanish-translation short-comings. The fourth relates to the length of time between the original Review of the Literature and assembly of the dissertation. Although, the middle two were partially addressed in Chapter 3 and 4, they had an impact on the study and are, therefore, study limitations.

Time sequencing issues. Navigating Time

An important limitation of the study was the dimension of chronology or sequencing of time, or lack of it, by all participants. Gathering historical data on the diabetes of each participant was difficult, arduous, and oftentimes there was never a clear response about some content areas. In the prevailing American culture, one is accustomed to thinking of events chronologically. To some extent, this occurred with each participant as well; however, it was difficult to exact general dates and events. Moreover, the sequencing of events related to the *Pre-Discovery* and *Discovering diabetes* periods, as well as the personal and medical management that followed, was challenging to track. Even the most educated and articulate of the participants had difficulty with sequencing and the idea of the flow of time, particularly surrounding *Discovering diabetes*. The concept of Living in the “now” seemed to mark the approach each of the participants took in understanding their process of *Discovering* and managing diabetes.

Participant Sample

A natural limitation of this qualitative study was the small convenience sample. Because all of the participants had access to health care and needed diabetes supplies, those with limited access need further study. The age range was satisfactory; however, the sampling from each generation was limited due to the small sample size. Most importantly, there were a limited number of men. The unfortunate attrition due to Research Assistance unavailability was also an important limiting factor. Not uncommon to qualitative research, some of the major constructs of the study were not explored by earlier participants. Having their input on major cultural influences and more in-depth exploration of decision-making might have further substantiated the study findings. Finally, the type of person who agreed to participate might not represent those in the general population; the decision-making process in those persons may be unknown.

Translation Issues

A limitation discussed in Chapter 3 Methods – Interpreting was the incomplete and/or inaccurate interpretation by the first two RAs for some responses. Accurate translation of four of the interview recordings by a certified interpreter/transcriptionist provided full responses on transcripts, although it came after the IVs so the opportunity to clarify with the participant was lost.

Extensive Literature Review

The final limitation is the extensive Review of the Literature (ROL) not typical of a qualitative study. Due to the extended time between the original ROL and completion of the study and analyses, the ROL was updated as is standard.

Significant changes had occurred in diabetes in the interim and the author chose to broadly cover several diabetes-related areas in order to be current. The author recognizes that this could be interpreted as a bias, although it was revised following study analyses, and writing of the Results and Discussion.

Conclusion

In conclusion, this qualitative investigation about the decision-making of DSM by Mexican-born, immigrant adults with T2D sheds a beginning understanding about how the participants *Discovered*, navigated/*Negotiated*, and *Mastered* their self-care within the context of their culture, communities, families and the constraints of their disease. More research is needed to further develop the substantive theory that was derived from this study.

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Appendix A

Institutional Review Board Project Action Summary

Action Date: October 5, 2010

Note: Approval expires one year after this date.

Type: New Full Review New Expedited Review Continuation Review Exempt Review
 Modification

Action: Approved Approved Pending Modification Not Approved

Project Number: 2010-09-013

Researcher(s): Virginia Hart-Kepler Doc SON
Dr. Susan Instone Fac SON

Project Title: How do Mexican-born immigrants make decisions about type 2 diabetes self management?

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

Modifications Required or Reasons for Non-Approval

None

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited review at any time.

Dr. Thomas R. Herrinton
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University of San Diego
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5998 Alcalá Park
San Diego, California 92110-2492



Institutional Review Board Project Action Summary

Action Date: October 24, 2016

Note: Approval expires one year after this date.

Type: New Full Review New Expedited Review Continuation Review Exempt Review
 Modification

Action: Approved Approved Pending Modification Not Approved

Project Number: 2010-09-013

Researcher(s): Virginia Hart-Kepler Doc SON
Dr. Susan Instone Fac SON

Project Title: How do Mexican-born immigrants make decisions about type 2 diabetes self-management?

