

Mexican-American Families Experience of Type 2 Diabetes:

A Narrative Inquiry

A Dissertation

by

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Abstract

Title: Mexican-American Families Experience of Type 2 Diabetes:
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For Mexican-Americans, Type 2 diabetes is the most common and severe chronic illness. Mexican-Americans suffer a disproportionate burden of death and disease from Type 2 diabetes, including metabolically more severe disease, increased incidence and occurrence of complications of diabetes and a lack of access to health care. While much is known of the epidemiology of this disease, less is known of the day to day experience especially for families impacted by this disease.

In this qualitative narrative study, stories were elicited from unstructured open-ended interviews with Mexican-American families about their experiences living with diabetes.

Ten Mexican American families living in the mid-Willamette Valley of Oregon participated in this study. Twenty seven interview events occurred with a total of 42 participants, which included persons with diabetes (PWD) and adults and children who were members of the family. Each family had at least one adult member who had lived with Type 2 diabetes for more than six months.

Consistent with the methodology, I represented the findings with six story types which occurred across individuals and families. The overriding story for all of these ten families is that Type 2 diabetes creates profound emotional burden and turmoil. The six

story types were Those Who Have Gone on Before, the Scourge Upon the Generations, The Shock of Diagnosis-*Un Gran Susto* and *Coraje*-anger held within, *El Susto del Bill que te va a llegar*-The Shock of the Bill That Arrives (The Financial Burden of Type 2 Diabetes), *Cambios en Nuestra Vida* (Changes in our Lives), Tale of the Tortilla, and *Preocupaciones por el Futuro* (Worries for the Future).

These stories have implications for clinical practice where upon Mexican Americans understandings of Type 2 diabetes and families' experience is profoundly different than the dominant Euro-American culture. Based on these families' stories, clinicians need to develop an understanding of this disease, not as an individual process, but a disease which affects the entire family. Interventional research is needed which encompasses the role of story and story telling for this population.

Key Words

Diabetes Mellitus-type 2
Mexican-Americans
Family
Narrative

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Chapter 1: Introduction

Type 2 diabetes is the most common and severe chronic illness in Mexican-Americans, the largest subset of the Latino population in the U.S. With a prevalence of Type 2 diabetes four times higher than in the white population (Harris et al., 1998), Mexican-Americans suffer a disproportionate burden of death and disease from Type 2 diabetes, including metabolically more severe disease, increased incidence and occurrence of complications of diabetes and a lack of access to health care. (R. M. Anderson, Goddard, Guzman, & Vazquez, 1998; Black, Ray, & Markides, 1999; Flegal et al., 1991; Harris et al., 1998; Tripp-Reimer, Choi, & Kelley, 2001; Walsh, Katz, & Sechrest, 2002).

Chronic illness research has primarily focused on quantifying coping processes and on quality-of-life issues rather than on describing day-to-day experience of disease (Ironsides et al., 2003). Moreover, due to scant research on rural Mexican-American families and Type 2 diabetes, little is known on how these families experience the day-to-day realities of this disease (Fisher et al., 1998; Fisher, Chesla et al., 2000). Finally, while culturally competent care is known to improve health outcomes for Mexican-Americans with Type 2 diabetes (Sharon Brown, Garcia, Kouzekanni, & Hanis, 2002) one aspect of culturally competent care has received less attention, the family. By focusing on the family and their daily experiences of diabetes, clinicians may gain understanding of the meaning of Type 2 diabetes for families. This understanding may lead to interventions and treatments, which are both patient and family centered. Therefore, the goal of this proposal is to explore the day-to-day experiences of Mexican-American families living with Type 2 diabetes, providing a foundation for clinicians to respond more effectively

and empathetically to the needs of this population. Exploring the day- to-day experience of Mexican-American families allows expression of their voice, actively locating these marginalized families in their own particular time, place and setting (Clandinin & Connelly, 2000).

Significance of the Study

As noted initially, Type 2 diabetes is a devastating disease for Mexican-Americans, yet the general U.S. population is also profoundly impacted; with 17 million adults, approximately 8% of the U.S. population, diagnosed with Type 2 diabetes. The rate of Type 2 diabetes has increased dramatically over the past 30 years, and is now reaching epidemic proportions (E. Fisher et al., 2002). In the past 5 years alone,(National, Center, for, Health, & Statistics, 2003) the number of persons with diabetes increased 72%. Due to the morbidity, mortality and costs associated with complications of diabetes, such as blindness, amputation, end-stage renal disease, coronary heart disease and stroke, these dramatic increases are of great concern (Weinstock, 2003). Overall, Type 2 diabetes and its complications are the fifth leading cause of death in the U.S. (Harris, 1998). One third of persons with Type 2 diabetes have no recognizable symptoms, and are not aware they have the disease (E. Fisher et al., 2002) leading to delayed diagnosis, secondary complications and increased human suffering. The Centers for Disease Control (2002) projects an additional 800,000 new cases of Type 2 diabetes each year threatening the health care delivery system (Bradley, 2000; Tripp-Reimer et al., 2001; Weinstock, 2003).

The Costs of Type 2 Diabetes

The financial burden of Type 2 diabetes in the U.S. on individuals, employers and government funding agencies is staggering. In 2002, the financial costs of medical care of Type 2 diabetes alone was 92 billion dollars a year in the U.S. in 2002, up from 44 billion in 1997 (ADA, 2003). One out of every 7 dollars spent on medical care in the U.S. is related to diabetes. Type 2 diabetes accounts for more than 3 million hospital stays and more than 15 million physician visits each year (ADA, 2003). Persons with diabetes have higher rates of disability, almost 30% in comparison to only 10-20% of nondiabetics, and much higher rates of absenteeism (ADA, 2003; Black, 2002).

In addition to the epidemic proportions and high financial costs, persons with Type 2 diabetes incur enormous personal costs and face potential devastation. The majority of diabetic adults are less healthy than nondiabetic adults, even when they attempt to control the disease (Quackenbush, 1996). While diabetes management can control the progression of the disease, patients must adopt demanding self-care behaviors such as regulating dietary intake, exercising, administering medication or insulin and monitoring blood sugar levels by means of frequent finger sticks (Fisher, Gudmundsdottir et al., 2000; Hunt, Valenzuela, & Pugh, 1998; Jezewski & Poss, 2002). These self-care regimens require many difficult lifestyle changes and can be overwhelming for many patients, often leading to depression (Black, 2002; Quackenbush, 1996). Overall, persons with Type 2 diabetes are at higher risk for depression, cognitive impairments, and subsequently a poorer quality of life (Black, 2002; Hunt, Arar, & Larme, 1998).

Mexican-Americans and the Willamette Valley of Oregon

This research study is locally situated in the mid-Willamette Valley of Oregon, a rural agriculturally rich region of the Pacific Northwest. In this region, the Mexican-American population has grown 162% in the past 10 years (Davis, 2002b). The Mexican-American history of the mid-Willamette Valley is unique based upon U.S. immigration policies, the evolving agricultural industry and the continual need for cheap labor.

Mexicans came north to Oregon as a result of the Bracero Accord. During World War II the need for cheap and available labor was great, due to the shortage of European-American agricultural workers who left the fields for work in munitions factories and naval shipyards. Thus in 1942, the U.S. and Mexico established the Bracero Accord which granted temporary worker status to Mexicans who came and aided with the harvest for six months at a time (Gamboa & Buan, 1995).

During the 1950's the "migrant streams" were institutionalized as part of the agricultural industry. The Western migrant stream began in California and spread northward to the apple orchards of Washington. For the mid-Willamette Valley, the epicenter of the Western stream was Woodburn, Oregon, where in the summers the population would swell by thousands of Mexican migrants. Today, Woodburn is a "Mexican" town with the majority of the population of Mexican descent (Gamboa & Buan, 1995). The agricultural industry is evolving in the mid-Willamette Valley from a focus on beans, berries and nuts which are harvested once a year, to year around industries such as nursery work, grass seed production and wineries and vineyards. The shift in local agriculture meant that cheap labor was needed year round, hence, the movement from temporary workers to permanent year round workers (Gamboa & Buan,

1995). This shift from migrant workers to year round agricultural workers has swelled the Latino population in the mid- Willamette Valley, with Salem, the state capital having 21% of its residents Latino, and communities McMinnville, 14.6% and Dayton, approximately 24% (Vera, 2001).

The social and economic history of immigrant groups often has implications for the current health status of these groups (Suarez-Orozco & Suarez-Orozco, 2001). Due to the dramatic population growth of Mexican-Americans, the burden of Type 2 diabetes upon this region has increased. Many agricultural workers are undocumented, and lack access to Medicaid or the Oregon Health Plan for their families. Due to low wage worker status, many are unable to afford the health insurance offered by employers. Additionally, being non-English speaking and of a different ethnic group impacts access to health care services (IOM, 2002).

Researcher's Clinical Experience

This proposed research study is influenced by my fifteen years of clinical experience as a Family Nurse Practitioner dealing with the difficulties and frustrations of caring for Type 2 diabetic Mexican-American patients first in Chicago and for the past five years in the mid-Willamette Valley of Oregon. Based on my clinical experience, Type 2 diabetes has a strong emotional component for Mexican-Americans compared to European-American patients. From diagnosis to initiation of insulin therapy, patients were often overwrought and grief-stricken. Yet, patients did better clinically and appeared to cope better emotionally with family support for all aspects of diabetes care and management.

Maria, a 36 year old Type 2 diabetic, struggled with the daily finger sticks and the blood glucose monitoring necessary for her complex insulin regimen. She was not successful until her sister-in-law Claudia moved in with her. They shared one monitor, strips and one record book thereby decreasing expenses. Maria was then able to adjust her insulin and her blood sugars were better controlled.

My Mexican-American patients taught me that their experience of chronic disease resides in the family. For this population, the family-*la familia*-is both the context and crucible for the disease experience in contrast to the typical focus on patient self-management of disease. I believe that diabetes care must be situated in the family context, a cultural strength, to develop prevention strategies, decrease rates of secondary complications, manage the day to day aspects of the disease and reduce subsequent suffering.

In order to address the health disparities experienced by Mexican-Americans, health care professionals must develop culturally competent skills in their interaction with this population (IOM, 2002). By expanding their understanding of the daily realities of the lives of Mexican-American's and embracing this diverse population's strengths as a source of personal and family empowerment, health care professionals can develop more culturally competent relationships with their patients (Clark, 1998) (Flaskerud & Nyamathi, 2002). Based on the significance of the problem, the devastating financial and personal cost of Type 2 diabetes and my clinical experience, the goal of this proposal is to develop narrative accounts of the day-to-day experiences of Mexican-American families with Type 2 diabetes. Narrative, the telling of stories, is a central thread of Mexican-American culture (Hunt, 2000) and narrative inquiry has been found to be a trustworthy and rigorous research methodology (Clandinin & Connelly, 2000).

The Specific Aims of the Research Study:

1. Describe the day to day experience and meanings of Type 2 diabetes of Mexican-American families living in the mid-Willamette Valley of Oregon.
2. Describe the interpersonal and relational aspects of the family's experience of Type 2 diabetes.
3. Describe the socio-cultural-economic context impacting the family's experience of Type 2 diabetes

Chapter 2: Literature Review

Type 2 diabetes is a devastating disease, and with dramatic increases in the past 30 years is now considered an epidemic in the U.S. (E. Fisher et al., 2002). Mexican-Americans have been profoundly impacted by the epidemic of Type 2 diabetes. The prevalence of diabetes for Mexican-Americans is 2-4 times greater than in non-Hispanic whites as documented by the San Antonio Heart Study, (Flegal et al., 1991); the Hispanic Health Nutrition Examination Survey (HANES) (Mitchell et al., 1990), the National Health Interview Survey (NHIS)(CDC, 2004) and the National Health and Nutrition Examination Surveys (NHANES III)(CDC, 2004; Harris et al., 1998).

Because of the chronic nature of this disease, its impact is felt not only by the individual but also by the entire family. For example, standard treatments such as significant changes in diet and exercise patterns, home blood glucose monitoring, and medication regimens are demanding on individuals, and impact the entire family. This family impact may be felt more strongly in cultural groups with strong family traditions, such as Mexican-Americans. Health care research on the Mexican-American family context has been scarce, resulting in a lack of interventions that are both culturally oriented and family centered. From my critique of the extant literature, as well as results from numerous studies, minimal information exists on the Mexican-American family's experience of Type 2 diabetes (R. M. Anderson et al., 1998; Bautista-Martinez et al., 1999; Bertera, 2003; Chesla, Skaff, Bartz, Mullan, & Fisher, 2000; Fisher et al., 1998; Hosey, Gordon, & Levine, 1998; Oomen, Owen, & Suggs, 1999; Weller et al., 1999).

This chapter critiques the relevant literature on Type 2 diabetes in Mexican-American families. This literature review will address epidemiological aspects of Type 2

diabetes in Mexican-Americans, the experience of Type 2 diabetes for Mexican-Americans, and the family context of Type 2 diabetes specifically for Mexican-Americans. Although the focus of this study is local-Mexican-Americans who live in the mid-Willamette Valley of Oregon-this literature review will examine research on Mexicans both in the U.S. and in Mexico to provide a foundation for this study. By examining the family's experience of Type 2 diabetes, I hope to show how Type 2 diabetes is interwoven into the Mexican-American family.

Type 2 Diabetes among Mexican-Americans

This section will discuss the incidence and secondary complications of Type 2 diabetes among Mexican-Americans. Risk factors, including social and health care access, will be addressed.

Epidemiology

It is estimated that the rate of Type 2 diabetes among Mexican-Americans, the largest subset of the Latino population in the U.S., is 55% higher than among other Latinos (Shepherd, 1999). In certain Mexican-American communities, diabetes affects half the adult population (Sharon Brown & Hanis, 1999; Flegal et al., 1991). Ominously, diabetes, normally seen in persons ages 40 and older, is now being diagnosed in Mexican-American children as young as six years of age, with potentially devastating consequences for their quality of life as young adults along with potentially lifelong secondary complications of the disease (Bradley, 2000). Elderly Mexican-Americans with diabetes are severely impacted as well, with higher rates of co-morbid conditions, including myocardial infarction, stroke, hypertension, and angina, higher rates of functional disability and a death rate twice as high as elderly non-Hispanic whites (Black

et al., 1999). However, the above mortality statistics are in direct contrast with the Latino death rate paradox (Liao et al., 1998).

The death rate paradox is seen as a mortality advantage since Latinos have age-adjusted mortality rates similar to European-Americans, yet their socioeconomic status is comparable to African-Americans (Liao et al., 1998). Additionally, Mexican-Americans, as stated above, have increased prevalence of certain risk factors for mortality, including diabetes. Yet the death rate paradox, although noted widely in the epidemiological literature, is felt to be due to underreporting of mortality data, particularly for Latino women, and is an advantage only for first generation immigrants and disappears in subsequent generations (Patel, Eschbach, Ray, & Markides, 2004).

Mexican-Americans have higher mortality rates from Type 2 diabetes and its complications due to higher rates of disease and severity of complications (Black et al., 1999; Flegal et al., 1991). Type 2 diabetes is considered the third leading cause of death for Mexican-American women and the fourth leading cause for Mexican-American men (ADA, 1996; Geiss, Herman, & Smith, 1995). The profound impact of the secondary complications of diabetes such as blindness, amputation, end-stage renal disease, coronary heart disease and stroke makes addressing the dramatic increase in the disease for this ethnic group most urgent (Weinstock, 2003).

Risk Factors

While Mexican-Americans are generally at increased risk for Type 2 diabetes, certain risk factors contribute to the increasing prevalence of this disease among Mexican-Americans (Kahn, 2002). Increasing the chance of Mexican-American's developing diabetes are: 1) genetic factors; 2) medical factors, such as impaired glucose

tolerance, gestational diabetes, hyperinsulinemia and insulin resistance, 3) lifestyle factors, such as obesity and physical inactivity (Harris et al., 1998; 1999) and 4) low rates of insurance are often the result of poverty or lack of legal residency status.

Unfortunately, many epidemiologists fail to consider social factors such as poverty and lack of access to health care as risk factors for Type 2 diabetes resulting in a decontextualized understanding of this disease.

Genetic risk factors. A family history of diabetes increases the chance that one will develop diabetes. The San Antonio Heart Study showed that diabetes prevalence was twice as great among Mexican-Americans who had a first degree relative with diabetes as among those with no family history of diabetes (Flegal et al., 1991). More than any other Latino group, the genetic makeup of Mexican-Americans is strongly linked to that of American Indians, who have a similarly high incidence of diabetes. This genetic link is considered by some expert to be the reason why Mexican-American's rate of diabetes is higher than other Latino subgroups (Flegal et al., 1991; Harris, 1998)

Medical risk factors. Impaired glucose tolerance occurs in 20 percent of Mexican-Americans age 40 to 74 in the NHANES III survey (Harris et al., 1998). This compares to 15% of European-Americans. Mexican-American women with gestational diabetes develop Type 2 diabetes at a younger age than European-Americans (Black et al., 1999). Contrasting the incidence for men and women, 29% of Mexican-American men age 50-69 and 24% of Mexican-American women age 50-69 have been diagnosed with Type 2 diabetes (Harris et al., 1998). Hyperinsulinemia (higher levels of fasting insulin) and insulin resistance (an inability to use the body's own insulin to properly control blood glucose) are markers for an increased risk of developing Type 2 diabetes and both are

seen frequently in Mexican-Americans secondary to obesity and genetic factors (Black, 1999).

Lifestyle risk factors. Mexican-American adults, especially women, have higher rates of obesity, a major risk factor for diabetes, than European-Americans (Harris et al., 1998). The risk of Type 2 diabetes is even greater among overweight Mexican-American children (Goran, Ball, & Cruz, 2003). Obesity is strongly linked to the family's genetic background (Hosey et al., 1998). Additionally, 65 % of Mexican-American men and 74% of Mexican-American women participate in little or no leisure time activity in part due to family responsibilities (Harris, 1998; Harris et al., 1998). No leisure time activity leads to less exercise predisposing one to obesity and Type 2 diabetes.

Social risk factors. Higher rates of poverty predispose Mexican-Americans to diabetes due to the complex interactions of environment, stress, and the unhealthy lifestyle of poverty (Robbins, Vaccarino, Zhang, & Kasl, 2001). Life in a deprived physical environment such as overcrowding and substandard housing can lead to the development of an unhealthy lifestyle with inadequate diet and exercise activity. Similarly, the chronic stress of poverty signals the body to accumulate abdominal fat (central obesity) which is more likely to lead to diabetes and other cardiovascular diseases than total obesity (Goran et al., 2003). Therefore, the environment, the stress of poverty and strong genetic risks interact to lead to dramatically high rates of Type 2 diabetes in this population (Hosey et al., 1998).

Health care access. Many Mexican-Americans lack adequate access to health care due to lack of insurance and social and language barriers (R. M. Anderson et al., 1998; Betancourt, Johnson, & Valadez, 2000). Mexican-American individuals with

diabetes often experience difficulties with transportation and maneuvering through the health care system to specialists and laboratories due to language and cultural barriers (Betancourt et al., 2000). Undocumented Mexican-Americans without proper visas, work permits or legal residency status, may also fear that using or accessing government programs will jeopardize their application for residency status. (Lipton, 1998). In the Harris (1999) study, only 66% percent of Latino persons with diabetes between 20-64 years of age had any type of health insurance. Mexican-Americans, in particular, had the lowest rates of insurance of any ethnic minority group (Harris, 1999). Fifty-four percent of Latino adults said they had difficulties paying for health care (Betancourt et al., 2000). Latinos as a whole are less likely to be insured than other Americans (National Heart, 2003).

This lack of access means that diabetes, a hidden disease which does not manifest many symptoms in its earlier stages, is not being diagnosed early enough or treated aggressively as needed (Black, 2002). In addition, lack of primary care means that risk factors for diabetes are often not addressed and treated (Bertera, 2003; Black, 2002). Moreover, even if Mexican-Americans have access to health care, few culturally competent health care programs have been implemented and as a result, primary care providers do not have a good understanding of Mexican-American culture and how patients experience or perceive their disease (Bertera, 2003). The lack of culturally competent care negatively impacts long term outcomes of Type 2 diabetes (Alcozer, 2000; Bautista-Martinez et al., 1999; Lipton, 1998).

In summary, given these epidemiological dimensions, Type 2 diabetes is fast becoming an epidemic among Mexican-Americans and will not respond to a quick and

easy fix. Improved health outcomes are not easily achieved. The need for additional research is evident. The severity of this disease for Mexican-Americans, as well as the challenge of understanding the complexities of the cultural and familial context, justifies research in this area.

Chronic Illness Experience

Little has been written specifically about Mexican-American's chronic illness experience. Moreover, chronic illness research has focused on quantifying certain defined aspects of chronic illness rather than on description of the experience (Ironsides et al., 2003). Addressing experience helps the researcher move beyond focusing only on the individual to include an examination of the social context (Clandinin & Connelly, 2000). The larger social context impacts the course of chronic illness. In this section, the chronic illness experience will be explored. Specifically, the experience of Type 2 diabetes will be addressed with the central focus on the experience for Mexican-Americans.

In order to understand the conceptualization of chronic illness as a day-to-day experience, it is important to define basic terms. Illness is defined as "the innately human experience of symptoms and suffering, also referring to how the sick person and the members of the family or wider social network perceive, live with and respond to symptoms and disability" (Kleinman, 1988). Illness is differentiated from disease, which is defined as an alteration in biological structure or functioning. Kleinman (1988) further differentiates the illness model by defining sickness as an understanding of a disorder in its collective sense across populations and the impact of economic, political and institutional macrosocial forces on sickness. Chronic illness is defined as a disease or injury that has lasted more than 6 months, causing the individual to significantly alter

his/her day-to-day activities (Ironside et al., 2003; Kleinman, 1988). In developing his theoretical understanding of chronic illness, Kleinman emphasizes that the illness experience has meaning, and that this meaning is important for research. According to Kleinman and other researchers, the chronic disease experience is a universal experience, covering many different disease entities rather than one specific disease (Ironside et al., 2003; Kleinman, 1988).

Although Kleinman's conceptualization of the chronic illness experience has been widely embraced by nurse researchers, he is not without his critics. Arthur Frank contends that Kleinman uses only the language of symptoms to express the chronic illness experience, though Frank does recognize Kleinman's efforts to interweave the complexities of bodies, cultures and lives (Frank, 1995). While Kleinman's focus on symptoms can be traced to his professional background as a psychiatrist and his dependence on the biomedical model, the focus of Frank's research has been on the experience of the body as the locus of the illness experience. Frank's premise is that in order to understand the chronic illness experience, one needs to give the body a voice and allow it to tell its story (Frank, 1995). Frank (1995) embraces narrative research as "discovering the body", finding the truth in the uncovering of experience. Although the focus of this research endeavor is not the bodily experience, Frank's thesis supports embedding the chronic illness experience in the intimate knowledge of the day-to-day experience.

Cultural Understanding of Health/Illness

A focus on the cultural context is necessary in researching the chronic illness experience of ethnically diverse individuals and families. Culture is broadly defined as

the learned patterns of thoughts and behavior characteristic of a particular social group (P. J. Brown, 1998). Culture influences health by affecting exposure and vulnerability to disease, risk-taking behaviors and access to and availability of quality health care. In addition, culture shapes the perceptions of, and responses to health problems and their effects on individuals' and families' lives and well-being (Helman, 1995; Kleinman, 1988). It is important to note the multitude of domains in which researchers can examine culture.

Daily experiences, beliefs and understandings are also influenced by culture. The cultural beliefs and practices around health and illness that are learned and shared by a group of people are called a medical system. Culturally constructed medical systems or ethnomedicine systems (Kleinman, Eisenberg, & Good, 1978) traditionally were viewed as exotic, non Western or folk health beliefs and practices. However, current thinking regards biomedicine, or specifically Western scientific health care practices, as another form of ethnomedicine.

It is important to note that both the illness experience as well as disease categories are socially constructed (P. J. Brown, 1998). The illness and health experience is based on culturally learned assumptions about how and why the world works. Disease categories are often culturally agreed upon. These categories are fluid rather than fixed states, change over time and are the result of cultural circumstances, such as migration or language acquisition (P. J. Brown, 1998; Helman, 1995).

An important influence on the social and cultural construction of illness is acculturation. Acculturation is defined as the degree to which individuals change their behavior and attitudes toward those of the host society (Padilla, 1980). Extended to

groups, acculturation is the adoption of the culture of the dominant group by the minority group (Roysircal & Maestas, 2000). As a result of acculturation, both an individual's and a family's health beliefs and understandings may change, lending a fluidity to the cultural construction of health and illness.

Based on ethnomedicine and a theoretical understanding of the social construction of illness, Kleinman, an anthropologist as well as a psychiatrist, developed the theoretical construct of explanatory models (EM)'s to gain knowledge of the cultural dimensions of chronic illness. Many anthropologists believe the explanatory model construct to be the theoretical foundation of medical anthropology as a discipline. Explanatory models are based on a distinct set of meanings, often derived from the stories individuals develop to make sense of an illness within the context of their culture. These stories are based on the beliefs and values of the individual and often are manifested in their behavioral responses to their illness. The focus for the individual is the etiology, symptom severity, and treatment of the illness and often includes both folk and biomedical perspectives (Kleinman et al., 1978).

Qualitative Nurse Researchers and the Chronic Illness Experience

Nurse researchers use a variety of methodologies to study the chronic illness experience. According to Ironside (2003), chronic illness researchers use quantitative methods to measure coping and quality of life, and other particular aspects of chronic illness, but pay little attention to the day-to-day experience of chronic illness., By focusing on particular aspects or one particular chronic illness the totality of experience is overlooked (Ironside et al., 2003; Thorne & Paterson, 1998). One of the initial nursing studies by Corbin and Strauss focused on the central issue of how chronic illness is

managed at home (Corbin & Strauss, 1988). In this grounded theory study, 60 couples were interviewed in which one person had a chronic illness. The results demonstrated that chronic illness had a profound impact on the couple's life together. In addition, the researchers developed a theory of the trajectory of chronic illness with various stages such as a comeback phase, stable phase, unstable phase, and downward phase. The experience of the spouse was explored; for example depending on the stage of illness, spouses of chronically ill persons experienced various levels of stress and strain.

More recently, a number of nursing studies have used qualitative methods to conceptualize and to understand the chronic illness experience. Anderson, Blue and Lau (1991) describe how life is restructured in the face of chronic illness not only by the ups and downs of the illness course, but also by the "furniture of everyday life" such as employment concerns, making ends meet, and forming new relationships. These researchers emphasized that the chronic illness experience is "nested" in a complex personal, socioeconomic and political web (J. Anderson, Blue, & Lau, 1991). This qualitative study found that the health care delivery system focused on an ideology of self-care defined as the ability of each individual to influence their health and fully participate in their health care, while ignoring the larger and more complex, sociopolitical, cultural, and economic context of the illness experience (J. Anderson et al., 1991).

A phenomenological study (Ironsides et al., 2003) concluded that measuring functional status alone does not fully encompass the chronic illness experience, but that narrative accounts can elicit specific meanings of an individual's chronic illness experience. Participants described wanting more discussion with their health care

provider on the meanings of the chronic illness experience rather than focusing solely on symptom management. This particular study found the space between “acutely ill” and “being well” is neither understood nor documented in the nursing research literature, and yet, this is the space in which most individuals with chronic illness live. The concept of space was not fully developed in this study, but elicited as one of the themes to emerge from the data. Rather than focusing solely on deficits and disabilities requiring intervention, health care providers need words and concepts that address all the possibilities of living with chronic illness (Ironside et al., 2003).

The very specific focus of Charmaz’s (1999) qualitative research focused on suffering in the experience of chronic illness. Charmaz found that hearing the ill person’s story is essential and appreciating suffering is key to unlocking the daily experience and meaning of chronic illness both for the ill person and the researcher alike (Charmaz, 1999).

In summary, medical anthropologists and nurse researchers have conceptualized chronic illness experience in a variety of ways. Qualitative research has focused on explanatory models (EMs), embeddedness of the bodily experience, macrolevel understandings of illness, the furniture of every day life, and suffering as part of the chronic illness experience (J. Anderson et al., 1991; Charmaz, 1999; Frank, 1995; Ironside et al., 2003; Singer, 1998). Yet, qualitative research has only begun to touch the surface of the intimate knowledge of chronic illness experienced by both patients and families which is often devalued by the biomedical system. I believe examining the day-to-day experience will encompass both the sense of embeddedness addressed by Frank

and the macrolevel influences important to Anderson, Blue and Lau as well as addressing the large gap in the research literature on the family's experience.

Diabetes Experience

Persons with Type 2 diabetes face multiple complex self-care regimens and the potential burden of secondary complications. Therefore, it is necessary to research the diabetes experience as its own experience distinct from the global chronic illness experience. There is disagreement in chronic illness research, whether specific disease entities rather than the global chronic illness experience should be examined. As stated earlier, Kleinman (1988) and Ironside (2003) and other chronic illness researchers believe the chronic illness experience is universal. Yet diabetes researchers counter that Type 2 diabetes is its own unique experience because of the complexity and burden of self-care and the propensity for secondary complications (Hunt, Arar et al., 1998; Hunt, Valenzuela et al., 1998; Quackenbush, 1996).

Although the focus of self management is greater for diabetes than for other chronic diseases, it is important that self-management not be divorced from its complex sociopolitical, cultural and economic context (J. Anderson et al., 1991). Historically, Type 2 diabetes research has stressed self care management strategies and philosophies, and has not focused on the day-to-day experience of Type 2 diabetes. Scant literature exists on Type 2 diabetes and the day-to-day or lived experience. There are studies examining the lived experience of ethnic groups such as Native American Indians and First Nation persons in Canada, but these focus very specifically on cultural understandings and not on daily experiences (Hernandez, Antone, & Cornelius, 1999; Parker, 1994).

Diabetes Experience for Latinos/Mexican-Americans

For Mexican-Americans, little attention has been given to the unique cultural, emotional and day-to-day experiences of living with this chronic disease (Flegal et al., 1991; Hamman, Marshall, & Baxter, 1989; Hanis, Ferrell, & Barton, 1983; Mitchell et al., 1990). Historically, diabetes researchers have narrowly viewed the patient orientation to diabetes self-management as psychological using such concepts as locus of control or personal motivation (Hunt, Valenzuela et al., 1998). Specifically for Mexican-Americans, these patient-centered models failed to consider “the socio-economic and life-world context of illness management, not considering the subjective process of interpretation and the creation of meaning which may generate these orientations” (Hunt, Valenzuela et al., 1998).

By focusing on the socio-cultural and life-world context, the Mexican-American diabetes experience is situated as its own unique cultural and emotional experience. The Mexican-American chronic disease experiences, according to Napolitano (1992), are distinctive, meaningful experiences unique to their culture. This experience blends with the patient’s life and family development. These unique cultural and emotional experiences (Napolitano, 1992) are central to understanding the day-to-day experience, the focus of this study. In this section both the patient’s perspective and family’s-day to-day experience will be examined.

Day-to-day experience was found to be critical to the patient’s perspectives on the management of Type 2 diabetes according to Hunt, Arar and Larne (1998). This study found the overwhelming goal for patients was learning to effectively integrate diabetes control into the fabric of their daily lives (Hunt, Arar et al., 1998). Mexican-Americans

continually adapted personal diabetes care recommendations to fit the context of their daily lives and the needs of their family, rather than following treatment recommendations as structured by their health care providers (Hunt, Arar et al., 1998). Mexican-Americans often use their own causal stories, based on personal behavior or a traumatic event to form their personal perceptions and observations of their disease course (Hunt, Valenzuela et al., 1998). According to Hernandez (1995), the traditional “adherence paradigm” used in diabetes education with Latino/Mexican-Americans needs to be replaced with an understanding of the day-to-day experience of living with Type 2 diabetes (Hernandez, 1995). In a recent study by Garcia (2005), the day to day experience was explored by examining the frequency of diabetes related symptoms, the perceptions of seriousness, treatments used to manage the symptoms and ratings of treatment effectiveness for Mexican-Americans with Type 2 diabetes. This study concluded that participants used self-care treatments of symptoms which were not appropriate and often did not check blood glucose even though they had glucometers (Garcia, 2005).

Nurse researchers embrace explanatory models (EMs) to explore the specific cultural experiences of diverse groups. Alcozer (2000) used explanatory models as part of a secondary analysis of data from a larger research study of the perceptions and meanings of Type 2 diabetes among Mexican-American women. The data were analyzed and collapsed into various explanatory models of diabetes as defining, getting, having, describing and taking care of diabetes. The central meaning of having diabetes was viewed as a life threat with complications and a shortened life (Alcozer, 2000).

Jezewski and Poss (2002) explored explanatory models (EMs) among a population of Mexican-Americans with Type 2 diabetes living along the United States-

Mexican border. The results of this study showed that participants incorporated both folk and biomedical perspectives. The primary cause of diabetes was thought to be *susto* (a fright or scare), yet participants also incorporated biomedical causes into their understanding. Treatments included both herbal and biomedical modalities (Jezewski & Poss, 2002). A recent study by Coronado, Thompson, Tejeda and Godina (2004) found among focus groups participants in the Yakima and Skagit Valley in Washington that strong emotions such as fright (*susto*) intense anger (*coraje*) or sadness and depression (*tristeza*) are thought to precipitate diabetes (Coronado, Thompson, Tejeda, & Godina, 2004). Carranza and LeBaron, (2004) found that the vast majority of participants believed that a past traumatic event (*susto*) rather than their behavior was the primary cause of their diabetes (Carranza & LeBaron, 2004); this stands in contrast to Hunt and Valenzuela's (1998) study, which found that personal behavior was thought to be the primary cause of diabetes.

Adams (2003) discusses EMs in her qualitative study, stressing that meaning needs to be a function of the group norm as well as the individual and that an understanding of both is essential to the development of culturally competent diabetes care (Adams, 2003). Beyond simply understanding personal and group meaning and cultural understanding, social factors, fears, and concerns also need to be considered. Social factors, such as being employed in a low paying job, impact the ability of patients to remain healthy. Fears and concerns are influenced by socio-cultural beliefs, specifically for Mexican-Americans with Type 2 diabetes for whom the disease experience evokes such strong emotional content (Betancourt, Carillo, & Green, 1999;

Betancourt et al., 2000). Social factors, fears and anxieties are incorporated into the day-to-day realities of Type 2 diabetes.

Other researchers have focused on the unique experience of Type 2 diabetes for Latino/Mexican-American populations and how it differs from European-American populations. Latinos overwhelmingly view diabetes from an experiential model focusing on symptoms, lifestyle, and day-to-day experience while European-Americans view diabetes from a biomedical model (Chesla et al., 2000). Mexican-Americans with diabetes focus on behavior control and the need to make micro-decisions in the context of daily lives, balancing the management of Type 2 diabetes against other competing factors in their lives, while providers focused on glucose control as a measurement of diabetes self-management (Hunt, Arar et al., 1998; Hunt, Valenzuela et al., 1998). Jezewski and Poss (2002) explored the constructs of cause, symptoms, treatment and social significance in Mexican-Americans perception of Type 2 diabetes. They found that Mexican-Americans have unique understandings of cause, symptoms, and treatment of diabetes such as weight loss being a symptom of diabetes and eating cactus leaves (nopales) as a treatment for high blood sugar (Jezewski & Poss, 2002).

Summary

All these studies examined the unique cultural and daily experiences of Mexican-Americans with Type 2 diabetes from a diversity of perspectives. Based on the importance of the socio-cultural context and life-world view, researchers examined explanatory models (EMs), meaning, causal stories, social factors impacting diabetes and the model of diabetes care based on personal and daily experiences (Chesla et al., 2000; Hunt, Arar et al., 1998; Hunt, Valenzuela et al., 1998). All of these factors or concepts

are clearly a part of the day-to-day experience of Mexican-American families, yet none of the researchers focused exclusively on the daily realities of the family living with Type 2 diabetes.

The Family Context of Type 2 Diabetes

The epidemiological literature clearly demonstrates both the severity and the complexity of Type 2 diabetes for Mexican-Americans. In addition, Mexican-Americans' unique experience of Type 2 diabetes differs from providers' understandings as well as European-Americans' experience of the disease. This section will explore the family context of Type 2 diabetes, and the family context and the cultural importance of the family for Mexican-Americans.

Type 2 Diabetes and the Family

It is important to study the family context of chronic illness since the family is the primary source of illness beliefs and the key social influence in sustaining disease management in chronic conditions (Rolland, 1994). However, chronic illness in relation to the larger family context has not been widely studied. Most studies have focused on some aspect of the family such as cohesion or other measures of family functioning, yet a multidimensional view of family life has not been a part of most research studies (Chesla et al., 2003). The longitudinal research studies examining adults and the impact of the family with various chronic diseases suggests that the family context can influence the long-term course or progression of disease. Specifically, family beliefs and structures had a considerable effect on disease management and patient survival in renal disease (Reiss, Gonzalez, & Kramer, 1986; Turner-Musa et al., 1999). The family context was shown to positively impact mental illness, cancer, and hypertension in a number of longitudinal

studies (Leff & Vaughn, 1985; Reiss et al., 1986; Turner-Musa et al., 1999). However, the family context and its long term impact on Type 2 diabetes remains unexplored.

Additionally, a synthesis of nursing research studies on family processes and chronic illness in ethnically diverse families found that ethnically diverse families are underrepresented and that there are multiple methodological concerns in the existing research. The existing studies of ethnically diverse families were of chronically ill children and their parents (Chesla & Rungreangkukij, 2001). Also, the researchers found in a number of studies that not only the family but also the cultural context strongly impacts the health and well-being of chronically ill individuals (Chesla & Rungreangkukij, 2001).

Literature specifically focusing on Type 2 diabetes and the family is limited. A study of adolescents with Type 2 diabetes and their families found that other members of the family shared many anthropometric (body type measurement) and lifestyle risk factors. The researchers concluded that treatment programs for adolescents with Type 2 diabetes must address lifestyle and health habits of all members of the family (Pinhas-Hamiel et al., 1999). At the other end of the age spectrum, Silliman, et al, (1996) examined family members' participation in the day to day management of diabetes in the elderly. The patients in their study were over 70 years of age. The findings of this study demonstrated that family members were involved in the daily management of diabetes and one-third of the families participated in the older diabetics' medical encounters. The family members felt health care systems and physicians became involved in supporting family members only when the patient was frail and functionally disabled (Silliman, Bhatti, Khan, Dukes, & Sullivan, 1996). An ethnography conducted by Gerstle, Varenne,

and Contento (2001) of predominantly European-American suburban women found that diabetes care occurred within the social context of the family. In challenging the traditional model of diabetes self-management, this study concludes that diabetes management should include an evaluation of the diabetes task being completed, the family support system present, and the family routines present (Fisher et al., 1998; Gerstle, Varenne, & Contento, 2001). Recently, Scollan-Koliopoulos (2005) developed a framework for understanding the multigenerational legacy of Type 2 diabetes that showed how multiple family members and generations are impacted. As apparent from the small number of studies, this area has not been widely investigated.

A conceptualization of the family context and Type 2 diabetes has come from the Family Diabetes Project. In this project, Fischer (1998) and colleagues focused on an ecological model which suggests that personal, family, and provider characteristics and processes impact long term health in chronic disease (Fisher et al., 1998). This research project conceptualized the family's role in diabetes care and management and identified four broad groups of factors that have been linked to self-management behavior in Type 2 diabetes over time: (1) individual characteristics of patients, (2) amount and management of stress, (3) characteristics of providers and provider/patient relationships, and (4) characteristics of the social network/context in which disease management takes place. Least studied and not easily applicable to intervention is the social network context (Fisher et al., 1998). Since 90% of adults marry sometime in their lives and the percentage of married adults increases with age, the vast majority of patients with Type 2 diabetes are married (Fisher et al., 1998). The Family Diabetes Project broadly defines family as a "group of intimates living together or in close geographic proximity with

strong emotional bonds (identification, attachment, loyalty, reciprocity, solidarity) and with a history and future” (Fisher et al., 1998). This conceptualization of the family sets it apart from other types of social relationships that have been identified as providing social support. In the case of diabetes, the family context is divided into 4 subcategories 1) family relationship, 2) patient and spouse/partner beliefs and agreement, 3) current and foreseen stresses, and 4) allocation of disease management behaviors (Fisher et al., 1998). A gap in the literature identified by the Family Diabetes Project is that research on chronic disease and families focused solely on European-American families. To remedy this, the focus of the Family Diabetes Project was on a sample of both European-Americans and Latinos and will be discussed later in this chapter (Chesla et al., 2003).

Mexican-American Families and Type 2 Diabetes

Cultural importance of family. A focus on cultural context is crucial to any research on ethnically diverse families. Specifically for Mexican-Americans, the family is both a strong cultural value and social reality. Based on cultural and religious traditions and the social realities of immigration, transnational families and poverty, the family focus is central. In this section, familism will be discussed. Components of familism; group orientation and social support, will also be addressed.

Familism. Familism, defined as a strong focus on the family, is key to understanding the significance of family for Mexican-Americans. Familism is an integral part of Mexican life and a strong cultural value (Galanti, 2003). Central to familism are the values of loyalty, reciprocity, and solidarity within the immediate and extended family (Galanti, 2003). The impact of acculturation for Latinos living in the United States on familism is minimal, according to Vega (1995). The family remains central to the

Latino individual's identity and can be a source of strength in volatile socio-environmental circumstances such as substandard housing, the lure of gangs and drugs for teenagers (Marin & Marin, 1991; Vega, 1995). Familism is nearly identical across the many diverse ethnic Latino groups who have immigrated to the United States (Saez-Santiago & Bernal, 2002). Studies of Latino families who must contend with immigration issues and hardships that result from poverty and minority status show a flexibility and ability in these families to solve various problems and offer support and shelter to one another. The family for Mexican-Americans is considered a natural support system according a number of sociologists and family researchers (Hayes-Bautista, 1990; Hurtado, 1995; Marin & Marin, 1991; Suarez-Orozco & Suarez-Orozco, 2001) Familism helps protect individuals against a multitude of stresses associated with being both an ethnic minority and an immigrant (Marin & Marin, 1991).

The Mexican-American family includes both the nuclear as well as extended family, including fictive kin. *Compadres* and *comadres* are terms used for close family friends who are given the status of relatives because they are involved in child rearing such as godparents at a child's baptism (Marin & Marin, 1991). Familism has two distinctive value orientations: (1) the perceived obligation to provide material and emotional support of members of the extended family, and (2) the perception of relatives as behavioral and attitudinal referents (Marin & Marin, 1991). Social support patterns among Latino families have been extensively studied. Of note is the existence of large kin networks with frequent visitation and exchange (Ortiz, 1995). While non-Hispanic whites have migrated away from kin networks, Latinos migrate toward them (Vega, 1995).

The needs of the family collectivity supersede the needs of each individual family member (Friedman, Bowden, & Jones, 2001). Latinos are oriented toward a family first and individual perspective second with interdependency being both a healthy and necessary part of life. Reciprocity among family members, the nuclear family as well as extended kin, is valued (Hurtado, 1995; Ortiz, 1995; Vega, 1995). Furthermore, it has been demonstrated that the social support of the Latino family keeps people healthier and helps them recover from illness more quickly (Vega, 1995), specifically in terms of improved birth outcomes for low income Mexican-American women (Solow, 2003).

The family was validated as an integral part of Mexican-American culture in Warda's (2000) qualitative study examining Mexican-Americans' perceptions of culturally competent primary health care, which concluded that family support was understood by the participants as a key component of cultural self or cultural identity (Warda, 2000). Based on four focus groups of Mexican-American RNs and lay participants in health care, Warda found that respondents viewed family support as expected, welcomed, and reciprocal. The family rather than the individual was found to be the locus of health care decisions (Warda, 2000).

Group orientation. Specifically, the Mexican-American cultural context of family is in contrast to the self-orientation of most aspects of diabetes care. Historically, diabetes care and educational interventions have relied on self-oriented theories and models focused on the concepts of self-care, taking control, and knowing one's own body (Paterson, Thorne, & Dewis, 1998). Diabetes educational models are based on the ability of an individual to manage multiple personal routines requiring a high degree of self efficacy such as exercise, weight management, nutritional therapy, and blood sugar

monitoring (Oomen et al., 1999). Constructs such as self-efficacy, internal locus of control and perceived health value, the bases for many behavioral change theories, may be culturally inappropriate for Mexican-Americans as well as other collectivist groups which emphasize cooperation and family over self (Oomen et al., 1999; Schwab, Meyer, & Merrell, 1994). According to Oomen, Owen and Suggs (1999), many of the treatment models in use are self-oriented in design and based on male culture and on theories and models such as the Transtheoretical Model of behavior change, (Oomen et al., 1999). In addition, Schwab, Meyer, & Merrell (1994) found the Health Belief Model (HBM) an ineffective framework for assessing Mexican-American health beliefs and attitudes because Mexican-Americans generally lacked a sense of personal control over diabetes (Schwab et al., 1994).

Two research studies found that health care providers had difficulty integrating family concepts into the diabetes care they provided. Oomen, Owen and Suggs's (1999) study concluded that health care providers focused exclusively on self-care recommendations that require personal responsibility, and often ignored the group-orientation of the Mexican-American population. This focus on self could potentially lead to victim blaming when adherence to treatment regimens becomes difficult. The priority of family over self was validated by Lipton, Losey and Giachello (1998) in their focus group study of practitioners working with Latino diabetic patients in Chicago. According to these practitioners, family needs were most important to their Latino patients, while adhering to a treatment regimen was viewed as self-indulgent (Lipton, 1998).

Social support. Another component of familism is social support. While a number of studies have examined the crucial role family plays in social support, the family

network/context of diabetes management among Mexican-Americans has been understudied. A sample of 95 insulin-requiring Latino adults showed that the source of social support was felt to come overwhelmingly from the family, in contrast to European-American women who identified friends as the primary source of support (Gleeson-Kreig, Bernal, & Woolley, 2002).

The importance of family as a source of support for Mexican-American/Latino diabetics was validated by conclusions of several additional studies. Weller et al. (1999) surveyed 161 Latino adults from 4 diverse communities (Hartford, Connecticut, Edinburg, Texas, Guadalajara, Mexican and rural Guatemala) on their personal beliefs about diabetes. The researchers concluded that historically, practitioners are taught to understand and focus on very specific cultural beliefs and practices, rather than attending to the broader cultural context, including family support. Engaging family support, a cultural strength, would influence patient adherence with dietary and other aspects of diabetes management (Weller et al., 1999). Bautista-Martinez et al. (1999) concluded in their study of diabetes knowledge and its determinants in a Mexican population that family involvement is essential in the day to day management of this disease (Bautista-Martinez et al., 1999). Four focus groups of Mexican-Americans in the Detroit, Michigan area attempted to identify the unique cultural expression of diabetes for them. The central theme to emerge from data analysis was that a social network was essential to managing one's disease. Secondly, the impact of diabetes was unique for women not only because of their distinct role in the family but because of their involvement in food preparation (R. M. Anderson et al., 1998). A recent study by Wen, Shepherd and Parchman (2004) demonstrated that for Mexican-American adults over 55, higher levels of perceived

family support and greater self-efficacy were associated with higher levels of diet and exercise. This study concluded that interventions designed to improve diabetes self-management should address family support, self-efficacy and barriers to self-care (Wen, Shepherd, & Parchman, 2004).

Additionally, Adams (2003), in her qualitative study, found that it was essential to include the family in education and management of Type 2 diabetes in order to address the emotional components of the disease. For example, Adams found that children struggled with having to “nag” their mothers about their eating habits (Adams, 2003).

In contrast, Napolitano (1992) found in her qualitative study of Mexican-American women and selected family members that women with Type 2 diabetes believed that families neither helped nor harmed them with their diabetes. However, the family members demonstrated several supportive behaviors, such as translation and transportation assistance, preparing special foods for their diet, and frequent calls and visits. The women felt loved and worried about by their families (Napolitano, 1992).

Some non-supportive behaviors by family members were also noted in this study. Family members often bombarded the women with advice about diabetes, especially diet. Women felt that their families did not accept the necessary changes in the family diet and were often offered unhealthy foods at family gatherings (Napolitano, 1992). The results of this study demonstrate the role of the family in supporting family members is uncertain. A recent study based on focus groups of persons with diabetes and a family member found that family members were supportive and desired to help in managing diabetes yet family members often did not have the necessary information. Family members would often tempt the person with diabetes by bringing home or preparing

“treats” that were high in fat. The family caregivers also agreed they were unclear as to what the person with diabetes should eat. Clearly the family role is often a mixture of both help and hindrance (Vincent, Clark, Zimmer, & Sanchez, 2006).

Family Diabetes Project

Based on the conceptualization of the family and Type 2 diabetes as previously described, the Family Diabetes Project initially researched couples, comparing the experience of European-Americans and Latinos with Type 2 diabetes. It is not known what percentage of the Latino couples were Mexican-American. The researchers view this project as giving a bio-psychosocial and cultural perspective to the management of Type 2 diabetes (Skaff, Chesla, Mycuc, & Fisher, 2002). The purpose of this study was to examine the characteristics of European-American and Latino families in disease management and self-care practices. 74 Latino patients and 113 European-American patients were assessed on domains of family life and disease management. The study found that family setting was significantly linked to patient self-care behavior. However, there were significant differences between the two ethnic groups. For Latino patients, successful disease management took place in families described as well organized and with clear traditional sex roles, whereas in European-American patients diabetes was best managed in families with a cohesive world view and stable emotional management (Fisher, Chesla et al., 2000).

Additional research papers from the Family Diabetes Project (Fisher, Chesla, Skaff, Mullan, & Kanter, 2002) and (Fisher, Gudmundsdottir et al., 2000), focus on the couple as the primary relationship in the family. The results discussed in both research papers reveal the impact of Type 2 diabetes on the emotional state of the partner (non-

diabetic) and how couples manage and resolve conflict around Type 2 diabetes. There was no difference in rates of anxiety and depression between the Latino couples and European-American couples (L. Fisher et al., 2002). However, management styles were different between European-Americans and Latinos couples. Latino couples were more emotionally close, less avoidant and less hostile toward each other, and the person in the couple with diabetes was less dominant. However, Latino couples had significantly less problem resolution skills and were more often off-task than European-American couples.

Intervention Research Studies

Intervention research on Mexican-American adults with Type 2 Diabetes is rare. Only one intervention study has been conducted specifically addressing culturally competent diabetes education and management for Mexican-Americans (Sharon Brown & Hanis, 1999). This four year longitudinal, randomized clinical investigation was based on the efficacy of a culturally relevant community-based intervention that met national standards for diabetes care (Sharon Brown et al., 2002; Sharon Brown & Hanis, 1999). The study found that outcomes improved dramatically when diabetes health-related interventions were specifically designed to be compatible with Mexican-Americans' lifestyle. In Starr County, an impoverished border county along the Rio Grande, 50% of the population of 40,500 persons, of which 97% were Mexican-American, had either diabetes or a first degree relative with diabetes (Sharon Brown et al., 2002). The results of this study identified five key components to culturally competent care: language, diet, social emphasis, family participation and incorporation of cultural health beliefs. When these five components were in place, HgbA1C rates and fasting blood glucose in the sample participants were significantly reduced (Sharon Brown et al., 2002).

More broadly, a chronic disease self-management trial involving Hispanics, the majority being Mexicans-Americans in the Los Angeles area, was based on self-efficacy theory (Lorig, Ritter, & Gonzalez, 2003). In this one year randomized longitudinal study, participants demonstrated improved health status, health behavior, self-efficacy and fewer emergency room visits after a 6 week peer-led training. In order to evaluate its effectiveness in a different setting, the intervention was administered along the Texas-New Mexico-Mexico border where participants showed similar improvements in health behaviors, health status and self-efficacy (Lorig, Ritter, & Jacquez, 2005). This study did not specifically address Type 2 diabetes but focused on chronic disease. The researcher's position was that interventions should be targeted most broadly on chronic disease. However, participants struggled with identifying themselves as having a chronic disease versus being a diabetic or having hypertension. Although, this study did not emphasize the family context, the intervention contained elements of culturally competent care, in that the education component was peer-led and may have included elements of social support. The intervention was conducted in Spanish, and the booklet, written in broadcast Spanish (defined as the Spanish used by mass-media in the United States), included a small section on family communication. Although the researcher emphasized the theoretical underpinnings of the intervention as based in self-efficacy theory (Lorig et al., 2003), clearly this intervention was also based on components of culturally competent care.

Summary

Clearly, there are gaps in the research literature on Type 2 diabetes in the Mexican-American family context. While there is a dearth of studies of how ethnic

minority families experience chronic illness, there are even fewer that examine specifically the experiences of Mexican-Americans. The Family Diabetes Project addresses the differences between Latino and European-American families but does not specifically examine Mexican- American families. The Starr County Study, a targeted intervention study of Mexican-Americans living with Type 2 diabetes, clearly demonstrates the benefit of culturally competent diabetes care, though the family context was not strongly emphasized. Although family participation in diabetes care was identified as a key component of culturally competent care, the weakness of the Starr County study was its failure to identify which elements of the culturally competent care most impacted outcomes. Additionally, discussion of family participation was minimal.

This gap underlies the need for further investigation of the relationship between diabetes care and family context in the Mexican-American population.

Overall, the family context of Type 2 diabetes has been understudied. Type 2 diabetes has been conceptualized and studied as an individual health concern, yet treatments that require lifestyle and diet changes are known to be amenable to the family context (Chesla & Rungreangkukij, 2001). The direction needed in both diabetes research and interventions is to focus on the family. This direction is most needed in ethnic groups such as Mexican-Americans, whose larger cultural context involves the family, and on whom there has been scant research.

Conclusion

In summary, there are significant gaps in the literature on a number of levels. The majority of the literature on family context and chronic illness is focused on either children or the elderly. Also, with the exception of the Family Diabetes Project, the focus

of the literature on the family experience and Type 2 diabetes examines primarily children and their parents or the elderly. In addition, the literature is limited in its treatment of ethnically diverse families.

While the Family Diabetes Project conceptualizes the family context of Type 2 diabetes and includes Latino families in this research project, the families live in the multicultural and urban San Francisco Bay Area, and the focus is almost exclusively on the couple's relationship. The Mexican-American family context is not specifically examined, although Mexican-Americans were included in the Latino sample.

Specifically, for Type 2 diabetes and the daily or lived experience, the literature focuses on the experience of women and on native groups in the U.S. and Canada. Family themes were present in this group of studies but only indirectly and superficially. The Mexican-American experience of Type 2 diabetes is based on unique social, cultural, and emotional understandings within this population. While explored in a variety of dimensions, none of the research studies focused exclusively on the family.

It is evident from this literature review that the day-to-day experience of Type 2 diabetes for Mexican-Americans occurs within the family. Attending to this day-to-day experience of Mexican-American families will allow for expression of this population's own distinct experience. This expression will lay the foundation for much needed family-centered interventions to address the impact of the epidemic among Mexican-Americans.

Chapter 3: Research Design and Methods

Humans naturally communicate and express the depths of their identities, relationships, emotions and beliefs through the telling of stories (Priest, Roberts, & Woods, 2002; H. White, 1981). Story telling is a way to make sense of the world by providing meaning and understanding (Priest et al., 2002; H. White, 1981). Exploring the unique experience of chronic disease for both patient and family, stories can provide an avenue to meaning, context, and perspective (Greenhalgh, 1998; Greenhalgh & Hurwitz, 1999).

Mexican-American culture relies heavily on storytelling, the cultural construction of narrative (Garro & Mattingly, 2000). Storytelling provides the basis for narrative inquiry because the impulse to narrate is so strong, especially about one's illness experiences. I selected narrative inquiry as a research methodology to explore the meaning and perspective of Mexican-American family's experience of living with the chronic disease of diabetes (Greenhalgh, 1998, 1999) because of its focus on experience as told in stories (Clandinin & Connelly, 2000).

Narrative Inquiry

To understand narrative inquiry as a research methodology, certain terms need defining. Story refers to the tale as a whole, whereas narrative is defined as the written account, representing the tale or the oral telling (Poirier & Ayres, 1997; Riessman, 1993a). Story is seen as the actor's, teller's or more specifically the research participant's account, whereas narrative is considered the researcher's account.

In the research world, reproducing the story is not an easy endeavor, as the story needs to be represented by some manner of analysis (Redwood, 1999). Creating a

narrative is a representation, since it selects events, details and explanations to be told while other parts of the experience are not relayed (Riessman, 1993a). Narrative inquiry is based on the interpretation of the story, understanding that “human agency and imagination determines what is included or excluded in the story, and which details and explanations are presented by the teller” (Riessman, 1993a). Knowledge and understanding is needed of the “contested ground” where the narrative is created (Poirier & Ayres, 1997). Contested ground is understood as the potentially vast differences which exist between the reader’s interpretation of the narrative and the teller’s understanding of his/her story. This contested ground does not weaken the research methodology, but is a foundation upon which narrative inquiry is built (Poirier & Ayres, 1997). An understanding of the ambiguous nature of representing another’s story and the difference between the teller’s understanding and the researcher’s interpretation is essential for narrative inquiry.

Additionally, the nature of narrative inquiry is contested, due to the fact that narrative does not fit into any one theoretical understanding, being that it is interdisciplinary and utilized in a variety of disciplines. Historically, there has been a shift from the realist and positivist limitations of the natural sciences toward “narrative as the organizing principle for human action” (Riessman, 1993a). Narrative understanding is a comprehensive framework and includes the story-like qualities of an illness experience as well as the temporal, spatial and personal-social dimensions of that experience (Clandinin & Connelly, 2000). Increasingly, thinkers from a postmodern perspective doubt that reason provides access to absolute, universal truths; narrative is then seen as a way to describe, understand and potentially bridge the structures and concepts of various

disciplines, resulting in a significant shift toward an elevation of the status of narrative (Morris, 1998). This shift has been aptly named the narrative turn.

Narrative and Nursing

Based on this turn toward narrative, narrative inquiry is being used more commonly as a research methodology in nursing. Historically, qualitative nurse researchers created conditions in which stories were told, yet often did not use methods to specifically analyzing these stories (Sandelowski, 1991). Increasingly, nurse researchers are studying narrative to understand and clarify the patient's experience, with a focus on the illness experience, and are emphasizing interpretation and subjectivity over positivistic, realist thinking (Sandelowski, 1991). Narrative is considered a means to discover new knowledge, to uncover the knowledge embedded in practice, and to recover the art of nursing (Sandelowski, 1994).

Nurse researchers are moving from focusing on factual knowledge and towards a focus on meaning. Reality from a social constructivist perspective is based on meaning rather than truth. Specifically, having a multi-layered understanding is more important than ultimate knowledge (Lincoln & Guba, 2000). One of the most common forms of the construction of meaning is narrative. Researchers who advocate the use of narrative describe it as an empowering methodology to the participants because it gives respondents an arena to articulate their own viewpoints and standards (Garson, 2001). There is an emotional connection to narrative, a certain excitement connecting to the known event as well as a glimpse into unfamiliar territory. Stories are a way for nurses to know their patients as well as a way to communicate their own clinical experiences (Redwood, 1999). In the field of nursing, narrative inquiry has been used to explore

caring, (McCance, McKenna, & Boore, 2001), to help patients deal with suffering (L. Fredriksson, 1999) (Lennart Fredriksson & Eriksson, 2001); and to aid in gaining understanding of the meaning of chronic illness (Ayres, 2000; Bailey & Tilley, 2002; Lawson, 1998).

Justification of the Method

Other qualitative methods have been used to explore the chronic illness experience among diverse ethnic groups. While each qualitative methodology has unique understandings and perspectives, potentially encompassing narrative inquiry, their central focus is not narrative. Ethnography focuses on culture as the lens to view individual or family realities through multiple data collection methods, including narrative. Yet narrative is not the central focus of ethnography. Phenomenology focuses on the lived experience, searching for meaning in phenomena. Grounded theory focuses on the development of theory (Creswell, 1998). Although it may be beneficial to explore these other methodologies, for a novice researcher, the desire is to focus exclusively on story and to explore the family's experience of Type 2 diabetes in these stories. Therefore, narrative inquiry is the method of choice for this investigation.

Philosophical Assumptions

Narrative inquiry, as a research methodology, is guided by the philosophical tenets of social constructivism and post-modernism, and grounded in an understanding of the construction of knowledge (epistemology) and the understanding of the nature of reality (ontology). This section will review the assumptions and contributions of social constructivism and postmodernism to narrative inquiry as a research methodology.

Social Constructivism

Specifically, social constructivism provides a strong basis for narrative, providing a link between meaning and stories. According to social constructivism, knowledge is created by transaction/interaction between the researcher and the researched.

Understanding of reality is subjective and relative based on the experience of the researched. Additionally, meaning and truth are understood through the experience of the respondent. Reality is constructed and found in local settings (Lincoln & Guba, 2000). For social constructivists, knowledge derived from stories is as essential as knowledge gained from science in enabling the researcher to make sense of the world (Bruner, 1986). The focus is not on the historical truth but rather on the selection of components of the story to convey the meaning the storytellers intend the listener or researcher to take away from the story (Bailey & Tilley, 2002).

In this research investigation, three concepts based in social constructivism assist in gaining further understanding of meaning and stories: life world, hermeneutics and narrative as time.

Life world. Life world is understood as the world in which we pursue our goals, the scene of all human activity (Bruner, 1986). Life world also can be viewed as the natural setting or world rather than the world of the laboratory in which scientific discoveries occur (Lincoln & Guba, 1985). For chronic illness, the experience is embodied in the patient's and family's life world. "Acting like a sponge, the illness soaks up personal and social significance from the world of the sick person" (Kleinman, 1988). In contrast to cultural understandings of illness where the person's or family's understanding of the chronic illness experience is transferred from the larger culture

outside the family, life world demonstrates that from the individual patient's or family's life, meaning is brought to the illness experience. (Bruner, 1990; Kleinman, 1988). Life world is more than the patient's inner world, it also extends to the world of interpersonal connectedness, binding the patient to the outer social world (Kleinman, 1988).

Researchers seeking to study narrative must start with a social constructivist understanding of the lived world of immediate everyday experience, the need to be situated in the experience prior to reflecting or attending to that experience (Riessman, 1993a).

Hermeneutics. Hermeneutics is defined as the study of interpretation. Language, in the empiricist tradition, is viewed as a neutral or transparent medium of communication, in contrast to the application of language to ourselves or the world as messy, inexact and indeterminate (Riessman, 1993a). If the experience of chronic illness is of an interpretive nature, then the existence of interpretive possibilities implies subjectivity, ambiguity and room for disagreement (Greenhalgh, 1998). Hermeneutics contends that the narrative articulates what is observed in terms that communicate understanding to the readers of the narrative. Narrative inquiry is not only an interpretation of spoken word, but also of the perception and meaning associated with the story telling event (L.Kincheloe & McLaren, 2000).

Narrative as time. The third concept impacting one's understanding of narrative as a research method is narrative as time. Ricoeur, a philosopher, struggled with a basic understanding of narrative, believing that the relationship of time and story impacts the analysis of narrative. Unquestioningly, researchers apply traditional sequences of time as a "linear succession of instants" p170. (Ricoeur, 1980). The understanding of narrative in

relation to time is key to gaining understanding and exploring the meaning of the experience. Ricoeur proposes that narrative in all its theoretical aspects, such as anthropology, literary theory and sociology, needs to be based in plot. From plot, two dimensions emerge, one chronological and the second non-chronological. The first would be called the episodic dimension, in which story is made of a series of events. The second would be seen as configuration, in which plot confers wholeness out of a series of events (Ricoeur, 1980). This relationship between narrative and time is essential for plot analysis to occur since a plot always has a beginning, middle and an end.

Postmodernism

In addition to social constructivism, postmodernism also informs narrative inquiry in this investigation. Based on the tenets and understandings of a constructivist's worldview, postmodernism does not fully reject social constructivism but evolves in a different direction. For postmodernists, epistemology determines ontology, how I understand the world determines what I see. Postmodern epistemology rejects the ideas of universality, necessity, objectivity, rationality, essence, unity, totality and ultimate truth and reality. Postmodern epistemology is difficult to define because it rejects worldviews or overarching belief systems. Postmodern ontology is seen as locality, partiality, contingency, instability, uncertainty, ambiguity and contestability of any particular account of the world and self (Linn, 1996). Based on this epistemological understanding, totalizing metanarratives, otherwise known as overarching belief systems, are rejected. This rejection means there can be no complete unifying theory of the world that captures the whole truth (Morris, 1998). The postmodern thinker embraces narrative while rejecting the role of metanarratives in understanding and knowledge production. Mini-

narratives rather than metanarratives assist in explaining small practices and local events, rather than large scale universal or global concepts. Postmodern narratives are situational, provisional, contingent, and temporary (Flax, 1990). Narrative inquiry as a research methodology, embedded in postmodernism, embraces the story-like qualities of an illness experience as well as all the possibilities in that story, beyond merely telling the story (Morris, 1998).

Based on postmodern understanding, three concepts emerge that are key to understanding narrative inquiry: voice, reflexivity and representation (Currie, 1998).

Voice. Hertz (1997) describes the struggle for voice as three-fold: 1) presenting oneself as an author/researcher, 2) writing the respondent's accounts and 3) attempting to represent the respondent's experience. The first expression is that of the author, the researcher self. The second expression is the presentation in the text of the voices of respondents. The third expression is when the self evolves to be the subject of the inquiry (Hertz, 1997).

It is difficult to locate oneself within a text of research, which is in direct contrast to a detached objective researcher, the position valued by empiricist scientific research community. Historically, disciplines such as anthropology have existed to give voice to others, focusing on cultural realities rather than individual realities, and ignoring the position of the researcher in the process (Behar, 1996). Similarly, some feminist researchers believe that they give voice and empower marginalized groups through the research process, yet realistically, researchers using narrative inquiry can only hear and interpret other's voices (Riessman, 1993a).

Reflexivity. Reflexivity, also known as self-consciousness, is about personal vulnerability or critical self-reflection (Behar, 1996). In the research setting, three different selves come into play: a) the self as researcher, b) the selves we bring with all our history, both socially and personally created and c) the researcher being transformed, potentially as a new person, in the research endeavor (Lincoln & Guba, 2000). In the postmodern tradition, reflexivity-what the researcher brings to the narrative telling as well as the analysis process-is key to understanding the research process (Lincoln & Guba, 2000). Reflexivity stands in contrast to the long-held belief that researchers are dispassionate clinical observers who obtain hard facts. Reflexivity has been defined as the process of “entailing researchers to view their own beliefs in the same fashion as they view those held by their subjects” (Porter, 1993). The anthropologist, Ruth Behar believes that ethnography and other qualitative methodologies have lost their heart and soul. She concludes that field work and other qualitative methodologies which involve the experience of another need to embrace the researcher’s feelings about the experience. In *The Vulnerable Observer*, Behar (1996) identifies three examples of reflexivity from her field work in Southern Spain and Northern Mexico: personal memories of traumatic events, reflection on the death of family members and one’s own mortality. In health care research, according to Cheek (1999), analysis of clinical practice entails multiple layers, initially examining basic concepts and then going deeper to explore truths and voices, as well as questioning the taken for granted assumptions and understandings of health care practices and the practices of individual practitioners (Cheek, 1999).

Crisis of representation. The crisis of representation is both a crisis of authority and voice. Authority is often based in the scientific method, which understands the world

in simpler terms and with a singular focus, whereas a postmodern approach recognizes authority as resting in a diversity of voices, views and methods (Cheek, 1999). The crisis of voice asks whether or not the researcher can truly represent in text the experience of the participants (Denzin & Lincoln, 2003).

There is potential for silencing the voices of subjects or respondents whose lives are represented in the research. Silencing may end up recreating the same world, rather than bringing forth a more complex and complicated world (Lincoln & Guba, 2000). The crisis is understood by whose world the researcher is representing, the participants or his/her own? Can a researcher truly represent another's world through the process of data collection and analysis? The question begging to be asked is, can one also account for the other (Denzin & Lincoln, 2003) through the process of interpretation and writing the research findings, while also accounting for and acknowledging one's own perspective? The above questions have no easy answers, but need to be in the forefront of the researcher's mind.

Representational issues are particularly present in (the task of) analyzing narrative. How can we truly represent the story of another? Does our social class, culture, language, race and ethnicity filter what we hear, read and see? As the researcher how should I be in relation to the stories and the storytellers (Denzin & Lincoln, 2003; Riessman, 1993a; Schwandt, 2000)? Said (1994) questions whether there can be true representations of anything, for all being embedded in language, culture, institutions, and politics. He concludes that representation is "implicated, intertwined, and interwoven with a great many things besides truth, which is itself a representation" (Said, 1994).

Yet representational issues cannot be avoided when doing qualitative work, for the researcher has access only to ambiguous representations of another's experience. Therefore, an understanding of the various levels of representation is essential in narrative inquiry will aid in the process of analyzing narrative data (Riessman, 1993a). Five levels of representation are explicated here to highlight postmodern representational issues. According to Riessman (1993), the five levels of representation have porous boundaries and are not mutually exclusive. Her belief is that these levels do not have firm, rigid boundaries but they assist the researcher in being more "conscious, reflective and cautious about the claims we make" (Riessman, 1993a). It is important to view the levels of representation not as a rigid stepwise approach but as a way to gain understanding.

- The first level is the attending to the experience, being present and aware in that moment, then reflecting, remembering, and recollecting these remembrances into observations. By attending to the experience, a segment is selected from the total experience for the respondent, a choice in what one notices. For example, in the interview session, there is the story recorded on audiotape, but the storytelling experience is much greater than that. The story is a piece of the greater context or setting, the interaction between researcher and participant, and the way the researcher asks questions to elicit narrative. All of the pieces are part of the creation of narrative, but the researcher makes a choice as to what is attended to from the potential totality of the experience through the process of journaling or field notes (Riessman, 1993a).

- The second level is the telling of the experience, the performance of the personal story (Riessman, 1993). The events are re-presented by describing the setting and characters, unfolding the plot and stitching the story together. There is a gap between the actual lived experience and what the participant chooses to disclose about it. Issues of meaning are present since the experience is constructed during the telling of the story, through the interaction between the researched and the researcher. The story may be much different than the actual event. Additionally, the storyteller or subject may tell the story much differently in the research setting. Also, it is important to note that the personal story is considered a form of self representation.
- The third level, the transcription of the experience through taping or some method of recording, captures only a small portion of the narrative or conversation (Riessman, 1993). An audio recording would be more limiting than video since video is able to capture non-verbal communication. However, what is captured would need representation in the form of a text or a fixation (Ricoeur, 1980). Transcription is incomplete, partial and selective. The representation of spoken language or the transformation of spoken to written language can be compared to photography. A visual image can be transformed into multiple types of images by using a variety of photographic techniques. In narrative inquiry, like photography, the transcribed product can take a variety of forms; the transcriber could attempt to capture the rhythm of the talk, silences, false starts or nonlexicals such as “uhm”. (Gee, 1991) The choices are endless, depending on the depth and variety of analysis techniques (Riessman, 1993a).

- The fourth level is the analysis of the experience, in which an investigator with pages of tape-recorded stories reduces the flow of talk to interpretive themes to create sense. In the end, the researcher creates a hybrid story by telling what the interview narrative signifies. In the fourth level of representation the researcher explicitly analyzes the transcripts. According to Riessman (1993), the researcher sits with tape recorded interview and reduces the flow of talk into specific narrative, thereby creating sense and eventually editing and reshaping the data into a unique story. This story is defined as the core narrative of the larger research interview. However, values, politics, and theoretical commitments again enter into this narrative by the interpretations and choices the researcher makes. In terms of procedure, Level 4 involves transcribing the words into text. This process can often be very lengthy and time consuming. Riessman (1993) advises to begin initially with a rough transcription, a first draft of the entire interview to get words and striking features such as crying, laughing, and pauses. Then the researcher returns to the transcript and retranscribes certain portions for detailed analysis. Text created in transcription allows for the analysis of interruptions, pauses and other spoken features of discourse.
- The fifth level of representation comes through generating the written report, which is open to various readings and constructions. It is important to realize that written texts are created within and against certain traditions and audiences and are open to several readings and constructions (Riessman, 1993a). All texts “stand moving or contested ground” (Poirier & Ayres, 1997; Riessman, 1993a).

Meaning

In analyzing narrative data, representational concerns lead to questions of meaning. Are we the researchers true and faithful to the respondent's meaning (Bruner, 1986)? For the health care researcher, the historical account is not the primary concern, but the researcher needs to recognize that storytellers select components from the stories they tell to reconstruct for the listener the larger meaning they are striving to convey (Bailey & Tilley, 2002; Riessman, 1993a). Yet meaning can be seen as ambiguous; it is a created entity, arising out of the process of interaction between various persons: self, teller, listener, recorder, analyst and reader (Riessman, 1993a). Therefore, meaning is "fluid and contextual, not fixed and universal" (Riessman, 1993a). As qualitative researchers we analyze data looking for meaning. In other forms of qualitative data analysis, chunks of data are categorized and then reconceptualized, whereas in narrative analysis, data is meaningless without the greater context (Ayres & Poirier, 1996). Yet the research question predefines what is meaningful. Statements that are not meaningful within the context of the research question are, for the purpose of analysis, not meaningful. In other words, the research question must drive the analysis (Ayres & Poirier, 1996). Statements may have great personal meaning for the research participant, yet the research question frames the discussion, aids in the search for meaning and responds to representational concerns. In summary, for narrative inquiry, philosophical assumptions impact data collection and analysis and are truly embedded in the research process.

Since narrative inquiry is multidisciplinary, nurse researchers also must begin to develop awareness and understanding of specific theoretical understandings or disciplines

that impact the development of narrative research methodologies. Several disciplines focus on narrative in greater depth and these understandings of narrative will be explored.

Theoretical Underpinnings

According to Polkinghorne (1988), the theoretical underpinnings of narrative are based in several disciplines: history, autobiography/biography, ethnography/medical anthropology, literary theory and psychology. Each of these disciplines is described below.

History. History, as a discipline, has focused its inquiry on past activities of human agents and the occurrence of non-repeatable events by employing narrative descriptions and interpretations (Polkinghorne, 1988). Narrative, in history, has demonstrated by linkages between literary theory and history that knowledge construction can be interdisciplinary (Polkinghorne, 1988). In history, all the extraneous noise or static is cut out and only those events necessary to move the plot along are related, whereas in the narrative of experience, particularly chronic illness experience which is the focus of this investigation, the extraneous pieces are often essential for exploring meaning (Poirier & Ayres, 1997; Polkinghorne, 1988; Riessman, 1993a). Narrative examines events that can only be explained in retrospect. The sense of past time is key to the historical understanding of narrative (Sandelowski, 1991).

Autobiography/Biography. Narrative is strongly based in autobiography and the use of biographical tales (Sandelowski, 1991). Autobiographical accounts have value as narrative of witness, especially in the realm of understanding chronic disease (Jones, 1999). Autobiographical narratives of suffering and redemption have a long history in health care literature until the rise of medical technology in the later half of the twentieth

century (Hogarth & Marks, 1998). Autobiography can be understood as reflection upon reflection. Narrative built upon autobiography is “an account given by a narrator who existed in the there and then, the story terminating in the present, when the protagonist fuses with the narrator” (Bruner, 1990) p.121).

Narrative can also be viewed as a collaborative biography created between the subject and the researcher (Cortazzi, 1993). It is important to understand the interviewer’s understanding of biography. Biographers based in Western culture work within a great person tradition, and autobiography coincides with the rise of the idea of individualism in this culture. Yet, other groups or cultures have emphasized the social collective, the story of the group. It is important for narrative researchers to realize that biography is a social construct, created in that particular research space.

Ethnography. Behar (1996), an anthropologist, advocates connecting ethnography and autobiography, since both rely on the study of narrative. Anthropologists look for narratives within the cultural patterning of customs, beliefs, values, performance and social context. In this ethnographic context, narratives are studied in terms of ways of speaking and oral traditions. Various anthropological and folkloric frameworks have been used to analyze the structure and function of oral narratives (Cortazzi, 1993). The value of ethnography lies in the narrative, the telling of the story that is based in cultural representation (Chambers, 2000). One of the earliest narrative methodologies developed by ethnographers was the life-history or biography. Their aim was cultural representation, as stated earlier, rather than individual lives or certain aspects of personality as thought of in a historical or more literary sense of life-history or biography (Tedlock, 2000). A critique of anthropological models is their tendency to focus on cultural differences rather

than on universals. Some anthropological models rely extensively on written texts about oral traditions rather than examining the oral tradition or stories themselves. The discipline has focused on the exotic rather than the culture of groups in the dominant Western culture (Chambers, 2000).

Medical anthropology. Kleinman (1988), a medical anthropologist noted for integrating the concepts of medical anthropology and psychiatry, embraces patient narratives as part of an understanding of chronic disease. He is known for extensive research and writing around culture-bound syndromes and mental illness. His landmark book, The Illness Narratives (1988), developed the idea that the chronic disease experience resides in the patient and family's life-world. A criticism of the The Illness Narratives is that Kleinman often speaks for the patient by paraphrasing their words rather than using the patient's own words (Frank, 1995). Often the cultural norms of a rational empiricist biomedical system are demonstrated by Kleinman's focus on symptoms and disease processes (Singer, 1998). Although Kleinman acknowledges the value of the patient's life-world, the illness experience is not truly situated there.

Literary theory. The field with the strongest tradition of studying narrative is literary theory. Although narrative theory has been a central topic in literary study, no orderly development of analytic structure and theory have emerged (Polkinghorne, 1988). Literary theorists' interest in narrative has increased greatly in the past two decades so that now the discipline is strongly focused on narrative. In the first half of the twentieth century, narrative structure, plot, and time sequence was the theoretical focus. The evolution of literary theory has evolved from a focus on common themes in the content of stories to the study of narrative from the perspective of communication models

(Polkinghorne, 1988). The framework of communication models is evaluating the pieces that encompass narrative, such as focusing on phonemes, words and sentences used to convey meaning. The model of syntax, as developed by Noam Chomsky, was that narrative structure was universal and inborn to all humanity (Polkinghorne, 1988). The blending of literary theory and anthropology occurs with the study of monomyth or archetypal patterning, where certain myths or folktales are present across cultures (Polkinghorne, 1988). There is a major limitation in transferring insights from literary theory to the analysis of oral narratives of human experience since the focus of literary theory is on narrative as a mode of expression. In human science, narrative is viewed as a way of explaining human actions, studying human experience and behavior, and developing an understanding of behaviors (Cortazzi, 1993). Literary theorists have much in common with qualitative researchers prying into the secrets of writers. For example, qualitative researchers seek to understand the words of the people they interview and create mechanisms to record or maintain their interpretations (Poirier & Ayres, 1997). Often the act of storytelling, seen in research, is similar to the tales elicited by one's favorite novelist, similarities of plot, beginning, middle and end, and a wide variety of characters who have goals and desires. The focus is on meaning to the storyteller, the listener and the researcher (Poirier & Ayres, 1997).

Psychology/Psychotherapy. Freud in his desire to elevate psychotherapy to the level of "science" was troubled by the story-like quality of his subject's discourse. He often felt case histories read like novels. In more recent times, there has been a move in psychology away from the rigid psychoanalytic and behaviorist approaches towards more narrative approaches (McLeod, 1996; Polkinghorne, 1988). In therapy, the therapeutic

relationship is the basis of the story, which is co-created between therapist and client. In viewing narrative as a therapeutic technique in psychotherapy, the first task of the therapist is to assist the client in telling her story. The therapist should assist the client in reshaping her story into a more cohesive pattern (McLeod, 1996). White and Epston (1990) are two psychologists who developed a type of narrative therapy. They believe in helping clients pay attention to a different set of events that are more positive to the client. This process is done through the recreation of narratives in the therapy session. The therapist helps clients unearth knowledge about themselves which may have been silenced. The stories a person lives by have consequences for the way ones lives both their current and future life (M. White & Epston, 1990).

In conclusion, the theoretical underpinnings for studying narrative are not well-defined and are truly multidisciplinary, yet if one's methodology is embedded in a defined philosophical stance, the foundation exists for one's research. In the postmodern world, with a pluralistic respect for the wisdom and meaning of a variety of traditions, the stories we tell as individuals and as cultures have an impact on illness and health (Morris, 1998). The question arises whether statistical instruments, case histories and randomized double blind studies can illuminate the day to day experience of living with a chronic disease. I believe it is stories that convey the hard to grasp concepts of belief and emotional and cultural context, making narrative a meaningful research endeavor for me personally and for the population I desire to study.

Research Design

Narrative inquiry was chosen as the research method for this study as a way to explore the day-to-day experience of Mexican-American families living with Type 2

diabetes. I specifically chose this methodology based on its participant-centered focus and the paradigms under which it operates. Based on my life experiences, both personally and professionally (see my story in Chapter 4), I chose a qualitative methodology for my research, out of a desire not to create or test theory but to generate understandings based on who I am (reflexivity) as well as the participant's understandings of their world.

To understand specifically the experience of rural Mexican families, recruitment was based in the larger Mexican-American community of the mid-Willamette Valley of Oregon. Because 80-85% of all Latinos in the mid-Willamette Valley are Mexican (Davis, 2002c), and due to the need to understand specifically the unique cultural experience of Mexican families, recruitment was targeted to Mexicans only. Latinos in the United States are often classified as one group even though their culture and circumstances are not similar. Knowing the specific cultural information for each distinct ethnic group will make data analysis and interpretation relevant to their needs and aid researchers in addressing long-term health disparities (Bertera, 2003; Zambrana & Carter-Pokras, 2001). This knowledge potentially will assist in designing effective nursing interventions.

Recruitment Procedure

Recruitment efforts were directed toward those who do not seek regular medical care as well as those who have a regular primary care provider. However, all participants and their families had a regular source of health care. One migrant-community health center in the mid-Willamette Valley was used in the recruitment. Patient recruitment occurred both through the use of fliers with clinic staff directing patients to the fliers, clinic diabetes classes and in community outreach activities. A phone number with a

Spanish/English message was available for potential participants in the study. Non-clinic recruitment occurred through informal contacts in the Mexican-American community. The goal of this clinic and community based recruitment strategy was to obtain a mix of both established clinic patients and those who do not seek regular medical care. In actuality, study participants were a mix of established clinic patients at the migrant-community health center and patients whose regular source of health care was private physicians and clinics. The most successful recruitment strategy was an informal process where permission was granted by a community member for me to contact potential participants. I then contacted the potential participant and families and then answered any questions or concerns these potential participants had. After answering questions and concerns, the participants were then asked if they were willing to participate, and if they agreed, an interview was scheduled.

Community Involvement

Involvement of the community being studied is essential in research with diverse populations. Community based participatory research (CBPR) is considered the model for research with ethnic minorities. Some basic components of the CBPR approach are (a) recognizing the community as a unit of identity, (b) building on the strengths and resources of the community and (c) promoting learning between researchers and community participants (Giachello, Rodriguez, & Sayad, 2001; Holkup, Tripp-Reimer, Salois, & Weinert, 2004).

Although this project was not a full CBPR study due to the focus on a specific ethnic group, many of the principles of CBPR were utilized. Examples of CBPR principles related to this research are: a) community members were viewed as equals and

involved in various stages of the project, specifically data collection and data analysis; b) specific culturally-based understandings of the data were sought from the community members, potentially leading to richer and more in-depth analysis; c) I provided support and facilitation to community members or participants; d) researchers' self awareness and values were important to consider, as alluded to earlier; and e) the potential for individual and group empowerment was essential in the research process (Giachello et al., 2001).

Although empowerment is not a stated goal of this research, CBPR studies are considered to be empowering for research participants and team members since they support the notion that the synergistic effect of interpersonal and intrapersonal interaction increases the feeling that one has the ability to affect change. Liberatory research methods, such as CBPR, focus reflection on social structures that maintain the status quo and can serve as a form of "resistance to counter the domination and authority of canonical discourse" (Ellis & Bochner, 2000). Specifically for this study, a narrative methodology can also serve as a liberatory research method and as a source of empowerment in that it uses many of the principles of CBPR and can humanize the experience of illness, locating that experience within the health, economic and social structures of how it is lived in everyday life. Through this process, strategies can then be developed based on real life experiences rather than theories or assumptions, thereby overcoming prevailing biases.

Other examples of empowerment processes to be used in this research project include: hearing the voices of participants in telling stories about their lives, and participants being able to express their thoughts and feelings through mutual sharing. Prioritizing voice, mutual interaction and everyday life can reveal the dynamics of the

multiple locations and realities in which oppressed and marginalized people live. Participants' views of Type 2 diabetes, within the context of their lives and the social and economic structures in which they live, will be valued as much as the biomedical understandings of their illness. It is anticipated that the results of this research will be beneficial to Mexican-Americans with Type 2 diabetes and that strategies for affecting change will be recommended to families and health care providers.

In addition, two community members, a man and women, have been recruited from the researcher's professional and personal contacts among Mexican-Americans in the mid-Willamette Valley. These community members are college graduates from Mexico who live and work among Mexican-Americans in the mid-Willamette Valley. Because they are marginally employed in this country, it was personally empowering for them to be closely involved in the data collection and data analysis processes for this project. Both of the community members are bilingual. The researcher is also bilingual, and has more than 15 years of clinical work with this population. Thus, immersion and entry into this community was possible.

These two Mexican-American community members had very separate and distinct roles which evolved over the course of the study. Rosa Maria Medina translated all consent forms from English to Spanish (see translation procedure for details), and provided recruitment assistance both at the migrant-community health center and among community members. Alfonso Juarez, the second community member, assisted in most of the interviews conducted in Spanish. Alfonso was an invaluable help in making participants feel at ease about the consent process, as well as making male participants feel more comfortable in the interviews. However, I was present at all interviews, so

between Alfonso and myself, a conversational style developed, creating a climate conducive to sharing among family members. Alfonso analyzed all interviews based on a specific format (outlined in the data analysis section), thereby enriching the interpretation of data. He also assisted in some transcription of interviews.

The community workers received the required OHSU training for responsible conduct of research and signed a conflict of interest statement. Training also included a written handout in Spanish produced by the researcher describing the study and the process of interviewing and data collection. In addition, I met once with Alfonso to provide training on how to conduct qualitative interviews, and in the use of a conversational style the use of follow-up questions, or probes, used to advance the conversation. Feedback given after each interview included tips on how to improve interview skills. Since Alfonso had extensive experience in church work in Mexico, he was comfortable developing his own conversational style and using an open-ended interview format consistent with a narrative methodology. Both RosaMaria and Alfonso were volunteers and were compensated by in-kind and monetary donations. Due to their volunteer status, their time was respected by the researcher. However, some interviews were very lengthy due to Alfonso's investment in the interviews and family conversations, and we often stayed late at the participant's homes. For his demonstrated dedication to the research, I remain very grateful. Throughout the research process, I was fully responsible for all procedures and worked toward demonstrating self-awareness and reflexivity in my dealings with the community members and research participants.

In addition, two other community members were involved in this research project. Neither was Mexican-American, yet both had extensive professional involvement with

the Mexican-American community in the mid-Willamette Valley. Elisabeth Mann, a Certified Diabetic Educator with 25 years experience, served as the diabetes expert on the Dissertation Committee. Margaret Belzer, a public health nurse who currently works almost exclusively with Mexican-Americans, had translation experience in South America. She transcribed and translated most of the interviews. Both of these community members received the OHSU required training for responsible conduct of research and a conflict of interest statement was signed.

Field Site

Data was collected in Yamhill and Polk counties, in the mid-Willamette Valley of Oregon. According to census data, 11% of the population in Yamhill County and 8% of the population in Polk County are Latino (Davis, 2002c). The 80-85% of those designated to be Latino are of Mexican descent (Davis, 2002a). The employment patterns in these two counties have been historically agricultural, including cannery and nursery work. Due to the nature of employment in the mid-Willamette Valley, Mexican-American immigrants are often less well-educated than their urban counterparts. Education averages 5-6 years of primary education in Mexico due to emigrating from poorer regions in central Mexico (Davis, 2002c). One migrant/community health center, Virginia Garcia Clinic in McMinnville, Oregon, was used in recruitment. In 2003, Virginia Garcia Clinic estimated 120 regular Mexican-American patients with Type 2 diabetes.

Sampling

A convenience sample was initially obtained of 10-12 Mexican-American adults with Type 2 diabetes and their family members who speak either Spanish or English. Ten

to twelve families were chosen as a result of multiple interviews within each family leading to a potential of 30-35 interviews, which is deemed adequate for an in-depth qualitative study according to Morse (2000). In addition, the nature of narrative inquiry has great potential for generating rich in-depth data (Morse, 2000). This study used shadow data, meaning information was obtained not only about the participant but about other persons in the family as well (Morse, 2000). In addition, data analysis occurred in both English and Spanish. Both of these factors added a layer of complexity to this study. Based on the depth and complexity of the data generated, a sample size of 10-12 families is justified (Morse, 2000).

With increasing numbers of second generation Mexican-Americans, bilingual families were an important addition to the study (Suro, 2003). Two second generation families participated in this study. Both English and Spanish speaking participants' family cultural values are believed to be an enduring cultural construct and there should not be a great difference in family understandings of Type 2 diabetes and the family based on language spoken at home or level of acculturation (Ortiz, 1995). Inclusion criteria for the proposed study are families, defined as a "group of intimates living together or in close geographic proximity with strong emotional bonds (identification, attachment, loyalty, reciprocity, solidarity) and with a history and future" (Fisher et al., 1998) with (a) one adult member diagnosed with Type 2 diabetes, (b) the adult member with diabetes older than 18, (c) the adult member with diabetes self-identified as Mexican-American, and (d) the diagnosis of Type 2 diabetes having occurred 6 months or longer prior to the study, in order to avoid issues related to adaptation/adjustment and personal confusion of the new diagnosis of diabetes (Mann, 2003). Exclusion criteria are

families with (a) women with gestational diabetes, (b) women or men with Type 2 diabetes who are over 65 years of age, in order to avoid the experience of the elderly with multiple medical conditions, and (c) children with Type 2 diabetes, due to pediatric Type 2 diabetes being relatively rare and a unique experience of its own. However, one adult over 65 with Type 2 diabetes did participate, but her 54 year old daughter also had Type 2 diabetes, and the daughter was the key adult diabetic participant. Children ages 8-18 in the family were asked to participate in the study if an adult member of the family has a diagnosis of Type 2 diabetes.

The initial convenience sample was based on families volunteering to participate in the study. Maximum variation sampling, a form of purposive sampling, was then used to obtain the experience of men with Type 2 diabetes (Patton, 2002). Snow-ball sampling was used to identify families from people who know which families may be information rich. At the point in the data collection process when names of information rich families were given to me, ten families had already agreed to participate. Sampling and data collection was concurrent as the data was analyzed (Lincoln & Guba, 1985; Patton, 2002).

Data Collection

Data collection consisted of individual interviews or group interviews of family members such as daughters or sons. Often an individual interview became a family interview since most of the family members listened in on the interviews. Because of the interest in the impact of Type 2 diabetes on the family, information was collected from the entire family not as a complete interactional unit consisting of all members of the family but from smaller groups of family members as well as individuals. According to

Ransom, Fisher, Phillips, Kokes & Weiss (1990) family research needs to include both relational family patterns as well as individual understandings of living with chronic disease. This double perspective can lead to a greater understanding of the family's experience. Yet family interviews were groups of individuals, two daughters would discuss their mother's experience while the mother looked on and injected comments. At other times one member of the family spoke and other family members looked on. Although these interviews were not family interviews in the traditional sense, relational family patterns were explored as well as principles of "multidirected partiality", that is, facilitating the interviews so that all family members who desired were involved and their perspectives were heard (Ransom, Fisher, Phillips, Kokes, & Weiss, 1990).

Based on the cultural background of Mexican-American families, the expectations about interview questions and process and the role of conflict in the family were very different than European-American families. The interview with the two daughters mentioned in the previous paragraph is an example of this, as the division between individual vs. family is different than the dominant Euro-American culture. Alfonso and I took time to establish a personalized, trusting and respectful rapport before initiating the interview itself. I was aware that conflict may not be expressed overtly and role relationships are more strictly defined, impacting the family dynamics (Vega, 1995). With monolingual Spanish-speaking Mexican-Americans, questions were answered in a nonlinear style, through dialogue and storytelling, which did at times lengthen the interview process (Becerra & Zambrana, 1985; Land & Hudson, 1997). These stories, often expressed in a nonlinear fashion, became part of the results discussed in Chapter 4. To assist with the complexities of the cross-cultural communication, Alfonso was present

at most interviews to assist in gathering in-depth and rich data about the experience and meanings of living with Type 2 diabetes and the interpersonal and relational aspects of the family's experiences with Type 2 diabetes.

After the adult participants signed consent and child participants assent forms, the initial interview was usually with the person with diabetes (PWD). A follow-up interview was scheduled with some or all of the family members-the family member most involved in daily management as well as other family members-to explore their individual perspectives of the family member living with Type 2 diabetes. Often the person with diabetes would sit through the interviews with family members. The interview consisted of a dialogue between me, Alfonso and one to three of four family members as a way to generate stories. This smaller family unit in the interview process generated tales reflecting the persons, relationships, and actions of the whole family (Asted-Kurki, Paavilainen, & Lehti, 2001). Children age 8-18 were included and were sometimes interviewed individually and other times as a group. The interview process potentially could lead to three to four interviews per family so in actuality a total of 27 interview events occurred in this study.

The interviews usually took place in the family's home; on one occasion an interview occurred in an office during a lunch break. Establishing interpersonal trust was understood as necessary when working with Latino/Mexican-American families. Forming a relationship or engagement is central with Mexican-American families. In the data collection process, establishing trust occurred through a) the use of the formal you, *Usted* and *Senor/Senora*, b) showing interest in all members of the family and c)

engaging in *la platica*, chit-chat or catch-up talk before starting the research process (Skaff et al., 2002).

An open-ended interview question guide was used initially to elicit individual's and family's story of the experience of living with Type 2 diabetes as well as basic demographic information (see Appendix C). As time progressed, the interviews became research conversations with very broad questions such as "tell me what it is like having a husband/wife with Type 2 diabetes" and then brief follow up questions to elicit conversation. This unstructured interview format is consistent with the methodology. The open-ended interview guide and informed consent forms were translated into Spanish by RosaMaria Medina, a native Mexican speaker and community member, who is fluent in English and Spanish. Observations on the family's experience with the interview process were written as field notes. This information became part of the data and assisted in the analysis of narrative. Individual family members' understandings of how they experience diabetes, as well as various members of the family's stories were explored. At the end of the interviews each family was thanked and compensated with a \$50.00 grocery certificate.

Data Analysis

In narrative analysis, there is not a set analysis procedure as in other qualitative methodologies. Narrative analysis is based in a number of theoretical backgrounds, leading to a diversity of analytic approaches to narrative data (Daiute & Lightfoot, 2004). In this study, the analytic approach of Riessman (1993; 2001) and Poirier & Ayres (1997) served as the basis for the analysis of data. Data analysis was also influenced by the concept of emergent design, common to other qualitative methodologies (Lincoln &

Guba, 1985), and defined as flexibility in modifying the design based on the data, findings and insights that arise during the research process and analysis once out in the field. Emergence and revision are essential features of narrative analysis.

In this research study, focusing on Mexican-Americans who predominantly speak Spanish presents additional challenges both in translation and data analysis. In this section, translation and data analysis procedures will be addressed. Desiring to gain the insider's or emic perspective, capture "in vivo" concepts and offer interpretations of the data which may be elusive to the researcher, a portion of data analysis was in Spanish and those procedures will be outlined under specific analysis steps.

Translation Procedures

- All audio-taped interviews were transcribed in the original language by myself or the certified translator, Margaret Belzer.
- All interviews were read in the original language by me.
- Narrative structures were identified in the original language (see analysis section for additional info) by me in consultation with a native speaker if necessary.
- Identified narratives (stories) were initially translated into English by a certified translator. As the study progressed, I gained fluency in reading Spanish and felt encumbered by the translation. Only those segments which the dissertation committee or qualitative seminar needed to read were translated into English.

- Three long segments of Margaret's translation were back translated from English to Spanish (Suarez-Orozco & Suarez-Orozco, 2001), and I noted great accuracy in her translation work.

Narrative Analysis

Consistent with the methodology of narrative analysis, the goal of the interview was to create conversation between the respondent and the researcher, based on broad open-ended questions. Narratives were analyzed in successive layers, first by plot and thematic analysis and then by core narrative analysis, which examines the essential elements of the narrative using two techniques-overreading and virtual text-explicated by Poirier and Ayres (Ayres & Poirier, 1996; Poirier & Ayres, 1997). These two techniques of narrative reduction will be described under the data analysis steps. For analysis by community members, a modified, less time-intensive procedure of writing responses to questions asked of the narrative text (story) was implemented. The specific procedure is described under analysis steps.

Narrative Analysis Procedure.

- Transcribe interview.
- Read entire interview. The purpose of this step was to explore the overall interview structure and context of the interview. The researcher wrote extensive interpretive memos at this point. These memos became part of the field notes.
- Identify narrative structure. From the transcribed interview, certain sections identified as narrative were re-transcribed. The narrative was re-transcribed with lines in the Ethnograph analysis program for a more focused view than

the initial interview transcription (Riessman, 2001). These segments are “the stuff” of narrative analysis, needed to develop interpretive categories, hear ambiguities and examine the meaning of the oral record (Riessman, 1993a).

Where narrative begins and ends were identified by listening for entrance and exit talk. For example, certain words or phrases the participant uses aids in defining basic narrative structure. Examples of both entrance and exit talk are *let me tell you, well, as I recall, that's all for now, and I guess that's it*. For these Spanish speaking participants, *pues, bueno, and asi es* were terms used for entrance and exit talk. Additionally, listening for brief, topically specific stories organized around characters, setting, and plot were used to identify narrative as well as discrete stories told in response to a single question (Riessman, 2001).

- Identify plot. Plot is the basic structure of narrative, easily identified by the beginning, middle and end of the story (Polkinghorne, 1988). Plot was identified in each narrative. Identifying entrance and exit talk helped with plot identification. Plot was labeled simply beginning, middle and end of the story. The process of plot identification was written about in interpretive memos. Riessman (1993) advocates the structure of narrative being more than simple plot or the functional elements of story. For some of the stories, the structure was nonlinear and so I labeled a narrative often based on entrance and exit talk rather than on structural elements. However, after this analysis experience I agree with Mishler that examination of plot can tie

together individual and family experiences and create a larger context for meaning (Mishler, 1986).

- Identify themes. Based on the re-transcription of the interview data into narrative, themes were identified within each narrative. The narrative was defined by a theme or descriptive word, usually in the participant's own words. Sub-themes or descriptive words helped further delineate the type of narratives. Themes were identified through a coding procedure. Each of the narrative segments was read carefully line by line to identify themes and particularly sub-themes. Inductive codes were developed by the researcher. The main theme was the labeling of narrative, such as a narrative of diagnosis or *Un Gran Susto*, in the participant's words. The sub-themes were coded and described, such as symptoms or emotions related to the above narrative of diagnosis. Both plot and thematic analysis and the development of codes were assisted by the computer software Ethnograph, which brought precision and organization to this analysis (Qualis & Research, 2005).
- Compare within and between case analysis of narratives. The plots and themes of identified narratives were compared between individual respondents, other members of the family, the family as a whole, and other families (Ayres, Kavanaugh, & Knafl, 2003). Questions to be answered included: are the stories similar or different?, are the sub themes similar or different?, how and why are they different? and what is the meaning of the similarities and differences?

This level of analysis will occur through two techniques - overreading and virtual text. All narrative data collected will be analyzed in this more in-depth manner.

Overreading of the narrative text. Overreading attends to inconsistencies, endings, repetitions and silences implicit in narrative. By noting inconsistencies, repetitions and omissions, the researcher can identify a respondent's confusion about, discomfort with or avoidance of a subject (Poirier & Ayres, 1997; Polkinghorne, 1988). Often qualitative data management practices fail to take into account the unspoken or what is not said. Recognizing evasions or omissions is as important as what is stated (Poirier & Ayres, 1997).

- Close and Careful Transcription. The foundation of overreading is close and careful transcription. The previously transcribed narrative text identified from the interview is re-transcribed with close listening by the researcher to both the transcription as well as the flow of the narrative. This level of analysis is known as in-case analysis (Ayres et al., 2003).
- Coding procedure. The process of overreading involves a very in-depth level of analysis. A symbol code will be used to note non-lexicals, repetitions, silences, endings and utterances (Gee, 1991). These symbol codes have been developed by the CELT Institute of Education as transcription conventions for conversational analysis (CELT, 2003) In the process of analysis, the transcription conventions and subsequent coding became extremely time consuming. A modified transcription convention procedure used by Mishler was adopted (see Appendix D) (Mishler, 1986). Inconsistencies and evasions were noted by a descriptive code developed by the researcher.

- Analysis. The context of the narrative is often overlooked. By attending to non-lexicals, repetitions, silences, endings and utterances, there appears to be greater understanding of the narrator's purpose in telling the story. This in-depth coding procedure and subsequent memoing can assist in exploring the context in which the narrative was created, and the respondent's confusion about and his/her discomfort with or avoidance of a subject, adding depth and richness to the data analysis process (Poirier & Ayres, 1997). Attending to the context was essential and this level of analysis brought increased depth to my understandings. I felt attending to transcription conventions did not meet the aims of my study. I continued to memo extensively on the context of the interview, about what was said and not said. After the fifth family, I did not continue with analysis using transcription conventions since I found it very detailed and overwhelmingly time-consuming.

Virtual Text created through field notes, memoing. Creation of interpretative memos is a form of across-case analysis (Ayres et al., 2003). The virtual text is based on reader response techniques used to teach literature and literary appreciation in middle school and high school. Reader response theory is defined as interpretive strategies to find meaning beyond the text. The basis of reader response theory is answering the key question: how can this story mean different things to each person? Virtual text is created in the mind of the reader in response to the written word (Iser, 1980).

Specifically in the research process, a text is created when the dialogue between the interviewer and respondent has been transcribed and turned into words on paper. It is the belief that narrative data or text is meaningless without context. In this analysis, the context is the mind of the reader and in the case of research, anyone who is involved in the data analysis process. For the researcher, meaning and understanding will evolve, develop and change over the course of deciphering, identifying and analyzing multiple interview texts (Ayres & Poirier, 1996; Poirier & Ayres, 1997).

The creation of the virtual text occurs through the transaction of the mind of the reader and the content of the text (which arose from the mind and personal history of the interview respondent). This transaction occurs when text is read and exists in the thoughts of the reader. This virtual text will be written down as an account of how the researcher interprets the data during the analytic process.

Data analysis occurs from a succession of documented accounts of the virtual texts to the final research report. The creation of a succession of virtual texts can be seen as a form of constant comparative analysis, well known to many qualitative nurse researchers (Ayres & Poirier, 1996), by comparing the researcher's understanding in one text versus another section of text. The beginning point of the research process is the research question, thereby setting the initial boundaries of what is relevant and meaningful (Ayres & Poirier, 1996).