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

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Administrator, Institutional Review Board
University of San Diego
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San Diego, California 92110-2492

Appendix B

Script for Informed Consent for Participation in the Diabetes 2 Research Study By Researcher Virginia Hart-Kepler

My name is Virginia Hart-Kepler. I am a nurse who is doing a research project. This project is part of my graduate studies at the University of San Diego. The purpose of this research is to explore (*exploracion*) how people born in Mexico (or lived there a few years) make decisions and choices about or decide how to take care of their type 2 diabetes (*diabs tipo 2*)

If you decide to do this, here's what it will involve. You will do one interview with me. I will ask you questions about the things that affect (*afecter*) and influence (*influencia*) and motivate (*motivation*) how you make decisions about your diabetes tipo 2. The interview will last from 60-90 minutes; or you can talk longer if you want. I will also ask you some questions about you, such as your age, religion, type of work and your culture in Mexico and different things that affect your diabetes. I will be recording what you say, but your name will NOT be used. Nobody will know it's you.

Sometimes when people think about issues like having diabetes or family far away, they feel emotions like sadness or anxiety. **If you would like to talk with someone about your feelings, you can call the L.A. County Mental Health/Crisis Line toll free, anytime, at 800-854-7771.**

There are three benefits (good things that happen) if you participate (*participacion*) in the study. You will receive a \$30 grocery gift card. I will give you this card even if you do not finish the interview. You also receive information about diabetes. The other good thing about being in the study is to know that you helped nurses learn in a better way how to help people from Mexico who have diabetes.

Everything you say is confidential/ private (*privado*). That means that your real name will NOT be used. I will keep the recordings and the paper I write on locked in a file cabinet at my house. Nobody else will have access or be able to get to these things. I will keep this stuff locked up for at least 5 years. Then I will destroy it. I hope to use what you tell me to help other nurses and doctors. I will publish (write in a professional magazine) what I find out in professional journals and present (or talk about) what I find out at conferences for doctors and nurses. But nobody will ever know that it's you, because your real name and personal information will never be used.

OK, here's an important thing. You don't have to do this. It is 'OK' to say 'no', or to start and then decide to quit. It's perfectly OK. Nothing about your health care anywhere or anything else will change if you decide that this is not for you.

I will give you a copy of this paper to take with you. That way you will have the phone numbers to call if you have any questions, any time. If you have questions, you can call me at: (626) 963-xxxx. You can also call my professor at the University. Her name is Dr. Susan Instone, and her # is (619) 260-xxxx.

OK, do you have any questions? Is there anything I said that you don't understand, or you'd like me to say again?

Do you give your permission (dar la permission d'Eustedes) to be in this study?

Time and date participant gave consent: _____

Appendix C - Demographic Guide

Interview Date _____ Time _____ am/ pm to _____ am/ pm ID Code _____
Research Study: How do Mexican-born immigrants make decisions about self-management of type 2 diabetes?

Investigator: Virginia Hart-Kepler, Principle, University of San Diego School of Nursing

1. **What is your ethnicity** – that is what is your culture or heritage?

Hispanic Latino Mexican Declined answer _____

2. **How old are you?** _____

3. **Gender** ___ M ___ F

4. **What is your marital status?**

Married/ # years _____ Never married Separated Divorced Widowed No answer

Children? Ages of sons: _____ Ages of daughters: _____ Deceased: _____

5. **Who lives in your house with you?**

Spouse Children Boys ____, ____, ____, ____ Girls ____, ____, ____, ____ Parents
 Grandparents Brother(s) # ____ Sister(s) # ____ Aunt(s) Uncle(s) Cousin(s)
 In-Laws Friends _____ _____

6. **Tell me what language(s) you speak at home (or most of the time) ?**

Spanish Mostly Spanish Equal Mostly English English _____

7. **Where and how did you learn to speak English? When?**

In school At home Both Other _____

How _____

8. **How many years did you go to school? Where?**

____ grades in Mexico # ____ grades in USA Other _____

0-6 7-11 12 (graduated) Com. College College Trade _____

9. **What is your religion?**

Catholic Christian Protestant Native None No answer Other _____

10. **What type of health insurance do you have?**

Medi-Cal MediCal sign-over MediCal managed care Ability to pay Private None

Medicare Other _____

11. **What kind of work do you do or have you done in the past?**

Professional Secretarial Laborer Housewife Service Unemployed None

12. **How long have you been in the United States? What about your family?**

13. **From what part of Mexico do you come? Does your family come from different parts? Where?**