The researcher reads identifying plots, themes and patterns through a coding process, comparing each new text with the one before, and in so doing the written virtual text begins to grow in size and complexity (Ayres & Poirier, 1996). The

written text expands based on the analysis of subsequent narratives, and is recorded through memos or field notes. Narrative inquirers describe a process of moving from “field text” which contain memos, field notes, interview transcripts and analysis to a research text or research report (Clandinin & Connelly, 2000).

- Memoing. As in other qualitative methodologies, recording interpretive and reflective notes is an aspect of rigorous data analysis. Through the above analysis procedures, I generated memos at every step. Since data analysis occurred in two languages and encompassed cultural understandings, reflective note taking (or documented virtual text) was essential to fully develop the meaning of the narrative text. Based on the thematic analysis, I recorded memos or field notes based on my interpretation of the narrative data. This interpretation was based on my own expectations and experiences which I brought to the analysis. These personal experiences are described more fully in Chapter 4 under the heading My Story. In addition, this understanding is defined as the virtual text and grows as the analysis progresses so one’s interpretations or understandings is the basis for further understandings of another participant’s or family’s data.
- Coding/Documentation Procedure. A code book was developed in Ethnograph to document the themes/patterns noted in the narrative. Memos were written along side codes developed in the analysis process. Through the process of memoing, interpretations of participant’s narratives assist in gaining understanding and meaning and then were used to interpret other member’s of the family, as well as the narrative of other families.

- Analysis. The interpretation offered by generating memos based on the conceptualization of virtual texts is another layer adding depth and richness to the analysis. As data collection expands, so does analysis, until I moved multiple interpretations to the final research report (an interpretive written account) potentially encompassing larger conceptual concerns.

Analysis in spanish. Members of the ethnic community need to be involved to ensure accurate representation of participants' beliefs and words and meanings. However, the in-depth analysis as portrayed earlier could be a burdensome task to the community members and cost prohibitive to the researcher (a graduate student). In order to maintain the emic perspective, a modified analysis procedure for Mexican-American community members was adopted.

- Narrative segments (stories) were read in Spanish.
- Alfonso, a community member answered specific questions about each story.
- These responses were written in Spanish and read by myself and became part of the data. As stated previously, there are various approaches to narrative analysis. This approach of asking questions of the data has been used by other narrative researchers (Vegdahl, 2002).
- The specific questions were in English: a) What is the storyteller trying to say? b) What is the main point of the story? c) What is uniquely Mexican about this story? d) What did you learn about the family's experience of diabetes from this story? and e) What are your personal reflections/your own thoughts and feelings about this story? These five questions were

derived from the research aims as well as the analysis procedures undertaken by the researcher.

Construction of a summary representation. In narrative studies, there are sections of participant text, descriptive passages, lengthy interpretive writing, personal reflections and specific for this study, analysis in another language. However, in an applied, practice oriented discipline such as nursing, a summary representation is most useful to practitioners (McLeod, 1996). For this research study, summary narratives of each family with subthemes and themes were created, labeling of various types of narrative and exploring of the larger context were all part of the summary representation. This summary representation emerged from the data and analysis process and is presented in Chapter 4.

Protection of Human Subjects

The proposed study adheres to the protection of human subjects via written informed consent and approval by the Oregon Health and Sciences University (OHSU) Institutional Review Board (IRB). A phone number was given for all participants to contact me (the researcher) directly. In addition, I could contact participants after permission was granted from a community member as per the recruitment protocol. After initiating contact, the study was explained to them and their questions were answered before they were asked to participate and were screened as to whether they met inclusion criteria. At the time of the interview, I again explained the study and answered the participants' questions before obtaining written consent to participate and be audio-taped. Parents provided consent for their children. All consent forms in English and Spanish were approved by the institutional IRB prior to their use.

Protection against risks. Referral procedures were in place to refer participants as necessary to bilingual mental health services, as well as culturally appropriate primary health care services. For Mexican-Americans, immigration status is of concern. In this research study, no questions were asked or information gathered regarding the participant's or any family member's immigration status. All participants were assured on an on-going basis that they were free at any time to withdraw from the study without consequence, and measures were put into place to reassure participants that information was kept confidential. Informed consent was obtained at the time of the interview, as well as throughout the research process by re-explaining the purpose of the study and obtaining verbal consent before any subsequent interviews during the data collection process. During the proposed study, all audio tapes, transcripts, hard copy notes, disks and signed consents were stored in a key-secured cabinet in my office. Personal identification of the participants was kept secure and separate from the data. The researcher as well as all community members involved in the proposed study completed the institution's required training on responsible conduct of research and conflict of interest. Only ID numbers assigned to transcripts were used to link data to the family being studied. Families were informed that all information would remain confidential and not be shared with anyone outside of the study research team.

Potential benefits of the proposed research. There were no direct benefits to participating in this study, but an indirect benefit may be gained from discussion of one's life experience with Type 2 diabetes, which could potentially impact the quality of one's life.

Importance of the knowledge to be gained. Valuable knowledge for health care professionals has been gained from understanding the experiences of this understudied ethnic group and could potentially improve the health care for this population. This knowledge and understanding is explored in Chapters 4 and 5. Furthermore, the results of this study could potentially lay the foundation for future research in effective nursing interventions for diabetes in this population.

Inclusion of children. Children were included in the study, if they were eight or older, can give assent and parents are willing to give consent, and are a member of a family in which one of the adult members has the diagnosis of Type 2 diabetes.

Gender and minority inclusion. Due to the specific focus on persons of Mexican-American descent, other ethnic minorities were excluded. Women were encouraged to participate due to the involvement of women in family life. Women participated as a person with Type 2 diabetes, or as a spouse or other family member.

Trustworthiness

In evaluating narrative analysis specifically, standards of validity based on positivist assumptions are not realistic or meaningful for narrative. The position of some theorists is to take a standard of art- does the account move us? Yet when narrative inquiry is more than an artistic endeavor, especially in health sciences research, the standard needs to be greater and there needs to be more attention given to the rigor of the study (Riessman, 1993a). Riessman (1993) in Narrative Analysis develops four criteria of trustworthiness to evaluate narrative accounts: persuasiveness, correspondence, coherence, and pragmatic use.

Persuasiveness and its related term, plausibility, refer to whether the interpretation is reasonable and convincing. One may have had the experience of reading a piece of research and stating “a-ha! that makes perfect sense,” even when the explanation may go against one’s own sense of intuition. According to Riessman (1993), persuasiveness is greatest when theoretical claims are supported by the respondent’s account and when all potential interpretations of the data are considered. For this proposal, data analysis was conducted in close collaboration with the dissertation chairperson, members of a qualitative analysis group and the community member who assisted in the data collection. In addition, the results of this research endeavor as written in Chapter 4 are persuasive and plausible as written.

Correspondence is parallel to the process of member checking which is used by many qualitative researchers. Ideally, the researcher takes the analysis back to the individuals and groups who provided the data. However, a researcher’s interpretations and understandings may not be validated by member checks, since human stories are not static and the meaning of experience shifts over time. The theorizing across a number of narratives may be difficult the individual respondents to evaluate and they may not agree with the researcher’s interpretation. In the end, the work is the researcher’s, who takes full responsibility for its interpretation (Riessman, 1993a). Member checking was done by giving the results to one participant who read English well. In addition, Elisabeth Mann, a CDE, read the results for persuasiveness and plausibility based on her experience as a diabetic educator.

Coherence consists of three levels-global, local and thematic. These three levels of coherence assist the researcher in determining whether the interpretation is ad lib,

casual observations or more substantive. Global coherence refers to the overall goals the narrator is trying to accomplish by telling the tale. Local coherence refers to what the narrator is trying to effect in the narrative itself, such as the use of linguistic devices of silence, false starts and non-lexicals, context and setting. Thematic coherence involves content, having chunks of interview data exhibiting certain consistent themes.

Meaningful interpretation is limited by an ad lib approach to the narrative (Riessman, 1993a). In this proposal, the layering of the analysis is an attempt to address concerns of coherence. Initially the narrative was analyzed for plot and theme. Core analysis occurred by the process of virtual text and overreading.

Pragmatic use, or what is known as transferability, refers to the extent to which a particular study becomes the basis for other's work, the belief that knowledge needs to be validated within a community of scientists as they think about solving problems.

Pragmatic use can also refer to how researchers present information; by the manner of interpretation that will be possible for others to determine the trustworthiness of the work. The steps to transferability occur by describing how the interpretations were produced, making visible what was done, specifying how we accomplished successive transformations and making primary data available to other researchers (Riessman, 1993a). The final write-up contains implications for practice which potentially will aid clinicians. For researchers and scientists, the manuscript will be presented publicly in the academic community. Through these two mechanisms, information from this study will be made available to both researchers and clinicians.

While no attempt will be made to generalize the proposed study's findings to other Latinos or cultural groups, data has been provided in the characteristics of the

study's participants so that other health care providers, community members, researchers and research consumers may determine for themselves the relevance of the findings to their own settings. I believe narrative inquiry offers an exceptional opportunity to explore the experience of an ever-growing ethnic minority, Mexican-Americans.

Chapter 4: Results – Summary Representation

Setting the Stage

In the study of narrative, the researcher must account for many things beyond the participant's words or particular story. The story is not an absolute truth, but rather the telling of events and personal or emotional experiences. Narratives display multiple truths with many layers of meaning and context. These stories were created by participants in a unique moment in time, in a certain setting-usually the home-and in a local context (the mid-Willamette Valley in Oregon). Many influences impacted the creation of stories, including the interview conversation, interaction between the researcher, her partner and the participants, cultural understandings and the geo-political and socio-economic contexts occurring in the summer of 2005. In order to understand and represent the participant's lives and stories with integrity, the setting must be viewed through various lenses signifying the multiple contexts in which these families live. These contexts include location, the social-economic dimensions of the immigrant experience, housing and living space, the larger geo-political context and the researcher's and her partner's own stories. All these various contexts will be explored.

Initially, demographic information about the families and participants will be presented. The mid-Willamette Valley of Oregon is home to an increasing number of Mexican-Americans and is the location of this research study. The researcher and her partner told their own stories and how it related to the interview events. The scene, in terms of the moment in time (the summer and fall of 2005), and the place, the homes of many of the participants, are described in the following section.

The Participants-Demographics of the 10 Families

For this research study, 10 Mexican-American families with Type 2 diabetes were interviewed. Within these families, 42 people participated in the study: 11 persons with Type 2 diabetes, 7 spouses, 6 children under the age of 18 and 18 other adults. These 18 other adults included adult children: 9 daughters and 9 sons, 2 daughters in law and other relatives in the home who chose to participate such as uncles and aunts. There were 16 male family members and 15 female members who participated in the study. The age range for all participants was from 10 years old to 73 years old. Six participants were minors under the age of 18. One participant was older than 65. The majority of the children were adults living with their middle aged parents or living nearby. These families all resided in the mid-Willamette Valley of Oregon and self-identified as Mexican-American.

Two families had more than one adult with Type 2 diabetes. There were 3 men and 9 women with diabetes. The length of time participants were diagnosed with diabetes was from 9 months to 35 years. The average length of time with Type 2 diabetes was 9 years. Two participants used insulin as well as oral medication in their diabetic management. One participant's diabetes was diet controlled and the other nine managed their diabetes through oral medication, diet and exercise. The variety of medical management of Type 2 diabetes in this sample reflects the variety of treatments for Type 2 diabetes currently used in the general population.

The majority of the families participating in the study were immigrants. The length of time in the United States ranged from 1 to 20 years. Participants who had lived here many years compared their experience with diabetes to what they remember or had

known from Mexico. For the newer immigrants the difference between here and there were salient and central to their stories. Two families were second generation with 2 members having immigrated as either small children or over 50 years ago as adolescents, while the rest of the members of the family were born here. Of the adult participants, only two chose to be interviewed in English. Only three of the six children under 18 chose to be interviewed in English, even though they were attending school here in the U.S. The dominance of Spanish speaking participants confirmed for me what is known, that one's original language is the language of thoughts, feelings and emotions. Many participants chose to express themselves in Spanish; often it was a blending of Spanish and English.

The education level of the persons living with diabetes and their spouses was very low. The range was zero years of formal education to technical training after high school. The average level of education was only 4th grade. Some of the participants were illiterate, unable to sign their names; others were functionally illiterate struggling to read the consent form as well as understand the questions that were asked of them. As a researcher, I needed to continually adapt and be flexible in my approach to the consent process as well as the structure of the interview.

The employment pattern of the adult participants mirrors the education level. The majority of the adult participants worked in an agricultural based setting such as nurseries, canneries or were working with farm equipment. Other participants worked in service industries, such as fast food restaurants as cashiers. Two participants were employed in sales. The remainder had office based employment such as secretarial or receptionist work. Some of the women worked in the home taking care of their children or grandchildren.

This employment pattern led to only three families having access to private health insurance and Medicare/Medicaid. The rest of the families had no source of health insurance and relied on community health centers or paid out of pocket for their health care. Based on this information, many family's stories were about the financial burden of Type 2 diabetes.

As a researcher there were many things I expected of the sample. I expected that the education would be lower than a similar sample of European-Americans and that many of the participants would be immigrants. However, it was surprising to me that the education level of the sample was so low. There are many implications for research with this population based on being minimally literate in one's native language. They had difficulty understanding questions, struggling with consents and other paperwork. Research with this population needed to be based on oral communication, such as interviews, rather than written communication, such as questionnaires.

Certainly, being in a rural area, the number of participants employed in agriculture was not surprising. Yet I thought the employment patterns would be more diverse with light industry and construction represented. With current employment patterns of the participants, I believed that more participants would have access to private health insurance since they were all employed and working full time.

The sample being equally male and female was a positive quality, due to having the perspectives of both genders living with Type 2 diabetes. Having a male research partner helped ensure a higher sample of male participants. I was also surprised at the age of the children. Many of these couples started having children at age 16 or 17. As middle aged adults, their own children were in their twenties. Clearly, the children had an adult

perspective on their parent's disease. Since only one child was under 12, and 5 under 18, a child's perspective was not dominant in this study.

Local Context Mexican-Americans in the mid-Willamette Valley of Oregon

The mid-Willamette Valley of Oregon is the local context for this research study. In describing the mid-Willamette Valley as a local context, I found immigration scholars Portes and Rumbauts (1996) idea of context of exit and reception helpful. The context of exit is the experience of leaving Mexico and crossing over. The crossing over experience was prominent in some families' stories. In rural Oregon, the context of reception of the undocumented dark-skinned working class Mexican immigrant is one of an "unwelcome" guest. This guest is recruited by local agribusiness searching for an easily exploited labor pool, denied access to governmental aid including medical assistance, forced into a somewhat underground economy, scorned by English speaking Anglo neighbors and often dependent on other *migrantes* for housing and employment connections (Portes & Rumbaut, 1996). Within this context of reception lies the experience of the immigrant families in this study. For the two second generation families, the immigration experience was only a generation away, and they often spoke of their parent's lives as immigrants. In summary, my sample represents the typical demographics and experiences of Mexican-Americans in the mid-Willamette Valley.

Situate the Researcher

My story. As participants in this study often told personal and revealing stories, it is important that the researcher's story be told. I asked myself, "Do I have the right to ask participants to share and be vulnerable, and I not share and be open about myself?" In this spirit of openness and sharing and also to view my story as another prop in setting

the stage, I explore who I am, as both a lens through which I engaged with these participants and the data, as well as an intersection of how these interactions influenced the process.

I believe this dissertation study was born of two interwoven processes in my life—my faith and my vocation or career. I was born into the church, the child of a Christian Reformed minister. Church was the center of our existence. I attended 2-3 services a Sunday and a mid-week service. I also attended Christian school from kindergarten through the first 2 years of college. I memorized large sections of the Bible since the “Communists were coming to take our Bible away”. My family’s faith was rooted in Calvinism and doctrines such as total depravity and original sin and election shaped my understanding of the world. Growing up in a Calvinistic home, there was a strong work ethic and so I worked hard in my academic subjects.

Being a woman, my occupational choices were indirectly dictated. Although not stated, women either became teachers or nurses, worked a few years and then stayed home to take care of their children. I chose nursing, graduating in 1983 from Rush University. Initially I was employed in the hospital. I left after two years to work for the Visiting Nurses Association (VNA) of Chicago on the South Side of Chicago in the Robert Taylor Homes. The 1 ½ years I worked with the VNA was a personally and spiritually transformative experience. I worked with predominantly African-American families who lived in the housing projects and often in great poverty. For much of my life, I believed that God blessed those who worked hard and followed him. Most of my patients were devout Christians, whom I viewed as spiritual giants but who had not been blessed in the way I believed. They were often spiritually stronger than I was and yet

struggled in poverty. My understanding of Christianity shifted dramatically at that point. I came to view God as having a preferential option for the poor meaning God's kingdom and work is often hidden in the lives of the poor. There were many structural sins that needed to be addressed and which I saw every day in my work as a nurse. I came to believe that a Christian mission was not only to serve the poor but to stand beside them and address structural and societal inequities.

My VNA work propelled me to graduate school to become a Family Nurse Practitioner, a primary care provider. I went to work with migrant farm workers in northern Wisconsin for a summer. Returning to Chicago, I was employed by Claretian Medical Center, a community health center in the neighborhood of South Chicago. Working at Claretian Medical Center, I was a minority among a staff of Latinos and African-Americans. The patients were 90% African-American and Latino. My 5 years at Claretian were transformative and I saw the community health center movement as a means to live out my Christian mission. At Claretian, I was able to gain Spanish fluency. I always felt that at Claretian Medical Center, the quality of the health care was equal to that in the insured community. They strove for excellence and always treated patients with dignity and respect and as partners in their health care.

Eventually I relocated to Oregon and eventually moved to McMinnville in 1997. I again was employed in a Community Health Center. At Virginia Garcia Clinic, I was the sole provider for a small satellite clinic. Since the majority of patients were Mexican-American, diabetes was a huge patient problem. I struggled with managing and coordinating the care for hundreds of diabetics. In the fourteen years since starting at Claretian Medical Center, the burden of uninsured patients on community health centers

nationwide had increased dramatically. The situation became untenable. It was like a walled fortress and the masses of uninsured were at the gates. The gates were only opened periodically, and a small number could pass through. Overwhelmed and exhausted by this need, I made the decision to enter a PhD program in order to try to gain a further understanding of how I might be able to improve the care of this underserved population.

I believe I offer a unique perspective to this study. I am neither bi-cultural nor simply a cultural visitor. I worked the majority of my career with this population, and have a great appreciation for their ways and struggles.

Personally, I have found this research study very meaningful. I had the time I never had in primary care practice to merely sit down and talk to families about their lives and how they lived every day with Type 2 diabetes. Over the several months I was involved in the interviews, I felt increasingly connected with the Mexican people living in my community. I continually struggle with the best way to represent their lives and stories.

In addition, a Mexican-American man who became a partner in this research project tells his experiences with this project. Alfonso was a brother of a good friend of mine and had been involved in church work visiting members in their homes. He felt comfortable visiting in homes of persons unknown to him and was willing to do this.

His caring and concerned presence in the many interviews put participants at ease and created an atmosphere where participants felt comfortable. The sense of a partnership evolved over many interviews and home visits, since our conversational style intertwined. Alfonso defined the relationship as a partnership which I felt was more

appropriate than terms others researcher use such as cultural broker or community worker. His reading and analysis by answering specific questions (see Chapter 4 for specifics) of the family's narrative influenced my thinking and is integral in my summary representation of these families' lives.

Since his story was written in Spanish, and out of respect for him and his writing, it will remain in Spanish and be translated into English.

Researcher partner's representation

Alfonso Juarez's Story

Mi experiencia en el proyecto Quiero expresar como parte de este interesante proyecto, mis experiencias y vivencias que a lo largo de todas y cada una de las entrevistas tuvimos y que sin duda nos otorgaron un conocimiento y una transformacion emocional en mi vida, hablando especificamente de mi persona.

Sin duda, cada una de las familias entrevistadas para saber acerca de sus experiencias con la diabetes o si eran parte de la familia del paciente. Me enseñaron muchas cosas en varios aspectos, por ejemplo, cuando yo vine a este país para cumplir propósitos personales un año y media atrás, jamás me imagine que tuviera la oportunidad de participar en un proyecto como este. En el cual pude conocer de cerca la vida de muchos de mis compatriotas en este país y sobre todo, como ellos se desenvuelven en un país ajeno totalmente al suyo para combatir una enfermedad tan propia de los mexicanos como lo es la diabetes. Me pude dar cuenta que en la mayoría de los casos, sigue existiendo esa unión familiar que tanto nos caracteriza como cultura latina, un deseo grande de hacer las cosas con esfuerzo y dedicación, pude ver el sacrificio y luchando de muchas de ellas que trabajando muy duro, logran controlar la enfermedad y además guardan el equilibrio de lo que representa la familia. Esta experiencia estuvo llena de muchas satisfacciones, poder ayudarles con

respuesta a sus preguntas, con el simple hecho de solo escucharles y ellos decir las cosas en frente de un micrófono y una grabadora, lograba que ellos se sintieran un poco mejor. Pude ver el deseo de salir adelante con la enfermedad sin perjudicar a los demás, el interés de controlar la diabetes por muchas razones y van desde sentirse mejor físicamente hasta estar preocupados por salvar y no perjudicar la relación íntima de la pareja, lo cual se me hace un buen gesto de preocupación e interés por los demás.

Aprendí muchas cosas acerca de la enfermedad, cosas que yo mismo desconocía aun teniendo a mi padre con diabetes, eso me permitió estar mas informado y así sentirme mejor preparado para ayudar o ayudarme a mi mismo, es muy interesante el ver como las personas reaccionan ante una enfermedad. Eso es algo que conocí, como algunos son necios para cuidarse a si mismos y otros toman muy en serio su nueva vida enfermos y aprenden a como cuidarse y realmente controlan su enfermedad con mucha dedicación y determinación.

Cada una de las familias fue diferente, cada una representaba una experiencia totalmente distinta, así que pude aprender muchas cosas atravez de las entrevistas, por ejemplo, como una niña o un joven minusvalidos dentro de la familia, logran Milagros y desafios dentro de una familia. Cuando el papa es el diabético o la mama lo es, siempre ellos tratan de ser Buenos ejemplos para el resto de la familia, lo cual creo es algo muy valioso e importante.

Creo sin temor a equivocarme, que la mejor decisión que puedes tomar al contraer esta enfermedad de la diabetes, es dedicarte a cuidarte en tus hábitos y malas costumbres, desarrollando así autoestima y madurez, controlando tus impulsos negativos y así lograr que la enfermedad no te venza sino al contrario. Tu vencerla a ella, eso es algo que yo aprendí con muchas familias que me enseñaron que esto si es posible, si tan solo tu decides hacerlo.

Gracias Sarah por permitirme ayudarte en este proyecto tan importante!

Atte.

Alfonso Juarez.

My experiences in this project. Having shared in this interesting project I'd like to relate my experience and the knowledge I obtained from each and every interview that we did. Without a doubt they rewarded us with an increased understanding and speaking for myself, a moving experience. There's no doubt that each one of the families that were interviewed regarding their experiences with diabetes, whether it was the patient or a member of the family, taught me a great deal in a number of ways. For example when I came to this country with personal objectives one and half years ago I never thought I would have the opportunity to take part in a project like this, in which I could learn about the life of many of my countrymen here: above all how they adjusted to combat a disease so common to Mexicans like diabetes, in a country totally different from their own. I could see that in the majority of cases there continues to be this family union which is such a part of Latin culture and a great desire to do things with strength and determination. I saw the sacrifice and struggle made by many of them working very hard, managing to control their illness while at the same time maintaining the balance between this difficult disease and family. It was a very satisfying experience to be able to help them by answering their questions, by the simple fact of just listening to them and their speaking into a microphone and tape recorder made them feel somewhat better. I noted their desire to overcome their disease without detriment to others. Their interest in controlling their diabetes varied from feeling better physically to concern with saving or not spoiling their relationship with their partner. It seems to me that this shows great care

and concern for those around them. I learned much about the disease, things that I myself weren't aware of even though I have a father with diabetes. This allowed me to be more informed and feel better prepared to help and also help myself. It's very interesting to see how people react to illness and this is something I knew about: how some are foolish in taking care of themselves while others take their new life as a sick person very seriously, learn to take care of themselves and trying to control their disease with much dedication and determination. Every one of the families were different; each one related completely different experiences so I was able to learn a lot from the interviews. For example with a little girl or a handicapped youth in the family they perform miracles and rise to the challenges involved. When the father or mother is diabetic they always try to set a good example for the rest of the family and I think that this is something very worthwhile and important. Without a doubt I believe that the best decision you can make when you become diabetic is to devote yourself totally to watching your way of life and bad habits, developing self esteem and maturity and controlling your negative impulses. In this way you'll manage not to let the disease overcome you and on the contrary you'll overcome it. This is something I learned from the many families who taught me that it's possible if you only make up your mind to do it.

Thank you Sarah for allowing me to assist you with such an important project!

Yours,

Alfonso Juarez

The Scene

Time. The time of these interviews was from May, 2005 to October, 2005. The summer of 2005 was a time of renewed racism against Mexican-Americans as demonstrated by the events in the national news. The issues and images of illegal immigration were seen and heard daily. There was a call in Congress for some type of immigration reform. Senators Gordon Smith and Lindsay Graham called for the renewing of the Bracero Accords of the 1940 and 50's, creating a class of temporary workers who would be allowed in the U.S only for the growing season. A class of temporary workers would compete with permanent farm workers for agricultural work (PCUN, 2005). This legislation has been opposed by many Latino advocacy groups (PCUN, 2005).

During the summer of 2005, governors of both New Mexico and Arizona declared a state of emergency to stem the tide of illegal immigrants crossing over. A heat wave caused hundreds of immigrants to perish in the desert. In addition, vigilantes calling themselves Minute Men organized in Arizona to assist INS, the border patrol, in rounding up illegal immigrants in the desert. The Minute Men believed the Border Patrol is inadequately funded and their duty as citizens is to protect the border from foreigners. (USAToday, 2005).

Locally, the strawberry growers of Oregon did not have enough labor to pick the berries before they rotted in the fields. The growers blamed current immigration policies which increased border patrols, making immigrant cross over from Mexico difficult (Sarasohn, 2005). In addition, in McMinnville and surrounding communities, hate mail made its way to the doorsteps of Latino's homes, threatening immigration raids. The FBI

was called in to investigate (Bates, 2005). This larger political context which encompasses the geography of the U.S./Mexican border is an integral part of the setting for this research.

Overall, in Oregon, the Latino population suffers many economic and health disparities. Approximately 27% of Latinos in Oregon live below the federal poverty level, almost 3 times the level for White-non-Hispanic Oregonians, and earn about half the average state per capita income. Currently, approximately 35% of Latinos in Oregon have no health insurance. However, it is believed those who live in the greatest poverty are the undocumented seasonal agricultural workers who live on the edge of society. The Mexican Consulate of Oregon estimates that approximately 90,000 undocumented Mexican nationals work in Oregon (Novak, 2003). This is the social and economic reality, the stage upon which the families' stories are told.

Place. Due to the poverty of many of the ten families interviewed, they experienced many housing issues. Although not often stated directly, it was noted by myself and my partner that the participants spoke indirectly of the cost of rent. For example, one participant alluded to renting out a bedroom in a small 2 bedroom apartment in order to supplement the family income. I observed 6 or 7 individuals living in small 2 bedroom apartments. Families spoke of difficulty paying monthly rents of \$500-600.

The tight living quarters impacted the setting for the research and interviews. Since all the family members tended to gather in the kitchen or living room, all conversations were heard by other family members. Sometimes they listened silently, other times they interjected comments. At times extended family members such as

cousins or uncles, were watching small children and listening to the interview conversation at the same time. What I would have viewed as private personal concerns from a dominant cultural perspective were often family issues and concerns, discussed freely among family members. One could argue that openness within the family is a cultural reality, a different understanding of family issues vs. personal and private concerns. Yet I wonder whether it is just a matter of overcrowding, an economic reality of living in poverty.

A Glimpse through a Window – A Narrative Representation

In presenting these families' stories, I made representational decisions guided by two main foci. The first is the aims of a qualitative research study that guide data collection, analysis and writeup; while the second focus is the desire to faithfully and with integrity represent the experience of Mexican-American families based on my understandings and life experience, in other words, my lens. I am also influenced by the thoughts, reflections and analysis of Alfonso Juarez, my research partner.

The aims of this research study were:

- 1) Describe the day to day experience and meanings of Type 2 diabetes of Mexican-American families living in the mid-Willamette Valley of Oregon.
- 2) Describe the interpersonal and relational aspects of the family's experience of Type 2 diabetes.
- 3) Describe the socio-cultural-economic context impacting the family's experience of Type 2 diabetes.

I do not believe one can fully describe nor understand the experience of another. Huge gaps exist between white academia and the lives of Mexican-American families. Class, race, culture, language and immigration status profoundly impact the research interaction. Yet Mexican-Americans live in our communities, and they are our neighbors. Their experiences deserve to be known, valued and respected. But I personally struggle with whether any researcher can bridge these gaps in understanding the experiences of Mexican-American families. Can a researcher respect the dignity of these families in representing their experience?

I believe that from my life and professional experiences I can only glimpse context in which these families live. As a research methodology, narrative inquiry can, through its less rigid structure and participant centered focus, facilitate this view of these families' context. I offer a glimpse through an open window into these ten families' day to day reality by both exploring and describing their lives.

I have chosen to represent these families' reality through use of some writing conventions. In order to have the participant's stories and experience come alive and as means to respect their dignity by not using a label such as participant #1, I have chosen to use pseudonyms, and to segment their stories from larger narratives. Some of the participants were natural storytellers, for their interviews were their stories. My role was not as an interviewer with many questions, but rather as a listener to their life stories. The structure of their stories was very similar. Starting with *antes/despues*, before and after the diagnosis, these storytellers took Alfonso and me through changes in their lives, economic burdens, family conflicts and worries and concerns for the future. Unfortunately, I cannot fully record their stories. While there are numerous possible

stories or representations to be told from any one research study, I can only represent one. However, I have chosen to view these narratives as segmented stories, parts and pieces of a greater narrative. Yet the structure of these certain natural storyteller's larger life stories provides the structure for these segmented stories.

Segmented Stories

These segmented stories are indeed part of a larger story. For these families, diabetes begins in the past with the experience of parents and grandparents, exists in the present with the day to day struggle of managing a chronic disease within the family, and extends into the future with family's worries and concerns for themselves and the risk that other family members have. So clearly, it is a story over time with a distinct past, present and future. Oftentimes in qualitative research, multiple interviews can generate many different stories, yet in this study many of the stories told by persons with diabetes and family members alike fell into this pattern of a disease over time. Diabetes, as a difficult and dreaded disease, exists not just in the current moment or recent past but extends back 10-30 years. In keeping with the methodology of narrative inquiry, and so as to remain as participant centered as possible, each of these types or collections of segmented stories is named or labeled in the participant's or family's own words. These labels encompass not one individual's expression but the thoughts and feelings of others.

Often narrative health care researchers such as Arthur Frank use literary techniques. In his work, *The Wounded Storyteller, Body, Illness and Ethics*, the stories of people with serious illness fall into three basic categories: restitution, quest and chaos, corresponding to the literary genres of adventures, tragedy or nonsense (Frank, 1995). I have chosen to structure the writeup of these stories with a literary sense, that narrative is

the unfolding of events and actions over time (Aristotle, 1996(translated). For me, these narrative segments represent events occurring over time within the central story of emotional burden and turmoil. The organizing framework based on the code book can be found in Appendix D.

Emotional Burden and Turmoil: The Central Story

The central story throughout all the family narratives is the experience of the emotional burden and turmoil of Type 2 diabetes. Although there are differences among families as to how they experience emotional burden and turmoil related to diabetes, all families experience this to some degree within the contexts which provide additional meaning: the political-social and family context. For example, Ignacio describes chronic disease as *una carga muy grande* (a heavy burden). Carlos, diagnosed just 9 months previously, describes Type 2 diabetes as something he *habia cargada*, (something he is now burdened with) and which he worries about constantly. Rocio, a 53 year old living with diabetes, describes the burden like living with a heavy stone upon your back.

Political and Social Context

For some families in this research study, the larger political and social context described earlier creates an extra burden. These families live in poverty, are immigrants with undocumented legal status and lack necessary medical and social services. Living in crowded apartments, the families often struggle to pay for special foods needed on a diabetic diet. These contexts are vividly described by the participants.

Family Context

In addition, individual family contexts, lead to great emotional turmoil with a family member with diabetes. Poverty can lead to illiteracy in a participant's original language, making the migration experience very difficult. Luz struggles to find employment and realizes she cannot obtain a driver's license often necessary for employment in the U.S. Other families struggle with alcoholism and domestic violence. When the father is an alcoholic, a diagnosis of Type 2 diabetes causes grief and guilt among his children. Similarly, a mother with Type 2 diabetes suffers stress and fear from her husband's blows. Her adult daughters believe it makes her diabetes more difficult to control and they are at a loss how to help her.

In the past, Euro-American researchers have attributed Mexican alcoholism and domestic violence to cultural and psychological failings (Behar, 1993). Due to this history, I struggled whether to address alcoholism and domestic violence in the study, desiring not to have these experiences construed as stereotypical or labeled. Yet the diabetes experience is embedded in the family context, and therefore alcoholism and domestic violence are included as part of these family's stories, but is not emphasized.

The struggle to make the necessary life style changes also causes emotional turmoil for families. Children worry when the parent living with diabetes does not follow the necessary diet. They struggle with whether to discuss it with their parents. Children want to support their parents in making dietary and lifestyle changes but are unsure how to do that. Teresa and Adriana, two teenagers, want to support their mother with eating the right things but they do not want to nag. Both express conflict with their role, wondering if as kids they should be telling their Mom what to do. Florencia and her adult

son and daughter in law have conflict over the cost of necessary dietary changes. These are examples of the emotional burden of diabetes.

Ten Families

To shed a light on Mexican families' lives, allow me to introduce the ten families interviewed (see Table 1) and their stories. In this table, each of the ten families are family or *familia*. Family indicates a 2nd generation family and *familia is* a first generation family. The families are introduced by their pseudonyms and their ages. The person with diabetes (PWD) is introduced, including the length of time he/she has had the disease and how his/her disease is being treated. The education level of each parent in the family is presented. The major theme of the stories told is presented as well.

Table One
Family Characteristics

	Immigration Status	Members and Ages	Persons with Diabetes	Parents Level of Education	Family Themes
Family 01	2nd generation	Ernesto age 41 (Immigrated age 5) Elvia age 38 Teresa age 18 Adriana age 16	Elvia diabetic x 8 years treatment diet and medication	12th grade education U.S. both parents	Conflict and Struggle over Wife/Mom's Diabetes
Family 02	2nd generation	Manuela age 73 (immigrated at age 15) Cristina age 54 (born in the U.S.) Manuela's husband did not participate	Cristina diabetic x14 years medication and diet controlled Manuela diabetic for 35 years, insulin, medication and diet controlled	Cristina = technical education post-high Manuela = 2 years- Mexico	Intergenerational impact of Diabetes
Familia 01	Immigrant family in U.S. for 10 years	Berta age 53 Enrique age 48, 2 of 12 children participated Altagracia age 21, Isabel age 10	Berta diabetic x 7 years medication and diet controlled	Berta = 3 years Mexico Enrique = 3 years Mexico	A natural healthy diet, no sugar is best for everyone
Familia 02	Immigrant Family in U.S. for 1.5 years Father in U.S. for 7 years	Pedro age 49 Luz age 48 Gabriela age 21 Miguel age 23	Pedro diabetic x 4-5 years diet & medication controlled	Luz = 0 years Pedro = 3 years Mexico	Alcoholism and Diabetes are so difficult

Table One
Family Characteristics (cont.)

	Immigration Status	Members and Ages	Persons with Diabetes	Parents Level of Education	Family Themes
Familia 03	Immigrant family in U.S. for 5 years	Ignacio age 32 Dominga age 34 Fernando age 16 Maribel age 13	Dominga diabetic x8 years diet and medication controlled	Ignacio = 12 years Mexico Dominga = 9 years Mexico	Medical bills in addition to chronic disease overwhelm a family
Familia 04	Immigrant family in U.S. for 9-10 years	Edgar age 48 Patricia age 47 Fernando age 30 Inez daughter in law age 31 Liliana age 25 (do not live in home-Patricia provides child care) 14 y.o daughter did not participate.	Patricia age 47 diabetic x 14 years diet and medication controlled	Edgar = 4 years Mexico Patricia = 3 years Mexico	Mom with Diabetes is a symbol of strength. All the children respect her. Intergenerational impact of Diabetes
Familia 05	Immigrant family in U.S. for 15 years	Lino age 53 Juanita age 50 Tomas age 28 Jesus age 26 Francisco age 23	Lino diabetic for 8 years insulin and diet controlled	Lino = 0 years Mexico Juanita = 3 years Mexico	Diabetes is difficult and complicated when both parents have the disease. Different health beliefs interact with the health care system

Table One
Family Characteristics (cont.)

	Immigration Status	Members and Ages	Persons with Diabetes	Parents Level of Education	Family Themes
Familia 06	Immigrant family in U.S. off and on for 23 years. Oldest daughter 8 years Youngest daughter 3 years	Rocio age 52 Esmeralda age 30 Beatriz age 21	Rocio diabetic for approx 5 years diet and medication controlled	Rocio = 9 years Mexico	Violence affects the disease of diabetes
Familia 07	Immigrant family father in U.S. 23 years Mother in U.S. 19 years	Carlos age 41 Lupe age 39 Arturo age 16 Antonio age 13	Carlos diabetic x 9 mos medication and diet controlled	Carlos = 6 years Mexico Lupe = 6 years Mexico	Changes needed with Diabetes are hard and affect the entire family
Familia 08	Immigrant family mother in U.S.x3 years Son in US. X 14 years Daughter in Law-Euro-American	Florencia age 58 Roberto age 30 Debbie age 29 Euro-American	Florencia diabetic x 3 years diet controlled	Florencia = 3 years Mexico	Dietary Changes can cause conflict between family members

Six Story Types

These segmented narratives are divided into 6 Types or Sections. Each type encompasses either a past, present or future dimension of this disease. Two sections- Those who have gone on before and the Shock of Diagnosis-occur in the past. The Shock of the bill, Changes in our lives and Tale of the Tortilla occur in the present moment, while *Preocupaciones por El futuro* (Worries for the Future) is the future dimension of the disease.

- 1) Those who have gone on before – The Scourge upon the Generations
- 2) The Shock of diagnosis – *Un Gran Susto* and *Coraje*-anger held within
- 3) *El susto del bill que te va a llegar* – The shock of the bill that arrives (The financial burden of Type 2 diabetes)
- 4) *Cambios en Nuestra Vida* (Changes in Our Lives)
- 5) *Ah, La Comida Mexicana* – Tale of the Tortilla
- 6) *Preocupaciones por el futuro* (Worries for the Future)

Those who have gone on before – The Scourge upon the Generations

When they tell their diagnosis story, the *antes y despues* (the before and after), persons living with diabetes begin not with themselves but with family members who have Type 2 diabetes. These persons with diabetes have their personal understanding of their disease inscribed with a historical legacy. These are not stories in response to a question about family history, but rather how persons with diabetes respond to the question; “Tell me about your diabetes, the before you were told you had the disease and the after.”

I have been educated in the biomedical perspective. History taking is a regimented procedure in that you need to ask certain questions and obtain the necessary information from the patient. This information then becomes the foundation of a diagnosis, a label which is given a patient. How different this research experience was for me. How connected were these participants to their larger historical family narratives. I reflect back on those moments in the interview, there was a leaning back and then *pues* or *bueno* and the story began.

Yes, these diagnosis stories for these persons living with Type 2 diabetes are vastly different from my biomedical understanding. Their stories began with either their parents or grandparents. Pedro, a 48 year man living with Type 2 diabetes for the past 4-5 years, begins his diagnosis story with his mother's disease.

Mi madre tiene diabetes. Tiene 14 años, 15 años con la diabetes tipo 2. Sobre de eso yo me he dado cuenta que ella me platicaba que su enfermedad iba avanzando más y más y me decía "mi hijo no comas tanto, mucho para que no engorde, porque eso te va a provocar enfermedad. como yo, la que tengo, la diabetes que es muy peligrosa." Pero pues yo no la tomaba como a mal ni a bien como dijo aquel, si no yo decía "no pues yo me siento bien, me siento fuerte," estaba yo un pocito gordito. En el 2000, en el 2002 me cayo exactamente la diabetes.

My mother has diabetes. She's had Type 2 diabetes for 14 years, 15 years. I haven't forgotten that she used to tell me about this, that her disease was becoming more and more advanced and she said "son, don't eat so much so you don't get fat, because this will bring on the disease- like the one I have, diabetes which is very dangerous." But then I didn't pay attention either way, like she said, I just said "no, I feel well, I feel strong," I was a bit fat. In 2000, in 2000 exactly I got diabetes.

This story illustrates how Pedro connects his own diabetes with his mother's. His mother gave him advice, but he did not heed it for he was healthy. Then Pedro did not see his disease in relation to his own lifestyle, for he was strong and fit when he was

diagnosed. In addition, he does not look to his immediate family for support but rather he looks to his mother for the needed support when in emotional angst over his disease.

Pero si en la verdad a mi me afecto mucho de que pues me cayo la diabetes verdad de sorpresa. Yo se lo platique a mi mama y mi mama me dijo, dice "mi hijo, no es tan grave. Este es lo que esta pensando ahorita pero no te espantes. Trata de comer poco, de llevar tu alimentación adecuadamente y veras que te vas a sanar. Y tu medicina que te la dio el medico, tómatela. Actué ahora y ya no piensas mas en tu avance de tu enfermedad porque tu mismo te vas a, a veces se traumatiza uno."

But in truth when I got diabetes the shock affected me a lot right. I talked about it with my mom and my mom said, she says, "son, it's not so serious. That's what you're thinking right now but don't be scared. Try and eat small amounts, and follow an appropriate diet and you'll see that you'll get better. And the medicine that the doctor gave you, take it. Act now and then don't think any more about the progression of your disease because you yourself are going to... sometimes one gets affected so deeply."

Pedro is reassured by his mother's words since he is not sleeping well, preoccupied with his disease. Lying in bed at night, worrying about whether he will wake up or not or whether he will die in his sleep from his diabetes.

Rocio, a 53 year old, begins her diabetes story with "*Nosotros venimos de una familia tanto*". We come from a family with so much (referring to diabetes).

Bueno, por parte de mi mama, su mama de ella, su papa sus hermanos han sido diabeticos. Por parte de mi papa nada mas mi papa osea que yo vengo de mi papa y mi mama son diabeticos, yo este somos una familia de 13 hermanos, ya murio mi mama, murieron dos hermanos, estamos nada mas yo y otra hermana diabetica en la familia hasta a horita, mi mama nunca se cuidaba mucho, es lo que mi papa siempre nos recomienda, cuidense.

...okay, on my mom's side, her mom, her dad, her brothers have been diabetic. On my dad's side just my dad but for me both my mom and my dad are diabetic. We're a family of 13 kids. My mom already died and two brothers died. Up to now another sister and I are the only diabetics in the family. My mom never took much care of herself. That's what my dad is always telling us-take care of yourself.

Rocio's mother and two brothers have died from diabetes. She and one sister are the only diabetic survivors of her family. Yet Rocio knows her mother did not take care of herself, while her father followed the recommendations and took care of himself and is still alive.

Rocio's two young adult daughters Esmeralda and Beatriz understand their mother's complications of diabetes within the context of their grandmother's disease. They both remember their grandmother lying in bed in the hospital, wasting away.

A veces la pobrecita , parecía un muerto, pálido sin color y todo y entonces también nos ponemos a pensar si mi mama llegara así, a lo mejor no seríamos así tan fuertes.

Sometimes the poor little thing, she looked like a corpse, pale and colorless and everything and then we start to think that if my mom gets like that, we probably wouldn't be that strong.

When their grandmother died, she was blind, most likely due to diabetic retinopathy. When their own mother was sent for a diabetic eye exam by the doctor, they panicked. Had Rocio's (their mother) diabetes, which went undiagnosed for many years, impacted her eye sight? They expressed concern about their mother's potential complications, such as vision loss, kidney disease and skin infections. These two daughter's understanding of their mother's diabetes had been colored by the experience of their grandmother.

Florencia, 58 years old, begins her diabetes story by describing *La Herencia de mis Padres*, her diabetes as being "inherited". Florencia's mother's death from undiagnosed diabetes and cardiovascular conditions at age 78 is vividly described. Florencia was not personally told her mother had diabetes until after her death, causing Florencia to feel guilty she had not done more for her mother while alive.

Florencia described her maternal grandmother as having a stroke event which left her paralyzed. When her grandmother was bed-bound and immobile, Florencia learned her *arbuelita* had diabetes. Florencia feels her mother and grandmother suffered terribly and continues to grieve over these losses. She also recalls how difficult it was for her when both her *madre* and *arbuelita* passed on, literally silenced by the strokes they suffered. Florencia regrets not knowing what they were feeling when they died.

Patricia, who has been living with Type 2 diabetes for 14 years, described her diabetes story as beginning after the birth of her daughter, when she had a caesarian scar which did not heal and sought medical care. Patricia often wonders if diabetes emerged during her pregnancy. She currently has her disease well-controlled and is asymptomatic. Walking up to three times a day, she maintains her blood sugar always lower than 130.

Like Florencia, Patricia is grieving her deceased father. Normally a quiet woman, Patricia sobs as she describes how her *padre* passed away 7 months ago from stroke, a complication of hemodialysis due to diabetes. Now at the end of his life, exhausted by suffering, he was tired and no longer wanted to live. Although her own diabetes is well controlled, Patricia begins to think about herself.

Y pues sin comer ya que, luego me pongo a pensar, digo yo ya despues que tenga yo mas tiempo con diabetes a lo mejor yo tambien a eso voy a llegar, pero lo pienso y luego me levanto, y no lo tengo que pensar.

And when I finish eating, then I start to think. I say to myself later when I've had diabetes for longer I'll probably end up like this as well (referring to her father) but I think about it and then I get up so I don't have to think about it.

Patricia does worry for her own future but she does not want to dwell on it. She gets up and gets busy so she does not have to be preoccupied.

Clearly for these participants, the living memory of family members who had

suffered and died from complications of the disease was difficult and painful and ever-present. Patricia not only experienced the suffering of her father but also her mother and a younger sister who are living with diabetes in Mexico. Patricia worried about her mother and does not believe her sister is controlling her disease. Patricia was especially saddened because her sister is so young.

Due to the burden of having many family members with this disease and in spite of the fact she has worked very hard to control her disease, Patricia believed she would not escape the same fatal outcome as her father. Reviewing her family's experience with diabetes, she could not look to the future with any confidence of a long and healthy life.

34 year old Dominga has been a diabetic for eight years. Only in the last year and a half, since her husband's heart attack has she aggressively treated her diabetes. How she lives with diabetes is really her family's story. She describes living with diabetes as *suffrimiento* (suffering). She experiences no symptoms with her diabetes except a headache when her blood sugar is over 300. She suffers due to the death of many of her family members. Her mother died of complications of diabetes. After her father died of a heart attack, the family learned he was diabetic. During the three to four years she has been in the U.S., Dominga's uncle and three of her brothers have succumbed to either diabetes or cardiovascular events. Burdened by death and loss, Dominga does not want to think much about her diabetes. Only 34, she knows she too will die some day and therefore must enjoy her family now.

Dominga vividly describes her mother's suffering with diabetes.

Mi mama, mi mama ya era una mujer muy bonita y muy llena de vida y era muy gorda. (participant crying) Pero mi mama era como dos veces mía, gorda. Y mi mama, ella era una mujer muy buena gente y a base de tantos problemas y descuidos de ella y de nosotros como sus hijos porque

yo no cuide a mi madre como debí cuidarla, mi mama ella murió un huesito. Y mi madre cuando la podían traer de la casa a la cruz roja, ella gritaba mucho porque decía que sus huesos se le quebraban. Que ella la lastimaban mucho. Y ella estuvo como 2 días en el hospital y fue cuando murió. Pero mi madre era una persona muy, muy, muy fuerte. En muy poco tiempo mi madre se acabo. En menos de... que será... 2 años, mi madre ya no era nada.

My mom, my mom was a very beautiful woman, very beautiful and very full of life, also very fat. [Participant crying] my mom was like twice as fat as me. And my mom, she was a really good woman, and because of so many problems and not having the proper care, and from us as her children, because I didn't take care of her like I should have, my mom was like a stick when she died. And when they were able to take her from the house to the red cross she cried a lot because she said that her bones were breaking, that they were hurting her a lot. And she was in the hospital about 2 days then she died. But my mother was a very, very, very strong person. She wasted away in a very short time. In less than...what would it be...2 years, there was nothing left of my mother.

Dominga expresses both sadness and remorse in remembering her mother. In looking backward she wishes she had done more for her mother.

Cristina, a 54 year old English speaking woman born in Texas, described diabetes as a scourge upon her family. Cristina described diabetes as a disease which just goes right down the line. Her grandmother, a double amputee in Mexico, died secondary to complications of diabetes. Cristina's mother had diabetes for 35 years and has had two open heart surgeries. Her mother currently has inoperable heart disease and is living on *borrowed time*. Cristina's daughter had gestational diabetes, and now has borderline diabetes.

Cristina describes initially being in denial of her diabetes and then the time came when her mother had two open heart surgeries. Her mother almost died following a second open heart surgery. Cristina began to have better control of her disease as a result

of seeing what was happening to her mother and grandmother and began to watch her diet and exercise.

*She is a mirror of what I am going to be when I get older a daily reminder.
So.... That was one of the things that made me take a better look at myself.*

Cristina went every summer to visit her grandmother in Mexico and watched her grandmother slowly deteriorate. Experiencing first hand the life of a double amputee confined to a wheelchair, Cristina was at Grandma's bedside the summer she died. In her words: "*So I know what diabetes does to a patient. I know exactly how bad it is.*"

Adolescent children often did not look backwards at their grandparents, aunts and uncles experience of diabetes. They glanced briefly in the past to acknowledge their own personal risk of diabetes and then worried for their future as they themselves would be diabetic someday. For example, Teresa and Adriana, two teenagers who know that both sets of grandparents have diabetes and their mother Elvia has diabetes, worry about themselves becoming diabetic. Can you prevent this, they both ask? AltaGracia, the 21 year old daughter of Berta, asks the same question, but she is reassured that her father Enrique has the family on a strict, no sugar diet.

In summary, for these persons living with diabetes, a family understanding is much more than the immediate family, it is a multigenerational understanding. Family experience extends backward to tell the stories of parents and grandparents, and the stories are not stories of hope but rather of suffering. But this suffering still occurs today for these Mexican-Americans living with diabetes. Listening to these stories, the suffering was palpable, the emotion painfully authentic as these men and women recalled their family members who had passed on. The strong genetic predisposition for Type 2

diabetes cited in the literature translates into a powerful emotional burden for Mexican-Americans living with the disease.

Yes, from my perspective, I can no longer ignore those who have gone before. I am a product of my culture and society and therefore focus on my patients as individuals with a family history. From my perspective, the family history was a piece of medical data to be put in a chart. For these Mexican-Americans with diabetes, the family history is the memory of past generations who suffered with the same disease they now bear. I need to remember that family history is not disconnected from the daily reality of Type 2 diabetes.

The Shock of diagnosis-Un Gran Susto and Coraje-anger held within

For the immigrant participants in this study there are unique emotional expressions of their own diagnosis, beyond the experience of those who have gone on before. These emotional expressions are vastly different than health care providers' understanding of diabetes. The development of Type 2 diabetes, as conceptualized by health care providers, occurs over time and often no symptoms are present, or the patient presents with symptoms very specific to a high blood sugar. Yet, the immigrant participants and their families tell of an event, a *susto*, a great shock and profound emotion, which leads to the development of diabetes. It is a moment in time, before this event they were healthy, afterward they had a great illness. In addition, the *susto* events of parents and relatives are described. I believe shock, a strong emotion, leads to the overall sense of turmoil and anguish with a diabetes diagnosis for these immigrant families.

Carlos, 43 years old, tells of the onset of his diabetes 9 months ago with a *susto* event. He went to Mexico to visit family for Christmas and upon returning to the U.S.

Hasta donde yo se, lo poco es que hice un viaje a México y de regreso tuve un susto en el avión, en el avión entramos a territorio americano y en Dallas o Texas hubo mucha turbulencia, muchas bolsas de aire y eso provoco que el avión se moviera de cierta manera, y ahí fue donde yo me espante mucho, entonces, paso esto a la vuelta de un mes yo me sentía mareado, me sentía cansado, me sentía sin fuerzas y tome la decisión de ir con el doctor para decirle que me esta pasando, que me esta pasando porque yo no me siento así, el me dijo o.k. Vamos a checarte esto y esto.

As far as I understand it, to cut it short, I took a trip to Mexico and on the way back I got scared in the airplane. We were on the plane coming in to America and in Dallas or Texas there was a lot of turbulence, a lot of air pockets that made the plane move in a certain way, and that's where I got very frightened. So a month later what happened was that I felt dizzy, I felt tired, I had no energy and I decided to go to the doctor to tell him what was happening, what was happening to me because I didn't usually feel like that. He said okay, we're going to check all that out.

Carlos equates his symptoms to the shock he experienced during air travel. His symptoms made him seek medical care and be diagnosed with diabetes.

Florencia experiences many *susto* events leading to her diabetes diagnosis.

Como tuve sustos. Tuve cuantas cosas. Nos asaltaron a mi hija y yo que hemos salido del mercado. Nos asustaron y yo sentí que me asuste bastante. Y varias veces tuve varios sustos así que también nos iban a robar. Nos pusieron una pistola. Aquí me pusieron una y yo sentí que a de momento no me asuste, no me quede impresionado pero después como, al como, eso fue a las 3 de la tarde, como a las 6 de la tarde ya empecé a sentir como miedo. Después ya de todo que me habían amenazado. Y ya quede, como que empecé a sentir mucha, mucha sed, ganas de ir al baño. Iba al baño hasta me sorprendía, casi como cada 3 horas.

Like I had *sustos* (shocks). I had so many things. They attacked my daughter and me when we came out of the market. They scared us and I felt very scared. And several times I had various scares like then when they were going to rob us. They held a gun on us. They put one here and right then I wasn't scared I wasn't upset but afterward like, like this was at 3 in the afternoon like at 6 in the evening then I began to feel afraid. Then after everything they had threatened me with. And then there I was, like I

started to get really, really thirsty, wanting to go to the bathroom. I was going to the bathroom almost every 3 hours; it even caught me by surprise.

In her story, there are multiple *susto* events since she was a victim of more than one violent attack in Mexico. She describes being frightened and feeling threatened by the muggings. It is unclear from her story if one event or the combination of many events led to her diabetes. Yet, very powerful emotions are expressed prior to the onset of diabetes. For these participants, the strong emotion of *susto* sets the stage for the chronic disease experience of Type 2 diabetes.

Pedro, animated, relays the events of an auto accident which brought on his diabetes. He was going fishing with his wife and 2 other people, then the car stalled and it went over a barbed wire fence and hit a house. The young girl driving got shook up and banged up, and she was crying and yelling, yet Pedro felt no fear. Since he did not express fear, he suffered a *susto*, a great shock he could not feel. Around 4 days later, he began to urinate very frequently.

Pedro then relays with great detail his symptoms, recalling what his mother had told him in the past.

Y mi mamá me lo había platicado, unos tiempos atrás también, y yo nunca le creía pues, yo nunca le creía que la orina se pusiera dulce como miel. Y yo salía muy seguido. Ya llevaba una semana, 2 semanas y mi boca muy seca, amarga. Me levantaba yo en la mañana, mi boca amarga y seca y para eso de que cuando tiene uno la azúcar alta, la diabetes alta, ya a una posición de 300 a 400 ya te ataca el cuerpo. Cuando esta uno un poco gordo, que sea harto de manteca, te ataca mas y o en México que hay calor te ataca a una fatiga, un calor, pero un calor caliente que te quema, te quema la piel, te quema el cuerpo; y la cabeza la siente caliente, caliente que parece que tiene uno abrasa, que te metes al baño y quisiera estarte debajo del agua porque lo siente bueno, sabroso, fresco pues. Pero estar en el agua también es mucho, muy mal y malo porque agarra frialdad. Y de eso y a me, yo me bañaba.. En México yo me bañaba 3 veces al día o a veces a media noche me tenía que parar a bañarme para que yo fuera a descansar un poco, porque el calor me mataba. Y a veces que allí voy bajando de peso; pues estaba yo como unas 250, 60 libras y

estaba yo bien gordito. Ahorita ya me ha venido acabando el azúcar, la diabetes y estoy delgado ya. Ahorita me acabo de pesar, peso 166 libras.

And my mother had told me about it some time ago also and I never believed her then; I never believed that urine would turn as sweet as honey. And I was going very often. It was already a week, 2 weeks, and my mouth was dry, with a bitter taste. I got up in the morning, my mouth bitter and dry and this was because when you have high sugar, severe diabetes, already at a level of 300 to 400 then it attacks your body. When you're a bit fat, or with too much lard, it attacks you worse, or in Mexico where it's hot the fatigue gets to you, the heat, but a fiery heat which burns you, it burns your skin, it burns your body; and your head feels hot, hot like it's on fire, and you get in the bath and you'd like to be underwater because it feels good, delicious, fresh you see. But being in the water is also very bad, bad because you catch cold. And so I used to bathe...in Mexico I used to bathe 3 times a day or sometimes I had to get up to bathe in the middle of the night so I could get some sleep, because the heat was killing me. And sometime there I start losing weight; you see I was like 250, 60 pounds and I was quite fat. Now that the sugar, the diabetes has taken its toll on me I am thin. Now I just weighed myself, I weigh 166 pounds.

The language used to describe Pedro's symptoms is very rich. He describes the dry mouth as with bitterness, and how diabetes attacks your body, causing an incredible heat and burns away your extra calories. The diabetes causes you to want to bathe, because of the heat, but Pedro worries that he will catch cold. This is vivid imagery describing the symptoms of hyperglycemia. According to his understanding, a powerful emotion, a shock not felt (*susto*), led to these significant symptoms vividly described.

For Rocio, a participant living with diabetes, her mother and father became diabetic due to a powerful *susto*. In 1975, her brother was killed in a car accident. At that point, her mother began to lose weight. In 1993, another sister suffered injuries in an accident with a motorcycle. Her father developed diabetes at that point. Both of these accidents as described were a heavy burden to bear for her parents.

Rocio's diagnosis story, although not related to *susto*, has much sadness and suffering.

Yo empecé precisamente hace cuatro años que , ya me habían dicho que yo necesitaba esa operación , por adherencias en el estomago, tenía muchos problemas digestivos pues , todo me caía mal, comía y todo me hacia mal, ya me había dicho el doctor que tenía que hacerme esa operación, pero para eso yo ya empezaba a ver nublado y a marearme mucho, tome mucha agua, un día por no dejar dije, voy a hacerme el análisis, no vaya a ser que tenga la diabetes, y como mi mama se quedaba conmigo, iba al baño, y ya fui y y traía la azúcar a 325, le lleve los resultados al doctor y me dijo que no era nuevo, me dijo que no es de horita ya tu azúcar ya tiene tiempo, como unos 3 años atrás ya la tenía y no me daba cuenta. Pero cuando me operaron yo la traía a 218 y el doctor dijo que no había problema, ósea fue una negligencia lo que a mi me paso, porque me hicieron , como 4 veces me metieron a quirófano porque le digo, no me cerraba, una vez fui a bañarme, se me cayo el jabón y me agache y voy viendo toda la sangre y se abrió otra vez, me ponían las gasas y me la sacaban llenas de pus, y olía feo, horrible como un animal muerto, y dicen que fue porque no me controlaron el azúcar, sufrí mucho.

I started exactly four years ago when... they'd already told me I needed this operation, for adhesions in the stomach; you see I had a lot of digestive problems, nothing agreed with me and the doctor had already told me that I had to have this operation but I was already starting to have blurred vision and to get dizzy a lot; I drank a lot of water. One day so as not to let it go on I said I'm going to get the check, let's hope it's not diabetes. And like my mom was staying with me, I kept going to the bathroom and when I went in I had a sugar of 325. I took the result to the doctor and he told me that it was nothing new. He said that it didn't just start. You've had sugar like this for some time. Like I'd had sugar like that for perhaps 3 years and I hadn't realized. But when they operated on me I had it at 218 and the doctor said that there was no problem. This might have been negligence because of what happened to me. They took me to the operating room like 4 times because like I say, it didn't close. One time I went to bathe, the soap fell and I bent down and then I'm seeing all this blood and it opened again. They used to put gauzes on and they took them off full of pus and it smelt terrible, horrible like a dead animal. They say it was because they didn't keep my sugar under control. I suffered a lot.

Rocio's diagnosis story is based in powerful emotions, surprise at being diabetic, the shock of an ugly, foul smelling infection and the personal suffering of a disease that runs rampant and is difficult to control. Rocio's story demonstrates the devastating

consequences when Type 2 diabetes is not recognized and managed by health care providers and the person with diabetes does not have good control of their blood sugars.

Lino was diagnosed in 1997 with Type 2 diabetes. At the time of his interview 8 years later, his *susto* event, a farm accident, is described with amazing clarity.

Mira a mi se me detecto diabetes en '97. Si porque aquí fue un accidente. Andamos trabajando y una persona que traía la maquina, que anda levantando, tuvo un accidente. Entonces yo andaba aquí por esta camino por allá la maquina. Y yo oía con el ruido de la maquina yo escuche unos gritos muy fuertes, luego este viejo no que esta malo. Pero no cuando yo fui a la maquina mire el señor que estaba aquí en la puerta y bajo. Pero fue que se, esta mano. Se la corto la maquina. Se la agarro el gusano que hala el arroz para atrás de la front de la trailer. Entonces yo me arrime, yo pienso que de allí por acá fue que cuando se me, no se, esa es la confusión que llevamos. Fue donde se me declaro. Pues yo me impresione mucho, me arrime y yo mire pues la mano siempre ciertos movimientos y yo me impresione. O sea no me asuste así de decir pero si me impresiono bastante. Entonces al poco tiempo fuimos y ya me dijeron allí que si me la autorizara yo que me hiciera el test de la diabetes.

Look it was discovered that I had diabetes in '97. Yes because there was an accident here. We were working and the person who was driving the machine, the one that picks up, had an accident. So I was going here this way and the machine was over there. And above the noise of the machine I heard real loud shouts, then oh no that old guy is bad. But no, when I went to the machine I saw the guy he was here in the door and he got down. But it was that hand. The machine cut it off. It had caught in the 'worm' that pulls in the rice behind the front of the trailer. So I was close to it. I think that from then on was when I, I don't know, this is what we don't know. It was when it was discovered. You see it left a great impression. I was up close and so I saw the hand and it was still moving and it gave me a shock. Let's say I didn't really get what you'd say scared but yes it made really shocked me. Then soon after we went in and there they asked me if I'd consent to a diabetes test.

In Lino's telling of his *susto* event, he speaks very clearly of the farm accident but does not recall any symptoms of diabetes. Interestingly, he goes to the clinic and is offered a diabetes test, yet it is not clear to the reader why he was offered the test. From Lino's perspective, the precise symptoms are not as important in the telling of the event

as the dramatic loss of a hand by a farm machine. Lino's *susto* story is an example of how narrative is not based in historical accuracy but in the remembering of an event. For Lino, a long time farmworker, the loss of a hand deeply impacted him.

Lino's wife Juanita experienced her own *susto* event, a car accident, 2-3 years later. A short while before the accident, she went to the clinic and her blood sugar was 100, a normal level. Two weeks after the accident, she went to the emergency room with chest pain. At that time she was told she was a diabetic. For her the shock of the accident led both to the development of chest pain and diabetes. In her *susto* story, as well, no symptoms of diabetes were recalled.

Coraje-an anger held within.

In addition, another powerful emotion-*coraje*-was expressed by the immigrant families in this research study. *Coraje*, an anger turned inward and a rage not expressed, leads to the development of many illnesses including diabetes. *Coraje* is caused by an injustice or wrongdoing, either personal, social or political. For some Mexican-Americans, *coraje* is the causal agent of many illnesses and diseases including diabetes.

Florencia, living with diabetes, hypertension, hyperlipidemia and other cardiovascular diseases describes the *corajes* of both her mother and herself.

Empezó no más de un momento a otro porque hizo coraje mi mama. Y de eso se enfermó ella. Pero ya tenía 78 años. Falleció a los 78 años.

It started from one moment to the next because my mom became angry (*coraje*). And this made her ill. But she was already 78. She died at 78 years old.

Florencia herself became ill with *corajes*

Y de allí empezó ella o sea que, que de allí yo pues, será que de eso también hacer corajes y todo lo que también estuve yo pasando; problemas graves porque mi esposo también, nos dejamos, nos divorciamos y todo. Bueno no precisamente no nos hemos divorciados si

no nos separamos y allí empecé yo y luego mi, el fallecimiento de mi mamá y bueno pues todo y se me junto y no mas de repente también empecé yo mala.

And she started like that. Well I might do the same if getting angry (*coraje*) has to do with it, what with everything that I was going through as well; serious problems because my husband left us also; we divorced and everything. Okay we haven't actually divorced just separated and since then I started, and then the death of my mom and well everything happened at once and then suddenly I became ill as well.

Coraje similar to her mother's led to Florencia's development of multiple chronic illnesses. In her home town in rural Mexico, Florencia suffered stigma and felt intense rage from being an unattached woman and abandoned with all her children. Since divorce was not a possibility for her, she lost all economic support from her common-law husband. Florencia believes that in addition to the grief of losing her mother, she suffered *coraje* due to the loss of her husband. It was the beginning of Florencia's health problems.

The Families experience of Susto and Coraje.

Even though diagnosis stories are usually constructed by the person living with the disease, they can also be part of family members' ways of understanding an experience.

Pedro's *susto* event holds a prominent place in his family's tale of diabetes. Pedro's wife Luz, who was in the car at the time of the accident, did not experience a *susto* event. In her understanding of *susto*, it was because she did not have a mother with diabetes as Pedro did. She believed *susto* could only occur within the context of a family history, there needs to be a person in the family with the disease. In her understanding of the onset of diabetes, Luz weaves both the genetic risk as well as the *susto*, the emotional shock, combining both of these factors to explain the onset of symptoms.

Pedro's two adult children express their father's *susto* event as part of their own story, living with a dad with diabetes. Gabriela recalls when she was a teenager, she came home from work and no one was home. She panicked. A neighbor relayed that her mother and father were in an auto accident and ran into a house. Although relieved that no one was hurt, Gabriela did not realize until later that her father had symptoms of diabetes and would become ill. Her understanding of her father's diabetes begins from the moment of this great shock.

Pedro's alcoholism is a large part of Gabriela and Miguel's story of a dad with diabetes. Gabriela and her brother Miguel, while their parents were away during the interview, spoke dramatically of living with an alcoholic father and the many difficulties they experienced as children. In addition, they both had difficulty accepting their father's diabetes, not believing he was really sick. Gabriela expressed appreciation at being able to share their stories. She felt that she was filled with *corajes* at remembering all the abuse she experienced as a small child. Gabriela would come home from work and walk away from her father because he was not helping out. Not knowing what to do with all the *corajes* built up inside, both she and her brother struggle with nurturing hate and the need to unburden themselves. Gabriela believes if you do not unburden yourself, these *corajes* can lead to many great illnesses, including diabetes.

In the context of family violence, *susto* and *coraje* are expressed. Rocio's daughters express openly the violence their mother experienced at the hands of their father. Esmeralda and Beatriz shared their family secret of family violence with us. For me, as well as Alfonso, this was a powerful experience. During the interview, both of these two adult daughters expressed great frustration that their mother was returning to

Mexico for a 2 month visit and would be in contact with their father. She was calmer here and her diabetes was doing better. Both Esmeralda and Beatriz worry because their mom's emotional life in Mexico is not stable, her blood sugars will climb and she will not do well. Beatriz believes her mother's diabetes came about from the *sustos* and *corajes* her mother experienced from her father's violence.

Mira de versa. Mi mama yo digo que eso fue su diabetes los corajes, los sustos que pasaba.

Look at it this way. My mom... I say that this (referring to the violence) caused her diabetes los corajes, los sustos that happened

In summary, diagnosis events, either *susto* or *coraje*, occurs in the more recent past, a memory easily recalled in vivid detail. *Susto* and *coraje* are often viewed as a culturally bound syndrome, explanatory models of disease or part of a folk health belief system, which stands in stark contrast to the dominant biomedical belief system. However, I believe the understanding of *susto* and *coraje* is more than a cultural label. These strong emotional responses, believed to bring on illness, are the foundation upon which the diabetes experience lies for these families. This foundation is one of profound emotions, shock and rage. Due to these intense emotions, diabetes for these immigrant families is a powerful emotion-filled experience.

Likewise, these *susto* and *coraje* accounts engross readers. The stories are conveyed with an intensity not lost in translation. One colleague expressed her thoughts by saying-“these stories are kind of stupid, that someone would believe a little scare would cause diabetes when they probably had it all along.” Another colleague expresses sadness that for the second generation families, these *susto* and *coraje* accounts were not part of their story. She believed they had lost part of their culture. For me personally, it is

difficult to make sense of stories of *susto* and *coraje*. It is easy to exoticize them, to find these stories interesting and even quaint. From my perspective, these stories signify what we have lost or is missing in our society and culture. For health care providers and patients alike, there is a mind-body-emotion disconnect. The connection is needed between mind, body, emotion and soul. I think we, the dominant Euro-American culture, lose because we no longer connect stories of powerful emotions to our chronic disease experience.

El Susto del Bill que te va a llegar (the shock of the bill that arrives) – the Financial Burden of Diabetes

Shock was also the emotion experienced in telling of the financial burden of chronic disease for these Mexican-American families. The shock of the bill is the day to day burden of the diabetes experience. Participants relayed having either no access to health insurance or experiencing difficulty paying for supplies even when they did have health insurance. Other participants spoke of the hardship in Mexico. Here, there are programs for farmworkers and their families which lower the cost of medication and supplies, but in Mexico one must pay full price on the spot for medications and physician visits, or you do without.

Dominga, a 34 year old woman, speaks of the economic burden of her husband's heart attack. Her 32 year old husband experienced a heart attack last year and was hospitalized for 3-4 days. Subsequently, the family was sent to collections and suffered financial devastation. According to Dominga, "Everyone want their money from radiologists to anesthesiologists, bill after bill, it never ends".

Entonces precisamente apenas hace poco que salí de una colección. Me estuvieron quitando de mi trabajo. Si, entonces de mi cheque, de mi trabajo me quitaban a me dinero. Se no lo podemos evitar. Entonces

nosotros estamos viviendo aquí solos. Nosotros tenemos que pagar la renta solos. Billes. Todo. Gasolina del carro. Y realmente pues con lo que el gana y con lo que yo gano apenas y luego no se alcanza. Lo que ganamos por ejemplo son casi \$600 de renta. Allí se va lo de un cheque de el. Y pagamos aquí, pagamos allá, pagamos luz, pagamos teléfono, pagamos carro, pagamos todo y que comemos? Y yo se realmente si fue, es muy duro. En ese aspecto si es muy duro para nosotros. Y es muy duro. A veces queremos ya tirar la toalla mejor.

So it's just a short while ago that I finished with collections. They were taking it from my work. Yes, so they were taking money from my check, from my work. We can't avoid it. We are living alone here. We have to pay the rent by ourselves. Bills. Everything. Gas and the car. And really we just scrape by with what he makes and what I make and then it's not enough. For example out of what we make almost \$600 goes on rent. There goes one of his paychecks. And we pay here, we pay there, we pay electricity, we pay the telephone, we pay for the car, we pay everything and then what do we eat? I know that it's been, it is really hard. In this respect yes it's very difficult for us. And it's very hard. Sometimes, maybe it would be better, we just throw in the towel.

Dominga describes why the economic burden is so difficult. When the family went to collections, almost all of her check went to her husband's medical bills and then they had to live on his check alone. "How can we live with so little money? Sure I have many expenses with my diabetes, but the clinic helps out with various programs and I can always pay on the bill" states Dominga. From her perspective, the cost of her diabetes pales in comparison with the cost of her husband's hospitalization. "This financial burden makes life so hard" she sighs.

Personally, the financial burden imposed by the institution I am affiliated with is troubling. Dominga brought up being sent to collections upon signing consents for this study and seeing my ID badge. She then elaborated the painful details in telling her life with diabetes. For me, there is a large disconnect between the research emphasis presented to me as a student-reducing health disparities and addressing the needs of underserved populations-and the fiscal policies of large medical institutions. These

policies create a real disparity by sending undocumented Mexican-Americans to collections and potential financial ruin.

Dominga's husband, Ignacio, also experiences a great financial burden. Family members experience economic stress related to diabetes and other chronic illnesses. Ignacio describes the devastating financial blow his heart attack and subsequent hospitalization dealt his family. First of all the hospital bill was \$ 80,000 to 100,000 dollars. Then, while he was recuperating at home, they almost were evicted and had to go to court.

Tuvimos muchos problemas no más por esa situación. Lo pasamos muy difícil entonces por eso digo que fue una, ha sido una experiencia muy fuerte para nosotros entonces si, si hubo gran impacto en nuestra economía y nuestra forma; porque pues yo creo que todo el mundo sabe que casi la mayoría de los hispanos o latinos ganamos el mínimo, ganamos muy poco entonces no mas de eso se da una idea que impacto pudo haber causado a nosotros pagando renta, billes y esto fue muy difícil.

We had a lot of problems just because of this situation. We went through a very difficult time so it's because of this I say that it was, it has been a very hard experience for us, so yes, yes there was a big impact on our economy and our life; because well I think the whole world knows that the majority of Hispanics or Latinos make the minimum wage, we make very little so with this alone you get an idea of the effect it might have had on our paying the rent, the bills and that was very difficult.

Ignacio speaks most eloquently of the personal struggle with medical bills. He adds that doctors and nurses need to understand that Latinos always make minimum wage and they will always struggle with bills, and to add a large hospital bill is a terrible burden that is hard to bear.

While his wife Dominga is burdened with her diabetes as well as the stress of the family's financial situation, Ignacio views life more positively. He believes they as a family need to rise above the financial strain and need to look to the future. While his

wife is burdened by bills and her illness, he feels as a new Christian he needs to look to the future. He also continues to hold onto immigrant optimism that things will be better here and his family can *salir adelante*, move on, and improve themselves.

Forced choices.

Other participants experience the financial shock and burden through having to make forced choices. Berta, living with diabetes for the past seven years and residing in the United States for the past 11 years, often struggles to pay for physician visits and supplies. For Berta, diabetes cost is a big problem in the winter when her husband, an agricultural worker, is often laid off. Oftentimes she does not go to the doctor if the bills are too much.

Elvia, who was born in the United States, has been a diabetic for the past 8-9 years. Currently employed with a public agency and having health insurance, Elvia still experiences the financial strain of diabetes. Her financial difficulties are due to her husband being a straight commission salesman whose income can go up or down. At times, according to Elvia, she is unable to buy her diabetes supplies or certain medications.

Ernesto, husband to Elvia, describes *yo me siento barbaro*, “I feel cruel about not always having enough money”. He feels partially responsible for his wife’s lack of control of her diabetes. The financial struggle is apparent as this husband tries to provide for his family. He works in a sales position where his income is not consistent. They cannot always afford his wife’s medication or blood glucose strips. Ernesto feels this could be holding his wife back in her diabetes management. Yet at the same time he feels she stops taking the medication even though she has an adequate supply. Clearly she is

ambivalent about taking the medication, yet the story is told from her husband's perspective. Elvia's ambivalence may be due to financial constraints, trying to make the medication stretch or her ambivalence about being diabetic.

Cristina, as well, has private health insurance through her employer. She struggles this year since the co-pay for her medication on her insurance has gone up. Her physician put her on a medication which cost her \$50 a month. She normally spends around \$100 a month for medication and diabetic supplies. She couldn't afford an additional \$50 a month. She spoke with her provider, telling him she simply could not afford the new medication. It was too much. He was willing to take her off the medication and put her on a medication with a much smaller co-pay.

Roberto is the only breadwinner in his family. His mother, Florencia, lives with him and his American wife, Debbie. He speaks of his trouble paying the bills, and meeting his wife and kids' dietary needs as well as his mother's. He expresses his frustration.

Por lo mismo de, por la diferencia de lo consume ella con lo que consumimos nosotros. Como que nos tenemos que comprar usted sabe, poco separado uno comprando cosas para ella, sana, sin sal, poco que el dinero que tenemos. Porque hay veces como hay veces que no tenemos como pues ahorita pues no más yo trabajo. Y lo que yo pago pues lo que yo gano pues lo uso en pagar los biles, la renta, otra parte para comprar comida. Si a veces que no me alcanza y tengo que compartirlo porque a veces nos queremos por ejemplo... bueno no exactamente yo, por los niños o ella quieren algo como decir quieren una hamburguesa o algo y pues yo tengo que compartir el poco dinero que tengo y no pues ahora si va a agarrar tu una hamburguesa cómprala pero tienes que comprar unas ensaladas, algo que puede comer mi mama, para ella, para cosas que usted sabe, equilibrando el balance y todo eso en la comida. Y si hay veces que si no nos alcanza, pues ella tiene que comer pocito no mucho porque por el que tenemos pero hay veces que no tenemos como para comidas especiales que debe comer ella. Pero pues días contados. Que hace siempre casi por lo regular compramos para la comidita.

The same thing, because of the difference between what she eats and what we eat. Like you know we have to buy separately, you're buying things for her, healthy things without salt, and we only have a little money. Because sometimes, like there are times that we don't have it, like right now I'm the only one working. And what I pay, well what I earn I use to pay the bills, the rent, another part to buy food. Sure at times I don't have enough and I have to split it up because sometimes we want for example...okay not really me... for the children or her... they want something, let's say a hamburger or something, and then I have to split the little bit of money I have and say well now if you're going to grab a hamburger buy it but you have to buy some salad, something that my mom can eat, something for her;' you know, keeping a balance and all that in the food. And yes there are times that we don't have enough so she has to eat a little bit, not much, of what we have, so sometimes we can't afford the special foods that she needs to eat. But it's not often. Almost always we normally buy some food for her.

For Roberto, different than other families, the financial struggle is meeting the costs of a healthy diabetic diet for his mother and being able to provide the foods his wife and kids like. He expresses the difficulties of being a low wage breadwinner.

These participants were forced to choose between taking medication or not taking it because of costs. They often had to take less expensive medication. At times, participants were unable to keep their regular medical appointments due to costs. For Roberto, it was a choice between making his wife happy and ensuring his mother followed her diet.

Mexico vs. U.S.

Dominga tells of her mother's life with diabetes, describing the poverty in Mexico as a disgrace. In Mexico, a person with diabetes such as her mother does not have the real possibility of taking care of oneself. The cost of medication is one's weekly salary, approx. \$30-40 dollars. Regular medical care is also difficult to obtain due to the cost. For Dominga, the suffering is not just personal, limited only to her family, but to the county of Mexico as a whole.

Allá en México es muy difícil de decir aye no voy a trabajar porque tengo que ir al medico. No se puede. La situación en México es muy dura, es muy difícil. Hay mucha pobreza y si no lo hacemos todo por dinero no hacemos nada. Entonces ahorita realmente yo en México nunca me cuide

There in Mexico it's very difficult to say 'oh I'm not going to work because I have to go to the doctor.' You can't do that. The situation in Mexico is very hard, it's very difficult. There's a lot of poverty and unless we're doing it for money we don't do it. So in Mexico I never really took care of myself

Dominga had a 9th grade education and was employed as a policewoman in Mexico. Yet while in Mexico she did not manage her diabetes due to the costs of medication and supplies, indicating that the financial burden of diabetes is great in Mexico even for those who are gainfully employed.

For another participant, Pedro, the cost of his medication in Mexico could be approximately \$50-80 more per month. In the U.S., special programs help farmworkers such as Pedro with his medication costs. In Mexico, patients pay at the time of service, leaving no possibility to pay on a bill. Even though his diabetes medication and supplies take a large piece of the family budget, based on what he makes here, it is a smaller percentage of his income than in Mexico. Yet there are many things which cost so much more here than in Mexico.

Gabriela, a 21 year old daughter of Pedro, lives at home. She works hard in a restaurant and also goes to school to earn a GED. Gabriela describes her family's financial plight as there is never enough. There are bills, lights, electric and food that have to be paid, and diabetes medication and special food are just one more thing to pay for on top of all those bills.

In Mexico, the cost of diabetes medication was high. Gabriela's father took all the money he earned and it went to medication and diabetes treatment. Conflict ensued

between him and his wife over the money he used to buy medication. Gabriela felt the family was blind to the fact that their Dad was really ill and needed the medications. Fights were commonplace in her family. “It is just so hard to live in Mexico” is how she ends her story.

Edgar, as well, describes *aqui no es como en mexico, aqui le dan oportunidad de pagar poco a poco y en mexico no, en mexico si va al medico y no tienen dinero no la atienden*. “Here it’s not like in Mexico. Here they let you make payments and in Mexico they don’t. In Mexico if you go to the doctor and you don’t have money they don’t see you.” He recently had gall bladder surgery and is making payments. Although the bills are high, in Mexico there would be no surgery for him and he would have suffered because he could not pay.

While many of these stories are of financial difficulty and families suffering and not having enough, Patricia’s family’s story is different. It is a story of a family’s financial support; how grown children help their parents.

Patricia stays home and cares for the grandchildren so her children can work, and her husband works at an automotive detail department, making a little above minimum wage. Her daughter, son and daughter in law believe Patricia is a model for other diabetics as well as for her whole family; all three stated there is something you need to know. We are *somos unidos* “ a united family.” *Mi papa el solo mantiene la casa, aca nosotros trabajamos la pareja es diferente entra un poco de dinero mas extra*. “My dad supports the household by himself. Here both work, it’s different, there’s a little extra money coming in. The children stated we know how hard Patricia works to control her diabetes.” *ella nunca nos quiere preocupar , ella nos ha dado mas que lo que le podemos*

dar, lo que le debemos a ella es mucho por que nos ha dado She never wants to worry us; she has given us more than we can repay her. We owe her a lot because she has given us so much. We will do what it takes to help her. Often in families there is much conflict and emotional turmoil. Yet for Patricia's family, there is financial support for her in managing the costs of her diabetes, especially since her husband is in a low wage job.

In summary, the families in this study experience economic burdens. As participants looked backward to Mexico, the financial difficulties of having a chronic disease in a third world country were evident. The pervasiveness of poverty was present in their stories. Many expressed gratitude for the assistance of the migrant/community health center in lowering costs of medical visits and medication, helping them with diabetes management. In addition, some family members were able to articulate the desire to provide financial support to help their family members manage this often costly disease, though this was not always possible.

Many families were able to understand the larger context in which their poverty occurred. Ignacio and his family, for example, understood their stance in American society as being on the bottom rung, the workers who only make the minimum. Even though they had escaped the grinding poverty of Mexico, they felt it would be difficult to rise above their economic place as low wage workers and improve their lives and the lives of their children here in the U.S.

Lack of financial resources brought a wealth of emotions, frustration, guilt and overall sadness. For these families, the economic burdens of diabetes and other chronic diseases placed an even heavier burden upon them, making diabetes a more difficult disease to manage and control. For me personally, it is difficult to see this level of

poverty in a country of so much wealth. For these families, there are many burdens—being an immigrant, a foreigner, poverty and the burden of chronic illness such as diabetes. These stories of burden are difficult to hear.

Ah, La Comida Mexicana-Tale of the Tortilla

The tortilla was the food staple for the Aztec civilization and it has evolved today to be the basis of Mexican cooking, often eaten with every meal, day in and day out. For Mexican persons with diabetes, often it is a daily struggle to limit how many tortillas one eats. Many of the participants love to cook and eat Mexican food, especially tortillas, as it is a part of their identity and culture. In telling these tales of the tortilla, some women move their hands as if making or preparing the tortillas, as if it was a part of their being.

Fond of tortillas, Patricia realizes the difficulty in balancing her love of Mexican food and maintaining good control of her diabetes. She recalls in Mexico making tortillas by hand and eating them with a little salt and piping hot. While talking she sprinkles salt and moves very hot tortillas with her hands as she remembers her own homemade tortillas.

When she was first diagnosed with diabetes, she struggled with hunger as her children ate tortillas and she only has a salad of *nopales* (prickly pear cactus).

Pues hacia yo lo comida para mis hijos y eso si me sentía como desesperada porque yo quería comer, yo quería comer y lo que hacia es que comía ensalada de nopales .eso si me servia hasta comía y comía y con eso. O las tortillas bien doradas, bien doradas así me mataba poquito porque mucho hambre, ya después poco a poquito se fue quitando todo esto o que ya les hacia enchiladas.

Well I used to cook for my kids and it like drove me crazy because I wanted to eat. I wanted to eat and what I did eat was prickly pear salad. I fixed this and ate it and ate it and that had to do. Oh nicely browned tortillas, well browned I was dying for them because I was very hungry. Then afterwards all that gradually went away and then I made them enchiladas.

Patricia recalls nicely browned tortillas and she was tempted. She would then make enchiladas, cover the tortillas with sauce and those feelings then went away. Clearly for Patricia, following a diabetic diet was a deprivation, deprived of the foods she loved as well as being hungry, and eating a salad when she needed something more substantial.

Yo nunca hice tamales porque nunca supe hacerlo, mi mama como yo vivía cerca de mi mama, a una cuadra, mi mama seguido hacia los ollas de tamales, y vénganse a comer tamales, y vamos a comer pero poquito. Antes yo comía mucho con leche o atole pero a horita ya no, mi mama hacia enchiladas pero ya no. También seguido hace taco como hace muchos años vendieron ellos, tenían su puesto de tacos de cabeza de lengua de todo eso, y a horita pues ahora ya no tienen nada de eso, yo no lo hacen para vender solo para ellos y a veces que les digo, denme cinco pero con una tortilla y solo dos o tres y no mas, el mismo cuerpo se va imponiendo a estar comiendo poquita cosa.

I never made tamales because I never knew how. My mom, I lived close to my mom like a block away, my mom used to make pots full of tamales all the time and ‘come over here for tamales’ and we’d go and eat but just a little. Before I used to eat a lot with milk and corn flour soup but not any more. My mom used to make enchiladas but not any more. She used to make tacos all the time as well because many years ago they used to sell them. They had their taco stand but now they don’t have any of that any more. They don’t make them to sell, just for themselves and sometimes for me when I say give me five but with one tortilla and two or three, no more. Your own body starts to tell you to eat less.

Patricia’s mother’s cooking and the foods they use to sell are described most eloquently. For Patricia, her mother’s cooking has personal as well as cultural significance. Both Patricia and her mother have diabetes and need to give up or decrease the amount of the foods they love. Even though initially Patricia felt deprivation, after 14 years with diabetes she has adjusted, closely watching what she eats, but she does recall with great fondness her mother’s favorite dishes.

A second generation woman, Elvia’s Mexican identity is intimately tied with

cooking and eating Mexican food.

*So the cooking part is very hard. Anything you eat its fattening. The beans, you use the lard out of the bacon, you save it to make the beans, to make refried beans. Uhm Just everything. The way we eat tortillas. **Tortillas** are eaten with every meal. So It is either corn or flour. I really don't like corn. I'll eat more flour, I'll eat two or three when I make them but I'm not that big of a **tortilla** eater. The more is basically the food. I/We eat a lot out, especially here at work. But that's going to stop. (laughs) But we do eat a lot out and I know that's not good for us either but the cooking has been the hardest on what to do, cause everything is fattening in the Hispanic, the way we cook the Mexican food. So, it's harder ...*

Elvia's need for dietary changes has been both a source of inner and family conflict. Elvia has both cultural and personal conflict around what the nutritionist tells her in terms of portion control, manner of cooking and eating raw vegetables. Her struggles around diet are both personal and familial. Her husband, Ernesto, and 2 daughters, Teresa and Adrianna, desire to help Elvia manage her diet but are unsure how to do it, leading to family strife.

For Elvia, Mexican food is a significant part of holiday celebrations. Preparing tamales is a labor intensive process at Christmas. The nutritionist counseled her to limit herself to only two tamales. Elvia struggles, "how could she possibly limit herself to only two since they are so good". Elvia cooks them with lard and the "lard makes them taste so good but yet lard is so very bad for you".

A different loss for Carlos is junk food. Carlos, living in the U.S. for over 20 years, is good friends with American junk food. His identity has changed in the twenty years he has lived here. He eats tortillas but has developed a strong emotional, rather cultural connection, to junk food. He describes with emotion in his voice the changes he has made after his diagnosis of diabetes.

Ah, bastante-cuatro veces frituras a la semana, bastante tortilla, bastante pan, menos verdura, era enemigo de la verdura, fruta? Ciertas frutas nada mas, muchos pasteles, café, si se podía tres cuatro cinco al día, dos tres cucharadas de azúcar, chocolate, bastante chocolate soy una persona que el chocolate era mi favorito, no me importaba pagar 5 dólares por dos chocolates pero era calidad de chocolate y horita, coca tomaba mucha coca, agua no tomaba, por ese lado, ahora que ha cambiado, dos tortillas, menos frituras, verdura cosidas crudas, menos carne, un poco mas de pescado, el pescado no me gusta pero trato de comerlo cuando lo hay, pollo mas pollo. Carne roja, no mucha carne roja, pero si he tratado, café, nada mas un café sin azúcar, una pieza de pan, ahí se mezcla el sabor de mi café sin azúcar con mi pan de dulce y ya se que do mas agua natural, coca, le dije al doctor si podía tomar coca y me dijo que de dieta, algo que no me gustaba pero ya la empiezo a tomar otra vez así que tiene que ser dieta y he dejado mucho de mis hábitos que tenia.

Ah, a lot (referring to his changes in diet) Fried stuff four times a week, lots of tortillas, lots of bread, not so many greens, I was against green vegetables. Fruit? Just certain fruits. Lots of cakes, coffee, three, four, five a day if I could, two, three spoonfuls of sugar. Chocolate, loads of chocolate; I was someone who's favorite thing is chocolate. It didn't bother me to pay \$5 for two chocolate bars because it was the quality of the chocolate and right now...coke, I used to drink a lot of coke, I didn't drink water. On the other hand what's changed now; two tortillas, less fried food, fresh steamed green vegetables, less meat, a bit more fish; I don't like fish but I try to eat it when there is any. Chicken, more chicken, red meat, not much red meat, so I've tried. Coffee, just one coffee without sugar, one piece of bread; the taste of the coffee without the sugar mixes with the sweetness of my bread and that's good enough. More plain water. Coke... I asked the doctor if I could drink coke and he said diet coke, something I didn't use to like but I'm already starting to drink it again and now it has to be diet. I've cut out a lot of the habits I used to have.

Yes, Carlos is trying very hard to make difficult changes. He has cut down from eating twelve tortillas at meal times to eating six. He has lost 17 lbs. Not enough, his doctor says, and Carlos feel frustrated. Patience, says the doctor, it takes time. Carlos describes going with his 2 boys to get fast food after a sporting event. He does not want them to suffer as he is suffering so he will eat minimal quantities with them. Being denied junk food is viewed as suffering, demonstrating that food is the passion of Carlos' life.

Enrique tries to make sense of his wife's diabetes and prevent his twelve children from becoming ill with this disease. In his role as father and head of the family, he dictates the family's diet. Enrique recalls an event from his childhood.

Es que yo estaba chiquillo, yo y mi papa y a una amiga de mi papa, que vivíamos juntos con otros en la casa, y una viejita. Tenía yo que como unos 7 años y dice la viejita, estaba viejita, viejita y esta señora me decía "el azúcar es malo, es malo". Era comadre de mi papa y decía que el azúcar es malo nunca me ha comido tanto azúcar, nunca deje a sus hijos que coman el azúcar porque el azúcar les hace muchas enfermedades. Entre menos come el azúcar es mejor. Sal también dijo, la comida no muy salada porque lo afecta... esta viejita era como unos, era una señora muy viejita ya tiene, ya tiene mas que, como diría yo, como 80 años... tiene que morir. Y ella era la que me advirtió. Yo estaba chiquillo y ella metió algo en la mente y ella luego creciendo y creciendo y nunca se me ha olvidado de eso del azúcar.

I remember when I was little. My Dad, a girlfriend of my dad's and I lived in a house with other people. One of those was a very old woman. I was around 7 years old and this very old woman said, 'sugar is bad, it is bad.' She was the godmother of my father who said that sugar was bad, and she said do not eat too much sugar, none of her children ate sugar because sugar caused many illnesses. Less sugar is better. Salt also, she said, food should not be very salty because it will affect you. She was a lady very old, easily more that 80 years old when she finally died. She had warned me. I was little and she put this idea in my mind which she believed in very strongly. I have never forgotten her words about sugar.

This experience at the age of seven, impacted this 48 year old man deeply and influenced his family's eating habits today. Enrique believes that this woman lived a very long life because she did not eat sugar.

Enrique drinks coffee but never with sugar. It is okay with a little cinnamon, after all this is a natural Mexican sweetener. For himself, he believes there are benefits to no sugar and a healthy diet. Enrique describes having a cut on his finger and having stitches put in. He was bothered by the stitches and went back to the doctor three days later. The doctor was angry he came back early. But after three days the wound was completely

healed. “The doctor asked what do you eat?” Enrique replied, “Only beans.” In the background during the interview, the wife replied, “Yes, but with no oil.” Occasionally, he eats eggs but with no oil or lard. Enrique eats very few tortillas, trying to eat only the most natural things. For him, eating natural Mexican foods is part of his cultural identity. Eating the most natural Mexican foods possible is his tortilla.

Enrique believes this natural diet will help his wife Berta with her diabetes and greatly benefit his twelve children.

Yo lo que yo le digo a mi esposa le digo “mira, lo mas que cuides es mejor y conmigo le digo “pues ahorita vamos a cuidarnos, tanto tu como yo” le digo “no por nosotros salud, porque nosotros de aquí vamos a salir, pero por estos muchachos que tenemos, por los hijos.”

I then said to my wife, Look, being careful is better and then we need to watch, be careful, You need to do as I do, Not for our own health but because we are here (in the U.S.) and we need to move ahead, for these kids we have, for our sons and daughters.

In conclusion, for persons with diabetes and their family members, food is imbued with layers of meaning. The meaning can be personal and intimate as in recalling the food business of your mother. Food is a fond memory of home, the making of tortillas by hand, something often not done in this country. In addition, food is a way to establish your cultural identity here as a second generation Mexican-American. Food is a large part of cultural and family traditions such as tamales at Christmas. For Mexican immigrants living here for many years, American junk food and sweets can have great emotional meaning as well, and becoming a diabetic and needing to give up or eat smaller amounts of your favorite foods can be challenging and difficult.

Due to the meaning and emotion associated with food, it makes following a regimented diabetic diet difficult. These stories were engaging in the manner in which

they were told because the participants were very animated. The emotion is not conveyed easily on the written page. For me, it reinforced how difficult it is to make changes involving food in managing a chronic disease. The day to day dietary experience of living with diabetes can be personally, culturally and emotionally challenging.

Cambios en Nuestra Vida (Changes in our Lives)

In the day to day existence living with Type 2 diabetes there are *cambios*-changes that were made in the past that needed to be readjusted and continually readjusted in the present moment. The behavior and life style changes needed with Type 2 diabetes are challenging and complex. Behavior change is often portrayed by health care providers as following an orderly step wise pattern and based in self care or self-efficacy, which are seen as personal attributes. After listening to countless stories of the changes made by individuals and families, I believe changes in a family's daily lives are more often confusing, complicated and difficult than understood by health care providers. Through an array of emotions, beliefs and attitudes, families struggle to manage and control this difficult disease. I endeavor to make sense out of the process and describe the changes made by these families. To shed light on the experience and faithfully represent these families' stories, I have organized *Cambios* into 6 subsections: Distinct Beliefs and Attitudes, Medication, Blood Glucose Monitoring, Insulin Administration, Diet and Exercise. In this way, the day to day experience for these families will be more fully described.

Distinct beliefs and attitudes.

Many uniquely Mexican understandings of the world are presented in this analysis and write-up. Oftentimes motivation and ways of pursuing necessary changes are

vastly different from dominant cultural understandings. For health care providers, behavior change and self-care activities are presented in a step wise and orderly fashion based on psychological models of health behavior. Often in these stories, very different understandings of the world are presented, adding to the complexity of understanding behavior change and self-care for Mexican-Americans.

As a diabetic, Lino has a distinct perspective on diabetes and necessary behavior change. His desires for change are not always consistent, and he has difficulty grasping the complexity of his illness. For example, he does not always watch his diet, he eats more at fiestas than he should, and he stops and starts his medication based on symptoms he is having.

Yet Lino, previously a 2 pack a day smoker, is proud of stopping smoking. His sons nagged him to stop smoking. His wife did not like the smell in the car. The doctors at the clinic told him he must stop smoking since diabetes and smoking is doubly dangerous. He did not respond to any of this until a significant event happened.

Yo por ejemplo en el invierno yo fumaba 2 cajetillos por día. O sea entonces quiero decir que yo me perjudique. Yo me beneficia porque mi esposa y mis hijos si como me ayudaron. Yo cuando decidí dejar de fumar no fue tanto porque ellos me dijeron. Sino no se, fue algo que al estar fumando yo mire a la columna de humo y yo no me explico que me da la columna de humo. No lo explico yo mire algo que no me gusto.

No se como alguna figura o algo en la columna de humo. Como una figura entonces lo que hice acabando, dando lo aun fumando cigarro, los que tuve, acabando la cajetilla que yo había comprado por paquete de dos cajetillas. Lo que hice cigarro por cigarro los saque, los rompí; yo en los primeros días que deje de fumar yo andaba muy nervioso. Pero ellos me entendieron porque yo cuando me ponía molesto como me salía por afuera o esa metía a su cuarto o los muchachos me sacaron de vuelta si pero eso fue algunos 2 o 3 semanas. La primera semana fue la más dura. Pero de allí por acá ni un cigarro. Estaba fumando me llevan la aroma me molesta pero no digo nada, no mas busco la forma de esquivar la aroma del cigarro si. Entonces yo económicamente no me perjudico.

For example in the winter I smoked 2 packs a day. So I mean I didn't do myself any good. I did benefit from my wife and kids help. When I decided to quit smoking it wasn't so much because they told me to, it was, I don't know, it was something I saw in the column of smoke when I was smoking and I can't explain how the smoke column affected me. I can't explain it but I saw something I didn't like.

I don't know, like some figure or something in the smoke column, like an image. So what I did while I was still smoking the cigarette, I took out the ones I had left in the pack and then the other pack, I'd bought a carton of 2 packs; and what I did was, cigarette by cigarette, I broke them. I got really agitated in the first days after I quit smoking but they understood because when I got upset like I'd go outside or she'd go in her room or the boys would keep away from me. This was for about 2 or 3 weeks. The first week was the hardest but from then on, not one cigarette. If someone's smoking and I smell it, it bothers me but I don't say anything, I just try to avoid the smell of cigarettes. So economically I'm better off.

Lino saw a figure in the cigarette smoke. The figure would not go away. At that point, in a cathartic action he opened his two packages of cigarettes, and broke each cigarette one by one and threw them all away. That week he was terribly nervous but little by little he felt better. His wife and children supported him in not smoking and in 3 weeks he started to feel like a new person. By not smoking, he saved himself and his family so much money that he was able to buy his wife a car, his family could go out to eat occasionally and they put a little money in the bank.

For Lino, ending smoking encompassed magical realism, defined as the telling of stories from the perspective of people who live in our world and experience a different reality from the one we call objective (Rogers, 2002). Beliefs in magical realism are so different from the dominant Euro-American culture yet are a way to explore and understand persons and communities outside the mainstream of our culture (Rogers, 2002). A figure in the smoke did not go away until Lino stopped smoking. For Lino, a farmworker with no formal education, the *cambio* (change) so needed in his life came not

from within, an internal process, but from outside himself, another world,-a vision in the cloud of cigarette smoke.

Debe uno de tener en la mente que un día va a morir pero mas uno no sabe que manda. No agarre la enfermedad como que de esas se va a morir. Le dije, 'Yo no agarro como si de esa se fuera a morir usted. Yo si me siento pues yo en mi corazón así siento. Yo me siento muy tranquila o sea yo tengo mucha fe en dios y pues cualquiera enfermedad' le digo... 'Dios nos mando a la tierra, nos enseñaron en la Biblia y todo. Cuando de chiquitos usted nos empezó a hablar de dios. Entonces si el nos mando a esa tierra, el mando también, dejo el paraíso y del paraíso que dejo de huerta, dejo toda la medicina para las enfermedades que puede uno agarrar aquí por comer cosas que no debe. La muestra que dicen que Adán tiene labor aquí porque Eva le dio la manzana. El también se la comió porque el quiso' le dije. 'Pues si ya le hubieron dicho que no comiera esta manzana... pero Eva le dijo que estaba bien sabrosa para que se creo' le dije. Y el se la comió verdad. Ya cuando supo y ya la dejo aquí a traer la adelantada porque yo le preguntaba a mi mama. 'Mama porque los hombres tienen aquí huevos, tienen una bola aquí? Y ya me empezó a decir así verdad que esa bola era la manzana que Adán se iba a....casi se la trago pero ya al ultimo se repinto y se le quedo atorada. Le dije 'entonces eso es lo que yo pienso. Yo pienso que hay cosas que no debe uno de comer porque le hacen daño al cuerpo a uno pero están bien sabrosas, bien, pues yo me la como, ya se que me va a hacer daño. Entonces yo me la como porque yo tengo ganas de probarla y esta bien sabrosa.' Mi mente trabaja así.

You need to keep in mind that one day you're going to die but you don't know what else will happen. Don't treat the illness like you're going to die from it. I said, 'I don't treat it like you're going to die from it. I feel, well I feel that way in my heart. I feel very calm or let's say I have a lot of faith in God whatever the disease' I say... 'God sent us to earth; they taught us that in the bible and everything. When we were very small you started to talk to us about God. So if he sent us to this earth, he also sent, he left paradise and he left a garden in paradise where he left the medicine for all the diseases that you can get here from eating things that you shouldn't. They say that Adam has work here is because Eve gave him the apple. Also he ate it because he wanted to.' I said. 'So if they had told him not to eat that apple...but Eve told him it was really good so he believed her.' I said. And he ate it right. Then when he realized and stopped, he left it here to push it on because I asked my mom. 'Mom why do men have eggs here, why do they have a ball here?' and she started to tell me that this ball and was from the apple that Adam was going to....the one he almost swallowed but at the last minute he changed his mind and it got stuck there. I said 'so this is what I think. I think that there are things that

you shouldn't eat because they harm your body but they are really delicious, and so I eat them when I already know that they'll cause me problems. So I buy a thing because I want to taste it and it's really good.' My mind works like that.