APPENDIX D
Interview Guide

1. In the first questions I would like you to tell me about your diabetes, how you found out about it, what it was like to learn you have Ds, and what you think it is....
 - a. How many years have you had diabetes?
 - b. How did you find out you had DM? How did they diagnose you? Sxs?
 - i. What did you think and feel when you found out you had DM? What was it like in the beginning?
 - ii. Where were you diagnosed - in Mexico or the United States?
 - iii. What happened after you found out? What did they tell you to do? w6
 - iv. Did you think or suspect you had diabetes before you were told you have it? Some people ignore sxs or pretend not to notice they are changing or deny they have sxs? Did you really not have any idea? Or did you ignore or deny you had sxs? w6
 - v. Pre-DM: Why do some people pretend they don't know there are changes? Or ignore or deny sxs or that things are different? w6

Why do people not try to find out sooner if they have diabetes or if something is wrong?

 - vi. How hard was it for you to *accept* that you have diabetes? Did you accept it when you first learned about it or did you accept it little-by-little or after something serious or it took a long time? Unjust?
 - vii. What makes it hard to accept that you have diabetes? Is it easier if you think you can control it? w9
 - viii. Why is it hard for people to *accept* they have DM & take care of it? Why do people pretend or ignore or deny they have it? w7-8

- ix. Before you knew you had diabetes what did your friends and family tell you about diabetes? What did you know about it?
- c. What it is like for you to have diabetes? What do you think about I have diabetes? (*What it means to you*)
 - i. Do you know HOW YOU GOT IT or what caused your symptoms?
 - ii. Why do you think your DM started when it did? What was happening in your life at that time?
- d. Please tell me what you think diabetes is and how you learn and get information about diabetes?
 - i. What have you learned from your doctors & DM information you read or classes about the cause of DM?
 - ii. Did you get enough information from your doctor at the start to take care of your diabetes? What information was missing?
 - iii. How do you learn and get information about diabetes now? From Whom? From where? Do you talk with a lot of people about diabetes?
 - iv. How easy or hard is it for you to understand information about your diabetes?
 - v. What makes it hard or easy to understand?
 - vi. How do you use the information you get about your diabetes?
 - vii. Why did you stop getting information or why wasn't it available? w2
- 2a. Now I'm interested in what you do about your diabetes. How do you take care of your diabetes? w2
- 2b. Do you have a routine or habit to take care of your diabetes? What is your routine or habit? w6
What do you do when?
- 2c. *If not provided:* Is medication part of how you take care of your diabetes? What kind? How often? Does it help/how? How long have you used it? Why not use it sometimes? w2
- 2d. Do you know how your sugars range? Lowest in the last few months? Highest? w4

- ii. Do you check your sugars? When? Time of day? How often? w4
- iii. Does your doctor/ HCP want you to check? If you don't check what made you choose not to? w4
- iv. Do you know your HgA_{1c}? w2 What was the latest #? What was it in the past? w4

2e. Who do you know who also has diabetes?

- i. What does it mean to you when you see diabetes and the effects of DM around you in the community, your family and your Mexican culture? w6
- ii. Does it feel that it is *Comun* / common to have DM b/c you know other people with it or do you feel different? HOW? Why? w6
- iii. If diabetes seems comun to you, how does that affect how you take care of your diabetes? w6
- iv. How do other people around you take care of their DM? What do they do about their DM?
- v. What have you learned about DM from watching observe him/ her / them? w3
- vi. How does the way others around you take care of their DM affect (afectar) how you take care of yours? How does it affects (afectar) what you do? (This Q may not be nec)
- vii. When other people rationalize to eat or drink more than they should or things that are not good for their dm does it make it easier for you to rationalize too? Why do people rationalize to have what they want? w7

2f. What kinds of things or people in your life get in the way of (interfere with (interferer)) you taking care of your diabetes?