Juanita speaks in biblical stories to explain male anatomy as well as to make sense of why she does not follow her diabetic diet. As Adam took the fruit from Eve, so Juanita cannot resist foods which are delicious. Juanita also speaks about things which are natural as the fruits in the Garden of Eden whereas medication is not natural and can cause you great harm. Juanita uses the Garden of Eden story to explain why she does not always eat well and why she does not always take her medication. Clearly, this understanding is vastly different than the dominant culture as to why persons with diabetes struggle with their dietary and other lifestyle changes.

Yet Ignacio and Dominga and their children have made many lifestyle changes. At the time of Dominga's official diabetes diagnosis and her husband's heart attack, the family became involved in an evangelical church. The church helped them with support and general assistance. Being part of the church has changed their way of thinking and being in the world, they have given up *los vicios* (the vices) such as drinking, dancing and smoking. For Latin American evangelicals, the giving up of *los vicios* is central to the conversion experience, of being made new in Jesus Christ (Stout, 2004). Ignacio and Dominga no longer go out on weekends, but do church activities on Friday evenings. The family is trying also to have a healthier lifestyle by eating healthier and together as a family and having less conflict and anger. The family receives support for the chronic illnesses they are living with as well as spiritual support from the church.

The family has embraced *la Vida Sana*-the healthy life as noted above encompasses more than the necessary dietary changes. For this family, making necessary

diabetic changes is much more than diet and exercise, it encompasses a spiritual dimension as well, a conversion experience. In the dominant Euro-American evangelical culture, conversion is often of a personal and spiritual nature, a personal relationship with Jesus Christ. Yet for this family, the conversion involved significant lifestyle changes which are healthier overall for a family living with Type 2 diabetes and other chronic illnesses.

Clearly, these stories are just three examples representing different experiences of controlling diabetes and making behavior changes. The dimensions of behavior change can be vast and complex, and influenced by a variety of spiritual beliefs and understandings of the world. These examples of behavior change demonstrate the complexity of thinking and feeling behind the behavior change. I think it is often easy to forget that other world views and realities exist beyond the biopsychosocial model, with vastly different understandings than our own.

Medications.

Only a few of the participants told stories about managing medication. It was an accepted routine part of life. It did not have the same emotional draw as other parts of the diabetes experience; however, it is meaningful because taking medication daily was a constant reminder of the chronicity of the disease.

Carlos, newly diagnosed 9 months ago, struggles with taking daily medication. He went to his doctor with his symptoms, was diagnosed with diabetes and hypertension, and then started taking medication and felt better. Carlos believed he then was cured, but his health care provider stated, “no, you cannot stop taking your medication, you need to continue to take it.” Carlos was disappointed. Now every morning when he has to take

his pills he is confronted with his chronic condition, a burden Carlos will live with the rest of his life.

Stories of ambivalence.

Lino and his wife Juanita have difficulty taking their medication regularly. These stories help me understand better their thinking and feelings about medications.

Y desde entonces me dieron medicina y yo la estuve tomando como me decía la doctora. Y yo la estuve tomando y yo fui, le dije 'sabe que doctora' dije 'yo me siento mal. Yo me siento mal tomando la medicina.' Y yo estaba en las mañanas, en la noche tome mi medicina pero yo me sentía mal. 'Siento aquí una bola. Una bola pesada que no me deja comer por, y siento como ganas de vomitar' le dije. 'Me siento mal y me siento sin ganas de salir por afuera no mas quiero estar acostada' le dije 'y yo no me siento bien con la medicina.' 'No' dijo 'usted sígase la tomando' me dijo la doctora. Y yo había decidido sabe que mejor yo estoy de mal y peor yo. Saben que yo dejo de tomar la medicina. Luego deje de tomar y la deje de tomar. A mi ponga me la música, ponga me a bailar, no me pone candado yo me salía por afuera. Y no me explicaba yo, no me explico porque era la medicina o será que la mente yo no se. Dije a la doctora 'yo no tomo sodas, yo no como dulces, yo no ando cada rato come y come con mucha hambre. No. Casi como muy poco. Como muy poco' le dije. 'No me explico porque estoy así' le dije yo a la doctora. Ella dijo 'pues usted hágase el test en la mañana y en la noche' dice. 'Y ya a según me viene al tiempo viene, viene y me la traiga.' Esta bien. La hice no mas 2 días, yo dije yo no hago mas y fui con el y le dije y salí bien. Dijo 'tomo la medicina?' le dije 'no. No. No me la afecta nada para que les voy a decir que si. Soy de esas personas que no me gusta mentirles.'"

And then afterward they gave me medicine and I was taking it like the doctor told me. I was taking it and I went in, I said, 'you know what doctor' I said, 'I feel bad.

I feel bad when I'm taking the medicine.' I took my medicine at night but it was in the mornings I felt bad. 'I feel a lump here, a heavy lump that won't let me eat and feel like vomiting' I said. 'I feel bad and I don't want to go out, I just want to lie down' I told her 'and I don't feel good with the medicine.' 'No' she said, 'keep taking it' the doctor said. I had decided that you know what; I was bad and getting worse. They know that I've stopped taking the medicine. Afterward I stopped taking it, just stopped taking it. Then give me music, let me dance, don't hold me back, I went out. And I couldn't explain it. I couldn't tell if it was the medicine or was it in my head, I don't know. I said to the doctor 'I don't drink soda, I don't eat candy, I don't go around hungry and eating all the time, no. I

hardly eat anything. I eat very little.’ I said. ‘I can’t explain why I’m like this’ I said to the doctor. She said ‘well do the test in the morning and at night’ she says. ‘And then depending what it is, after a while, come in and bring it to me.’ Okay. I just did it for 2 days; I said I’m not doing it any more and I went in with him and I told her and I came out okay. She said ‘did you take your medicine?’ I said ‘no. No. It doesn’t do me any good so why tell you I did. I am one of those people who doesn’t like to tell lies.’

For Lino, taking medication can be very challenging. He experiences side effects of the medication, appearing to be gastrointestinal.. These side effects are not merely a nuisance; they have severely impacted his life. He cannot go out and have fun; rather, he stays home and lies in bed. His health care provider, according to him, is not initially sympathetic to his difficulties, stating “you just need to take them.” Lino, who may have difficulty understanding the chronicity of his disease, does not understand fully why he must continue to take the medication. He stopped his medication and he felt better, and is able to go out and dance. His physician wanted him to check his blood sugar. He only did that for 2 days and the level was okay. He ends this segment by stating he does not like to lie. For him, the moral of the story is, you shouldn’t lie about what you do with your disease. From this segment it does not follow what we would understand as a linear progression of his disease. I do not know what happens next. But the point he desires to make is his honesty and therefore he is straightforward with his health care providers. He then tells of discussing his alcohol use with his provider. He feels he is honest about when he cheats with his diet or when he does not check his blood glucose. His self-projection is that I do not always do what I am suppose to do but at least I am honest about it.

His wife Juanita tells the story of her difficulties with taking medication.

Yo seguí con mi trabajo no mas como me dijo que como yo me sentía pues a veces decaída cuando me tenia el estomago la medicina y todo eso

nada mas. Lo que paso es que deje de tomar yo la medicina y yo me sentía bien. Yo fui y le dije yo a la doctora. Yo la deje de tomar pero yo fui y le dije a ella. No se si es igual del record verdad que cuando uno va y le dice pues todo eso. Yo fui y le dije que yo me sentía muy mal con la medicina y ya tenia varios días que no la tomaba yo y me sentía bien. Ella me dijo 'usted de todas maneras sigase la tomando aunque usted no se sienta bien.' Le digo 'no pero es que yo también me siento mal de la ulcera' le digo. Y entonces ya fue cuando dijo 'pues tomase lo en la noche antes de dormir.' Dijo 'tomasela en la noche.' Y luego yo, a pesar de que me la tome en la noche, de todas maneras yo amanecí con mi estomago mal pero me la seguía tomando. Y ya le dije a la doctora 'mire doctora yo le voy a ser franca. Yo a veces me siento pero bien mal, mal, mal. Me tomo la medicina pero yo la dejo de tomar para descansar de mi estomago y sentir un poco mejor. Y no se si estaré mal o estará bien pero duraba pues así como 2 semanas sin tomármela, duro como 2, 3 meses tomándomela porque a veces que me tiene un poco mas de la medicina. Dejo de ir un tiempo, luego después vuelvo a ir y no voy porque me siento mal de la diabetes sino que yo voy porque yo sufro de los bronquios entonces yo voy atender me de el porque en este tiempo me afecta mucho el tipo de calor y necesito el spray y me pone una vacuna la doctora. Y voy para el spray, voy porque me siento mal de mis pulmones pero ya he ido y todas maneras cada vez que a uno le hacen el chequeo y ya pues algo alta me dice la doctora y me vuelve a dar medicina. Me la vuelvo de tomar y de vuelto si le digo 'no se si me esta haciendo malo o me esta haciendo bien.' Y le digo 'pero yo me siento bien' le digo a la doctora 'yo me siento bien. Entonces yo me siento bien, no me siento mal como que deje de tomarla.

I kept on with my work except well I sometimes felt tired when the medicine was in my stomach that's all. What happened was that I stopped taking my medicine and I felt good. I went in and I told the doctor. I stopped taking it but I went in and I told her. I don't know if the record shows it when you go in and tell her all this. I went and I told her that I felt very bad with the medicine and I hadn't taken it for several days and I felt well. She said 'you need to keep on taking it even though you don't feel well.' I say 'but my ulcer's bothering me as well' I say. So that was when she said 'well take it at night before you go to sleep.' She said 'take it at night.' Afterward even though I took it at night I still woke up with a bad stomach but I kept taking it. Then I said to the doctor 'look doctor I'm going to be honest with you. Sometimes I feel really, really, really bad. I do take the medicine but I stopping it to give my stomach a rest and to feel a little better. I don't know if I'll end up worse or better but I went like 2 weeks without taking it. It lasts me for about 2, 3 months when I'm taking it because sometimes I have some medicine left over. I stop going in for a while, then afterwards I go again but I don't go because the diabetes is making me ill I go because I suffer with my bronchial tubes. So I go to see

about that because in this weather the heat affects me a lot, I need the spray and the doctor gives me a shot. So even though I go for the spray, I go because my lungs feel bad, I go in and each time they do the test on you and then when it's a bit high the doctor gives me the medicine again. I start taking it again and I go in again and I say 'I don't know if it's doing me any good or not.' And I say 'but I feel well' I tell the doctor 'I feel well.' I feel well, I don't feel bad because I stopped taking it.

Juanita she stops taking the medication for the same reason as her husband, the symptoms and gastrointestinal side effects she experiences. She also expresses a fear of medication. Like her husband, she suffers from asthma and needs to go in to obtain asthma medication, a spray and sometimes she needs an injection. Again, as with her husband, she believes she should be honest with the health care provider. Juanita is invested in having a relationship with the health care provider due to her asthma and the need for treatment. At that time, the provider will restart her diabetes medication. She does retake her medication. According to this story, she stops and starts her medication based on what she feels. Clearly, she is conflicted about taking medication for her diabetes, and she doesn't feel ill with her diabetes and therefore does not understand the need to take medication for a condition she does not feel ill from or have any symptoms of.

Taking insulin.

Insulin injections are often viewed by health care providers as simply another therapy for managing diabetes, possibly better than taking oral medication. For these families living with diabetes, administering insulin injections has great emotional significance.

La aguja (the needle) figured prominently in many of the stories of living with diabetes. Dominga feels that injecting with insulin, for that type of diabetes is *mas duro*,

very hard, as well be seen as *mas cruel*, very cruel. She *espero en Dios que no llegue yo a eso* hopes to God that she does not come to that point. Florencia follows her diet and exercises daily because she never wants to have to give herself insulin. She knows it is very painful. Rocio states that she would never want to use insulin. Again, looking to the past, she recalls that when caring for her mother she used to inject her in the stomach. Insulin injections made her terribly nervous and she does not want that for herself. As a diabetic, Cristina looks to her future and wants to prevent the *bad stuff*. One of the things she views as leading up to the *bad stuff* is using insulin. In comparing herself to her mother at age of 54, Cristina feels she is doing better with her diabetes since she is not using insulin. In her mind, insulin use is viewed as a downward progression of the disease.

Manuela, Cristina's mother, tells many stories of her thirty-five years of living with diabetes. Manuela's story of starting insulin begins with a trip to Mexico. On her last day there, her sister said she was taking her to the doctor because she looked very thin.

Cuando me llevo con el doctor me mando hacer los análisis. Allí salio que tenia el azúcar arriba de 500. Desde cuando traía yo el azúcar? Sabrá dios. Yo nunca me chequeaba. Ya, dijo el doctor, luego, luego me dijo 'señora usted tiene que ponerse insulina.' Yo que había ido ya con Clinica. Y siempre lo traía como 250, 200 y estaban tratando de ponerme insulina. No más me decían de insulina y ya no iba. Le tenía tanto pavor a la aguja. Aye no. Pero allá en México me dijo el doctor 'y mañana ya va a comenzar con la insulina.' Yo se que aquí les dan clases, o no se si ahora ya no, pero antes si les daban clases para como ponerse su insulina. Allá no mas me dijo el doctor 'mañana se va a poner 30 unidades de insulina en la mañana y 30 en la noche. 'En la noche yo no podía dormir porque dije yo 'aye me voy a picar y donde me voy a picar?' Y luego me dice mi hermana 'ya estas lista para tu inyección?' Le dije yo 'si. No puedo dormir' le dije 'porque yo no se como voy a vivir con esa piquete todos los días.' Y dice 'ya le mande hablar a tu sobrina de allá, ella es enfermera.' Y ella me dijo 'mire no tenga miedo, la aguja es

chiquita,' dice 'no mas donde se la quiere poner usted dice.' Empiece con un algodón cito con alcohol y me iba a sentir el piquete, o por ella bien fácil pero tenía miedo. Y luego a mi hija la que se le decía ella también dijo 'mami yo te pongo la inyección.' Le dije 'no, si yo tengo esta enfermedad yo tengo que quitarme el miedo y sobrevivir con este nuevo tratamiento que voy a comenzar. Luego, y ella le platico a mi esposo. Dijo 'yo te pongo la inyección, yo fui enfermero en el army.' Nadie me va a poner mi inyección' le dijo. 'Así que yo solita me pico mis dedos, me pongo mis inyecciones y ya nadie anda molestando.'

When she took me to the doctor he sent me to do some tests. There it turned out that I had a sugar of over 500. Since when had I had that sugar? God only knows. I never checked it. Now the doctor said, just after he said 'Mrs. [name] you need to be put on insulin.' I had already been to the Clinic. And I always had it 250, 200 and they were trying to put me on insulin. As soon as they talked about insulin I didn't go any more. I had such a fear of the needle. Oh no. but there in Mexico the doctor said 'and tomorrow you are going to start the insulin.' I know that here they give you classes on how to give yourself insulin, or I don't know about now, but before they used to give classes on how to give yourself insulin. There the doctor just said 'tomorrow you're going to give yourself 30 units of insulin in the morning and 30 at night.' At night I couldn't sleep, I was so nervous because I said to myself 'oh I'm going to stick myself and where am I going to stick myself?' And later my sister said 'are you ready yet to give your injection?' I said 'yes. I couldn't sleep' I told her 'because I don't know how I'm going to live with this stick every day.' And she says 'I've already sent a message to your niece there, she's a nurse.' And she told me 'look, don't be afraid, the needle is very small,' she says, 'just say where you want it given.' She starts with a cotton ball with alcohol and I was going to feel the prick, sure for her it is very easy but I was afraid. And later my daughter also said 'Mom, I'll give you your injection.' I said 'no, if I have this illness I have to overcome my fear and survive with this new treatment that I'm going to start.' Later, she talked about it with my husband. She said 'I'll give you your injection; I was a nurse in the army.' 'Nobody's going to give me my injection' I said. 'I will prick my fingers by myself, I'll give my own injections and that way nobody will be disturbed.'

This story clearly illustrates the range of emotions around the *aguja* (the needle).

The thought of the needle or insulin injection causes fear and then Manuela stopped going to the clinic (avoidance). Her family was willing to give her support, yet she was able to confront her own anxiety and fear and realizes that she learned to manage her own

disease. Manuela's story indicates intense fear of sticking herself, profound anxiety leading to sleeplessness. There are a range of emotions around injecting insulin, putting a foreign needle into your own body, a dependency on an injection and the chronicity of insulin injections, usually a life long therapy.

Lino, the only other study participant on insulin, started the injections 3 to 4 years ago. At first afraid of the needle, he describes his process of gradually learning to overcome his fear of the needle.

Al principio fue difícil por la, quizás por el miedo que le tenía al aguja no. Le buscaba yo un lado que tiene para no me confundiera. Yo verificaba las piernas, las piernas en que yo me inyectaba. Ahora el doctor me dijo 'si usted puede inyectarse todo va a volver al nivel bueno todo. Allí tiene lo mas gordito en donde.' Entonces yo me ponía la aguja de lado. Me dijo no. Dice es mejor que la ponga por abajo y si a caso tiene bastante gordito dice para que ya hace mas efecto. Y es cierto, así no más. Pues así no más.

It was difficult in the beginning because, perhaps because I was afraid of the needle, right. I was looking for which side it was so I wouldn't get mixed up. I was checking which leg I was injecting. The doctor told me 'if you can inject yourself everything will go back to a good level. You've got the most fat there.' Then I was putting the needle in sideways. He says it's better to put it in straight down so if you have a lot of fat it will take effect better. And it's true. Like this. Just like this.

Lino gradually overcame his fear and learned to inject in different locations on his body. As his blood sugar dropped to a more normal range, he gained weight and it was easier for him to give himself injections. By taking insulin, he had less medication to take and keep track of, a good thing for him.

Lino felt comfortable on his insulin. Yet he stopped abruptly using his insulin one year ago. For approximately 11 months, he did not treat his diabetes, an action that was potentially life threatening. Lino spoke honestly and acknowledged a mistake. His story

illustrates the vast complexity of diabetes management and the thinking and emotion behind the day to day management.

Mire. La razón fue que en ocasiones yo no me di cuenta de que posiblemente era eso que tenía la azúcar bastante alta. Yo aunque me ponía mi insulina pues yo sentía algo que es en el cerebro. Sentía no dolor o sea como si lo tenía pesado. Lo tenía pesado y yo dije deo de ponerme la insulina, deo de tomar la medicina y aparentemente yo me sentí bien. Me sentí bien. Pero con el paso del tiempo yo me di cuenta que, que estaba en un error. Estaba en un error porque yo les digo yo mis pantalones ya me quedaron flojos o sea y a '(name)' hablo y dije que si podía hacerme una cita. Hágamela. Me hizo la cita, le digo allí yo volví otra vez a, porque yo vi al, yo mire pues al doctor un poco preocupado. Me dijo 'asi yo no me gusta a estar escuchando a que tienen que hacer no.' Dice 'ustedes tienen que poner su parte 90%' dice 'o 100% tienen que poner ustedes' dice. 'Porque son personas que ya piensan ya saben lo que tienen que, lo que les puede perjudicar.

Look the reason was that sometimes I didn't realize that it could be that I had really high sugar. Even though I was giving myself insulin I felt something in my head. It didn't feel like pain, more like heaviness. It felt heavy and I said I'm stopping my insulin, I'm stopping my medicine and I seemed to feel better. I felt well. But as time went on I realized that I'd made a mistake. I had made a mistake because I tell you my pants were loose on me. I talked to (name) and asked if she could make me an appointment. Go ahead and make me one. She made me an appointment. I tell you I went there again because I saw the, well I saw that the doctor was quite worried. He said, 'and I don't like listening like this to what you have to do, right. He says 'you have to do your part 90% he says or you have to put in 100%' he says. 'because you are people who already think you know what, what will cause you problems.'

Lino, like other participants in the study, took action based on what he was feeling. After he stopped taking insulin, he felt better for a short period of time. But then he realized he'd made a mistake and then sought medical care. According to Lino, he didn't realize that it could be high blood sugar. Lino is now doing better. He currently has no symptoms other than occasional symptoms of low blood sugar when he does not eat enough for breakfast. Lino now knows those feelings and what he needs to do when they occur. Lino is now aware how dangerous and potentially life-threatening this

episode was. At the time his glucometer was not working, now it is functioning and he brings it into the clinic to have it checked, using a color chart to monitor his blood sugars.

Me dieron una forma con yo entiendo. 'verde, amarillo y ya' me dijeron 'mire usted esta a este nivel, sabe lo que significa?' 'O si,' le dije. 'Después pues es como los luces de un camino. El rojo, hay que pararlo.'
Dije 'yo entiendo'

They gave me a diagram with green and yellow marks and then they said "look you're at this level, do you know what it means?" "Oh yes" I said. "So it's like the traffic lights in the street, red you have to stop" I said. "I understand."

The message of the chart is simple. Green means go, continue doing what you are doing. Red is like a traffic light, you must stop and do something different like change insulin dosage, change medication or come into the clinic. For Lino, with no formal education, having a color chart is a better way to monitor blood sugar than to rely on numbers alone which may be difficult for him to understand.

For family members, taking insulin is generally seen as a worsening of the disease. Their family member is now in a more vulnerable and precarious state of health. However, each of Lino's sons responds very differently toward their father and his diabetes and use of insulin.

Lino's son Jesus feels that their dad does well with the insulin.

Para el padre es muy natural como el lo hizo antes es natural. En el estomago. Le dijo la doctora si se podía inyectar en el estomago y tal por aquí, por acá. Como uno acá anda muy mansado, tenemos que ir adaptándonos a esa calma no porque quizás nos da la, no batallar mucho. Es la más experiencia que tenemos. Y con mi abuela es un poco más grande no.

For him, my father it's very routine because he's done it before, it comes naturally. In his stomach. The doctor asked him if he could inject himself in the stomach like here, here. Like one need to be very laid back here, we have to adapt to this calm right, not fight a lot. This is the main experience we've had. With my grandma it's a bit more involved, right.

Jesus feels his Dad is relaxed and easy going. Even though injecting insulin for diabetes is difficult, his Dad has been able to adapt, approaching his injections with calm. He compares his dad with his grandmother who is more emotional and often overwrought with her disease. For Jesus, doing well is approaching injections with calm and having a relaxed manner, and not letting the disease overtake you emotionally.

Francisco, the youngest son, offers a different perspective. He is more worried about his father than his brother.

No es nada fácil si tener la diabetes. Mi papa no, usa la insulina yo pienso que no puede vivir sin insulina ya. Pasa uno por la insulina a ver. Porque mi abuela carga una bolsa llena de pastillas. Ella esta viva no más por las pastillas. Puras pastillas.

It's not an easy thing to have diabetes. My dad no, he uses insulin. Now I think he can't live without insulin. You see you end up on insulin. Because my grandma carries around a bag full of pills. She is only alive because of the pills. Just pills.

Francisco expresses concern about his father and insulin, believing he is dependent on insulin. Then Francisco thinks, "Well, my grandmother walks around with a bag of pills. Which is worse? An injection or being dependent of pills". (translated from Spanish). Tomas, the third brother, recalls an aunt of his in Mexico who has low blood sugar.

A veces lo que decimos ocupa que a ver si anda uno trabajando de repente le sube el azúcar o como una tía que se le subió y un día que se puso bien blanca y tuvo que acostar y dijo 'dame una pastilla de esas mi hijo' y dije 'porque tía' y dijo 'es que se me bajo mucho el azúcar' Y hijole todo tiene que hacer le digo y dijo si. Tiene una que cuidarlo mucho igual a tu papa y tu mama. Se que también ellos lo tienen. Le digo pues eso si. Bueno nos preocupa verdad ahora que mi papa inyecto o de acá es lo que nos pues estamos

Sometimes what we talk about is the concern that if you're working and suddenly your sugar goes up like with my aunt it went up and one day she

went really white and she had to lie down. She said 'give me one of those pills son' and I said 'why auntie?' and she said 'my sugar went down a lot.' And wow it's that I say and she said 'yes. You have to take great care of yourself like your mom and dad. I know that they have it as well.' I say well yes.

Tomas is concerned about these types of episodes occurring with his father on insulin. The chance of these episodes is what concerns him. All three sons speaking together had varying concerns about their father using insulin as a treatment for his diabetes. Clearly for these three sons, insulin use is not just another medical therapy, it has emotional implications such as worry and concern and for one son the need to avoid worry or anxiety. The emotional aspects are a significant part of these sons' stories of living with a Dad with diabetes.

These three sons, Jesus, Francisco and Tomas, in one interview event offer three distinct perspectives. Jesus has a positive approach, viewing his father as managing his illness and insulin with calm and if one does that they will be okay. While Francisco demonstrates a more tentative approach to his parent's diabetes, he expresses concern about the dependency on insulin and that it can be viewed as worsening of the disease. The third son, Tomas, expresses concern about hypoglycemic episodes with his father in terms of a personal memory and experience with an aunt. In the larger story, Tomas is often very concerned about his own risks of diabetes. He fears becoming a diabetic due to strong family history, and because he is wheelchair bound and unable to exercise. Meaning, therefore, is ascribed to insulin use based on personal interpretation. One cannot assume that the meaning of insulin use is always a sign of worsening disease; this meaning is embedded in personal context.

Manuela, Cristina's mother, experiences many episodes of hypoglycemia. For her

daughter these episodes are a daily reminder of her own future. Cristina views her mother's insulin use as making her diabetes increasingly more complex. Cristina sees her mother's disease pathway as her own. As the caretaker for her mother, she worries as she struggles to manage her mother's hypoglycemic episodes.

For family members, using insulin adds to the complexity of the disease and is viewed as a sign of worsening illness. They, in turn, become increasingly concerned about contending with this risk of hypoglycemia and increasing symptoms. Insulin injections are seen as dependency, since they need to inject themselves to stay alive.

Home blood glucose monitoring.

A daily task of the diabetic routine is home blood glucose monitoring. HGM (home glucose monitoring) is a way to monitor your blood sugar levels and keep track of your diabetes on a daily basis. For health care providers, home glucose monitoring is understood as a norm for persons living with diabetes, a daily routine to be incorporated into one's life. At health care visits, the question is asked, "How are your blood sugars?" Yet for many of the participants in this study, they did not always monitor their blood sugars. The reasoning was complex and involved various physical and emotional issues.

Juanita does not check her blood sugars. Her reasoning is simple-she washes lots of dishes daily and her fingertips hurt. She has no symptoms of diabetes and is unsure in what way the information will help her. Yet it troubles her that she often lies to her doctor about daily blood sugar checks. Juanita does not want to be a person who lies.

Similarly, Elvia does not check her blood sugar regularly. She does not like to see blood and her fingertips hurt. She knows she should develop a routine and check her blood sugar daily. After eight years of living with diabetes, she has not been able to do

this.

Berta does not check her blood sugars either, her thinking about blood glucose monitoring is complex as demonstrated by parts of her story.

Pues mas o menos. Porque no me pongo a pensar tanto, porque digo no, entre mas pienso mas me siento mal. (laughter) Trato de hacer lo bueno si no pienso tanto. Se que es una enfermedad seria verdad, pero no quiero exactamente estar pensando no mas de que es seria la enfermedad.

Well more or less. Because I don't think about it that much. I say no, the more I think about it the more I feel bad. I try to do the right thing if I don't think about it so much. I know that it's a serious disease right, but actually I don't only want to be thinking about the seriousness of the disease.

A una tambien se preocupa verdad por pensar que esta mal porque pues una tambien, verdad. No quiero vivir tan pensando en mas que estoy enferma, que estoy enferma. Quiero vivir un poco distraido verdad que no esta tanto en pensando que estoy enferma verdad. Yo trato de pensar tanto y vivir tranquila.

Also you get worried right, thinking that you're ill, because one does right. I don't want to live just thinking that I'm sick, that I'm ill. I want to be a little relaxed right, so I'm not thinking so much about being sick. I try not to think about it so much and live without worrying.

Berta's thinking influences her behavior. Berta does not check her blood sugar because what would she do if it were high? She does not know what she would change and then she would start to worry. For Berta, it is not denial that she has a disease but rather avoidance due to the emotional difficulties diabetes presents. Having an elevated blood sugar as noted by checking would indicate she was ill, and then she would have many worries and need to think about this disease.

Dominga responds similarly to the challenge of home blood glucose monitoring. Checking her blood sugar only occasionally, Dominga worries if the blood sugar reading is high. She tries to eat healthy and her level is never below 200. "*Pero yo siento nada.*

Me dijeron que mi cuerpo ya se acostumbro. I don't feel anything. I'd say my body has just gotten use to it (the high blood sugar level)."

A headache with a blood sugar over 300 is one symptom she experiences but otherwise she feels fine. She does not check her blood sugar because she is calm and relaxed. She does not want to become emotional about her diabetes. If she checks her sugar, her fingers start to hurt. Dominga believes she is currently in a good state of mind, and does not want to change that. She does not want to believe she is sick, desires to view life positively and does not want to burden her children. Due to her family history of diabetes and cardiovascular disease she believes she has suffered enough, she cannot worry about her health and burden her family.

In summary, home blood glucose monitoring is an integral part of diabetes management. Although there are many physical and emotional issues associated with home blood glucose monitoring, other persons living with diabetes in this study scarcely mentioned it. Family members, as well, rarely mentioned it in their stories, most likely because it is a routine daily experience similar to brushing your teeth and flossing. Yet for certain participants this activity represents another emotional dimension, adding to the complexity of the daily experience of Type 2 diabetes.

Diet.

Managing one's diet is a key component in taking control of diabetes, and dietary changes are complex. Seen earlier in the stories of Tale of Tortillas, there is a strong emotional and cultural connection to food. For these families, taking medication, injecting insulin or monitoring blood sugars are seen as individual personal activities. Yet dietary changes are a family affair. Families help and hinder the person making dietary

changes. Intense family conflict may ensue over diet; conversely, family members offer great support and encouragement. Food and mealtimes can define a family, so in this arena diabetes becomes the daily family disease.

Elvia's and her family's story is a story of struggle around dietary changes as well as other needed lifestyle changes. Elvia struggles on so many levels with dietary changes. A vending machine habit is difficult to break since she doesn't like to eat breakfast and then becomes weak and dizzy at work and grabs something from the vending machine. She realizes that there is only junk food in the vending machines and needs to stay away from them. Elvia has stopped drinking regular pop and only drinks diet pop, a dramatic move for her. Her two daughters, Teresa and Adrianna, regulate her buying regular vs. diet pop in the grocery store and also hide candy from her around the house.

Elvia presents the cultural expectations of a woman.

Because in our culture, the woman is supposed, not everyone does it but to serve their husband. When you are done cooking, you are supposed to serve him-have their tortillas ready there even if they're fake tortillas. Have everything there ready there for them, have their glass, you know.

Elvia states she needs to serve her husband. One way to serve her husband is to have his tortillas ready and hot at dinner. In addition, she butters his toast in the morning. For Elvia, this cultural expectation can often make it difficult for her to follow the necessary diet, since unhealthy food is readily available, making it difficult for her to follow her diet.

Elvia, however, knows her husband will support her in any dietary changes she makes.

Because I told him. You got to help me because I can't do it on my own. So he really would change his diet for me. He wouldn't eat some of things, doesn't like yogurt or anything. I would buy more yogurt and granola and stuff like that. And he would tell me. Buy it, Buy it so you can stay healthy.

Yet, dietary changes remain a struggle for her due to both family and marital expectations.

Her husband, Ernesto, also struggles with the family's need to make dietary changes. He wants to encourage his wife to cook healthy, make salads and such for dinner, yet according to him she has resisted changing her ways of cooking. Ernesto often comes home late from work and will eat whatever she has cooked. Ernesto feels they should go out to eat as a family only at healthy restaurants such as Olive Garden, but he blames himself and states that they are a bit lazy and are going to McDonalds, to taco stands or are getting take out fried chicken. Ernesto wants his wife to cook healthier, and at the same time wants himself to be more motivated to eat out in a more healthy manner.

The daughters, Teresa and Adrianna, want to help their mother, yet view themselves as kids and do not want to nag. They worry when their mother's blood sugar goes up and she becomes stressed out and does not feel well. Family members all want to help Elvia follow a diabetic diet but do not always make the necessary lifestyle changes themselves and at some level undermine her. The family feels bad when Elvia is unable to follow the diet. Elvia feels devastated by her own inability to follow a diabetic diet. Her husband Ernesto is emotionally overwrought when she drinks a 2 liter of soda at one sitting. Yet he is willing to go out to fast food restaurants for dinner when it is convenient for him. The whole family worries about her, but do not often do the constructive things needed to help her. For her part, Elvia does not follow through on her treatment and then causes a lot of stress in the home with her mood swings and not feeling well. For this family there are multiple dimensions which impact their ability to make dietary changes needed to help their mom and wife.

Florencia, who is age 58 and has diabetes, lives with her son Roberto and his wife Debbie, an white (Anglo) woman. After joining a chronic disease support group, Florencia tells her story of change. She has gone from being in chronic pain with decreased movement to integrating many dietary and other lifestyle changes into her life, and notes so many positive changes in her health.

Specific details are given about her daily diet. For example, for breakfast she eats a small amount of oatmeal with 1% milk and uses only “Splendor”. For lunch she eats diet yogurt with fruit. She eats only wheat crackers and wholegrain breads. She often makes a vegetable soup for dinner with 2-3 tortillas. In the past, she would eat 10-12 tortillas at a sitting. Now she is eating much less.

Her dietary changes have produced conflict with her daughter-in-law who likes hamburgers, French fries and sweets. At times, there is no healthy food in the house for her to eat. Her son, according to Florencia, is willing to go to the store to buy a salad, and so while there is conflict about her dietary changes, her son is willing to support her.

According to Debbie, the daughter in law, these dietary changes have been difficult. Although the conflict was understated, you could sense it during the interview. Debbie acknowledges there is often conflict about the kitchen and they work it out, laughing nervously. It is resolved by “*Whoever gets there first.*” Oil is used in cooking and the daughter in law likes to fry food. Debbie objects when the mother-in-law cooks without oil.

Roberto, the son, feels financial stress being the only breadwinner in the family. Yet he acknowledges being willing to support his mother. However, later in the interview he stated that since his mother is doing so well, *pues vale la pena* (it is worthwhile), and

Asi la siguen apoyando (they will continue to support her in spite of the extra costs for her food). In stating this, I thought about the context. His mother was sitting right there. Did he say this for her? Also did he say this for the benefit of us so we would view him more favorably? These are questions that arose in this interaction..

Many contexts interact in this particular family's conflict around food. The classic stereotypical conflict exists between daughter-in-law and mother-in-law, around household chores such as cooking and whose space it is, i.e., the kitchen. Cultural conflicts also exist. The daughter-in-law is Euro-American while Florencia, the mother in law, emigrated from Mexico only in the last couple of years. Clearly, an understanding of family roles is vastly different between Mexican and dominant Anglo culture. The financial strain upon this family is great, as described earlier, and this pervasive strain leads to a increased conflict between family members.

Gabriela, a 21 year old daughter of Pedro, describes the dietary conflicts their family has experienced.

Pues cuando el empezó, que llegamos aquí, que le hicieron que se tenia que cuidar mucho porque la tenia muy alta. El al principio si que mas vale [interruption with crying child] Cuando el lleo aquí ya le dijeron que tenia avanzada la enfermedad, muy alta. Tenia que cuidarse demasiado; que tenia que dejar de tomar, porque cuando lleo aquí también tomaba y no hacia caso. Entonces le dice mi mama, lo regaño y le decía 'no que tenias que dejar de tomar y allá andas comiendo carne de cochino. Que andas comiendo grasa y que andas comiendo esta y que andas tomando y todo.' Entonces el no mas le daba risa 'aye, no mas es un pedacito y ya.' 'Pero eso te hace daño' le decía mi mama y 'tienes que seguir las instrucciones de la doctora.' No se quien lo esta atendiendo ahorita y entonces dijo mi papa 'solo es un pedacito pues esto pasa.' Pero si, así paso y hasta que un día se sentía tan mal y se la tenia muy alta y volvió a ir con el doctor y entonces le dijeron que si tenia que ponerle mucho de su parte para controlar su misma enfermedad. Si el tiene también su ayuda de el mismo. Porque si el no la tiene esa ayuda de el mismo pues no la puede controlar. Entonces ya como dijo la doctora que tenia que comer mucha verdura y así cosas no tan pesadas para esa enfermedad que la

verdad no se que lo tiene que dejar de comer excepto la carne de cochino pero no se; porque es mucha grasa, no se. Y ese ahorita ya casi no lo comemos aquí en la casa porque para el. Porque el comía mucha carnita y traía mucha carnita de la carnicería y todo y todos los días la carnita y bueno y a eso dejamos de comer ahorita porque como vean todos estamos gorditos aquí. Y nadie quiere estar así. Y ya no. Si ya nada de carnita nada de nada. Mejor sana ahorita comemos y ya. Si. Y hasta que pues si. Ahorita la verdad esta siguiendo las instrucciones mí papa. Si, a cada ratito el va allí pinchando el dedo para ver bien su enfermedad que el tiene y chequeársela bien y todo. Y ahorita si esta siguiendo las instrucciones de su doctora y todo. Toma sus pastillas y todo y ahorita lo veamos más tranquilito. Cada vez que se siente mal el se chequea y si anda chequeando. Pues gracias a dios no, que ahorita la ciencia esta muy avanzada. Porque esta muy avanzada ahorita y ya la verdad si.

Well when he started, when we arrived here, they(the clinic/providers) made him take good care of himself because it (blood sugar) was very high. At the beginning it (blood sugar) was okay [interruption with crying child] When he came here they told him that the disease was advanced, it (blood sugar) was very high. He really had to take care of himself; he had to stop drinking because when he arrived here he drank as well and didn't take any notice. So my mom says, she scolded him and said 'no, you have to stop drinking and there you go eating pork. There you go eating fat and eating whatever and drinking and everything.' So he just laughed. 'Oh it's just a little piece.' 'But this will hurt you' my mom said and 'you have to follow the doctor's instructions.' I don't know who is his doctor now and so my dad said 'it's only a little piece and it's done.' But yes, that's what happened until one day he felt so bad and he had it so high that he went back to the doctor and then they told him that he had make an effort to control his own illness. He had to help himself also. Because if he didn't help himself well he wouldn't be able to control it. So then the doctor told him that he had to eat a lot of vegetable and things that weren't so rich for this illness; truthfully I don't know what he can't eat except pork, I don't know because it has a lot of fat, I don't know. And we hardly eat any of that now at home because of him. Because he used to eat a lot of meat and he brought a lot of meat home from the butcher and meat every day. So we've stopped eating this now because as you can see we're all fat here. And nobody wants to be like this, so no more. Now no meat, nothing. Now we eat healthy. Yes. Up to now. The truth is now my dad's following his instructions. Yes, every so often he goes to prick his finger to see how well he's doing with his disease and check it well and everything. And now he's following his doctor's instructions and everything. He's taking his pills and everything and he seems calmer. Every time he feels bad he checks himself and keeps checking. So thank God science is very advanced now. Because now it is very advanced and the truth is that now...

Pedro has great difficulty following through on the necessary dietary changes, continuing to eat barbecued pork and drink alcohol. His family is frustrated that he is not taking better care of himself. His doctor also feels that he needs to make more of an effort. Now Pedro has stopped drinking alcohol. Overall the entire family is trying to eat healthier, more vegetables and less rich, fatty meat, with Pedro doing better, both in diet and state of health.

His son, Miguel, and daughter, Gabriela, however, experience a range of emotional issues, including Pedro's alcoholism, around their father's disease. Gabriela feels the whole family suffers because of her father's condition. She also believes her father is wasting away from his disease. Gabriela expresses both conflict and guilt about her feelings towards her father not doing chores and at times, in the past, she did not believe that he was truly ill. Her family, according to her, is falling apart due to Pedro's illness, the stress of being immigrants and family conflict over household chores.

Another family, in contrast, Ignacio and Dominga work hard to support each other with dietary changes. The entire family attempts to follow a strict diet due to the mother's diabetes and the father having a heart attack at a very young age. Dominga discusses the changes they have made in their lives, especially dietary changes.

Y en nuestra alimentación pues, si antes éramos de los que comíamos hasta de lo que no encontrábamos. Ahora pues no le voy a decir que ya no comemos así cosas pero tratamos de evitarlo. Aquí en casa agarro una fruta, agarro una verdura; ahora la hay constantemente, frutas, verduras. Tratamos de... Anteriormente no, es que no buscamos hacer de comer. No pues no hagamos nada vamos a las hamburguesas o vamos al taco bello o vamos... Seguidos nos íbamos a comer por allá por la calle. Ahora si lo seguimos haciendo pero tardamos para hacerlo. Ahora ya mejor preferimos venir aquí a casa y por ejemplo mi esposo come y después de que come el se come un pepino; o el se asienta aquí a comer un pocito de verdura y mi hija de vez en cuando come lechuga con limón y tratamos

también de ir variando. Fue algo de lo principal que cambiamos en nuestras vidas. Nuestra manera de vivir y nuestra alimentación.

Well one of the things that has changed is our way of life and our eating. This is one of the main things that we've changed. We've tried to live life as best we can. Yes. Let's say that before we worried about every little thing and now we try not to; and really it's not just that we're afraid of dying, no. But we are trying to change our lifestyle a little. Before, my husband and I were people who liked to go out to dance. We were often up all night. Every weekend it was a question of going out and having a good time and well now we try to stay away from that because we know that that affects us as well. And then in our eating, before we were people who ate everything they could find. Now, well I'm not going to tell you that we don't eat certain things any more but we do try to avoid them. Here at home I grab some fruit, I grab some vegetables; now they're always on hand, fruits and vegetables. We try to...before we didn't... it's that we didn't make our own meals. No, don't make anything let's go out for hamburgers or let's go to taco bell or 'let's go out...we used to go out to eat all the time. We still do but we're not so quick to do it. Now we prefer to come home and for example my husband eats and afterwards he eats a cucumber; or he sits here and eats a little vegetable and my daughter sometimes eats lettuce with lemon and we try to vary it. This was one of the main things that changed in our lives. Our lifestyle and our eating.

Dominga describes the changes they have made as something they

are doing together as a family. All of the family are trying to eat more

vegetables and go out and eat less fast food.

Ignacio states:

Ella pues mas que nada lo que debe de tener es un ejemplo con migo porque a segun yo se lo poco que lei sobre esa diabetes es de que la diabetes también como es una enfermedad crónica viene afectando y viene terminando también en un infarto al corazón o un derrame cerebral o perdida de la vista. Entonces eso es lo poco que lei yo. Me gusta leer mucho. Yo pienso que si ella vea como soy, su, o sea no estoy sufriendo si no que como estoy luchando, no quiero utilizar la palabra sufrir porque no me gusta. Entonces yo mejor lo cambio por, porque ella vea como estoy yo luchando o que ella vea como estoy yo luchando para poder seguir o estar bien. Tomo mucha medicina y me toca estar bien echarle ganas que hiciera la fuerza. Pues ella que todavía o que tenga el chance ella todavía no llega al momento. O que sea ella que vea a mi, que la situación no es fácil. Ella debe de ver en mi creo yo que debe de echarle ganas para que ella no este como yo, tomando tanta medicina. Y aparte

de que, o que sea no me vea que como mucho o que yo como una cosa o como el otro

So more than anything what she needs is for me to set an example because according to the little I read about this diabetes, diabetes is also a chronic disease that continues to affect you resulting in a heart attack or a stroke or loss of vision. Well this is the little I read. I like to read a lot. I think that if she sees how I am, let's say I'm fighting/struggling instead of suffering, I don't like to use the word suffering because I don't like it. So I prefer to change it, because she can see how I am fighting or she might see how I'm fighting so I can carry on or be okay. I take a lot of medicine and I have to try hard to keep up my strength. So I hope she still might stand a chance of not getting to that point. Or it might be that she sees me, sees that the situation isn't easy. She should see in me, I believe that I should motivate her so she doesn't get like me, taking so much medicine. And apart from that, hopefully she sees that I don't eat a lot or that I eat one thing or another

Ignacio's heart disease and his wife's diabetes are similar diseases, according to him, and because of this fact, Ignacio and Dominga can support each other. In addition, Ignacio sees his role as head of the household as setting an example for his wife. He wants to use the word *luchando* (struggle) rather than the word *sufriendo* (suffering), believing that by changing the words or language you use, your mindset about your chronic disease can change. Ignacio believes his wife looks to him for support, yet she supports him in eating healthy foods he does not like.

Ignacio, like Gabriela and Miguel, express the emotional dimension of having a chronic illness. In constructing his story, his family's emotional concerns come after his description of dietary changes. *Antes y Despues*, (before and after) Ignacio acknowledges having an anger problem with his wife and children "no longer". With chronic illness affecting both of them, Ignacio knows he needs to respond more calmly to his wife and children. In the past, his anger was a problem with his wife, but "it is no more". This participant is working on responding more calmly toward his wife. In all of his stories,

Ignacio has a real positive tone, often ending narrative with *salir adelante*, meaning his family needs to better itself and move onward and upward.

Ignacio's children speak of a strong desire to help and support their parents. The family's diet has changed a lot, there are fruits and vegetables around the house and they rarely go out to eat anymore. Maribel and Fernando support their parents by trying new foods; there may be things they don't like but they will try them. Furthermore, Maribel and Fernando express concern about the emotional dimension of the disease, they want their whole family to stay calm and manage their anger better. Fernando does not want to stress his mother and make her blood sugar go up by staying out late or fighting with his sister. For this family, working hard to change their diet, the emotional dimensions of family change is important as well.

Patricia watches her diet closely yet her family did not change their diet. She was a quiet, self-disciplined woman. Growing up, her son and daughter did not know she was diabetic until they were adolescents. Her son realized once when he went grocery shopping with her that she purchased different foods. Her daughter, Liliana, had gestational diabetes during her last pregnancy and looked to Patricia for advice and support. Liliana gave up sweets and sodas and started to drink diet soda and water. Liliana believes that someday she may become a diabetic but she feels that she has a good example in her mother to follow.

Patricia's family is a family where the person with diabetes sets an example for the rest of the family. The children are concerned about their risk of diabetes and request information. They are motivated to change their behavior to prevent diabetes, encouraged by their mother's diet and lifestyle changes.

Since Carlos was diagnosed nine months ago, the family diet has changed dramatically. His wife Lupe desires to help him and relays the many changes they have already made in their diet. In the past, the family did not always eat so healthily which she attributes to lack of information as well as bad habits. Now she describes the changes they have made and her husband's struggle with losing weight.

A ellos no les gusta mucho comer vegetales pero yo he tratado de darles mas, incluirles mas vegetales, menos grasa y con migo no es tanto problema pero con ellos si es mas problema y en cuanto a mi esposo pues el esta comiendo menos, ha bajado un poco de peso, no tanto porque el sobrepeso que el había acumulado pues yo creo que en seis meses va a estar en el peso que el debería estar no pero ha ayudado un poco la manera de alimentación, pues el se animas un poquito cuando ve que ha bajado un poquito, y también cuando su doctor le dijo que tenia que bajar tantas libras, yo me quede con la boca abierta porque dije, 'yo no se si esta va a ser posible pero hay que intentarlo', pues también no puedo ser negativa diciéndole esto es mucho, nunca los vas lograr, pero, si asea ya tenemos que pensar mas seriamente que tenemos que alimentarnos mejor y como son hábitos también que uno tiene, tal vez no va a ser tan fácil pero yo creo no va a ser imposible tampoco a tratar, pero horita en cuanto a esto el ha estado perdiendo un poquito de peso y comiendo menos.

They don't like to eat vegetables much but I've tried to give them more, to include more vegetables, less fat and for me it's not such a problem but for them it's more of a problem. As for my husband well he's eating less, he's lost a little weight, not that much because he had put on a lot of weight but I think that in six months he's going to be at the weight that he should be, right. But the way of eating has helped some as he gets a bit more motivated when he sees he's gone down a little. Also when his doctor told him that he had to lose so many pounds I stood there with my mouth open because I said, 'I don't know if this is going to be possible but we'll have to try.' Like you can't just be negative saying that's too much, you'll never make it, but if you shape up... now we have to think more seriously about how we need to eat better and also what our habits are. Perhaps it's not going to be so easy but neither do I think it will be impossible to try. So right now in this respect he has been losing a bit of weight and eating less.

Lupe has tried to integrate changes in the whole family's diet. Her husband has made changes and lost weight but he has to lose a lot more. Lupe wants to support him

but is overwhelmed at the amount of weight he needs to lose. She does not want to say anything that could be seen as negative such as, that is just too much weight to lose. She feels that the family needs to rally around her husband.

Carlos's two sons know that following a diet is necessary for their dad's health. Arturo describes how the family buys different foods such as more fruits and vegetables. His mom lets them buy junk food but in smaller amounts and she wants them to eat it in the car. If he and his brother bring it in the house, they don't keep it in plain view of their Dad. Yet if he does eat junk food or sweets, they both noticed that he does limit himself. In the past when they went out for fast food, they used to bring whole meals home to their dad; now they just bring a little taste for him. Both sons think about not eating junk food in front of their Dad as they do not want to tempt him.

Antonio, the younger son, states he no longer brings donuts into the house. His mom lets them drink Gatorade but no sugary snacks in the house. When his mom cooks dinner, there is less fatty or greasy food and she cooks a lot of vegetables. Antonio hates vegetables but he eats them. He feels that if he eats them in front of his dad, it will be easier for him to eat the vegetables. Arturo as well, agrees that he also eats vegetables to help and support his Dad.

For Carlos and his family, his recent diagnosis has meant a lot of changes yet his wife Lupe and two sons have rallied around to support him with his diet. Certainly, there are hints of conflict. Lupe feels at times that her husband believes she is treating him like a child and that she nags him about his behavior. The boys feel a bit deprived that they cannot bring certain foods into the house, yet they certainly want to help their dad do the right thing.

The diet and necessary dietary changes are the family dimension of diabetes, for diabetes can no longer be viewed as an individual person's disease. Dietary changes with diabetes encompass both cultural and emotional dimensions, invoking passion for food as well as other strong emotions. Family conflict can ensue when the person with diabetes does not always follow necessary recommendations. Family conflict also presents with differing expectations around diet and necessary changes. This conflict can encompass family roles, and economic and cultural issues. Yet family members do support each other and make dietary changes together as a family. These families, while still struggling to make changes, see diabetes as a family issue and try to support each other as changes are being made. They recognize the importance of staying calm, decreasing stress and anger and everyone making changes together.

Exercise.

Becoming more active or increasing exercise is another *cambio* in one's life. Like diet changes it can be difficult for persons with diabetes and their families to make exercise routine and systematic. Exercise has emotional meanings for participants which at times makes the change more challenging.

Elvia finds exercise very difficult and constantly struggles to stay motivated. Elvia can't do situps, which she finds embarrassing. Her daughters have offered to buy her a membership to Curves (a health club) to exercise, however, she does not want to have anyone watch her exercise. Her doctor has encouraged her to exercise, especially to walk when her blood sugar is elevated. Elvia tells of one time she had a bad headache (which probably indicated her blood sugar was elevated) and she went for a walk around the block. Right now, Elvia feels the only thing she can do in terms of exercise is to walk.

Later in this story she also explains how in the past she had planned to start exercising, walking around the track or going out and walking the dog, but she doesn't follow through. She was going to join Weight Watchers but her husband Ernesto thought it was a waste of money due to her lack of follow through. In addition, Ernesto was concerned that dinner was not ready or other household chores were not being done. Yet she continues to try. She and some coworkers are going to start walking during lunch break. One of the themes of this story is her trying and trying again. Although making behavioral change is very difficult for her, she knows she needs to continue to try.

For Elvia and her family, her need to increase exercise is a source of family stress. Her family often helps and supports her like offering to buy a gym membership, while her husband hinders her by undermining her efforts at Weight Watchers and insisting that meals be ready at a certain time. This family's story clearly indicates the complicated dynamics around the necessary changes needed to manage diabetes.

Dominga's family works together to support one another in exercise, often going to church functions on Friday nights to play sports such as football, volleyball and other games. Dominga also has increased her walking. However she has a great fear of running or walking too fast, relaying this story of a co-worker and running.

Una compañera de trabajo porque a la hora de lonche ella se fue a correr y regreso bien cansada, bien agitada. Y yo le dije, porque ella también esta gordita y ella tiene colesterol; entonces yo le dije a ella 'sabes que, no corras así porque te puedes hacer daño. Te puede dar un ataque al corazón porque tu cuerpo no esta acostumbrado...'

: Si. 'Tu cuerpo no esta acostumbrado, entonces si de repente sales, corres, lo vas a forzar demasiado, entonces no hagas eso.' Y quizás por eso yo también, yo cuando salgo yo no corro. Realmente yo no corro. Porque para empezar, si me da miedo porque pues imaginase mi padre tuvo un infarto. Mi hermano tuvo un infarto. Y ahorita mi esposo. Si entonces realmente a mí si me da miedo porque dije yo pienso si corro y me agito, si vengo con alguien pues me va a ayudar, pero si vengo sola

allí me voy a quedar tirada. Entonces lo único que hago es caminar o a veces allí en la clínica nos dieron unos casetes que luego son para hacer también como relajamiento.

A co-worker because at lunch time she went jogging and came back really tired, really out of breath. I told her, because she's also overweight, and she has high cholesterol; so I said to her 'you know what, don't run like that because you might injure yourself. You could have a heart attack because your body isn't used to it... your body isn't used to it and so if you suddenly go out, you jog, you're going to put too much stress on it, so don't do it.' And perhaps because of this when I go out I don't run either. I really don't run. Because to start with I'm afraid because, think about it, my father had a heart attack. My brother had a heart attack. And now my husband. So for me I really am afraid as I said because I think that if I run and get out of breath, if I'm with someone well they'll help me, but if I'm alone I'll be stuck there flat out. So the only thing that I do is walk sometimes, or they gave us some tapes there in the clinic as well that are about doing like relaxation.

For Dominga, both her family history and her husband's heart attack have made her fearful of exertional exercise and she prefers relaxation tapes. In reality, she exercises occasionally. Based on her family's experience of heart disease, the change needed to exercise is emotionally difficult.

Rocio, on the other hand, has embraced regular exercise. As part of a chronic disease support group she has learned the benefit of exercise. Her oldest daughter, Esmeralda, has purchased a treadmill for her. Her daily routine is to get up and use the treadmill. Each day she walks a half hour to her sister's, to help her, sometimes walking 2-3 miles a day. Her daughter says "let me drive you over but Rocio says, no she can walk."(translated). For Rocio, exercise has given her new confidence in her abilities.

Carlos describes the changes he also has made since his diagnosis with diabetes 9 months ago.

Antes llegaba me bañaba comía me sentaba en el sillón y me ponía a ver la televisó, eso era antes, horita hago lo mismo, pero termino de comer y si el día es bonito me voy a caminar, ese es el único cambio, hacer

deportes no, no lo hacia así que siempre llegaba a casa pero horita he cambiado en salir a caminar mas seguido con los niños. Caminando 45 minutos media hora.

Before I used to come home, take a bath, eat and sit on the sofa to watch television. This was before. Now I do the same but I finish eating and if it's a nice day I go out for a walk. This is the only change. Playing sports, no, I didn't do that. I always came home but now I've changed in that I go out to walk more often with the children, walking 45 minutes or half an hour.

Carlos speaks very clearly in a before and after tone. He is trying to incorporate increasing exercise into his life. Carlos is trying to move from being a couch potato to having some form of regular exercise in his life. His two sons, Arturo and Antonio, have noticed a difference. Their dad is now somewhat agitated that he has diabetes. Before he was, as they described it, more laid back, just laying down and watching TV. The younger son describes how he now walks around and takes his little sister for walks. In the past, he never got any exercise.

For the *Cambios en Nuestra Vida*-changes in our lives, there are many complex dynamics which come into play. There are distinctly Mexican beliefs, attitudes and feelings which impact the multitude of behavioral changes needed for Type 2 diabetes. Beliefs in other worlds, legends and Latin evangelical understandings greatly influence the diabetes experience. Managing blood sugars and glucometers can be difficult for patients with low literacy skills who struggle with interpreting numbers and their meaning. In addition, symptom management is difficult for persons with diabetes and their families. What symptoms mean and what action should be taken based on symptoms is conflictual for persons with diabetes in this study. The response to symptoms can often be harmful to participants. Certain other participants avoid necessary diabetes management behaviors because they want to avoid worry. Insulin administration can also

evoke strong emotions of fear and anxiety for participants who are currently using insulin, and those who worry about the potential of worsening disease and needing insulin in the future.

Yet many of these *cambios* involved the entire family. These family stories demonstrate that family members worry about insulin; the dependency, and the worsening of disease it signifies. In the arena of food and diet changes, there can be intense family conflict when the person with diabetes does not follow the recommended diet. Family members do not fully support the person with diabetes by bringing take-out chicken or pizza into the house. Yet family members can be immensely supportive of necessary dietary changes such as children eating the vegetables they do not like to encourage a dad with diabetes. In the arena of exercise, family members attempt to encourage the person with diabetes to exercise with mixed success. Other times, family members are supportive and purchase a treadmill so their mother can exercise. Changes are varied, complex and chaotic, yet do involve the entire family. Families, as well, are complex, both helping and hindering the person with diabetes. Clearly, the *cambios* are being renegotiated frequently in the present moment-the day to day world of living with Type 2 diabetes for these families.

Preocupaciones for el futuro (Worries for the Future)

The future looms large in the stories of these persons with diabetes and their family members. For the health care provider, the future with diabetes is generally thought to be one which you can manage and control by making certain changes and addressing the multiple complexities of the disease. Rather, I believe, the narrative health care providers should be telling patients is that Type 2 diabetes is a difficult degenerative

disease and can be more difficult to control over time. These 10 families do not view their futures with great optimism and confidence but with worry about their health, thoughts about their own death and the impact their suffering and death will have on their family. These persons with diabetes, having seen their parents, brothers and sisters suffer and die from diabetes, now agonize over their children and the possibility that this disease might afflict them.

Cristina, a 54 year old diabetic, looks to the future, believing that secondary complications of diabetes cannot be prevented but only delayed, put off for a few years. Maybe if you manage your diet and exercise, you can hold off the *bad stuff*, hold off the complications for awhile, but you cannot truly control this disease as one is told in diabetes education classes. One can only forestall the inevitable. Cristina does not approach her future with confidence; because after all, diabetes “*affects every part of your body, every single part, your eyes, your limbs, your kidneys, your heart and your veins, everything, you know affects everything*”. Her hope for the future is that she can forestall her complications until she is 70 or 80, and not suffer in her 50’s while she is still young and active.

Dominga, 34 years old, worries about the future for her children. She has experienced much sickness and death in her own family. Dominga looks to the future and desires for herself and her husband living with heart disease at 32, not to become a burden to their children. Thinking about her own death, she wants it to be a quick one so she does not linger for her two children and cause them unnecessary suffering. Clearly, Dominga is a very young woman to speak of death. The family experience of Type 2 diabetes, for her, is one of overwhelming loss.

Patricia, a quiet woman who has lived with diabetes for 14 years, is concerned for the future of her children. She maintains strict control and has not experienced any complications. When her children were small she watched over their diets and continues to as they are young adults.

Y necesita a cuidate mucho a mis hijos porque con este enfermedad, siempre. Renegaba, siempre renegaba mucho con esta enfermedad, yo le digo. Porque nosotros tenemos esta enfermedad. Y le puro ya atendemos y renegaba, mucho. Si este con mis hijos, yo le digo no come este porque hace daño, no come tanto dulces porque hace daño, yo soy con ellos no comen lo que hacen daño me deben cuidarse a horita están a mío.

And I need to say take care to my kids because of this disease. I was in denial, I tell you I was always in a lot of denial about this disease. Because we've got this disease. And the truth is now we're paying attention and I used to really be in denial. Yes, with my kids I'm, I tell them don't eat that because it's harmful for you, don't eat so many sweets because they're harmful for you, with them I'm don't eat what will harm you and they need to take care of themselves right now.

After the death of her father, she looks back to the past and her family's life and then looks to her children's future with real concern. Patricia believes she has been in denial about the risk for her children.

Patricia also worries specifically about her 22 year old daughter. She is overweight and does not exercise. Patricia wishes she would work outside the home and then receive more exercise since she does not like to walk. Patricia is fearful her daughter will become diabetic soon, that it is only a matter of time. For Patricia, her worries are not of herself but of her children and their futures.

Rocio worries for her daughters Esmeralda, 8 months pregnant, and Beatriz, 6 months pregnant. Esmeralda has gestational diabetes, while Beatriz is now having additional testing for gestational diabetes. Rocio realizes that her daughters are at great risk for diabetes, and she is not sure how she will talk to them about the disease. She feels

they need to have a family talk. She desires to encourage them but is unsure how to do this starting now so they avoid the complications she experienced.

Carlos, with his recent diagnosis of diabetes, worries about the future with a disabled daughter. He voices his concerns.

No le gusta que lo diga y se los voy a decir a ustedes, si algún día yo llego a faltar, yo le pido a dios que primero recoga a mi hija y luego a mi, porque es mi preocupacion, si me preocupo, y es no poder controlar esto, mi hija me necesita, mis hijos me necesitan, pero gracias a dios ellos pueden salir adelante, mi esposa me necesita, pero ella puede salir adelante, eso es lo que me preocupa, mi hija, porque para ella mama y papa son pies y manos para ella, eso es lo que me preocupa.

She (my wife) doesn't like me talking about it but I'm going to tell you; if some day if I falter and end up unable to carry on, I ask God to take my daughter first and then me, because this is my concern. I worry, about being unable to control it. My daughter needs me. My sons need me but thank God they are able to move ahead. My wife needs me but she can move ahead. This is what worries me, my daughter, because for her, mom and dad are her feet and hands. This is what worries me.

I think for Carlos having a daughter so severely disabled impacts how he thinks about his disease and the future. The responsibility of a disabled child weighs heavily upon him. I view his life to be duly burdened with the care of a disabled daughter and a chronic disease, diabetes. Due to the heavy weight and responsibility of a disabled child, he does take his diabetes most seriously.

Lino has lived with Type 2 diabetes for 9 years. He worries about his wife and his 27 year old disabled son Tomas who is wheelchair bound.

Pues a mi lo que me preocupa en el futuro es mi esposa y este muchacho. Es lo que me preocupa. Si me preocupan todos pero ellos son que más me preocupan. Porque el otro muchacho pues el ya tiene su, ya prácticamente la vida esta hecha, tiene su familia. Este muchacho se mantiene todo también, entonces el es lo que me preocupa un poco más porque pues va a tener que buscar su muchacha para que lo acompañe. Si. Y estas son las preocupaciones. O sea ya de que yo me vaya allá de el camino que no tiene regreso, no se que me va a suceder, no se de un

momento a otro pero va tener que suceder y de eso ya platique con mi esposa, con mis hijos saben que yo, cuando yo me voy a quedar impedimento.

Well what worries me about the future is my wife and this boy. That's what worries me. Sure I worry about all of them but they're the ones that worry me the most. Because the other boy well he already has his, already his life is practically made, he has his family. This boy supports himself as well, but he worries me a little more because well he's going to have to look for a girl to be his companion. Yes. And these are my concerns. When I go down the path of no return, I don't know what's going to happen to me, I don't know from one moment to the next but it will happen and I've already talked to my wife and to my children about it and they know that I, when I end up disabled.

Like other participants with diabetes, Lino does not look at the future with optimism and does not believe that he will live a long life with diabetes. Rather, he looks to his future and sees the path of no return, the time when he will be disabled. He believes it is inevitable that he will be disabled. Yet he is concerned for those whom he takes care of, his wife who does not work outside the home and his disabled 27 year old son in a wheelchair.

As persons with diabetes worry about their impending death and leaving their families alone and burdened, family members worry about their loved one having an untimely death due to diabetes.

Ernesto, a husband, worries about a future without his wife.

'No vamos a llegar hacer bien a tu' Y luego me molesta porque las muchachas son parte de esa familia, y de ellas y no van a querer mirar a su grandma, no van a tener grandma, y duele verdad. Que vamos a hacer? Que vamos a hacer yo solo aca? Me duele mucho. Me duele bastante. Las muchachas tambien. 'No vas a vivir tu' y pues duele. No se, no se que hacer. Por eso le digo pues 'cuidate, cuidate, cuidate, cuidate, queremos vivir contigo muchos mas anos'. Pero a ella no le entra nada a la cabeza. Si le duele a todos, me imagino yo que asi como me duele a mi, tambien a mis hijas. Si esta duro todo eso.

Because I tell her 'we're not going to manage to make you better.' And then it bothers me because the girls are part of this family, and theirs, and they aren't going to want to see their grandma, they're not going to have a grandma, and it hurts right. What are we going to do? What are we going to do with me alone here? It hurts me a lot. It really hurts me. The girls also 'you are not going to live' and well it hurts. I don't know, I don't know what to do. Then because of this I tell her 'take care of yourself, take care of yourself, take care of yourself, we want to live with you for many more years.' But nothing gets through to her. Yes it hurts everyone; I imagine that it also hurts my daughters as much as it hurts me. Yes all this is hard.

Ernesto's anguish and frustration were palpable in the interview as he looks to the future and believes his wife will not be there with him. He finds the situation *tan duro* and *difficultoso* (very hard and difficult).

Ernesto's two daughters, Teresa and Adrianna, as teenagers look to the future and worry about themselves. They both know their grandparents on both sides of the family have diabetes. Their mother has diabetes; when will they get diabetes? Overall, they lack knowledge about diabetes and feel like there should be more information out there. Overall, the teenagers in the study felt they lacked information about diabetes since it wasn't taught in school.

Two other teenagers, Arturo and Antonio, worry about their own risk of diabetes. They both believe that with a father with diabetes, they will develop diabetes some day. Yet they are not willing to make the drastic dietary changes their dad made. Maybe later, they both say.

Luz worries about her husband Pedro. What will become of him?

No pues yo a veces me pongo a pensar porque digo yo, el esta enfermo y a veces me pongo a pensar que será de el mañana que le pasa algo a su mama. Y el pues allí le va a recaer mas la enfermedad, pues no va aguantar esa impresión pues que vaya a recibir. Su mama. A veces me pongo a pensar como es uno y ya aquí esta uno acabado. Tantas

enfermedades. Como el enfermo y su mama enferma y que será de una pues.

No, well sometimes I start to think about it because I say, 'he's sick something happens to his mother.' And well he would have a relapse because he wouldn't stand the shock that he might get. His mom. Sometimes I start thinking about how you are and that already you're worn out here. So much sickness. Like he's sick and his mom's sick and well what'll become of you.

In the context of the interview, both Luz and her husband Pedro were able to talk about her fears of her future without her husband, something she had not been able to do in the past. Luz is concerned about being left alone in the United States without her husband.

Another adult son in the study, Roberto, also worries about his future. He does not worry about his mother, Florencia. He believes with the way she follows the diet and exercises that she will be okay. However, he worries about himself. He is not sure whether he has diabetes. He knows he should probably be tested since one of his brothers in Mexico-27 years old -has the disease. "*Me preocupo porque tambien la misma sange. Ojala que yo no la tenga pero quien sabe, pero si me preocupa.*" I worry because I have the same blood (as my mother). Good God! I hope I do not have it but who knows but yes, I do worry. As his mother saw her diabetes/chronic disease starting from her mother, so his future and possible health problems are connected by the same blood of his mother.

In summary, these persons living with diabetes do not view their disease as their own to manage. They look to the future and worry for their spouses and children. In the case of Cristina concern is for herself, but the others are focused on the impact on their families. For a relatively young group of persons with diabetes-no one is older than 54-there is a strong emphasis on death. I believe for some of these participants diabetes is

seen as a death sentence, and they do not have great hope for the future for themselves and their families.

As family members look back to those who have gone on before, they look to the future to what is in store. The family expression of Type 2 diabetes for these families is the common “bad blood” they all share. Looking back, they see the struggle and suffering of parents and grandparents. Peering ahead, they view possibly their own disease, countless difficulties, wasting away and death. As I glimpse into this panorama called daily life with diabetes, I see the turmoil and angst this disease can cause families. Looking back they are not full of hope, peering ahead there are worries and anxieties about the road ahead. This turmoil and angst makes the disease a day to day struggle.

For these families the daily experience of Type 2 diabetes lies in the multitude of challenges, such as finances, medication, insulin administration, diet and exercise.

Conclusion

In summary, this tale of diabetes over time has many themes or meanings. Throughout all the stories, the central theme is of the emotional burden and turmoil of Type 2 diabetes. It is based in the larger political and social context in which these ten families live. Individual familial contexts are expressed through the six stories types. These familial contexts-illiteracy, unemployment, alcoholism, domestic violence and worry, conflict and struggle- all influence the diabetes experience.

The theme represented by story type of *Those who have gone before* is the experience of diabetes as a historical legacy. There is profound loss and sadness around those who have suffered from this disease and passed on. The loss of family members brings up emotions of guilt and sorrow. For persons currently living with diabetes, this is

a sense of borrowed time as well as a certain fatalism that it will all happen to me. For family members, they too worry about the future and are aware of their personal risk for disease.

The shock of diagnosis-susto and coraje explores cultural understandings of the onset of symptoms. These stories demonstrate that this is a disease associated with profound emotions at onset of shock and of an anger held inward.

El susto del bill que te va a llegar-The shock of the bill that arrives-the financial burden of Type 2 diabetes is much more than the bill. Looking back to life in Mexico, these families reflect on the economic difficulties there of managing a chronic disease in a third world country. However, in this country living with diabetes is often about forced choices. These choices are whether or not to go to medical appointments and about whether one is able to afford diabetic supplies or necessary healthy foods.

In Tale of the Tortilla, the cultural and emotional implications of food are explored. Understandings are explored about food as a form of cultural identity. Food is also viewed as an emotional expression. Long life is viewed as eating very little processed sugar and oil, and eating more natural Mexican foods.

Cambios en nuestra Vida describes the multitude of lifestyle changes involved in a diagnosis of Type 2 diabetes. Unique meanings are ascribed to lifestyle changes that are made and sometimes avoided. The meanings of medication, blood glucose monitoring and insulin are complex. There is avoidance of poking a finger to avoid pain as well as avoidance of worry about a high BS reading. Insulin use often signifies to family members a dependency and a worsening of the disease. The dietary changes needed in diabetes have a profound impact on the family. In families there is both conflict and

support. At times the person with diabetes is a role model for others in the family, while in other families a source of frustration and difficulty.

Preocupaciones por el Futuro are worries for persons with diabetes and family members alike. Persons with diabetes worry about disability and a shortened life for themselves. They not only worry about themselves, but about their children and the risk they have of getting the disease. Spouses also worry about being left alone. Overall, there is not optimism but worry and fear for the future.

These stories and their interpretations are borne out of hours of listening to interviews, careful and close listening to tapes, reading Spanish transcriptions and writing thoughtful reflections. But I need to leave the reader of these stories not a message of despair, but of a message of promise. These families do want to support and care for each other, they want to do better for themselves and the family member with diabetes. Although families can be a source of real conflict and difficulties, they also can be a real source of support. I believe for these ten families Type 2 diabetes is truly a family disease, impacting not only the person living with diabetes but all members of the family.

In the summer and early fall of 2005, ten families told their story which became this story. This story is not of one season in time but of living with a disease that has a distinct past, present and future.

Chapter 5: Discussion, Implications and Recommendations

Discussion

The results of this research study indicate a powerful emotional burden of Type 2 diabetes for Mexican-American persons living with diabetes and their family members. The unique thoughts, beliefs and understandings of the diabetes experience for these Mexican-American families are based in historical legacies, causal stories, cultural and emotional meanings of food, economic burdens of the disease and the complexity of changes needed in their daily lives. Based on these results, the findings of this study will be compared to other research studies and implications for clinical practice and research will be addressed. In addition, the strengths and weaknesses of this study will be explored.

Comparision of Findings of Present Study with Related Studies

The findings of this study are similar to other research studies on the Mexican-American experience of Type 2 diabetes. The literature reviewed is organized by the six story types presented in Chapter 4. In addition, due to the qualitative methodology of this study, other qualitative studies of diabetes and chronic illness will be reviewed in relation to the findings of this study.

The scourge upon the generation-those who have gone on before. These families' stories demonstrate the historical legacy of Type 2 diabetes. My findings indicate loss and sadness around family members who have suffered and died from this disease. This loss translates into emotions of guilt and sorrow for both the person currently living with diabetes and their family members. Persons with diabetes (PWD) view the future not with confidence but with a certain fatalism, that all these bad things

will eventually happen to me. Family members, specifically, worry about their personal risk for this disease.

However, the diabetes literature specific to Mexican-Americans has not examined the multigenerational experience of Type 2 diabetes. One nurse researcher extensively studied multigenerational legacies specific to Type 2 diabetes and developed a framework to assist in understanding how persons with diabetes (PWD) represent their world. In addition, this framework can empower persons living with diabetes to make necessary lifestyle changes based on their family's historical legacies of diabetes (Scollan-koliopoulos, 2004; Scollan-Koliopoulos, O'Connell, & Walker, 2005).

Scollan-Koliopoulos conceptualizes a mutigenerational legacy of Type 2 diabetes based on multigenerational determinants that impact an individual's adaptation to a diagnosis of Type 2 diabetes. The prior generation's experiences influence at-risk family members of subsequent generations. The need for attending to the multigenerational legacy of Type 2 diabetes is due to the epidemic status of this disease as well as the earlier age of onset now seen. For example, an individual may have preconceived notions or anticipated outcomes based on family members' experiences which impact their own attempts at management. An individual may carry over family myths regarding diabetes into his/her own perceptions of the disease. A family who has a history of repeating illness through generations develops certain myths and beliefs. Conversely, multiple members of the family having diabetes may enhance self-management attempts for other members impacted by the disease, providing greater support and cohesion around the disease (Scollan-koliopoulos, 2004). In my research study, both perspectives were evident in the families' stories. Myths and beliefs presented themselves in certain

families' stories as influencing behavior, while in another family, the person with diabetes provided an example of healthy lifestyle habits to her entire family.

This multigenerational legacy of diabetes can profoundly impact the next generation's illness representation or understandings of Type 2 diabetes. One or two members of a family's understandings of life with diabetes have implications for generations to come. Although Scollan-Koliopoulos (2005) does address the possibilities of culture-specific legacies for various cultural groups profoundly impacted by Type 2 diabetes, she discusses in generalities. What is needed is a uniquely Mexican-American framework for understanding the multigenerational legacy of Type 2 diabetes for this population, a noted gap in the research literature.

Un gran susto.

Certainly in my study, *susto* played a prominent role in diagnosis stories for immigrant families. *Susto*, a great shock and/or *coraje*, an anger held within, are the emotional foundation upon which the diagnosis of diabetes is built. I believe that *susto* and *coraje* can be understood in a number of ways. Explanatory models are stories people construct to make sense of an illness within the context of their culture (Kleinman, 1988). Chapter 3 presents additional information on explanatory models. For Type 2 diabetes, the concept of *susto* integrates both folk illness and biomedical beliefs, intersecting two cultures or world views. This integration occurs in Mexico or here in the U.S. as part of the immigrant experience. A *susto* event is often viewed as a causal story, an understanding of "what caused my disease".

Susto and other emotional attributes of Type 2 diabetes are discussed in the nursing literature examining the Mexican-American experience of Type 2 diabetes. *Susto*,

according to a study by Jezewski and Poss (2002), is an explanatory model of diabetes, since this great fright or shock was felt to be the primary cause of diabetes.

In anthropological literature, *susto* is a “folk illness” that results from a frightening or traumatic experience which leads to anxiety, insomnia, listlessness, loss of appetite and social withdrawal (P. J. Brown, 1998). In Jezewski and Poss’ study along the Texas-Mexico border, most of the participants did not view *susto* as an illness per se but as a precipitating condition that can lead to diabetes. For these participants, no specific treatments for *susto* existed, but there were specific biomedical and folk treatments for Type 2 diabetes, the disease that *susto* caused (Jezewski & Poss, 2002).

A focus group study conducted among Mexican immigrants in the Skagit and Yakima Valleys, two large agricultural regions in Washington, confirmed my findings of *susto* as the emotional foundation of Type 2 diabetes. The study demonstrates that experiencing strong emotions such as fright (*susto*), intense anger (*coraje*), and sadness (*tristeza*) precipitates Type 2 diabetes (Coronado et al., 2004).

Causal stories of Type 2 diabetes figured prominently in other researchers’ investigations of diabetic patients’ understanding of treatment behaviors. In a study occurring in South Texas, the vast majority of participants viewed the cause of diabetes as related to hereditary, dietary and lifestyle factors, while smaller numbers viewed the cause in relation to emotional and/or physical trauma (Hunt, Pugh, & Valenzuela, 1998 (b)). This research demonstrated that if one believes self-care behavior is related to disease onset, then one is more likely to be active in self care activities than those who did not cite behavior but rather a traumatic or emotional event as a provoking factor. The persons with diabetes who told a causal story based on physical and/or emotional trauma

were more likely to express skepticism about the relationship of their own behavior to the disease (Hunt et al., 1998 (b)). These findings of Hunt, Valenzuela et al, (1998) were vastly different from my own study, where personal behavior was never cited as a reason for the onset of diabetes. If a *susto* event or *coraje* was not the focus of the participant's causal stories, participants explored hereditary or genetic factors in their stories. Why these findings of causation of Type 2 diabetes are vastly different than my study is not clear. For example, how many of the participants immigrated recently is not known. Possibly, more of the participants were second generation Mexican-Americans who had integrated more of the biomedical beliefs in their understanding of Type 2 diabetes. The paradigm under which this study of causal stories operates may impact the type of questions asked and the manner of asking in the interview and thereby influence the responses of participants.

However, two studies confirm the findings of my study. Carranza and LeBaron (2004) found the majority of 76 Mexican-American participants from a community health center in Northern California believed a *susto* event was the primary cause of their diabetes, while the rest of the participants focused on genetic risk factors as the cause of their disease (Carranza & LeBaron, 2004). Most of the families in my study came originally from rural Mexico, where observations by Valenzuela et al. (2003) found *susto*, a past traumatic event, rather than their own personal behaviors, caused Type 2 diabetes (Valenzuela, Mata, & Mata, 2003).

Susto beliefs, adapted from folk medicine, are a key part of the diagnosis story for Mexican-American immigrants, indicating the need for further research into the

relationship between a *susto* event and the complex behaviors needed in the day to day management of Type 2 diabetes.

El susto del bill que te va a llegar the shock of the bill-the financial burden of Type 2 Diabetes.

The findings from my study indicate that for some participants the financial burden of Type 2 diabetes translates into a palpable and real emotional burden. Other participants found the cost of medication and treatments less of a burden than in Mexico, although diabetes care continues to consume a large percentage of their income.

The financial and subsequent emotional burden of Type 2 diabetes for Mexican-Americans is rarely addressed in nursing and health care literature. Many researchers present the epidemiology of the economics of Type 2 diabetes and Mexican-Americans, such as low rates of health insurance and the extreme poverty of life along the U.S./Mexico border (S Brown et al., 2005; Harris, 1999). Other authors show an interaction between the chronic physiologic stress of poverty causing hormonal changes and unhealthy environments, leading to the development of Type 2 diabetes (Goran et al., 2003; Hosey et al., 1998).

In one descriptive study on how patients adapt to diabetes self-care, the majority of patients describe treatment costs as an issue. For these participants the cost of healthy foods such as fresh fruits and vegetables was burdensome. Poverty played a big part in obtaining regular exercise as participants could not afford health clubs and they lived in “bad” neighborhoods and were unable to walk outside. The cost of medication and blood glucose monitoring (BGM) strips were high leading to participants taking their

medication irregularly and not often monitoring their blood glucose (Hunt et al., 1998 (b)).

Yet the most current source on both emotional and financial burden of Type 2 diabetes was a series of investigative articles entitled *Bad Blood-the epidemic of diabetes in New York* featured in the New York Times. One article in the series featured the neighborhood of Spanish Harlem in a segment entitled *Living at an Epicenter of Diabetes, Defiance and Despair*. This segment exposes both the economic and emotional despair of Type 2 diabetes for the Latino residents of this community. The sentiments echoed in this article were strikingly similar to what was found in my research study. A gentleman in the article had his toes amputated and receives a \$300,000 hospital bill which he can never pay. He never had health insurance so he took his medication and checked his blood sugar when he could afford it. He balances the varying economic demands of disease by doing whatever he needs to do to “keep away the blade,” meaning not have another amputation (Kleinfield, 2006).

It is often easy for researchers to speak of poverty and lack of access to health care in abstract and detached terms. However, the economics of Type 2 diabetes for the participants in this study is more accurately described as an emotional burden which causes much suffering.

Tale of the tortilla.

The findings of my study demonstrate that food is part of cultural identity and has strong emotional meanings as well.

In the research literature on Type 2 diabetes and Mexican-Americans, there is little discussion about emotional and cultural connections to food. In her qualitative study

of predominately Puerto Rican women with Type 2 diabetes, Adams describes the experience as an obsession with food. The participants describe needing to “be careful”. These women often developed obsessive thoughts about food and worry about what they were going to eat for the next meal. In addition, cultural issues came into play especially with family gatherings and not being able to eat the family favorites, and not being free on holidays to eat the foods they really enjoyed (Adams, 2003).

In an unpublished dissertation, Napolitano explores similar themes in regard to food. The female participants in her study felt they were often fixated on food, that it was the center of their illness experience. These Mexican-American women described feeling deprived and hungry and not being able to get enough of certain foods, and of their frustration not being able to partake of certain foods (Napolitano, 1992). In these studies, the emphasis is on food as a connection to emotions of loss rather than as a part of their ethnic identity as Mexican-Americans.

Cambios en nuestra vida.

The findings of *Changes in our lives* describe the many lifestyle changes involved in living with Type 2 diabetes. Distinct meanings are ascribed to lifestyle changes that are made and other times avoided. The meanings of medication, blood glucose monitoring and insulin are complex. These changes also impact family members. Family members view insulin use as a worsening of disease. Family members both support and hinder the person with diabetes (PWD) making the necessary dietary changes.

In the diabetes literature, self-care and behavior change is discussed in depth. Theories and measurements of self-care ability, behavior change and readiness to make change are plentiful. However, in my study with its narrative approach, the focus was the

range of emotions expressed regarding the necessary changes in one's life. This dimension is lacking in the research literature. Yet emotions such as fear, hope, frustration, anxiety and sadness are key to understanding the challenges of behavior change in Type 2 diabetes. In my research study, persons with diabetes desired to act and feel normal, and thus often did not check blood glucose nor follow the recommended diet when in social situations. Strong emotions were expressed around use of the needle in insulin administration as well as perceiving insulin usage as a worsening of their disease. Studies which examine meaning, understanding and emotion will be examined.

A qualitative descriptive study by Hunt et al. (1998(b)) explores how patients adapt diabetes self-care recommendations into everyday life. The key factors identified in this study are limited economic resources (Hunt et al., 1998 (b)). For the participants in this study, acting and feeling normal had to do with dietary changes and exercise very specifically. Participants in this study desired to avoid physical symptoms, even while their blood sugar was close to normal, indicating a focus on symptoms instead of on a number indicating a high, normal or low level. In conclusion, having access to resources such as time, autonomy, money and avoiding socioeconomic concerns may be the strongest determinants of self-care behavior.

Mexican-American patients' fears and hopes about insulin therapy were explored by the same group of researchers (Hunt, Valenzuela, & Pugh, 1997). This qualitative study focuses on the emotions connected with insulin therapy, and is very similar to my research study. The research findings demonstrated more negative than positive attitudes towards insulin administration. There was fear and worry about discomfort in using injections. In addition, these participants perceived insulin usage as a sign that their

diabetes was worsening and had progressed to a dangerous level. Participants also had difficulty accepting that their disease was at the point that they needed insulin, that it was that bad (Hunt et al., 1997).

Although self-care and self-care theories abound in the literature of behavior change with Type 2 diabetes, researchers have not fully explored the emotional dimensions of behavior change for Mexican-Americans living with Type 2 diabetes.

Preocupaciones por el futuro.

In my study, there are many worries for the future, both of the persons living with Type 2 diabetes and their family members. The nature of worry expressed by persons with diabetes focuses on becoming disabled and dying and not being able to provide for their family members, or becoming a burden to their children. Family members worry about potential complications and poor outcomes the person with diabetes may experience as well as their own risk for the disease. Due to the dearth of studies of the families' experience of Type 2 diabetes, little is examined in the research literature about the person with diabetes and family members' worries for the future. Napolitano (1992) in her unpublished dissertation briefly describes some family member's worries about the genetic risk of Type 2 diabetes. One qualitative study of 20 Mexican-American women found that most participants believed they would have a reduced life span and those who had known someone who had died from diabetes realized this would happen to them (Alcozer, 2000). The focus appeared to be more personal rather than family-based, most likely due to the nature of the investigation.

Yet the family context is critical to understanding this disease in families where diabetes impacts multiple members and several generations. Certainly to conceptualize

the multigenerational legacy of Type 2 diabetes, one needs not only to look backwards to the family history of diabetes but to what is in store in the future for families (Scollankoliopoulos, 2004). Worries about the future for families living with diabetes are another gap in the literature on Type 2 diabetes.

Qualitative Research Studies on the Chronic Illness and Diabetes Experience

Charmaz's (1999) stories of suffering resonate with the family's stories of suffering told in my narrative study. Family members who had gone on before and the loss that accompanied the death of loved ones as well as economic difficulties were viewed as a form of suffering not just for the individual but for the entire family. Participants with diabetes did not want their loved ones to suffer when they became infirmed with this disease. Yet in Charmaz's study, the individual perceives that he/she is placed on a moral status hierarchy of high moral status, sustained moral status or diminished moral status. The conclusion offered by Charmaz is that your own place on this moral hierarchy determines whether your story of suffering is believed or not. Her stories focused on the individual, the self and the individual's experiences. This individualistic understanding of suffering presented in Charmaz is a more uniquely Euro-American perspective (Charmaz, 1999).

Ironside et al. (2003) explored the experience of chronic illness with a graduate nursing class using narrative pedagogy. The conclusions of this study were based on the experience of seven individuals interviewed in the community regarding their own experiences of chronic illness. The similarity between Ironside's study and my own was that the meaning of the chronic illness experience is much more than the treatment of symptoms. Again, the impact on family members was not discussed in Ironside's

investigation, leading me to see these results as a uniquely Euro-American perspective (Ironside et al., 2003). This individual focus is found in a meta-ethnography, a synthesis of qualitative research (Paterson et al., 1998), focusing on self care themes-deciding to assume control, balancing by assuming control, knowing the body and fostering supportive, collaborative relationships. These themes were vastly different than the themes in my narrative research study of emotional burden, turmoil, loss and personal and familial suffering.

Implications for Clinical Practice

This narrative research study has many implications for clinical practice. In this section, the focus will be on primary care practice and the practice of clinical diabetes education. While this research has implications for other aspects of nursing care, only these two areas will be emphasized.

Although narrative inquiry is understood as a qualitative research methodology, narrative understandings have implications for the clinical setting. Exploring narrative understanding in the clinical setting is essential since clinical practice influences research and research drives clinical practice. In primary care, narrative can function to foster better patient/provider communication, and assist patients in constructing and working through elements of the personal story of their health experiences (Blakemore, 1999; Greenhalgh & Hurwitz, 1999). This narrative research study demonstrates there is a need to include not only patient's stories but also families' stories to aid in understanding the totality of the diabetes experience.

Narrative-based Primary Care Approach

Finding common ground and sharing experience lends itself to the balance of power between the patient's biographical story and the health care provider's professional one (Launer, 1999), thereby improving the patient-provider interaction, and leading to a more equalitarian relationship. Sharing stories can be empowering for patients by balancing the power equation and improving the patient-provider interaction, which in turn could lead to a more democratic arrangement of voices and more constructive listening (Elwyn & Gwyn, 1999). The expression of both the patient's and health care provider's perspective is a movement along a pathway toward negotiation of a shared perspective (Greenhalgh & Hurwitz, 1999). Narratives of illness have many possible interpretations but the patient is the ultimate author, and in that sense, narrative is empowering (Jones, 1999). Narrative-based clinical practice presupposes an interpretive paradigm in which the patient's experience of illness is positioned in a unique and contextual way (Greenhalgh, 1999). In this research setting, I believe, the personal and family narrative empowered these Mexican-American participants. Story telling also can empower Mexican-American patients in the primary care setting.

One practical application of a narrative based primary care approach is the manner of taking a history. From a narrative primary care approach, taking a history is based on obtaining both necessary biomedical information and patient specific information. This narrative-based approach to the medical interview is described as building a history rather than taking one, attending to the patient's perspective rather than noting mere pertinent positives and negatives (Haidet & Paternitti, 2003).

Type 2 Diabetes and Narrative Approach

In building a history with Mexican-Americans with Type 2 diabetes, primary care providers need to understand the patient's perspective on diagnosis of Type 2 diabetes and be attentive to emotional cues. Since patients may have unique beliefs and understandings of behavior change, it is essential that providers elicit patients' understanding of needed behavior change. The patient's perspective may be influenced by literacy, language, immigration status and the family context. These very specific contexts need to be elicited and understood by providers when obtaining a medical history and developing a management plan.

In obtaining a family history, a provider should inquire about recollections of family member's beliefs about diabetes, consequences and controllability of diabetes, and then inquire about the patient's own beliefs about onset of diabetes, consequences and controllability of the disease. In a narrative approach, such information is gathered using open-ended questions and other conversational devices to elicit responses. Very specific questions can be asked to elicit this information such as—"Do any of your family members have diabetes?" and "What complications did your relatives with diabetes experience?" For certain patients with significant family history of diabetes, the use of a genogram may be helpful to determine possible multigenerational legacies, and to understand major life events within a family and how they impact the disease (Scollan-Koliopoulos et al., 2005).

On an individual level, PWD-the person with diabetes' fears related to family member's experience of Type 2 diabetes needs to be elicited. For example, if a family member had an amputation secondary to diabetes, how might the person with diabetes

respond to that event? Will the person alter their own self-care behavior based on this family history or will the person with diabetes see themselves as very similar to family members and see an amputation in their future regardless of what they do? The provider can alter how this legacy of diabetes influences the person living with diabetes' perception of the disease.

Providers also can assist patients by acknowledging beliefs based on family experiences. After gaining an understanding of the specific beliefs of a family, the provider needs to communicate explicitly how things can be different for the patient than for family members who have the disease, such as how advances in diabetes management can improve patients' outcomes. Providers assist patients in problem solving through family-level interventions such as sitting down with relatives and talking about their experiences. For both primary care providers and clinical diabetes educators, these family-focused interventions demonstrate a new and innovative model (Scollan-Koliopoulos et al., 2005).

Clinical diabetes education typically entails very comprehensive teaching around five core areas: causes, pathophysiology, treatment options, self-care, and the prevention of complications. However, diabetes education needs to evolve to focus on the emotional impact of diabetes for both the patient and family members. Specifically in education about diabetes complications, there needs to be an elicitation of the emotional impact of complications based on family history and that person's intergenerational legacy. It is important for the diabetes educator to emphasize that complications do not automatically need to be part of the patient's future (Scollan-Koliopoulos et al., 2005).

Diabetes education needs to be a family affair. It is beneficial to trace family history together. Diet and other self-care activities also can be a family learning situation so all members of the family can participate in education and the multitude of lifestyle changes which occur in the home.

Implications for Other Research

Additional clinical research is needed to understand the beliefs families living with Type 2 diabetes have about the future. In comparing my study to the existing research literature, there was an obvious need for continued research in this area. In addition, research needs to be done to understand the relationship of *susto* events at the time of diagnosis to the daily management of Type 2 diabetes, as well how family members understand *susto* events. These stories figured prominently in my research studies, and the question that begs to be answered is, “what difference do these diagnosis stories make in how patients and families manage this complicated disease long term?” From my study, the difference these diagnosis stories make on patient and family management is not clear. As stated previously, these diagnosis stories are foundational to the larger emotional context of the Type 2 diabetes experience, though the implications of the stories for long term management is not known.

More research is needed into the economic burden of diabetes and how it impacts both the emotional and self-care management of diabetes. I think understanding the relationship between the many different beliefs and world-views Mexican-Americans hold and how this impacts daily diabetes management for themselves and their family members is another area of additional research.

Future Research Studies

This narrative research study about the family's experience of Type 2 diabetes raises questions and possibilities for interventional research. Although there are 2 interventional studies on Mexican-Americans and Type 2 diabetes in the United States, one seeking to improve the outcomes for Type 2 diabetes among Mexican-Americans along the Texas-Mexico border and the other seeking to improve the outcomes of chronic disease, the paradigmatic thinking these studies operate under is vastly different than the paradigm of narrative research. Information on these two studies is in Chapter 2 (S Brown et al., 2005; Lorig et al., 2003).

As I was listening to and analyzing these stories I often wondered what relevance they may have for support and education for families living with Type 2 diabetes. A feasibility study of diabetes education executed in a multi-ethnic deprived inner-city London neighborhood answered my question. The basis of the complex intervention was the sharing of stories in a facilitated group setting. This intervention study used an action research framework in partnership with clinicians, managers and service users draws on narrative methodologies. The perspective of this study moved from psychological models based on individual health beliefs and attitudes, to a more anthropologic model based on shared values and meaning systems that embed behavior change for members of a cultural group (Greenhalgh, Collard, & Begum, 2005).

This study was a four-phase model. Initial phase was to understand the extent which diabetes impacted certain communities and organizations. Based on this phase in the study, the researchers became aware of the organizations and facilities in which the interventions could take place. That awareness translated into understanding the

workforce and human resource issues. Based on the initial phase in the research the decision was made to train a large pool of appropriate individuals rather than rely on research staff. The second phase was the training for the bilingual health advocate (BHA) (lay health workers in this country). The third phase was using the bilingual health advocates in the work environment. The fourth phase was the development and support of the advocate-led user groups. Each group developed different strategies and methodologies around telling of stories. One example is a specific client's story is written up by the health advocate and the group answered questions about the story. Another group involved sitting in a circle with a physician with a strong interest in diabetes and each user brought their bag of medication. No lecture was given rather participants told stories about side effects they had experienced on their medication.

Each group had a unique identity and functioned very differently. However, the group process facilitated positive outcomes not merely by knowledge acquisition but providing a forum where the meaning of knowledge can be negotiated and then prompt action. There is a strong link noted by a number of researchers that story telling in a group setting can lead to subsequent action by individual participants and potentially family members if they were involved in the intervention (Greenhalgh, Collard et al., 2005).

This study provides a clear link between narrative-based qualitative research and the use of narrative in intervention-based action research. Certainly this type of Participatory Action Research (PAR) would be possible among Mexican-American families living with Type 2 diabetes here in Oregon.

Strengths and Weaknesses of this Study

Both strengths and weaknesses are evident in this study and the methodology used. The strengths and weaknesses of this investigation of Mexican-American Families' Experience of Type 2 diabetes are discussed in the following paragraphs.

One of the strengths of this study is the research methodology-narrative inquiry-is participant-centered rather than researcher-driven. This participant-centered methodology lends itself to participants more fully disclosing their thoughts, feelings and beliefs. In addition, making sense of an experience and its emotional impact is key to narrative truth rather than focusing on principles of scientific objectivity (Greenhalgh, Russell, & Swinglehurst, 2005; Riessman, 1993b). This epistemological stance helps marginalized groups such as Mexican-Americans make their understandings and experiences known.

A narrative methodology captures in-depth rich data, generating stories which are descriptive and often compelling to the reader (Gilgun, 2005). If, according to Gilgun (2005), the medium is the message, the data created in stories will fully engage the reader. Certainly, readers of these stories have found them engaging and thought provoking.

This study embraces both an Outsider and Insider Perspective-I am an outsider because this is not my culture. My stance, however, is clearly articulated in the beginning of Chapter 4. Although I was an outsider, I was shown respect and was regarded as credible by these study participants for a number of reasons. I am well-educated and by the accident of birth I was born into a white middle class family. In addition, I am a health care provider, *a doctora*, elevating my status even more in the eyes of the participants. A willingness existed among the participants to express their reality based

on my status as Other. The questions I ask and the information I seek are different than that of an insider. The obvious might be explained to me rather than to an insider, assuming they would have personal knowledge. Taboo subjects may also be expressed whereas they may not be when an insider conducts the interview (Behar, 1993).

As there is benefit in having the outside perspective, there is also great peril in having only the outsider perspective. In research with other cultures and marginalized groups, there is the tendency to project ourselves into Other's experience and the expression of the experience becomes truth, objective scientific reality. I believe that research needs both the insider and outsider perspective in a spirit of mutuality and respect. Based on this desire to create a climate of mutuality and address the weakness of having only an outsider's perspective, a Mexican-American man was involved in most interviews and contributed to the analysis, resulting in a blend of outsider/insider perspectives. This blend offers the "best of both worlds", giving the results a richness and depth not seen from only one perspective.

As a Spanish-speaking researcher, I was able to recruit participants, schedule interviews, and conduct interviews in the participants' native tongue. The ability of the researcher to communicate in the participants' language is clearly beneficial in a descriptive qualitative study. Interview transcripts were initially translated into English, but as the study progressed, narrative sections were analyzed in Spanish by the researcher using English to code and memo. The limitations of using translated data to do analysis became apparent to me as my Spanish fluency increased the more I was immersed in this experience.

I knew the population, since I worked in the mid-Willamette Valley for five years prior to embarking on this research endeavor, and I was able to have access to this population through various professional channels as well as personal connections to the community.

Weaknesses were also evident in this research study. Due to only Mexican-American families, who live in the mid-Willamette Valley of Oregon participating. These families lived in predominantly rural settings, making it difficult to transfer these findings to urban Mexican-Americans living for example in the Portland area or greater L.A. As the youngest participant with Type 2 diabetes was 34, it would be also difficult to generalize these findings to older adolescents and young adults with Type 2 diabetes, a disease found increasingly in this age group. Of the ten families in this study, only three men with diabetes were represented. Clearly, the male perspective was limited. The perspectives of second generation families were not fully explored as only two second generation families participated. No migrant farmworker families following work and crops were represented in this study. Clearly, their understandings of Type 2 diabetes would be different.

As far as the family perspective, many family members participated, though there were few families with young children under the age of 15 in this study. The child's perspective on a parent with Type 2 diabetes was missing from this research study. In a small study such as this one representing the experience of only ten families, it is difficult to gain broad perspectives.

The sample size was small with only 10 Families with a total of 42 participants involved in this study. Due to the small sample size and the non-representative nature of the sample, generalizing these findings is not possible.

The study lacked a longitudinal approach for these stories were created in a moment in time, the summer and fall of 2005. These families' narratives may have changed over the course of months in relation to the experiences of a family member with Type 2 diabetes, changing both the perspectives and meaning of the experience.

Conclusion

The results of this study indicate that for Mexican-American families living in the mid-Willamette Valley of Oregon, Type 2 Diabetes presents itself as an emotional burden and source of turmoil, very different than the experience of Euro-Americans. Clearly, Type 2 diabetes is a family disease, impacting all members of the family. As demonstrated, these understandings have implications for research and practice.

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Appendices
Appendix A
Consent and Assent Forms

Appendix A

IRB# 1130
Protocol Approval Date 3/25/05

Oregon Health & Science University
Child Assent Form
(Use for children ages 7 through 17)

Title: Mexican-American Families' Experience of Type 2 Diabetes

Principal Investigator: Judith Kendall RN, Ph.D 1-503-494-3890

Co-Investigators: Sarah Kooienga RN, FNP, MSN 503-474-7773
1-503-418-1396
Anne Rosenfeld RN, Ph.D 1-503-494-0133
Dena Phillips RN, Ph.D 1-503-494-2714
Elisabeth Mann RN CDE 1-503-418-1396

Part I

Sarah Kooienga (co-investigator) has explained this research study to me. I know how it may or may not help me. I also know that this study will help doctors and nurses know more about Type 2 diabetes and families.

1. Sarah Kooienga will ask me to tell her what I will be doing and what will happen during the study. This is to be sure I understand the study.
2. Sarah Kooienga will ask me if I have any questions or want to know anything else about this study.
3. Sarah Kooienga will ask me to explain some of the good things that might happen to me and others if I enter this study. She will also ask me to explain some of the bad things that might happen to me.

Part II

I have thought about being a part of this study. I have asked and received answers to my questions. I agree to be in this study. I know that I don't have to agree to be in the study. Even though I agree to be in it now, I know I may feel differently later on and can ask to stop being in the study. I know that I may talk with my parents about not being in this study at any time.

Name/signature: _____

Date: _____

Witness _____
Sarah Kooienga RN FNP

Date _____

Appendix A

IRB# 1130
Protocol Approval Date 3/25/05

Oregon Health & Science University
Forma de asentimiento para niños
(Para niños entre las edades de 7 y 17)

Título: Las experiencias de familias México-Americanas con la diabetes tipo2.

Investigador principal: Judith Kendall RN, Ph.D 1-503-494-3890

Co-Investigador: Sarah Kooienga RN, FNP, MSN 503-474-7773
1-503-418-1396
Anne Rosenfeld RN, Ph.D 1-503-494-0133
Dena Phillips RN, Ph.D 1-503-494-2714
Elisabeth Mann RN CDE 1-503-418-1396

Parte I

Sarah Kooienga (co-investigador) Me ha explicado este trabajo de investigación y se si me me va a ayudar, o no. También se que este estudio ayudará a doctores y enfermeras a saber mas acerca de la diabetes y las relaciones familiares.

4. Sarah Kooienga me pedirá que le diga que es lo que estoy haciendo y que es lo que va pasar durante el estudio. Y esto es para asegurarse de que yo entiendo el estudio.
5. Sarah Kooienga me preguntará si tengo alguna duda o si quiero saber algo mas acerca de este estudio..
6. Sarah Kooienga me pedirá que le explique algunas de las cosas buenas que puedan pasarme a mi o a otros si soy parte de este estudio. También me pedirá que le explique de las cosas malas que puedan pasarme

Parte II

He pensado en ser parte de este estudio. He preguntado y he recibido respuestas. Estoy dispuesto a ser parte de este estudio. Aunque estoy de acuerdo, se que si me siento diferente después, puedo pedir parar el estudio. Se que puedo hablar con mis padres si me quiero salir en cualquier momento.

Nombre/Firma: _____

Fecha: _____

Testigo _____
Sarah Kooienga RN FNP

Fecha _____

Oregon Health & Science University
Research Consent and Authorization Form

Title: Mexican-American Families' Experience of Type 2 Diabetes

Principal Investigator: Judith Kendall RN, PhD 1-503-494-3890

Co-Investigators: Sarah Kooienga RN, FNP, MSN 503-474-7773
1-503-418-1396
Anne Rosenfeld RN, PhD 1-503-494-0133
Dena Phillips RN, PhD 1-503-494-2714
Elisabeth Mann RN CDE 1-503-418-1396

Purpose:

You (meaning you and your children) are being asked to take part in a study because you or an adult member of your family has Type 2 diabetes. You have knowledge that will help nurses and doctors understand how Mexican-American families live with Type 2 diabetes day by day. This study will use interviews to learn how Mexican-American families live with Type 2 diabetes. Being part of this study will involve meeting with the co-investigator and her assistant on two or three separate occasions, 2-3 weeks apart, for approximately 1-2 hours each visit.

10-12 families will be interviewed for a total of 30-35 participants.