2g. What things or people in your life help you to take care of your dm?

2h. What *motivates* you to take care of your diabetes? W2 Include +/-

3a. Now I would like you to talk about how you decide what to do about your diabetes?

- i. Have you ever made a decision about your DM that had a + result, a good outcome? What made you choose? Tell me about it.
- ii. Has that decision helped you make more decisions about your DM? How? Why? Give examples.
- iii. What kinds of things affect (*afectar*) how you decide, how you choose what to do about your diabetes?
- iv. When you make choices that affect your diabetes do you think about the long-term side effects of DMs or more about what you would like right now (such as pleasure and enjoyment) W6
- v. Some people say they just want to do what they want even if it is bad for their diabetes? How hard is it to fight temptation to not eat what you want or as much as you want? W6, 7, 9
- vi. Please explain why you think people do not do what we know we should do? W6
- vii. Sometimes people pretend they don't know what to do or what is the right thing for their diabetes. Some patients call this "PLAYING DUMB". They say they 'play dumb' and act like they don't know what they are supposed to do, but they do know what to do. Please explain why people from Mexico who have diabetes do this.

Tell me what it means to you; when and why you might do this? Pls, explain how it works in the culture.

- viii. How does this interfere with making good decisions about dm care? W6

3b. What sorts of things or people *affect* (*afectar*) how you decide what to do about your DM? Necessary?

[What do you do when? How do you choose? What made you choose?]

- i. What do people in your family or your friends say about your diabetes? Do they treat you differently?
- ii. How does what they say or do help you to take care of your diabetes *or* make it hard for you to take care of your diabetes?
- iii. How do things, situations and people in your life influence (*influencia*) how you choose or affect (*afectar*) how you decide what to do about your DM?
- iv. Some people have told me that they feel responsible as a person from Mexico that the way they act or choices they make represent all people from Mexico and the Mexican culture and that affects how they behave/ act around others and the impression they want to make.
- v. Is this called pride? What is it called and why do people do it/feel like it?

STRESS

- a. Most people have stresses in life. How does stress in your life influence (*influencia*) or affect (*afectar*) how you make decisions about diabetes? Tell me about that...
 - b. How do you BALANCE your life with your family and their needs and expectations and your culture with how you choose to take care of your diabetes? w6
4. I imagine your life in Mexico was important to you. Tell me about how your life in Mexico influenced (*influencia*) your diabetes when you were living in Mexico.
 - a. If your DM was diagnosed in Mexico what did you do about your DM in Mexico? How take care?
 - b. How is dm care different in Mx than the US? Where you able to go to the doctor? How often? To get med'ns? Test your sugar? Have insurance?w9
 - c. Who taught you about diabetes & how to take care of it in Mx? How do people learn about diabetes in Mx? w9
 - d. How was life in Mexico different than it is here? Do you go often?

- e. What conditions/situations or people affected (*afectar*) how you took care of your DM in Mexico? How?
- f. What influenced (*influencia*) you to *leave* your homeland?
- g. What has changed in your life since you moved here?
- h. What decisions about your dm have been different in the US? Why?
- i. Of all the decisions (Choices?) you've had to make about your DM, which choices were easier?
- j. and which were harder? Why?

How did you choose? What made you choose?

- 5. Now that we have talked about all of these things, what have you thought about your future with diabetes?
 - a. What do you think diabetes does or can do to a person over time?
 - b. How do you think you will take care of your diabetes in the future?
 - c. Where do you think you will learn more about diabetes? How will you use that information?
 - d. How do you think you will make decisions about your diabetes?
 - i. Who and what do you think will have a part in (*contribucion*) how you decide what to do about your diabetes? (Why? How? When?)
 - e. What kind of things would help you take care of your diabetes?
 - i. What things that you do? Or others do? Or doctors and nurses might do would help?
- 6. Is there anything else you would like to tell me about yourself, or your diabetes, or how you make decisions about your diabetes?