Procedures:

All members of the family over the age of 8 will be asked to be part of the study. On the first meeting, a private interview with the nurse will occur. The interview will occur in Spanish or English. It depends on which language you prefer. An assistant may be present at the meetings. You will be asked questions regarding about what it is like living with Type 2 diabetes or having a family member with Type 2 diabetes. On the second visit, other members of the family will be interviewed and asked the same questions. On the third visit, a family discussion will occur in which all the members of the family will discuss the daily living with Type 2 diabetes. The interviews will last 60-90 minutes and will be tape-recorded and typed up. The three interview sessions will occur over a one to two month period of time.

The information will be kept in a locked file drawer or on a password locked computer. If you have any questions regarding this study now or in the future, contact Sarah Kooienga at 503-474-7773 or Judith Kendall at 1-503-494-3890.

Risks and Discomforts

You might find it upsetting or painful to talk about what it is like to live with Type 2 diabetes or live with a family member who has Type 2 diabetes. If you become sad and want to talk about your feelings with another person such as a counselor, we will help you do so.

Benefits

The study may not benefit you directly, but what we learn in this study may help doctors and nurses help persons with Type 2 diabetes and their families in the future. Being in this study and talking about your experiences may be helpful.

Alternatives

You may choose not to be in this study. You may stop taking part in the study at any time. Talking to the nurse about your health and illness(s) will not affect your health care.

Confidentiality and Privacy of Your Protected Health Information

All information you provide will be kept confidential. All information obtained from minors will be ensured the same rights to confidentiality as adults, with two exceptions: (1) according to Oregon Law, suspected child or elder abuse must be reported to appropriate authorities, or (2) when a child might be physically or psychologically harmed if information were kept secret, such as suicidal thoughts, significant physical or psychological illness or risk of injury.

In the unlikely event that information is discovered regarding abuse or neglect of a child, the study staff is legally required to report that information to the Department of Human Services-Child Welfare Division. If that situation should arise the information will be given to the parents before the report is made. Study staff will be available to provide support and referrals if requested.

Neither your name nor your identity will be used for publication or publicity purposes. All information you provide will be identified only with a code number and never linked to your name. Audiotapes will be destroyed at the completion of the study.

If you sign this form, you are agreeing that OHSU may use protected health information collected and created in this research study. The specific health information and purpose of each use and disclosure are described in the section below:

Interview results will be collected during the course of the study, which will be used to learn more about Mexican-American families' experience with Type 2 diabetes. This information will be used for teaching purposes and kept by the investigator for further analysis.

The persons who are authorized to use and disclose this information are:

- All investigators listed on page one of the Research Consent and Authorization Form
- OHSU Institutional Review Board
- The Office of Human Research Protections (OHRP)
- The United States Food and Drug Administration (FDA)

We may continue to use and disclose protected health information that we collect from you in this study until the study is completed.

While this study is still in progress, you may not be given access to medical information about you that is related to the study. After the study is completed and the results have been analyzed, you will be permitted access to any medical information collected about you in the study.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of the Consent and Authorization Form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date he/she receives your request. However, the Principal Investigator is allowed to use and disclose information collected before the date of the letter or collected in good faith before your letter arrives. If you withdraw, any information that was collected from you either will be destroyed or stored without any information that identifies you. Revoking this authorization will not affect your health care or relationship with OHSU.

Costs

You or your family does not have to pay to be part of this study. Each family will receive a \$50.00 grocery store certificate. The grocery store voucher is thanking you for your time and effort to this research project.

Liability:

It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating, to compensate or provide medical treatment for human subjects in the event the research results in physical injury.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you are hurt from taking part in this study and it is the fault of the University, its officers or employees, you can take legal action against the University, as agreed upon in the rules of the Oregon Tort Claims Act. You do not have to give away your legal rights when you sign this form. If you want more information, or if you have questions, please call the OHSU Research Integrity Office at (503) 494-7887.

Participation

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

If you decide to stop being in the study, you may keep the grocery store voucher.

Sarah Kooienga (503-474-7773) or Judith Kendall (1-503-494-3890) has offered to answer any other questions you may have about this study. If you have any questions about your rights as a member of this study, you can call the OHSU Research Integrity Office at (1-503-494-7887).

Your consent to take part in this study and your permission to let us use your protected health information are voluntary. You may refuse to sign this consent and authorization form. If you refuse to sign this consent and authorization form, your health care and relationship with OHSU will not be affected, however, you will not be able to enter this research study.

After you sign this consent form you will receive a copy of the form for you to keep.

Signatures

Your signature below indicates that you have read this entire form and that you agree to be in this study.

Subject's signature

Date

Parent's/ Guardian's Signature

Date

Sarah Kooienga RN FNP
Witness
Co-Investigator

Date

IRB # 1130
Approved: 3/25/05

Appendix A

Oregon Health & Science University
Forma de Autorización y Consentimiento para Investigación

Título: Las experiencias de familias México-Americanas con la Diabetes Tipo 2

Investigador Principal: Judith Kendall RN, Ph.D 1-503-494-3890

Co-Investigadores: Sarah Kooienga RN, FNP, MSN 503-474-7773
1-503-418-1396
Anne Rosenfeld RN, Ph.D 1-503-494-0133
Dena Phillips RN, Ph.D 1-503-494-2714
Elisabeth Mann RN CDE 1-503-418-1396

Propósito:

Ustedes (incluye a ustedes y sus hijos) han sido invitados a participar en este estudio de investigación porque usted u otro miembro de la familia tiene Diabetes Tipo 2. Se le ha informado que es para ayudar a doctores y enfermeras a entender como las familias México Americanas viven con Diabetes Tipo 2, día a día. Este estudio hará entrevistas para saber como las familias México-Americanas viven con Diabetes Tipo 2. El ser parte de este estudio consistirá en reuniones con el co-investigador y su asistente/s, de dos a tres ocasiones diferentes, separadas por 2 ó 3 semanas, por aproximadamente 1-2 horas cada visita

10-12 familias serán entrevistadas para lograr un total de 30-35 participantes.

Procedimientos:

A todos los miembros de la familia que tengan más de 8 años se les pedirá que participen en el estudio. En la primera reunión se llevará a cabo una entrevista en privado con la enfermera. La entrevista se llevará a cabo en español o inglés basado en el lenguaje con el que se sienta mas cómodo. Puede que un asistente esté presente en las reuniones. Se le harán preguntas acerca de como es el vivir con Diabetes Tipo 2, o el tener un miembro de la familia con Diabetes Tipo 2. En la segunda visita, otros miembros de la familia serán entrevistados con las mismas preguntas. En la tercera visita todos los miembros de la familia discutirán sus experiencias del vivir con la enfermedad de Diabetes tipo 2. Con su permiso todas las entrevistas se grabarán. Las entrevistas durarán de 60-90 minutos, se grabarán y se escribirán. Las tres sesiones de entrevistas se realizarán en un periodo de 1 a 2 meses.

La información se mantendrá archivada bajo llave o en la computadora. Si tiene alguna pregunta relacionada con este estudio en este momento o en el futuro, puede llamar a Sarah Kooienga al 503-474-7773 o a Judith Kendall al 1-503-494-3890.

Riesgos o molestias

Puede que se de cuenta que le entristece o le duele hablar acerca del vivir con Diabetes Tipo 2, o el vivir con un miembro de la familia que tiene Diabetes Tipo 2. Si esto pasa y le gustaría hablar con otra persona, acerca de esto, le ayudaremos a hacerlo.

Beneficios:

A la mejor el estudio no va a beneficiarlo a usted personalmente, pero lo que aprendamos de él ayudará a doctores y enfermeras que trabajan con personas con Diabetes Tipo2 y sus familias en el futuro. Su participación en este estudio y hablar de sus experiencias puede ayudar.

Alternativas

Usted puede escoger no participar en el estudio o salirse de él en cualquier momento. El hablar con la enfermera acerca de su/s enfermedad/es no le afectará en su cuidado médico.

Confidencialidad y privacidad para la protección de su información de salud

Toda la información que usted nos provea se mantendrá confidencial. Aseguramos que toda la información que provean los menores tendrá los mismos derechos de confidencialidad que la de los adultos, con dos excepciones: (1) de acuerdo con la ley de Oregon si se sospecha de abuso a niños o ancianos se debe reportar a las autoridades correspondientes (2) Cuando un niño este siendo dañado física o psicológicamente, si la información se mantuvo en secreto, como pensamientos suicidas, enfermedades físicas o psicológicas graves o riesgo de una lesión grave.

En el remoto caso de que la información acerca del abuso o negligencia de un niño se descubriera, al personal del estudio se le requiere legalmente el reportar esta información al Departamento de Servicios Humanos, división de bienestar del niño. Si tal situación se presentara informaría a los padres antes de hacer el reporte. El personal del estudio estaría disponible si se necesitara apoyo o referencias si se piden.

Ni su nombre ni su identidad serán usados en publicaciones o para propósitos de publicidad. Toda la información que provea será identificada solamente con números y nunca con su nombre. Las grabaciones de las entrevistas serán destruidas cuando termine este estudio.

Si usted firma esta forma, esta de acuerdo en que OHSU utilice la información que se junte en este estudio de investigación. La información específica de salud y el uso o exhibición que se le va a dar esta descrito abajo:

Los resultados de las entrevistas que se junten en este estudio, los cuales serán usados para aprender mas acerca de las experiencias de las familias México-Americanas con Diabetes Tipo2, se usarán con fines de enseñanza y la conservará el investigador para análisis en el futuro.

Las personas que están autorizadas para usar y exhibir esta información son:

- Todos los investigadores que están el la primera página de esta forma de consentimiento de la investigación.
- El consejo Institucional de revisión de OHSU
- La oficina de protección de investigación humana (OHRP)
- La administración de comida y drogas de los Estados Unidos (FDA)

Quizá continuemos usando y exhibiendo la información protegida de salud que obtuvimos de ustedes hasta que el estudio se termine.

Mientras el estudio se está llevando a cabo quizá no se le de acceso a su información que esté relacionada con el estudio. Una vez que se termine el estudio y los resultados se hallan analizado se le dará permiso de ver la información que hallamos obtenido de usted en el estudio.

Usted tiene el derecho de revocar esta autorización y el permiso de usar su información para este estudio mandando una nota escrita al investigador principal, que esta en la primera página de esta forma de consentimiento. Si manda una nota al investigador principal, el uso y exhibición de su información parará el día que ella reciba su nota. Sin embargo, el investigador principal está autorizado de usar y exhibir la información que se junto de Buena fe, antes que su petición llegara. Si se sale, toda la información que se juntó, ya sea que se destruya o que se almacene sin ninguna información que lo identifique. El revocar esta autorización no afectará su cuidado médico ni su relación con OHSU

Costos

Ni usted ni su familia tienen que pagar para ser parte de este estudio. Cada familia recibirá un certificado por \$50.00 dólares para el supermercado, por su participación. El certificado es para agradecerle por su tiempo y esfuerzo en este estudio.

Responsabilidad:

No es una póliza del Departamento de Salud y Servicios Humanos de los E.U. o de cualquier otra agencia federal el pagar por el estudio en el que usted va a participar o dar cuidado médico a la gente en caso de que el estudio los lesione físicamente.

La Universidad de ciencia y salud de Oregon OHSU está sujeta al acto de reclamo por agravios de Oregon (ORS 30.260 al 30.300). Si usted resultara dañado por tomar parte en este estudio, por parte de la Universidad, de sus oficilaes o empleados, usted puede tomar acción legal en contra de la Universidad como se acuerda en el ya mencionado acto de

reclamos por agravios de Oregon. Usted no renuncia a sus derechos al firmar esta forma. Si quiere mas información o si tiene preguntas, llame a la oficina de apoyo a la investigación de OHSU al teléfono (503) 494-7887.

Participación

No tiene que participar en este u otro estudio de investigación. Si lo hace y después cambia de opinión puede salirse en cualquier momento. Si se rehusa a participar o se sale muy pronto del estudio, no habrá penalidad alguna o pérdida de beneficios que ya se le habían otorgado. Si así lo decide, puede quedarse con el certificado del supermercado que haya recibido.

Sarah Kooienga (503-474-7773) o Judith Kendall (1-503-494-3890), Han ofrecido responder a todas las preguntas que pueda tener acerca de este estudio. Si tiene preguntas acerca de sus derechos como miembro de esta investigación puede llamar a la oficina de apoyo a la investigación del OHSU al (1-503-494-7887).

Su consentimiento de tomar parte de este estudio y su permiso para usar su información médica son voluntarios. Usted se puede rehusar a firmar esta forma de consentimiento y autorización. Si se rehusa a firmar esta forma de consentimiento y autorización, su cuidado médico y su relación con OHSU no se verán afectados, sin embargo, no podrá participar en este estudio.

Después de firmar esta forma de consentimiento usted recibirá una copia para que la conserve

Firmas

Su firma aquí abajo nos dice que leyó la forma completa y que está de acuerdo a participar en este estudio.

Firma del participante

Fecha

Firma del padre o tutor

Fecha

Sarah Kooienga RN MSN FNP
Testigo
Nombre del Co-Investigador

Fecha

Appendix B

Recruitment Flier

Families Invited!

A research study about Mexican – American families' daily experience of Type 2 Diabetes

I am a nurse practitioner seeking Mexican-American families who:

- **have one adult member between 18-65 with Type 2 diabetes.**
- **speak either English or Spanish**
- **are willing to tell their stories about living with Type 2 diabetes.**

Participants will meet 2 or 3 times with the interviewer. Each interview lasts 1-1½ hours.

The nurse practitioner conducting the interviews is bilingual and has worked with Latino patients for 15 years. A Mexican assistant will help her with the interviews.

Why are your stories important?

Doctors and nurses need to learn from the people they care for.

Your experiences with Type 2 diabetes will help nurses and doctors understand better how Mexican-Americans live with Type 2 diabetes.



Each family will receive a \$50.00 grocery store coupon upon completion of the interviews.

For more information please call:

Sarah Kooienga, RN FNP MSN

503-474-7773

OHSU IRB #1130
Approval Date: 3/25/05

INVITACION PARA LAS FAMILIAS

Una investigacion acerca de las experiencias de las familias Mexico-Americanas que viven con Diabetes Tipo 2.

Soy una enfermera especialista que anda buscando familias Mexico-Americanas que:

- Tengan un miembro de la familia de entre 18-65 años con Diabetes Tipo 2.
- Familias que esten interesadas en compartir sus experiencias de su diario vivir con Diabetes Tipo 2.
- Que hablen Ingles o Español

Los participantes se reuniran de 2-3 veces para una entrevistas que durara 1-1.5 horas cada una.

La enfermera especialista que va a hacer las entrevistas es bilingue y ha trabajado 15 años con Latinos. Un asistente Mexicano le ayudara con las entrevistas.

Por que son importantes sus experiencias?

Los doctores y enfermeras necesitan aprender acerca de la gente a la que dan cuidado. Las experiencias de su diario vivir con Diabetes Tipo 2 ayudaran a las



enfermeras y doctores a entender mejor como las familias Mexico-Americanas viven con diabetes.

Como una expresion de gratitud, cada familia recibira un cupon de 50.00 dolares para el supermercado al termino de las entrevistas.

Para pedir mas informacion llame a :

Sarah Kooienga, RN FNP MSN

503-474-7773

OHSU IRB #1130
Approval Date: 3/25/05

Appendix C
Interview Guide

Appendix C Interview Guide

Introduction: The purpose of this study is to discover what it is like for Mexican-American families to live with Type 2 diabetes. There is a lot known about treatments and educational needs of persons with Type 2 diabetes. Less is known about the experience of Type 2 diabetes especially among families.

Family Experience

- 1) Tell me about the experience of diabetes for your family?
- 2) What is it like having someone with diabetes in your family?

Probes:

Who has Diabetes?

What is it like living with someone with diabetes? Tell me about that?

For example, Tell me a story about living with or family life with a person with diabetes??

Open-ended conversational Probes:

For example

Tell me more about that

Anything else?

Person with Diabetes (Male or Female)

Demographics

Age

How long had Diabetes

Regular Medical Care Yes/No

Health Insurance Yes/No

Take medication/diet controlled/insulin or other therapies/herbals?

Patient Experience

- 1) Tell me about your experience of diabetes?

If conversation is difficult to start

Tell me about when you were diagnosed with diabetes?

The diabetes diagnosis, how did that make you feel?

Open ended Probes to generate discussion

Tell me about your diet?

Tell me about exercise/activity?s

What is it like taking the diabetes medication?

How is your economic situation,

Tell me about your relationships with others, your family?

In general, tell me about how you feel?

Tell me how diabetes affected you emotionally? How do your symptoms make you feel?

Open-ended conversational Probes:

For example

Tell me more about that

Anything else?

2) Tell me how diabetes impacts or affects your relationship with your family?

3) Tell me about your family's experience with diabetes?

Probes Tell me what happens on a day to day basis with your family??

Spouse or Significant Other

1) Tell me about your experience of having a spouse with diabetes

Probes:

What is it like having a husband/wife with diabetes?

How has this family member's diabetes(him/her person'sname)affected- impacted you?

2) What has been the experience of diabetes on your family?

Probes What happens on a day to day basis with your family

Tell me what it has been like?

What do you think is the social-economic impact of diabetes on your family

Open-ended conversational Probes:

For example

Tell me more about that

Anything else?

Children

1)Tell me about your experience of having a parent with diabetes??

Probes:

What is it like living with a parent with diabetes??

How has diabetes affected your family?

Tell me about any difficulties/problems diabetes has caused/created for your family?

Open-ended conversational Probes:

For example

Tell me more about that

Anything else?

Demographics of the Family

Age of Family Members

Marital Status

Children

Other relatives in the household?

Length of Time in the United States

Language Spoken-English/Spanish ?

Economic Resources-Employment?

Education Level?

Appendix C Interview Guide

Introducción:

El propósito de este estudio es el descubrir como es para las familias Mexicano-americanas el vivir con diabetes tipo II. Se sabe mucho acerca de tratamiento de la tipo 2 en general. Pero sabe menos acerca de las experiencias día a día especialmente entre la familia.

Experiencias en la familia

- 1) Dígame acerca de su experiencia con la diabetes en la familia
- 2) Como es el vivir con alguien que tiene diabetes, dígame acerca de eso?

Probes:

¿Quién tiene diabetes?

Como es el vivir con alguien que tiene diabetes, dígame acerca de eso

Por ejemplo, Cuéteme algo acerca de lo que es vivir con alguien que tiene Diabetes tipo 2.

Open-ended conversational probes:

Por ejemplo

Dígame algo más?

La persona con diabetes (mujer u hombre)

Información

Edad

Cuanto tiempo ha tenido diabetes

Tiene un cuidado médico regular

Tiene seguro de salud

Toma medicamentos, se controla con dieta, o usa otros remedios naturales

Experiencia del paciente

- 1) Dígame acerca de su experiencia con la diabetes día a día

Other Probes to create stories

Cuéteme como fue cuando le diagnosticaron diabetes?

¿Qué sintió acerca de eso?

¿Pensó en hacer cambios en su vida?

¿Cómo fue el tiempo en que le dijeron que tenía diabetes?

Probes

Por ejemplo: Como es su estilo de vida? que acostumbra comer? hace ejercicio? y si lo hace que tanto ejercicio hace?

Como es el tomar sus medicinas para la diabetes?

Situacion economica? situacion con el dinero? a que se dedica? le alcanza para su cuidado, cuanto gana?

Su relacion con otros, con su familia, como es?

Como se siente con respecto a su enfermedad? ha notado que le afecta emocionalmente?

Se irrita o se siente frustrado cuando siente sintomas?

Considera que le ha a pasado a cambios en su estado de animo que causa de su enfermedad o sus sintomas?

2) Digame como la diabetes ha impactado la relacion con su familia reaccionan ellos de manera diferente cuando esta enfermo?

3) Digame que experiencia tiene su familia con respecto a la diabetes

Probe:

Cuenteme con es un dia normal con su familia, que pasa cada dia normalmente?

Open-ended conversational probes:

Por ejemplo

Digame algo mas?

Conyuge o parejaa con l a que viven

1) Digame cual es su experiencia al vivir con un compañero que tiene diabetes?

Probe: Cual es el impacto en usted por causa de la enfermedad de su pareja?

2) Como ha sido la experiencia para la familia con la diabetes?

Probes

Que es lo que pasa en un dia comun y corriente en la familia al lidiar con la enfermedad de diabetes?

las consecuencias economicas?

que impacto tiene dia con dia socailmente o en su relacion con parientes o amigos?

Open-ended conversational probes:

Por ejemplo

Digame algo mas

Los hijos

Dime tus experiencias al tener un padre que tiene diabetes?

Probes Que se siente tener un padre con diabetes?

Como afecta el tener un padre con diabetes a mi familia, o mi relacion con ellos o con otros familiares?

Como la diabetes a afectado a mi familia en el pasado y si problemas como se han solucionado o no se han solucionado?

Other Probes to create stories

Cuenteme como fue cuando le diagnosticaron diabetes?

Que sintio acerca de eso

penso en hacer cambios en su vida?

como fue el tiempo en que le dijeron que tenia diabetes?

Informacion acerca de la familia

Edad de los miembros de la familia

Estado civil (si son casados o no)?

Famimiliares o amigos que vivan en la misma casa?

Cuanto tiempo han estado aqui en Estados Unidos?

Que idioma hablan? Ingles o español

Recursos economicos, empleo?

Educacion?

Appendix D
Transcription Conventions

Appendix D Transcription Conventions

In a simpler, easier to follow procedure. Each narrative will be overread for the larger context in which the narrative is created.

According to Mishler (1986) each narrative segment will be analyzed using the following transcription conventions.

- 1) Nonlexical expressions such as Hm, hm and A, ah.
- 2) Interruptions and overlaps between speakers by a left hand [.
- 3) Hesitations and Pauses by a (P)
- 4) Notes on Voice in parenthesis such as (quiet voice) (strong tone) and (laugh).
- 5) All capitals for words which are emphasized.

Appendix E
Code Book

Code Word	Parent	Text	Definition	Modified	Added
AVOID	BEHAVIOR	YES	avoid bad news or sometime that	08/12/05	08/15/05
CHANGE	BEHAVIOR	YES	What is needed for living with	06/21/05	07/27/05
CHRONIC	BEHAVIOR	YES	Diabetes is a chronic rather than	07/19/05	08/15/05
COMPLICADA	BEHAVIOR	YES	en espanol, diabetes is a very	11/28/05	11/29/05
CONTROL	BEHAVIOR	YES	Having control of disease	06/28/05	07/27/05
CRYING	BEHAVIOR	YES	Participant cries when she notes	12/12/05	01/14/06
CUIDA	BEHAVIOR	YES	In Vivo-demonstrating the need to	12/24/05	01/14/06
CURE	BEHAVIOR	YES	Hope for a cure, makes diabetics do	11/28/05	11/29/05
DAILYROUTI	BEHAVIOR	YES	this refers to daily routine not	08/14/05	08/15/05
ENCOURAGEM	BEHAVIOR	YES	Participant talks about the need to	11/21/05	12/02/05
EXCUSES	BEHAVIOR	YES	In-vivio code from the participant	08/10/05	08/15/05
EXERCISE	BEHAVIOR	YES	important and needed in the control	07/08/05	07/27/05
ISOLATE	BEHAVIOR	YES	PWD's behavior is to not go out to	11/24/05	11/29/05
MEDICATION	BEHAVIOR	YES	Taking medication and managing the	08/12/05	08/15/05
MONITORING	BEHAVIOR	YES	monitoring blood sugar a necessary	06/21/05	08/02/05
MOTIVATION	BEHAVIOR	YES	Needed to manage the complex	07/08/05	08/02/05
RESPECTFUL	BEHAVIOR	YES	The need to be respectful in all	11/29/05	11/29/05
SELFCARE	BEHAVIOR	YES	specifically around managing the	08/13/05	08/15/05
SPIRITUAL	BEHAVIOR	YES	an expression of a dimension or	08/14/05	08/15/05
SUPPORT	BEHAVIOR	YES	The need of family members to	11/13/05	11/29/05
SWEARING	BEHAVIOR	YES	participant swears when he has the	12/12/05	01/14/06
TOBACCO	BEHAVIOR	YES	Smoking is a behavior which needs	01/12/06	01/14/06
WEATHER	BEHAVIOR	YES	When the weather is bad- has	10/04/05	11/13/05
WORRY	BEHAVIOR	YES	Worrying about a family member with	08/20/05	09/26/05
BAGGLE	CONFLICT	YES	bug about diabetes control. In a	07/08/05	08/02/05
NAG	CONFLICT	YES	Encourages by family members which	06/28/05	08/02/05
BILINGUAL	CULTURE	YES	knowing both Spanish and English	06/21/05	08/15/05
ENDURES	CULTURE	YES	Culture endures or refers to long	06/21/05	07/27/05
FAMMEX	CULTURE	YES	The difference between American and	12/16/05	01/14/06
GENDEROLE	CULTURE	YES	specifically male vs. female	07/01/05	07/27/05
GO HOME	CULTURE	YES	There is a sense that one needs to	08/15/05	08/15/05
BELIEF	CULTURE	YES	there are certain cultural beliefs	08/13/05	08/15/05
HEAVY	CULTURE	YES	The sense of being heavy or fat as	08/12/05	08/15/05
HERBTREAT	CULTURE	YES	Herbal treatment-health beliefs and	11/27/05	11/29/05
HOTCOLD	CULTURE	YES	Can be a cultural health belief a	11/24/05	11/29/05
ILLITERATE	CULTURE	YES	Due to rural poverty and being a	12/19/05	01/14/06
IMMIGRATE	CULTURE	YES	Mexicans have a unique experience	12/19/05	01/14/06
MEDICALBEL	CULTURE	YES	Specific medical/health beliefs	07/01/05	07/27/05
MEXICO	CULTURE	YES	Things are always better in Mexico	08/12/05	08/15/05
PROVERB	CULTURE	YES	Speaking about death and dying and	11/28/05	11/29/05
PROVIDER	CULTURE	YES	provides for the family, a specific	07/08/05	08/02/05
SENSITIVE	CULTURE	YES	Cultural awareness	06/28/05	07/27/05
URINEDRINK	CULTURE	YES	This participant believes as a	11/24/05	11/29/05
SURGERY	CURE	YES	The desire for a cure makes many	11/28/05	11/29/05
AGE	DIAGNOSIS	YES	Age at Diagnosis	08/18/05	09/26/05
BEFOREAFTE	DIAGNOSIS	YES	A sense of what life was like	07/08/05	08/02/05
DATE	DIAGNOSIS	YES	an actual date when the participant	08/10/05	08/15/05
LOSS	DIAGNOSIS	YES	Before disease and after what was	07/08/05	08/02/05
SENSEWRONG	DIAGNOSIS	YES	the sense of something being wrong	07/01/05	08/02/05
SHOCK	DIAGNOSIS	YES	reactions to diagnosis of diabetes	07/01/05	07/27/05
AZUCAR	DIET	YES	Spanish word for sugar-in-vivo	11/04/05	11/13/05
COFFEE	DIET	YES	This participant always takes his	11/04/05	11/13/05
COOKING	DIET	YES	an activity which is enjoyed a	08/14/05	08/15/05
CUT BACK	DIET	YES	Restriction in the diet	06/27/05	07/27/05
EATING OUT	DIET	YES	Whether eating out healthy or	07/08/05	07/27/05

Code Word	Parent	Text	Definition	Modified	Added
FASTFOOD	DIET	YES	Diet that is problematic	07/07/05	07/27/05
FIBER	DIET	YES	Need to eat food or bread higher in	11/27/05	11/29/05
FRIJOLE	DIET	YES	Mexican/spanish word for beans-very	11/04/05	11/13/05
FRUITS	DIET	YES	This participant discusses the	11/27/05	12/02/05
HEALTHDIET	DIET	YES	The importance of a healthy diet	08/20/05	09/26/05
HERBS	DIET	YES	A natural diet is the best thing	11/04/05	11/13/05
HIGHCARB	DIET	YES	There is a need to monitor	08/18/05	09/26/05
HIGHFAT	DIET	YES	an unhealthy diet especially for	08/13/05	08/15/05
LAZY	DIET	YES	About and eating out and that kind	07/07/05	08/02/05
LOWFAT	DIET	YES	need to eat less fat with diabetes	11/28/05	11/29/05
SKINSFRVEG	DIET	YES	Eating the skins of fruits and	11/27/05	11/29/05
SPICE	DIET	YES	Eating foods with enough spice can	11/28/05	11/29/05
SWEETS	DIET	YES	Sweets the sesire for when you are	08/18/05	09/26/05
TORTILLAS	DIET	YES	Making and eating tortillas is both	08/14/05	08/15/05
VEGETABLES	DIET	YES	Part of a healthy diet is to eat	11/04/05	11/13/05
ANGER	EMOTION	YES	emotional issues associated with	07/17/05	08/15/05
ANXIETY	EMOTION	YES	One of the mental health issues	07/19/05	08/15/05
BRAVE	EMOTION	YES	The need to be brave against many	12/15/05	01/14/06
CORAJE	EMOTION	YES	specifically in Mexican culture,	11/04/05	11/13/05
DESPAIR	EMOTION	YES	Despair both at the accident and	12/12/05	01/14/06
FEAR	EMOTION	YES	an emotional state brought on by	08/13/05	08/15/05
GUILTY	EMOTION	YES	Feel guilt about not being able to	07/08/05	08/02/05
PANIC	EMOTION	YES	Daughter had feelings of panic over	12/12/05	01/14/06
SAD	EMOTION	YES	having diabetes is muy triste	11/28/05	11/29/05
SCARED	EMOTION	YES	Scared about what the future holds	11/28/05	11/29/05
SUSTO	EMOTION	YES	Susto is a state of shock or great	11/04/05	11/13/05
TRANQUIL	EMOTION	YES	Participant desires a sense of	10/04/05	11/13/05
TRAUMATIZE	EMOTION	YES	Receiving a diagnosis of diabetes	11/28/05	11/29/05
ALCOHOL	FAMILY	YES	Cam impact a family both in terms	10/04/05	11/13/05
BURDEN	FAMILY	YES	Often taking care of a family	08/20/05	09/26/05
COMMITMENT	FAMILY	YES	a sense of personal commitment to	07/10/05	08/14/05
COMPAREF	FAMILY	YES	comparison between different family	07/08/05	08/02/05
ECONOMIC	FAMILY	YES	There is economic costs for the	11/27/05	11/29/05
ENJOY	FAMILY	YES	We need to enjoy family members	12/15/05	01/14/06
FAMCARE	FAMILY	YES	physical care given by family	08/20/05	09/26/05
FAMCONFLIC	FAMILY	Yes	conflict experienced by any member	02/23/06	04/20/06
FAMHISTORY	FAMILY	Yes	family history of diabetes and	02/16/06	04/20/06
FAMLOSS	FAMILY	YES	Loss of family members to diabetes	08/20/05	11/29/05
FAMSUPPORT	FAMILY	YES	support from family members in	06/21/05	07/27/05
GENETIC	FAMILY	YES	One of the risk factors-genetic for	07/19/05	08/15/05
MARRIAGE	FAMILY	YES	marriage-important lifelong bond	07/10/05	08/02/05
PARADVICE	FAMILY	YES	Parents give lots of advice to	12/15/05	01/14/06
PARENT	FAMILY	YES	Role of a parent	07/06/05	07/27/05
ROLEF	FAMILY	Yes	What is the family role	07/10/05	07/27/05
SUPPORT	FAMILY	YES	Encouragement of family members.	06/28/05	08/02/05
VIOLENCE	FAMILY	YES	there is a history of family	12/16/05	01/14/06
WARNING	FAMILY	YES	The mother of the son warns of	11/21/05	12/02/05
WORRIES	FAMILY	YES	under family since family members	10/04/05	11/13/05
ACCEPTANCE	FEELINGST	YES	acceptance of disease/diagnosis	06/21/05	07/27/05
AFFECTION	FEELINGST	YES	using affectionate terms to	07/08/05	08/01/05
AMBIVALENC	FEELINGST	YES	a feeling state regarding diabetes	06/21/05	07/27/05
CONFLICT	FEELINGST	YES	diabetes control and mood state a	07/08/05	08/02/05
DENIAL	FEELINGST	YES	a way to cope with some aspect of	08/10/05	08/15/05
DIFFICULTY	FEELINGST	YES	subjective state-how the	06/21/05	07/27/05
EARLYIDENTI	FEELINGST	YES			

Code Word	Parent	Text	Definition	Modified	Added
FRUSTRATIN	FEELINGST	YES	feeling frustrated by spouse not	07/07/05	07/27/05
HARD	FEELINGST	YES	descriptive invivo word describing	06/21/05	08/02/05
HOPE	FEELINGST	YES	a sense of that maybe this person	08/14/05	08/15/05
IMPRISONED	FEELINGST	YES	participant feels imprisoned by	12/19/05	01/14/06
INSOMNIA	FEELINGST	YES	worrying about diabetes is a	11/24/05	11/29/05
JOY	FEELINGST	YES	emotion felt by participant who is	12/19/05	01/14/06
PATIENT	FEELINGST	YES	Invivo what is needed with someone	07/10/05	08/02/05
REGRET	FEELINGST	YES	A sense of regret looking back how	08/10/05	08/15/05
SLOWINGDOW	FEELINGST	YES	as part of aging- an invivo code	08/14/05	08/15/05
STIGMA	FEELINGST	YES	not wanting anyone to know about	11/28/05	11/29/05
STRUGGLE	FEELINGST	YES	Difficulty or hardship with	07/06/05	07/27/05
SUFFER	FEELINGST	YES	Invivo concept-both the patient and	07/08/05	07/27/05
SURPRISE	FEELINGST	YES	This participant expresses surprise	11/28/05	12/02/05
TRUST	FEELINGST	YES	There is a need to trust both	12/17/05	01/14/06
UPSET	FEELINGST	YES	This participant does not want to	11/02/05	11/13/05
WORRYF	FEELINGST	YES	Family members worry about the	07/08/05	07/27/05
COST	FINANCIAL	YES	Cost of medication is a financial	08/20/05	09/26/05
DISCOUNTS	FINANCIAL	YES	The ability to obtain discounts on	01/12/06	01/14/06
ECONLATINO	FINANCIAL	YES	Overall the economic issues	01/12/06	01/14/06
ECONOMICS	FINANCIAL	YES		07/27/05	01/14/06
FINSUPPORT	FINANCIAL	Yes	Family support in the financial	02/23/06	04/20/06
HOUSECOST	FINANCIAL	YES	The cost of household lights etc.	12/15/05	01/14/06
PATRON	FINANCIAL	YES	Economic Burden of diabetes need to	11/29/05	11/29/05
RESPONSIBL	FINANCIAL	YES	sense of economic responsibilty	07/06/05	07/27/05
UNEMPLOY	FINANCIAL	YES	Difficulties with unemployment or	10/04/05	11/13/05
WORK	FINANCIAL	YES	The importance of working hard to	12/16/05	01/14/06
DYING	FUTURE	YES	Concerns or what is thought about	11/28/05	11/29/05
INFORMATIO	KNOWLEDGE	YES	Need for information about the	07/18/05	08/15/05
KNOWLEDGEL	KNOWLEDGE	YES	Family members feel there is a lack	07/15/05	08/15/05
KNOWWORRY	KNOWLEDGE	YES	Don't know much so how can they	07/17/05	08/15/05
PHYSIOLOGY	KNOWLEDGE	YES	This participant takes his	11/28/05	11/29/05
SHARING	KNOWLEDGE	YES	Sharing of diabetic supples to help	08/12/05	09/26/05
UNDERSTAND	KNOWLEDGE	YES	Understanding is a way of	08/18/05	09/26/05
ASSESS	None	YES	Interviewer assesses knowledge t o	07/17/05	08/15/05
BEHAVIOR	None	YES	certain behaviors necessary in	06/21/05	07/10/05
CULTURE	None	YES	more narrowly defined as uniquely	06/21/05	07/06/05
DIAGNOSIS	None	YES	when first told had diabetes	07/01/05	07/06/05
DIET	None	YES	diabetic diet	06/21/05	07/27/05
EDUCATION	None	YES	Information given to the kids who	07/18/05	08/15/05
EMOTION	None	YES	emotional aspects of the disease	07/06/05	07/07/05
FAMILY	None	YES	relating family to some aspect of	06/21/05	07/06/05
FEELINGST	None		Different feelings about diabetes	07/27/05	00/00/00
FINANCIAL	None	YES	financial stress of diabetes, how	07/06/05	07/06/05
FUTURE	None	YES	Worry concerns about the future	08/20/05	09/26/05
GOOD LIFE	None	YES	in-vivo code that you may not be	08/10/05	08/15/05
INSULIN	None	YES	one of the treatments for Type 2	08/10/05	08/15/05
KNOWLEDGE	None	YES	Assess knowledge or the researcher	07/17/05	08/15/05
MIVIDALOCA	None	YES	in vivo code-describing lifestyle	08/20/05	09/26/05
NEEDLEFEAR	None	YES	A feeling anxiety about injecting	12/23/05	01/14/06
PREGNANCY	None	YES	Affect of pregnancy on diabetes or	07/01/05	07/06/05
SECONDARY	None	YES	secondary is connect to effects. So	07/01/05	07/07/05
SERIOUS	None	YES	Diabetes is a serious disease	07/10/05	07/10/05
STRESS	None	YES	stress and its effect on diabetes	07/10/05	07/10/05
SYMPTOMS	None	YES	symptoms of having diabetes	06/21/05	07/06/05
SYMPTOMS	None	YES	symptoms of having diabetes	06/21/05	07/06/05

Code Word	Parent	Text	Definition	Modified	Added
BAD STUFF	SECONDARY	YES	invivo code for complications of	08/20/05	09/26/05
CHEST PAIN	SECONDARY	YES	secondary side effects of diabetes	07/08/05	07/27/05
DEPRESSION	SECONDARY	YES	mental health issues often seen	07/19/05	08/15/05
EFFECTS	SECONDARY	YES	Secondary side effects of diabetes	07/01/05	07/27/05
FATIGUE	SECONDARY	YES	one of the secondary side effects	07/19/05	08/15/05
GANGRENE	SECONDARY	YES	One of many secondary complications	08/20/05	09/26/05
HEARTDISEA	SECONDARY	YES	One of the secondary side effects	08/13/05	08/15/05
HEAT	SECONDARY	YES	The anxiety feelings of being	12/12/05	01/14/06
IMMOBILE	SECONDARY	YES	Can be one of the secondary	08/20/05	09/26/05
IMPOTENCE	SECONDARY	Yes	impotence is a secondary side	01/31/06	02/07/06
KIDNEY	SECONDARY	YES	One of the secondary side effects	07/19/05	08/15/05
LIVER	SECONDARY	YES	Liver problems can be a secondary	11/28/05	11/29/05
MIGRAINES	SECONDARY	YES	Secondary complication of diabetes	07/08/05	07/27/05
MOOD SWING	SECONDARY	YES	symptom of diabetes or symptoms of	07/06/05	08/02/05
MUSCLEACHE	SECONDARY	YES	Due to hard work, this participant	11/28/05	11/29/05
NEROPATHY	SECONDARY	YES	numbness and tingling in my lower	11/28/05	11/29/05
PROGRESS	SECONDARY	YES	Disease progression which leads to	08/10/05	09/26/05
RETINOPATY	SECONDARY	YES	One of the secondary side effects	08/14/05	08/15/05
SHOOTUP	SECONDARY	YES	INVivo code-Bloodsugars go up with	08/18/05	09/26/05
SKININFECT	SECONDARY	Yes	I think of skin infections as one	02/09/06	02/16/06
WASTING	SECONDARY	YES	this participant has a real sense	12/12/05	01/14/06
WEIGHTLOSS	SECONDARY	YES	having high BS can lead to weight	08/12/05	08/15/05
RELAX	STRESS	YES	Away to cope with stress or mood	07/06/05	07/27/05
STRESSOUT	STRESS	YES	a in vivo code used to described	07/19/05	08/15/05
ACCIDENT	SUSTO	YES	An auto accident caused a great	12/12/05	01/14/06
DIZZY	SYMPTOMS	Yes	Being dizzy is one of the symptoms	01/31/06	02/07/06
DRYMOUTH	SYMPTOMS	YES	One of the symptoms of highbs.	11/21/05	11/29/05
FINGERPAIN	SYMPTOMS	YES	Can be one of the symptoms of	12/23/05	01/14/06
HEADACHE	SYMPTOMS	YES	One of the symptoms when one's BS	12/23/05	01/14/06
HIGHBS	SYMPTOMS	YES	Elevated blood sugar and what	07/17/05	08/15/05
LOWBS	SYMPTOMS	YES	low blood sugar is a symptom	08/20/05	09/26/05
OVERWEIGHT	SYMPTOMS	YES	being overweight how it affects	07/17/05	08/15/05
PAIN	SYMPTOMS	Yes	This participant had a chronic pain	01/25/06	01/31/06
TIRED	SYMPTOMS	YES	Being tired/fatigue is one of the	11/04/05	11/13/05
URI	SYMPTOMS	YES	Cold symptoms may keep this	11/29/05	12/02/05
URINARYFRE	SYMPTOMS	YES	One of the symptoms of highbs, can	11/21/05	11/29/05
VAGINFECT	SYMPTOMS	YES	Can be a symptom of diabetes or a	08/18/05	09/26/05
VISONCHANG	SYMPTOMS	Yes	symptom of potential complications	02/21/06	04/20/06
WEAK	SYMPTOMS	Yes	one of the symptoms this	02/09/06	02/16/06
WEAKNESS	SYMPTOMS	YES	one of the symptoms of diabetes	10/04/05	11/13/05

Appendix F
Organizing Framework

Appendix F Organizing Framework

I. Emotional Burden and Turmoil of Type 2 Diabetes The Central Story

A. Political/Social Context

- 1. Poverty**
- 2. Undocumented legal status**
- 3. Lack of access to medical and social service**

B. Family Context

- 1. Low Literacy**
- 2. Unemployment**
- 3. Alcoholism**
- 4. Domestic Violence**
- 5. Worry and Conflict**
- 6. Lifestyle changes and struggle**

II. Six Narrative Types within the Context of the Central Story of Emotional Burden and Turmoil

A. Those who have gone on before/ The scourge upon the generations

- 1. Experience of diabetes as historical legacy/multigenerational understanding**
- 2. Advice from an older generation**
- 3. Mirror of what will happen to me/awareness of personal risk for disease**
- 4. Loss/Worries for the Future for family members**
- 5. Living memories**
- 6. Death**
- 7. Guilt and Sorrow-Experience of Person with Diabetes**
- 8. Fatalism/Living on Borrowed Time-Experience of Person with Diabetes**
- 9. Generational Suffering**

B. Un Gran Susto-Culturally bound Causal agents of disease

- 1. Susto**
- 2. Coraje**

- C. The Shock of the Bill-the financial burden of Type 2 diabetes**
 - 1. Financial Devastation-the bills**
 - 2. Mexico vs. U.S.- the disgrace of poverty in a 3rd world country**
 - 3. Forced choices**
- D. Tale of the Tortilla-the meaning of food**
 - 1. Food as cultural identity**
 - 2. Food as emotional connection**
 - 3. Natural Mexican food- a long life associated with not eating sugar**
- E. Changes in our Lives-Cambios en Nuestra Vida**
 - 1. Distinct Beliefs and Attitudes**
 - a. Magical realism**
 - b. Latino evangelical beliefs**
 - c. Biblical legends-the forbidden fruit and diabetes**
 - 2. Medication**
 - a. Chronicity**
 - b. Beliefs for not taking medication**
 - 3. Blood Glucose Monitoring**
 - a. Avoidance to prevent worry**
 - b. Avoidance to prevent pain**
 - 4. Insulin Therapy**
 - a. Worsening of disease**
 - b. Dependency on "the needle"**
 - c. Management of Hypoglycemia**
 - 5. Diet**
 - a. Daily Family Experience**
 - b. Family Conflict**
 - (1) Increased Conflict**
 - (a) Relationship strain i.e. mother in law-daughter-in-law**
 - (b) Alcoholism and poor diet together**
 - (c) New diabetic = new roles**
 - (d) Poor dietary habits in general of person with diabetes**

(2) Decreased Conflict

- (a) When both adults in the family have a chronic disease**
- (b) Focus is on struggle rather than suffering**
- (c) Father as role model for the family**
- (d) Positive support in the family**
- (e) Staying calm-less anger**

c. Poor eating habits

- (1) Can lead to family conflict**
- (2) Source of struggle for persons living with diabetes**

d. Cultural/gender expectations around food

6 Exercise

- a. Avoid exercise (PWD)**
- b. Embrace exercise**
- c. Family member support**
 - (1) Purchase equipment**
 - (2) Exercise together**
- d. Source of family conflict**

F. Preocupaciones por el futuro-Worries for the future

- 1. Shortened Life**
- 2. Disability and Death**
- 3. Being unable to provide for family because of shortened life and disability**
- 4. Fear that children will develop the disease**
- 5. Children worry they did not have enough information**
- 6. Fear of being left alone without husband**

Appendix G
Exemplar Narratives

Appendix G-Exemplar Narratives

Based on the organizational framework of six story types presented in Chapter 4, these are examples of longer narrative threads presented in the interviews. Each of the six story types will have one or two examples.

Those who have gone on before-The Scourge upon the Generations

Family 02 PWD#1 04

Living with My Mother-It's a Daily Reminder

It is a daily reminder. When I see her, when I see her sugars, her levels have dropped so low. When her levels have bottomed out, you know. When I see her when she can't hardly walk or stretch. When I see her when she can't hardly move any more, you know. Because I know that is going to happen to me. Because living here has opened up my eyes. Because if I lived away, I wouldn't see the daily things she goes through. Sometimes, you know, we will be watching TV and she will fall asleep. She will be really tired. I'll be sitting there, you know, watching her to see if she is still breathing. Yup..... I worry about her all the time, all the time.

she almost died her second one. She was 64 in the year 2000, she had her second one. My husband had just passed away in October, 1999. And she was having shortness of breath. And she was having, problems with her legs. And they couldn't figure out what was wrong with her. So finally, her doctors sent her to a cardiologist in Portland. And my sisters took her. She wanted me to get away from here, because I was going through my own hard times. I was on my way to Mexico City, when I got called in Mexico to come home because Mom was in the hospital and she was having her second open heart surgery. And they didn't think she was going to make it, because her veins were so thin and so full of fatty tissue. She was.. They just didn't think she was going to make it. Her own doctor, her own cardiologist didn't want to perform the surgery. He got these two really young cardiologist to perform the second open-heart surgery, which was a three bypass. And didn't get to see her before she went into surgery, I got there like 5 hours after she was already in surgery. When I saw her all hooked up to the machines again and all swollen. I had just lost my husband, and I thought I was going to lose her too. It all became very real. That she was not going to be with us very much longer. For me, it was so very real. Three years later, about 2003 she started having chest pains and shortness of breath and all that. And again we made an appointment with her cardiologist. And again he told us we can't perform another open-heart surgery and she's got some of her arteries are plugged again. And we asked Mom what her wishes were and she said, Let me live, mi

vida loca and that is just what we are doing letting her live her life, the way she wants to.

She doesn't complain. She never lets us know. But lately she does not go to exercise anymore like she used to, it wears her out really easy. Uhm, she stays at home more. She just slowly starting to slow down. We have to face the fact that she is living on borrowed time. When they told us that, my dad went through a really hard time because uhm when they told us they couldn't do anymore for her. My dad went through a depression at that time and so did the rest of the family.

Yup, so now we just let her do what she wants to do. And let her live however she wants to live her life, you know. If she wants to go out we go out. If she doesn't want to go out, she'll stay home. Now like last Sunday, Saturday, Sunday we went shopping. She goes for short little walks and then she gets tired. She has to hang on to me. She can't walk very far or very fast.

But she is so sharp up here. So, so sharp, you know Recently, Well, it's her diabetes. She has bottomed out to where she knows what is going on. I'm afraid it is going to happen in the middle of the night and she is not going to wake up. But she wakes up and gets her juices and you know and huh and eats something. Eat fruits and regular pop. Because she says that works best for her.

Well, this week she has had like three of them. Today at noon when I came home at noon she had bottomed out again. And last night too or last Saturday I can't remember. Uhm, I saw her sitting in the chair, she had a cup like that and she was just resting. I pulled the cup away from her, I thought she was asleep. She goes No my sugar had bottomed out. And then She had oat meal with a lot of sugar. That was what she was eating. She went from the kitchen to over there to sit down. And she just all her energy pulls away from her body and she can't move and she gets like this cold sweat. We are constantly having to watch that. I come home every day for lunch. If I need to get away because I am here every day watching her. And then I call my sisters to come up here and to spend time with Mom. I've got four sisters and three brothers, you know. You need to give me a break sometime.

At times it does get to be a burden. Yea, but somebody has got to do it. What can I say. I need to be here. There is no other place. Right, right.

We kid around all day long. And you know, we talk about silly stuff, you know. We poke jokes at each other and she says you're not like my daughter, you are like my best friend. I tell her about all my male friends and she loves all that. It is like being a high school kid and dating guys again and she loves all that drama. I ask her for advice and she'll give me advice. It's hard seeing my mom like this. It is very hard.

Family 02 PWD 1 04.1 (continued)
Caring for my Grandmother

My mom didn't have to go that with my grandmother. Cause my mom since she was thirteen years old has lived in the United States and she only went back home once every year or once every three years and whenever grandma was got sick, you know.

She went home. She hasn't dealt with the illness of mother, like I have had to deal with her illnesses. It is different for me than it was for her and her mother.

Well, she always had her sisters that she depended on. So, uhm. So kind like my sisters depend on me to take care of my Mom. She had her sisters always on top of things. You know for my grandma. And at one time, after my grandma had her second leg amputated, my one sister next to me went to Mexico to take care of my grandma for three months. And uhm and then she came back. But my Mom only went over there in cases of emergency or to visit.

I was already married. It must have been in 1970, maybe in the 70's's. Let's see cause(Name) was born in 1972 so maybe like 1975 she started having health problems. And it all came about because she had one little sore on her toe and she didn't know she was diabetic. And so she got gangrene on the one leg and then they had to amputate her foot and then they went up to the knee and then they went all the way up to her hip. That was the first time...uhm, my Mom went to Mexico at that time with my Dad. When she got out of the hospital. Mom was only there at the hospital. My aunts cared for my grandmother. Then about 5 years later, she had her second amputation. And again my Mom would go for the surgery part., to visit her.

Uhm. And uhm, when she had her first leg amputation, they made her a prosthesis made out of wood. It was so heavy; It was so, so heavy. And hum, She would get sores on the nob leg trying to drag that leg around. It was terrible, so, so terrible. And then when she got her second one, they were going to try to get her two prostheses but she couldn't deal with it. She couldn't walk. I mean they were just too high up and she was 65 then. And she ended up not using them, so depended more on the wheelchair. To get her in and out of the wheelchair was another story.

*Uhm, She was a woman about my size, you know. maybe just a little shorter, you know. In order to get her up from the chair into a stool, or chair or a bed. You would have to pick her up like (show example)
under the arms*

Family 02 PWD 1 04.1 (continued)

And pick her up and lay her down. Because it was just dead weight, you know. Somebody had to do it and it was my aunts.

My mom never went through that. She never picked her up. She never picked up my grandma. I did when I would go visit her. I picked her up a couple of times when I went and visited her. She needed to either go from the bed to her wheelchair. From the wheelchair to the bathroom or something.

Oh yes, And we saw her one more time and it was like in summer of 1985, I took my kids. My husband and I took a trip to Mexico and we saw her and that winter she passed away. That summer all of my brothers and sisters took a trip to Mexico to go see grandma one by one. And that winter she passed away. So I know what diabetes does to a patient. I know exactly how bad it is.

We haven't dealt with the dialysis part but we have deal the all other disease, I mean all other bad stuff which comes

When you stop to think about it, yea. If you go on on a daily. It just becomes part of your life. It's just so normal for me to see it. It's so normal for me to not think about it. I mean because it's a normal way of life for us.

So the main key is to catch it early, take care of yourself early, exercise, eat right . Take your medication, go to the doctor. Take care of it before it gets, you know. I see patients, young patients, you know at the clinic less than 30 years old with glucose up to 400-450. And they are young and they don't understand, you know and they don't come to the classes. And you know if they could just see what it has to done to my family, you know. And they have little ones, who is going to take care of your little ones. You know

If you don't take care of yourself who is going to take care of your kids. And this young lady does not have a clue. She went to one class and she didn't come back. Her sugar, it was 400-450. They should have put her in the hospital to get her under control. And when you go through dialysis , you know, that is a different story right there.

Your kidneys....Diabetes affects every part of your body, every single part, your eyes, yours limbs, your kidneys, your heart and your veins. Everything, you know affects everything. Like I said, I would rather have these problems when I'm 70-80 if God willing. Rather than have them right now when I'm 54 and when I can still see and do and you know. And

Family 02 PWD 1 04.1 (continued)

get around. So much easier to do it right now than to have all these complications when you are so young. But people just don't get it sometimes, uh-hum. Maybe they haven't been or seen enough. Maybe they have not been educated enough. Maybe the doctor has not encouraged them enough. It is hard to say.

Familia O3 PWD#1

Those who have gone on before

Si yo se como mi mama murió de eso. Mi papa murió de un infarto y cuando el murió también le detectaron la diabetes.

Si. Entonces mis dos papas tenían diabetes. Y como yo he tenido muchos problemas con mi familia, con mis hermanos, y todos esos problemas yo fui la que pues la que trataba de resolverlos. Todo eso a mi me afecto mucho, entonces pienso yo que quizás sea por eso. Y como en México nunca me cuide, nunca hice nada por nada. Entonces ahora ya me esta, pues, no se, trato de no tomarlo muy... no quiero enfermarme mas yo pensando en que estoy enferma. Por eso a mis hijos les pedí que ellos trataran de estar tranquilos para que yo estuviera tranquila, porque yo tengo muy presente la forma en que murió mi madre y a me no me gustaría terminar igual a mi mama. Sufrió mucho, mucho, mucho. Y, pero igual a mis hijos yo les dije que yo no quería que tomaran mi enfermedad como, como para que me tuvieran lastima. Yo quiero llevar una vida normal. Yo no quiero... yo me tomo mis medicamentos y hago de cuenta que es cualquiera pastilla. Yo, o sea yo no estoy pensando nada mas en eso; no me gusta, no quiero, no quiero. Y problemas pues todos tenemos. Todos tenemos y trato de evadirlos los que puedo, los que no pues... y ahorita pues, gracias a dios, tengo el apoyo de mi esposo, tengo el apoyo de mis hijos y trato de llevar una vida normal, de no estar solo pensando en eso. Se que lo tengo, se que debo de cuidarme, se que debo de hacer muchas cosas para que yo pueda estar bien, pero a veces no se puede. Pero trato mas o menos de llevar una vida balanceada de no, pues junto con mi familia. Y pues los únicos que tengo aquí son mis hijos y mi esposo, mi sobrino y de allí nadie; todos están en México. Y tiene, en el transcurso de 3,4, anos murió mi tío y mis hermanos, 3 de mis hermanos, entonces prácticamente yo familia casi no tengo. Solo tengo otros 3 hermanos y ellos se están haciendo su vida cada uno tiene su manera. Y yo acá pues los únicos son mis hijos y mi esposo y por eso trato mejor de no pensar en ello. Porque también yo soy de las personas que yo pienso que si uno nada mas esta pensando, se enferma uno mas y para me eso no, no tiene caso. Ahora yo estoy consciente de que todos algún día tenemos que morir. Pero ya cuando me toca pues ya. Pero ahorita trato de no, mientras dios me de la oportunidad de poder todavía caminar, seguir mirando, porque yo se todo lo que me puede pasar. Ahorita tengo, tengo que una cita con el oculista porque he tenido mi vista un poco borrosa entonces tengo que ver eso. Pero igual trato de animarme, yo se que todo va a pasar. Y sigo tomando mis medicamentos como se me indica y trato de estar bien; un pocito de ejercicio de vez en cuando, porque, no todos los días. Aquí desgraciadamente nos mal acostumbramos a que ya tengo carro ya no quiero salir de

Familia 03 PWD #1

ningún lado si no es con carro. Pues no, desde ese año y medio que ya supe de mi enfermedad pues trate de no... mas que todo como que estaba yo como conforme, si, porque le vuelvo a decir yo ya me lo esperaba porque yo se que la diabetes es hereditario. Mis papas de eso murieron. Fue lo único que me llevaron.

Mi mamá, mi mamá ya era una mujer muy bonita y muy llena de vida y era muy gorda. (participant crying) Pero mi mamá era como dos veces mía, gorda. Y mi mamá, ella era una mujer muy buena gente y a base de tantos problemas y descuidos de ella y de nosotros como sus hijos porque yo no cuide a mi madre como debí cuidarla, mi mamá ella murió un huesito. Y mi madre cuando la podían traer de la casa a la cruz roja, ella gritaba mucho porque decía que sus huesos se le quebraban. Que ella la lastimaban mucho. Y ella estuvo como 2 días en el hospital y fue cuando murió. Pero mi madre era una persona muy, muy, muy fuerte. En muy poco tiempo mi madre se acabo. En menos de... que será... 2 años, mi madre ya no era nada.

No, no se realmente, no se durante cuanto tiempo tuvo diabetes, no me lo se. Pero ya cuando, cuando se le empezó a desarrollar mas, fue aproximadamente como 2 años que ella estuvo muy mal, mal y fue después que se murió. Y a los 4 meses murió mi papá. Mi papá también era una persona muy fuerte. (participant crying). También era gordo el y a el le dio un infarto. A el le dio un infarto y cuando llegaron al hospital, ya no lo pudieron a el volver. Pero cuando pues le hicieron allí sus estudios y todo también resulto que tenía diabetes mi papá. Entonces ellos se fueron siguiendo nada más por 4 meses. Murió mi mamá y a los 4 meses mi papá y los 2 tenían diabetes pero mi madre si sufrió mucho. Pero desgraciadamente allá muchas de las veces en México no tenemos la posibilidad de medicinas, doctores, hospitales, consultas. Aquí yo tengo la oportunidad de ir a la clínica y decir yo necesito mi medicina pero no tengo dinero y me la pueden dar pero en México no tenemos esas posibilidades. Entonces mi madre realmente medicamento poco lo tomo. Ella la única cura que luego tomaba era pues ahora si como decimos en México puros remedios caseros. Que toma te esto, te de esto, un te de esto y otro y yo no se si tomaba pero de allí no pasaba. Y pues mis hermanos... mi hermano mayor al parecer murió de cáncer en los huesos. Pero ellos tomaban mucho. Mis hermanos tomaban mucho. Mi hermano el más chico murió de 24 años. Si, el era alcohólico también y cuando estaba en el hospital le dio un infarto también. 3 infartos le dieron a el y de los 2 primeros lo pudieron volver pero ya de el último ya no y así fue como murió mi hermano también. Y realmente ahorita pues yo lo único que deseo es y mas que todo pedirle a dios que me de la oportunidad de ver a mis hijos mas grandes, que estén bien. Estoy conforme con lo que dios me ha dado y como le digo quizás mi enfermedad la estoy aceptando conscientemente de que eso tenía que pasar. Yo también no me cuide lo suficiente como para que no pasara. En México desgraciadamente también por cuestiones de trabajo. Todo el tiempo anda uno trabajando y uno se olvida de uno mismo. Si se olvida. Aquí, aquí tengo la oportunidad de decir no pues voy al medico y me llevo mi medicina. Allá muchas de las veces le piensa uno. Si aquí que estamos aquí en los estados unidos le pensamos para faltar a trabajar unas horas pues en México mas. Allá en México es muy difícil de decir aye no voy a trabajar porque tengo que ir al medico. No se puede. La situación en México es muy dura, es muy difícil.

Familia 03 PWD #1 (continued)

*Hay mucha pobreza y si no lo hacemos todo por dinero no hacemos nada. Entonces ahorita realmente yo en México nunca me cuide. Como le digo para empezar, no lo tome muy en serio cuando a mi me dijeron de mi enfermedad y para terminar pues no me daba yo la oportunidad porque en ese tiempo yo estaba sola y tenia que trabajar para mis hijos. Y pues nunca me di la oportunidad yo de decir hoy voy a decidir, ver por mi misma. Realmente no tuve la oportunidad. Y aquí pues si la tengo. Tengo la posibilidad de ir a un medico de que me chequea, tengo la oportunidad, pues tengo la oportunidad de tomar mas que todo un medicamento, aquí un medicamento
Pues si de hecho yo realmente no se como fue que le dio la diabetes a mi mama. Pero ella se cayó a un pozo muy hondo y al parecer por el susto que tuvo ella. Y después pues todos los problemas que tenia con sus hermanos y con su hermano de allá, después de eso. Y realmente como le digo ella no se cuidó, ella no se cuidó y ella no se cuidó y nosotros no la cuidamos y pues así fue como mi madre terminó, muy mal. Por lo mismo en México, no tiene uno la suficiente posibilidad para cuidarse. Ella tomaba puras cosas naturales. Se hacia licuados de nopales y como allá matan pollos; los pollos traen una hiel, una bolsita de hiel, y la hiel, que le dicen ellos, ella se la tomaba.
Si. Eso era lo que ella tomaba. La hiel del pollo y se hacia licuados de nopal y tes de no se cuantas yerbas. Todo eso era lo único que tomaba mi madre.*

Nada. Realmente no nada. Ahorita me han ofrecido el “nuni.”

Un producto que esta saliendo de hacer un cura de quien sabe cuantas cosas. Es mucho dinero. Cuesta \$43 y nada mas me duraría una semana. Entonces es mucho dinero para me ahorita. Tenemos nosotros muchos problemas y realmente no se, un producto natural también, no se. Nunca lo he tomado. Si pero no, yo no tomo nada mas que mi medicamento, solo mi medicamento.

So my two parents had diabetes. And like I've had a lot of problems with my family, with my brothers and I was the one who tried to solve them, all these problems. All this affected me a lot, so I think that it might be because of this. And like in Mexico I never took care of myself, I never did anything about anything. And so now, well, I don't know, I try not to take it very... I don't want to get any sicker thinking about the fact that I'm sick. Because of this I asked my kids to try and not worry so that I won't be worried, because I'm very aware of the way my mother died and I wouldn't like to end up like my mother. She suffered a lot, really a lot. And in the same way I told my kids that I didn't want them to treat my illness as something to pity me about. I want to lead a normal life. I don't want... I take my medicines and know what each pill is for. Or let's say that I'm not only thinking about this; I don't like to, I really don't want to. And well we all have problems. We all have them and I try to avoid the ones I can, the ones I can't well... and then right now thank god I have the support of my husband, I have the support of my children and I try to lead a normal life, not just be thinking about this. I know that I have it, I know that I need to take care of myself, I know that I need to do many things so that I can be well, but sometimes it's not possible. But I try more or less to lead a balanced life and not, well together with my family. The only ones I have here

Familia 03 PWD#1 (continued)

are my kids and my husband, my nephew, and no one else; they're all in Mexico. In the space of 3 or 4 years my uncle died and my brothers, 3 of my brothers, so really I hardly have any family. I just have another 3 brothers and they are each living their own lives. And me here well the only ones are my kids and my husband and so it's better that I try not to think about it. I'm also one of those people who think that the more you think about it the more you'll get sick and for me there's no point to it. Now I'm aware that we all have to die some day so then when it's my turn well that's it. But right now I try not to while God still grants me the ability to walk, to keep on seeing, because I know everything that can happen to me. Right now I have an appointment with the eye doctor because I've had a bit of blurred vision so I have to see about this. At the same time I try to motivate myself, I know everything that's going to happen. I keep taking my medicine like I'm supposed to and I try to stay well; a little exercise from time to time because, not every day. Unfortunately here we've fallen into bad habits; now that I have a car I don't want to go anywhere unless it's in the car. Well no, during this past year and a half that I've known about my illness I've tried not to ...more than anything because I was resigned to it, because like I say again I was expecting it because I know that diabetes is hereditary. My parents died from it. It was the only thing they handed down to me.

My mom, my mom was a very beautiful woman, very beautiful and very full of life, also very fat. [Participant crying] my mom was like twice as fat as me. And my mom, she was a really good woman, and because of so many problems and not having the proper care, and from us as her children, because I didn't take care of her like I should have, my mom was like a stick when she died. And when they were able to take her from the house to the red cross she cried a lot because she said that her bones were breaking, that they were hurting her a lot. And she was in the hospital about 2 days then she died. But my mother was a very, very, very strong person. She wasted away in a very short time. In less than...what would it be...2 years, there was nothing left of my mother, but sometimes it's not I really don't know how long she'd had diabetes, I don't know. When it started to get worse she was really, really bad for about 2 years and then after that she died. Then 4 months later my dad died. My dad was also a very strong person. [Participant crying]. He was also fat and he had a heart attack. He had a heart attack and when they arrived at the hospital they couldn't bring him back. Then when they did the studies and everything it turned out that my dad had diabetes. So they followed each other by just 4 months. My mom died and then 4 months later my dad and both of them had diabetes but my mother suffered a lot. Unfortunately many times in Mexico there's no possibility of medicine, doctors, hospitals, consultations. Here I have the opportunity of going to the clinic and saying I need my medicine but I have no money and they can give it to me but in Mexico that's not possible. Therefore my mother really didn't take much medicine. The only treatment that she took later was like we say in Mexico just household remedies. Drink this tea, that tea and the other and I don't know if she drank them but more than that she didn't do. And then my brothers...my older brother it seems died of cancer in his bones. But they drank a lot. My brothers drank a lot. My brother, the

Familia 03 PWD#1 (continued)

youngest died at 24 years old. He was alcoholic as well and when he was in the hospital he also had a heart attack. He had 3 heart attacks and the first 2 they were able to revive him but then not with the last one so that's also how my brother died. So really now the only thing I want and more than anything I ask God to grant me is the opportunity to see that my son and daughter are okay when they are older. I am resigned to what God has given me and like I say, perhaps I am consciously accepting my illness as something that had to happen. Also I didn't take enough care of myself so that it wouldn't.

Unfortunately it's a question of work in Mexico. You're working all the time and you forget about yourself. Yes you forget. Here I have the chance to say no, I'm going to the doctor and I'll get my medicine. You think about it there often. Now that we're here together in the United States we think about how we would have to work more in México. Well really I don't know how my mom got diabetes but she fell into a very deep well and it seems it came from the shock she got. Then later all the problems she had with her brothers and with her brother there after that. And really as I say she didn't take care of herself and we didn't take care of her so that's how my mom ended up, really bad. For the same reason, that in Mexico you don't have a chance to take care of yourself. She just used to take natural remedies. She made cactus juice and like there they kill chickens; the chickens have bile, a sac of bile and they say she used to drink that bile. Yes that was what she drank. The chicken bile and she made cactus juice and teas of I don't know how many herbs. All that was the only thing that my mother took.

Nothing. Not really anything. Right now they've offered me 'noni' juice. [mulberry]

A product that's supposed to cure who knows how many things. It's a lot of money. It costs \$43 and it only lasts me a week. So that's a lot of money for me right now. We have a lot of problems and I really don't know if I want a natural product also, I don't know. I've never taken it. No, I only take my medicine, only my medicine

There in Mexico it's very difficult to say 'oh I'm not going to work because I have to go to the doctor.' You can't do that. The situation in Mexico is very hard, it's very difficult. There's a lot of poverty and unless we're doing it for money we don't do it. So in Mexico I never really took care of myself

Familia 02-PWD# 1

The Shock of diagnosis-Un Gran Susto and Coraje-anger held within-

Mi madre tiene diabetes. Tiene 14 años, 15 años con la diabetes tipo 2. Sobre de eso yo me he dado cuenta que ella me platicaba que su enfermedad iba avanzando más y más y me decía "mi hijo no comas tanto, mucho para que no engorde, porque eso te va a provocar enfermedad. como yo, la que tengo, la diabetes que es muy peligrosa.

Familia 02-PWD# 1(continued)

Pero pues yo no la tomaba como a mal ni a bien como dijo aquel, si no yo decía "no pues yo me siento bien, me siento fuerte," estaba yo un pocito gordito. En el 2000, en el 2002 me cayo exactamente la diabetes y cuando de repente provoco un accidente una muchacha; que íbamos a una pesca y nos invito su esposo de ella y nos íbamos a buscarla a otro lado, pero la muchacha se le apago el carro y era automático y era un. Y al apagar el motor pues ya ve a ver que agarre el freno a ver que ya no, el automático es muy traicionado. Y ella agarro y le quiso meter los frenos y nada y nada y le digo "dale vuelta" y luego mal inclinó porque íbamos a chocar con una casa. Y antes de llegar, antes de pegar a la casa estaba una barba, pero no había casa. Yo con un cigarrillo y le metí la mano así, le hice volver adelante así y se fue pah. Por pocito tanto así, no entramos a la casa. Aparentemente yo no me asuste. Ella si se golpeo se presento contundida y se asusto. Y ella la muchacha se asusto muchísimo y lloraba y se reía a veces, del susto. Y yo tranquilo, yo le dije "no se espanten porque yo no estoy asustado." Dice "estas asustado?" "No yo no me asuste." Pero fue simplemente un susto, un impacto que yo no sentí. A los 2,3 4 días me resulto que empiezo, empecé yo a salir a orinar muy seguido, muy seguido, muy seguido.....*

Aye chingado pero que pasaba conmigo? porque salgo mucho a orinar, cada media hora, cada hora, cada media hora, seguido, seguido? Entonces yo había escuchado por allá, dicen verdad, había escuchado que cuando tiene uno diabetes, tiene uno dulce la orina. Y mi mama me lo había platicado, unos tiempos atrás también, y yo nunca le creía pues, yo nunca le creía que la orina se pusiera dulce como miel. Y yo salía muy seguido. Ya llevaba una semana, 2 semanas y mi boca muy seca, amarga.....

Me levantaba yo en la mañana, mi boca amarga y seca y para eso de que cuando tiene uno la azúcar alta, la diabetes alta, ya a una posición de 300 a 400 ya te ataca el cuerpo. Cuando esta uno un poco gordo, que sea harto de manteca, te ataca mas y o en México que hay calor te ataca a una fatiga, un calor, pero un calor caliente que te quema, te quema la piel, te quema el cuerpo; y la cabeza la siente caliente, caliente que parece que tiene uno abrasa, que te metes al baño y quisiera estarte debajo del agua porque lo siente bueno, sabroso, fresco pues. Pero estar en el agua también es mucho, muy mal y malo porque agarra frialdad. Y de eso y a me, yo me bañaba.. En México yo me bañaba 3 veces al día o a veces a media noche me tenía que parar a bañarme para que yo fuera a descansar un poco, porque el calor me mataba. Y a veces que allí voy bajando de peso; pues estaba yo como unas 250, 60 libras y estaba yo bien gordito. Ahorita ya me ha venido acabando el azúcar, la diabetes y estoy delgado ya. Ahorita me acabo de pesar, peso 166 libras.

Familia 02-PWD# 1 (continued)

OK now I've had, now I've had diabetes for 2 going on 3, 3 years. My mother has diabetes. She's had Type 2 diabetes for 14 years, 15 years. I haven't forgotten that she used to tell me about this, that her disease was becoming more and more advanced and she said "son, don't eat so much so you don't get fat, because this will cause disease like the one I have, diabetes which is very dangerous." But then I didn't pay attention either way, like he said, I just said "no, I feel well, I feel strong," I was a bit fat. In 2000, in 2000 exactly I got diabetes when a girl caused an accident all of a sudden. We were going fishing and her husband invited us and we were going to look for fish on the other side, but the girl's car stalled and it was an automatic. And when the engine stops well you brake and sometimes it doesn't work, the automatic is very tricky. And she pressed and wanted to apply the brakes but nothing happened and I say "turn" and then she swerved badly because we were going to hit a house. And before we got there, before we hit the house there was a barbed wire fence. I was smoking and I put my hand out like this, made her go forward again like this and she went pow. We missed the house by a tiny bit. Apparently I didn't get scared. She banged herself, she got bruised and she got scared. And she, the girl got very scared and was crying and laughing at the same time with the shock. And I said calmly "don't be afraid because I'm not." She says "are you scared?" "No I didn't get scared." But it was just a shock, a blow that I didn't feel. 2,3, 4 days later I ended up beginning to, I began to go to urinate very often, continually, very often.

Oh gosh but what was wrong with me? Why am I going to urinate so much, every half hour, every hour, every half hour, continually, continually? Then I'd heard, they say right, I'd heard that when you have diabetes your urine is sweet. And my mother had told me about it some time ago also and I never believed her then; I never believed that urine would turn as sweet as honey. And I was going very often. It was already a week, 2 weeks, and my mouth was dry, with a bitter taste. I got up in the morning, my mouth bitter and dry and this was because when you have high sugar, severe diabetes, already at a level of 300 to 400 then it attacks your body. When you're a bit fat, or with too much lard, it attacks you worse, or in Mexico where it's hot the fatigue gets to you, the heat, but a fiery heat which burns you, it burns your skin, it burns your body; and your head feels hot, hot like it's on fire, and you get in the bath and you'd like to be underwater because it feels good, delicious, fresh you see. But being in the water is also very bad, bad because you catch cold. And so I used to bathe...in Mexico I used to bathe 3 times a day or sometimes I had to get up to bathe in the middle of the night so I could get some sleep, because the heat was killing me. And sometime there I start losing weight; you see I was like 250, 60 pounds and I was quite fat. Now that the sugar, the diabetes has taken its toll on me I am thin. Now I just weighed myself, I weigh 166 pounds.

Familia 02 04.1

Un Susto Muy Grande

Aunque pues la diabetes de mi padre empezó desde que no hace mucho tiempo como me parece ser que unos 3 años creo, no recuerdo bien pero esa ocasión yo trabajaba, porque pues ya yo había salido de la escuela y todo y yo digo pues, no, tengo que ayudar a mi papa en la casa y con los gastos y todo porque pues allá la situación muy difícil. Entonces yo en esta ocasión estaba trabajando y ellos se habían ido a pescar. A pescar, si, que según iban a pescar porque como era tiempo de calor y todo y tiene una amiga allá que ella tiene carro y todo, entonces los fue a buscar a la casa y les dijo que iban a ir a pescar y todo pues encampanaron todos allí, el vecino y la vecina también, su esposa y la muchacha y mis papas también querían ir. Y entonces la ocasión pues yo salí a las 4 de la tarde. Yo trabajaba en un restorán también y cuando yo regrese yo regrese a mi casa como así muy desesperada. Yo quería mirar a mi mamá y todo y a mi papa también. Entonces nunca me había pasado eso a mí entonces yo quería mirar los a ellos y llegar a la casa yo y harta por el no venía porque yo quería verlos a ellos entonces cuando llegue me quede yo así, como bueno que pasa porque esta todo cerrada la casa? Nunca salían ellos pues y sin dejarme la puertita y ya cerrado todo; siempre me dejaban una ventanilla abierta. Entonces esta ocasión llegue yo a mi casa y tan paico y mi trabajo me quedaba cercita y allí me detuve pues. Que pasa? Esta todo cerrado y bien callado. Ya le pregunte a mi vecina, la otra, si no había visto a mis papas y me dijo que no y me fui para mas arriba porque nosotros así no vivíamos mas arriba. Entonces fui a preguntar que si habían visto a mis papas pero pues no estaban tampoco ellos entonces regreso otra vez a la casa y así como una preocupación así y parece que mi dijeron si les paso algo. Entonces yo digo, me quede sentada, sentada y pensando allí. Yo digo y si les paso algo y si tuvieron un accidente y se me corrieron ya mi corrieron las lagrimas de este lado así y si le paso algo a mi mamá, yo digo aye no, yo no quiero que les haya pasado nada y ojala estén bien. Pero si tal vez yo presentí algo a ese momento, no se, pero ya cuando regrese, cuando regresaron ellos, mi mamá llegó seria y todo y le digo "que paso?" Venían serios y yo me empecé a ver y le digo "donde andaban? Porque no me dijeron que iban a salir o porque no me dejaron unas llaves allí al lado de la puerta o que hice yo?" Y dice "no pues, íbamos a chocar" dice mi mamá y le digo "como esta esa? A ver, platiquen." Y ya entramos a la casa y me empezaron a contar que pues tuvieron un accidente pero no fue nada mal. Entonces pues a mi papa si se llegó un susto muy grande esa ocasión y me platico mi mamá que casi lo bueno a esa ocasión no habían niños allí, porque acostumbran haber muchos niños allí y que solo chocaron con una pared de una casa y todo. Y pues el que se asusto mas fue mi papa y mi mamá también pero ella dice que quería abrir la puerta para salir corriendo y todo y entonces. Pero nadie en vivo no abren las puertas ni nada porque pues si no mas que yo notamos todos y todos gritaron y esto. Pero al llevar los niños a veces, pero gracias a dios no les paso nada a nadie y ni que todo salió bien pero nosotros sospechamos que entonces, desde entonces paso la enfermedad de mi papa. Entonces ya él se vino a quedar como a los pocos días de que, porque todos las noches levantaba a ir al baño y muy seguido y va mucho al baño y que tomaba mucha agua y todo.

A Great Fright

Familia 02 04.1-(continued)

Even though my father's diabetes started not too long ago, it seems to me to be about 3 years ago, I don't really remember. But on this occasion I was working because I'd already left school and everything and well I say to myself no, I have to help my dad at home and with the expenses and everything because the situation is very difficult there. So on that occasion I was working and they had gone fishing. Yes, fishing. They said they were going fishing because the weather was hot and everything; he has a friend there and she has a car and everything; she went to find them at the house and she told them they were going fishing. And so they all went to some remote spot, the neighbor guy, and also the neighbor lady, his wife and the girl, and my parents wanted to go as well. And so on that day I got off at 4 pm. I was working in a restaurant as well and when I came home I came to my house like really desperate. I wanted to see my mom and everything and my dad as well. This had never happened to me before so I wanted to see them and when I arrived at the house, fed up because I wanted to see them and he didn't come, I just stood there, like okay what's happening, why is the house all closed up? They never used to go out without leaving the little door open for me, and everything was closed; they always left a little window open for me. And so on that occasion I arrived at my house and such panic and my work was close by and I stopped there. What's happening? Everything is all closed up and very quiet. I asked my neighbor, the other one, if she had seen my parents and she said no and I went further up because we used to live further up. So I went to ask if they had seen my parents but they weren't there either. So I come back to the house again, like start to worry and it seems like they asked me if something had happened to them. So I tell you I just sat there, sat there thinking. And I'm saying to myself if something's happened to them and if they've had an accident and then they started, the tears rolled down that side like that and if something's happened to my mom, and I say no, I don't want anything to have happened to them, I hope they are okay. But perhaps I sensed something at this moment, I don't know, but then when she came back, when they returned, my mom came back very serious and everything and I say "what happened?" They were serious and I began to notice it and I say "where were you? Why didn't you tell me that you were going out or why didn't you leave me some keys there by the door or what did I do?" and she says "well we were going to crash" my mom says and I say "what's this? Look, tell me about it." And then we went in the house and they began to tell me that they'd had an accident but it wasn't that bad. So my dad had a big scare on this occasion and my mom said that the only good thing about it was that there were no children there, because usually there were a lot of children there, and that they just crashed into the wall of a house and everything. And so the one who got the biggest scare was my dad, and my mom also, but she says that she wanted to open the door and take off running and everything. But nobody there opened the doors or anything they just screamed and all that. But sometimes they take the kids so thank god nothing happened to anybody and everything turned out okay. But we suspect that my dad's illness started from that day on. Then he came to stay and in a few days he was getting up

to go to the bathroom all the time and going to the bathroom a lot and he drank a lot of water and everything.

El Susto del Bill que te va a Llegar –The Shock of the Bill that Arrives. (The Financial Burden of Type 2 Diabetes)

Familia 03 PWD

Pues realmente si es, o sea, primero el susto de que te enfermaste y luego el susto del bill que te va a llegar. Entonces realmente si es duro no. Primero pues me espanto porque me voy a tener que ir al hospital y ya después que salí del hospital solo me voy a espantar porque me va a llegar el bill. Y es que pues aquí no es de \$20, \$30 es de miles para arriba. Mi esposo estuvo 3 días en el hospital. Ya se imaginaba... ugh. Cardiólogos, especialistas, anestesiastas, de todo, porque todos cobran por separados. Entonces ya después nos llegan los billes ya no sabemos ni de quienes son. Y realmente si así es un impacto fuerte porque no podemos, no podemos, realmente no podemos, es mucho. Y pues todo el tiempo estamos con esa preocupación también, no. Debemos aquí, debemos allá, tenemos que mandar a la (name of clinic), tenemos que mandar aquí al hospital de (town), tenemos que mandar al hospital de (large city), tenemos que mandar a todos lados. Entonces precisamente apenas hace poco que salí de una colección. Me estuvieron quitando de mi trabajo. Si, entonces de mi cheque, de mi trabajo me quitaban a me dinero. Se no lo podemos evitar. Entonces nosotros estamos viviendo aquí solos. Nosotros tenemos que pagar la renta solos. Billes. Todo. Gasolina del carro. Y realmente pues con lo que el gana y con lo que yo gano apenas y luego no se alcanza. Lo que ganamos por ejemplo son casi \$600 de renta. Allí se va lo de un cheque de el. Y pagamos aquí, pagamos allá, pagamos luz, pagamos teléfono, pagamos carro, pagamos todo y que comemos? Y yo se realmente si fue, es muy duro. En ese aspecto si es muy duro para nosotros. Y es muy duro. A veces queremos ya tirar la toalla mejor.

Pues realmente a me el medicamento allí a la clínica me lo dan para 3 meses. Entonces pues ya allí más o menos me voy balanceando. Pero si cuando me hace cita pues si. Si me hacen estudios ya tengo que pagarla. Laboratorio. Ya tengo que pagar no se que cosa y la consulta en ese momento. Entonces si. No pues, no así mucho en exageración pero siempre así se siente. Siempre así se siente porque como quiera la cuenta allá esta pendiente. Nos esta esperando todavía. Si. Entonces es algo que no lo podemos evitar. No podemos evitar y si nos enfermamos menos. Menos. Entonces ya ahorita todos tenemos cuenta. No tenemos cuenta en el banco porque tenemos cuenta en el hospital. Y los cuatro, mis hijos y nosotros dos, ya hemos llegado al hospital. Entonces ya todos le debemos al hospital. Ya definitivamente todos debemos al hospital. Si entonces pues, pues hasta ahorita hemos tratado de sobrellevar esa situación también porque si es algo duro.

First it's the shock of getting sick and then the shock of the bill that's going to arrive. So it's really hard right. First, I am scared because I have to go to the hospital, and then after I go to the hospital I am going to be scared because the bill arrives. And then here it is not

Familia 03 PWD (continued)

\$20, \$30 it is thousands. My husband was in the hospital 3 days-ugh. Cardiologists, specialists, anesthesiologists, and all, because all are covered separately. Then after all the bills arrive, we don't know who they are from. In reality, it is a powerful impact. Because we can't, we cannot, the reality is we are not able, it is a lot. And then all the time it is a worry as well. We have debt here, debt there, we have to send (the bill) to the clinic (name), we have send to the hospital here (town) and we have to send to the hospital in the (city), we have send (bills) all over. So it's just a short while ago that I finished with collections. They were taking it from my work. Yes, so they were taking money from my check, from my work. We can't avoid it. We are living alone here. We have to pay the rent by ourselves. Bills. Everything. Gas and the car. And really we just scrape by with what he makes and what I make and then it's not enough. For example out of what we make almost \$600 goes on rent. There goes one of his paychecks. And we pay here, we pay there, we pay electricity, we pay the telephone, we pay for the car, we pay everything and then what do we eat? I know that it's been, it is really hard. In this respect yes it's very difficult for us. And it's very hard. Sometimes we just want to throw in the towel.

But really for me the medication here the clinic gives me for 3 months. Then more or less I am going to be balanced (financially). But when they make me a appointment then yes. If I have to have tests then I have to pay. Laboratory. I don't have to pay in that exact moment when it is a consult. Then yes. It is not much of an exaggeration but it always how it feels. Always it feels this way because the bill is pending. We are always waiting. No, this something we can't avoid. We can't avoid it if we only less ill. Less. Now we all have bills. We don't have a bank account because we have an account at the hospital. All four of us, my children and us two, we have been at the hospital. Then all of us are in debt to the hospital. Yes, definitely, all of us are in debt to the hospital. Then now we need to try to bear this situation because it is something so hard.

Familia 03 -02

Un Impacto Fuerte

Pues tuvo un impacto fuerte al principio porque bueno, para nosotros como personas digamos latinas, (doorbell ringing) que vivimos aquí en los estados unidos, pues nosotros por ejemplo de cuando estuve primero aquí en urgencias aquí en Newberg y ya después de allí, me pusieron algunos medicamentos verdad en ese momento, y cosas así, el transporte después de la ambulancia, el ride de Newberg a Pórtland y el tiempo que, que estuve yo metido allá en el hospital allí en Pórtland y la operación que se me hizo. Pues vamos a estarnos hablando, no se, yo recuerdo que mas o menos nosotros luchamos como alrededor de 100, de 80 mil dólares. Para nosotros imaginase usted el hablar de 80 mil dólares se nos hacia o se nos hace algo muy fuerte para nosotros como, como hispanos. En realidad se nos hace ahora muy difícil verdad, una carga muy grande. Después de eso, estar pensando es eso y ya después los tratamientos de medicina que yo

Familia 03 02 (continued)

llevo. Yo estoy ahorita, hoy día yo a caso he tomado luego hasta 6 o 7 pastillas diario ok. Entonces si ahorita yo recibo mucha ayuda de parte de la clínica 'virginia garcía.' A mi me han ayudado mucho. Allí me han ayudado mucho y mi medicamento no sale tan caro, si. Pero los primeros ocasiones que yo no había aplicado, yo no había hecho nada, si salieron caros, de hecho tuve que pedir ayuda para poder obtener mis medicamentos. Entonces si fue el gran impacto. En realidad fue de gran impacto el económico para nosotros después de lo que paso con migo y aparte que como estuve, los días que estuve en el hospital, los días que estuve convaleciente o sea recuperándome pues dejamos pasarlo de una renta, no podemos pagarla, tuvimos problemas, nos llevaron a corte. Tuvimos muchos problemas no más por esa situación. Lo pasamos muy difícil entonces por eso digo que fue una, ha sido una experiencia muy fuerte para nosotros entonces si, si hubo gran impacto en nuestra economía y nuestra forma; porque pues yo creo que todo el mundo sabe que casi la mayoría de los hispanos o latinos ganamos el mínimo, ganamos muy poco entonces no mas de eso se da una idea que impacto pudo haber causado a nosotros pagando renta, billes y esto fue muy difícil.

Pues eso que mi familia se preocupo demasiado primero con migo porque yo estuviera bien. Primero fue eso y ya después, ya que salí, empecé a recuperarme y sin trabajo imaginase o sea yo cuando después de eso yo, ya no, yo sabía yo que yo no iba a poder trabajar exactamente. (tape recorder unplugged momentarily) Entonces después de eso yo quede después, es que se me junto todo y después de que me puse enfermo estuve internado, salí, me recupere, el problema de la renta que se nos acumulo, el ir a corte, y el estar, porque los billes no esperan. Los billes no dicen 'eh me voy a esperar,' no, los billes, esos siguen si acumulándose. Entonces fue una carga demasiado y después empiezan a llegar los billes de 2 hospitales y todo eso y o man, con unos cantidades exorbitantes. Llevamos de la ambulancia solamente, por mil y tanto dólares, por el ride. Entonces imaginase yo, tenemos, hablando de no, vamos con 1500 y un poco comprar fácilmente un carro y poder ir a mi trabajo bien y todo. No mas con este, eso a lo que me refiero, de que ha sido un impacto demasiado fuerte. Nos ha descontrolado definitivamente. Y hemos pasado mucho tiempo y aun no podemos recuperar nos totalmente. Ya ha pasado ya un año y no nos hemos podido recuperarnos.

Este problema es un impacto económicamente por su cuenta por 10 años, por 20 años, que?

No lo sabemos porque hemos estado... igual ha habido gente que nos ha estado ayudando como aplicarnos con aplicaciones para algunos descuentos que nos pudieron hacer, que nos pudieron hacer algunas rebajas, y cosas así o ir pagando de a pocito pero, o sea es igual manera, con 50 dólares que a nosotros nos quiten o sea que nosotros tengamos ya 40, 50, 30 dólares. Para el sueldo que nosotros ganamos que vienen siendo no se 520, 530 dólares pues no mas imaginase para pagar renta, para pagar nuestro lonche y billes y todo eso. Ya todavía nos quitan el pocito de digamos para el hospital, para una cosa y para otra. Entre todos esos billes de un hospital, de la ambulancia, de el otro vamos aunque haya sido de a pocito de a pocito de cada uno, son 100,150 dólares y no se puede no podemos hacerlo. Entonces por eso no nos podemos poder igual

Familia 03-02 continued

recuperar económicamente y no sabemos hasta cuando. Pero tenemos fe en que vamos a salir adelante aunque este es nuestro caso en realidad esta es nuestra situación pero bueno seguimos confiados en que las cosas se van a arreglar, las cosas van a salir adelante.

Okay, it has a powerful impact, okay first because we are like any person called Latino who lives here in the U.S. Well for example I first went to the urgent care center here in [place] and then afterwards they gave me some medicines then and there right , and things like that, the ambulance ride after that, from [place] to [place] and the time I was hospitalized there in [place] and the surgery that they did. So we're talking about, I don't know, I recall that we're dealing with about 100, or 80 thousand dollars. You can imagine that for us, talking about 80 thousand dollars, was, or is a big deal for us as Hispanics. In reality it's very difficult for us now, a huge burden. After that, thinking about the medicines I have take, ok. Now I have, daily, I take around 6 or 7 pills daily. Now I receive a lot of help on the part of the clinic (name). They have help me a lot. They have helped because my medications are not too costly. But, the first couple of times when I hadn't applied (indigent medication programs), I didn't have anything, the medication was expensive but I found out the clinic could help me obtain my medications at a lower cost. So it had a big impact. The economic impact on us was really big after what happened to me and apart from that, like I was, the days I was in the hospital, the days I was getting better or let's say recuperating, well we let ourselves get behind one time with the rent; we couldn't pay it, we had problems, they took us to court. We had a lot of problems just because of this situation. We went through a very difficult time so it's because of this I say that it was, it has been a very hard experience for us, so yes, yes there was a big impact on our economy and our life; because well I think the whole world knows that the majority of Hispanics or Latinos make the minimum wage, we make very little so with this alone you get an idea of the effect it might have had on our paying the rent, the bills and that was very difficult.

Okay, that my family worried a lot at first about me because I had always been well. First, that happened and then when I was released and beginning to recuperate and without work. Imagine or know that I when after something like this, I didn't know if I was really going to find work..... After this I was left in a state yet we were all together, and after I was hospitalized, left (the hospital) recuperating, the problem occurred with the rent debt we accumulated, went to court and there we were but the bills did not wait. The bills never say "I am going to wait" No, the bills kept coming and accumulating. Now we have a burden which is too great. And then began to arrive bills from two different hospitals, and with all of this o man, with exorbitant amounts. I went by ambulance for a thousand and some dollars, for the ride. Then imagine, we could, speaking to no one, go with \$1500 and a little and easily buy a car y can go to work and everything. No more with this, this that I have been referring to, it has had an overwhelmingly powerful impact. We have lost control (financially) definitely. A lot of time has past and we can recovered totally. It has been more than a year and we have not recovered.....

Familia 03-02 (continued)

We don't know because we have. as well some people that have helped us with applications with applications for some discounts that we can use. That we can obtain rebates and things like that. Or we are going to pay a little but you know in the same way, with \$50 dollars that we pay that we have only \$40, 50, or 30 dollars left. For the pay we make that comes to around \$520, 530 dollars then imagine paying rent, paying our lunches y billes and all that. And still we have to give a little for the hospital, for one thing or another. Between all of these bill from the hospital, ambulance, and others we go little by little on each one, although even 100, 150 dollars we cannot make. It is because of this, I don't know if we can recover economically and we don't know when. But we have faith that we're going to make it even though in reality that's our case, that's our situation. But okay we'll carry on trusting that things will work out, things will improve.

Cambios en Nuestra Vida (Changes in Our Lives)

Family 01 PWD

Hard. Cause I know I know the effects of it. I know what can happen if I don't take care of myself. But like I said, I just put it...like the nurse this morning came up to me and said, You know this is happening to your heart, your liver. I hear it. But it doesn't sink in. And I don't know.

Not that much. But I know I get angry when my husband points out (name) stop eating that, or (name) don't you think you should stop drinking pop. Why don't you get diet. I get offended. But he tries. (Name) Let's go for a walk, or let's go do this. Nay I don't want to. So, He is supportive. He would support me in anything. He comes from a family that also has it. He is a high risk also. He tells me (name) you need to watch your weight. Then I get offended, cause I go, what are you calling me? You know.... He goes, No, it's not that. (name), I just want you to be around. So You know I get sad. But.....

It's hard. I mean Okay right now I will be honest. I haven't really been checking my sugar levels. The strips. The strips that you buy are very expensive That's hard! especially when you have two teenage daughters when they want everything. To buy them each month, is hard at the moment financially. I mean, the food that you are going to buy, Before I would be better and buy the sugar, the diabetic sugar the pink one in the pink package is more expensive. If you notice when you go the store everything that is low fat or it's more expensive than the regular kind. I try to buy the oil. I use Wesson but I try to use the sunflower one, so it won't be so greasy but... Yea, it's pretty hard.....

Family 01-PWD

Because you have to change the way you eat. You have to. It's not easy. Even though he says you can just stop. I go no I can't. It took me a long time to just change to diet coke. I didn't want to let go. I didn't want to say I have it. I need to buckle down and do it. I haven't been able to do it yet. To be honest I haven't. so...

I tried. One year I tried. I go, After work, I am going to walk around the track twice. I started. But then my husband would go why isn't dinner ready? Ya know? Why isn't this done or what. So I stopped. Then I said, okay I am going to start walking the dog. Then so I would start that for a little bit, didn't last. Then they offered a class here Weight Watchers that we were going to join. But husband said Oh, God that is just a waste of money you know you are not going to follow through. I know myself I probably wouldn't have followed through. But we're going try here. A few of us are start to walk during our lunch break.

Ya know. We're going to try and see if I can motivate myself into it. I've tried to exercise. I don't do situps or anything. Walking is the only thing I've tried. My daughter has offered. They have built a new place in (town) called Curves to get a membership so we can go. I don't know how I'd feel to have someone looking at me doing my exercises. (Laughter). So really think I am going to stick with walking. Walking is good, so go for a walk. My doctor has recommended that too. She goes (name) when you feel your sugar is up high. Take a walk. Go around a block a couple of times so you can bring it down and then check it again. And I walked one time like I've had a headache and I'll go for a walk, maybe around the block nothing big but . I'll try to go around the block, but that the only main thing I've really tried is walking, I haven't joined any exercise class or any thing like that.

But it's me now. That's where I think it starts. It has to be you. To want to do it, to want to change. Like my kids will tell me- Mom, don't you want to see your grandkids? Why don't you take care of yourself? And that's true.

It scares me. Because I know. The doctor tells me (name) you need to take care of yourself right now when you are young because you don't want to be on dialysis. She goes, you don't want to be on that. She goes... nnnnn I feel bad. I feel lucky that my eyesight hasn't been affected Uhhh I feel lucky that right away they check your feet. The years are going by I need to be more careful. It makes me feel sad and it makes me feel angry at the same time because I know it is my fault. I know I should be taking care of myself better. You know. It's mixed feelings You get angry at yourself. Upset. Depressed. That you are a diabetic and you don't take care of yourself. So....I don't know it's just a lot of mixed feelings. And it's hard.

Family 01-PWD (continued)

And there is no one to blame but yourself. And I can see a lot of people like me, I have it Oh, Well. You know.

Family 02 PWD#2 01

Deje las pastillas por la insulina, bueno. Pues yo fui a México. Todos mis viajes son de México. Entonces yo iba muy delgadita, muy delgadita porque cuando usted trae el azúcar alto pierda mucho peso. Usted come y come y no se para donde se va la comida. Usted comienza a bajar mucho de peso. Y entonces me dice mi hermana que “ya estaba gordita así como yo,” me dice mi hermana. “Oyes cuando te vas a ir para Oregon?” “Ya me voy a ir.” “No” dijo, “tu no te vas a ir. Yo te tengo que llevar con el doctor.” “Para que?” “Tu estas bien enferma pero porque? Estas bien flacas. Mira hasta te vas así por un lado.” Le digo “ma, desde envidia porque usted esta bien gorda si yo estoy bien delgadita.” “No” dijo. “Algo esta pasando contigo. Te tengo que llevar con un doctor.” Cuando me llevo con el doctor me mando hacer los análisis. Allí salio que tenia el azúcar arriba de 500. Desde cuando traía yo el azúcar? Sabrá dios. Yo nunca me chequeaba. Ya, dijo el doctor, luego, luego me dijo “señora usted tiene que ponerse insulina.” Yo que había ido ya con Virginia García. Y siempre lo traía como 250, 200 y estaban tratando de ponerme insulina. No más me decían de insulina y ya no iba. Le tenía tanto pavor a la aguja. Aye no. Pero allá en México me dijo el doctor “y mañana ya va a comenzar con la insulina.” Yo se que aquí les dan clases, o no se si ahora ya no, pero antes si les daban clases para como ponerse su insulina. Allá no mas me dijo el doctor “mañana se va a poner 30 unidades de insulina en la mañana y 30 en la noche.” En la noche yo no podía dormir porque dije yo “aye me voy a picar y donde me voy a picar?” Y luego me dice mi hermana “ya estas lista para tu inyección?” Le dije yo “si. No puedo dormir” le dije “porque yo no se como voy a vivir con esa piquete todos los días.” Y dice “ya le mande hablar a tu sobrina de allá, ella es enfermera.” Y ella me dijo “mire no tenga miedo, la aguja es chiquita,” dice “no mas donde se la quiere poner usted dice.” Empiece con un algodón cito con alcohol y me iba a sentir el piquete, o por ella bien fácil pero tenía miedo. Y luego a mi hija la que se le decía ella también dijo “mami yo te pongo la inyección.” Le dije “no, si yo tengo esta enfermedad yo tengo que quitarme el miedo y sobrevivir con este nuevo tratamiento que voy a comenzar. Luego, y ella le platico a mi esposo. Dijo “yo te pongo la inyección, yo fui enfermero en el army.” Nadie me va a poner mi inyección” le dijo. “Así que yo solita me pico mis dedos, me pongo mis inyecciones y ya nadie anda molestando.” Pero mi hermana, la de México fue la que, ella me dijo que yo me veía bien mala y porque... porque traía el azúcar bien altísima. Tal vez que con todo se fije, se imagina cuanto tiempo yo podía haber traído la azúcar tan alta. Desde cuando yo tenía

Family 02 PWD#2 01 (continued)

esas infecciones que no se me quitaban. Dijo el doctor, dijo “usted no sabe desde cuando no se chequea el azúcar?” O, hasta se me había olvidado. Que nada mas me la chequeaba con el doctor. Bueno, y yo todavía no tenia la maquina para chequearme la azúcar. Cuando me operaron la primera vez del corazón, allí me dieron clases de nutrición y me dieron la maquina para chequearme la azúcar. Y ahora con que hay tantas oportunidades con el medicare, y que hay muchísima gente con esta programa de diabetes. Tenemos que educarnos mas, enseñar a las personas y ahorita que bueno que mi hija esta envuelta en esa porque no hay suficientes enfermeras que practican con las gentes, familias hispanas. Y no van con el doctor porque el doctor no les entiende o a los pacientes, los pacientes no le entienden al doctor y ese es un gran problema también. Yo cuando estaba yendo con Virginia García, yo quería ser voluntaria para educar a la gente, para enseñar les un pocito de mis experiencias verdad, pero no. Después ya ahora ya hay mas facilidades de que tienen personal bilingüe y están ayudando mas pero todavía con todo y eso yo si se de algunas personas que tienen ese problema. Yo estoy tratando de que “vayan con el doctor, tómense sus medicinas chequeense la azúcar a ver como la traen.” No se, nadie se decide en su enfermedad. La diabetes es un problema muy serio le digo, porque yo lo vi con mi madre. Ella que le cortaron sus 2 piernas hasta acá. No podía asentarse porque tenían que detenerla con un cinto. No tenía balance en su cuerpo. Y ya mi mama me decía “mira hija, aprende de la enfermedad de tu madre. Mira como quede.” Y esas son las experiencias.

I stopped the pills for insulin, ok. Then I went to Mexico. All my travels are in Mexico. Then I was getting very thin, very thin because when you have high sugar you lose a lot of weight. You eat and eat and I don't know where the food goes to. You begin to lose a lot of weight. And then my sister says to me “you used to be fat like me,” my sister tells me. “Listen when are you going to go to Oregon?” “I'm going to go now.” “No” she said, “you're not going to go. I need to take you to the doctor.” “Why?” “You are quite ill but why? You are really thin. Look how you look from the side.” I say “mom, She is envious because she is fat and I am nice and thin.” “No” she said. “Something is going on with you. I have to take you to the doctor.” When she took me to the doctor he sent me to do some tests. There it turned out that I had a sugar of over 500. Since when had I had that sugar? God only knows. I never checked it. Now the doctor said, just after he said “ Mrs. [name] you need to be put on insulin.” I had already been to the Virginia Garcia. And I always had it 250,200 and they were trying to put me on insulin. As soon as they talked about insulin I didn't go any more. I had such a fear of the needle. Oh no. but there in Mexico the doctor said “and tomorrow you are going to start the insulin.” I know that here they give you classes on how to give yourself insulin, or I don't know about now, but before they used to give classes on how to give yourself insulin. There the doctor just said “tomorrow you're going to give yourself 30 units of insulin in the morning and 30 at night.” At night I couldn't sleep, I was so nervous because I said to myself “oh I'm going

Family 02 PWD#2 01 (continued)

to stick myself and where am I going to stick myself?" And later my sister said "are you ready yet to give your injection?" I said "yes. I couldn't sleep" I told her "because I don't know how I'm going to live with this stick every day." And she says "I've already sent a message to your niece there, she's a nurse." And she told me "look, don't be afraid, the needle is very small," she says, "just say where you want it given." She starts with a cotton ball with alcohol and I was going to feel the prick, sure for her it is very easy but I was afraid. And later my daughter also said "mom I'll give you your injection." I said "no, if I have this illness I have to overcome my fear and survive with this new treatment that I'm going to start." Later, she talked about it with my husband. She said "I'll give you your injection; I was a nurse in the army." "Nobody's going to give me my injection" I said. "I will prick my fingers by myself, I'll give my own injections and that way nobody will be disturbed." But my sister, the one in Mexico was the one, she told me that I looked very bad and because...because I had very high sugar. Perhaps taking everything into consideration, you can imagine how long I could have had sugars that high. Since I had those infections that I couldn't get rid of. The doctor said, he said "you don't know when the last sugar check was?" Oh, I'd even forgotten. I only checked it when I went to the doctor. Well ok, I still didn't have the machine to check my sugar. When they operated on my heart the first time, there they gave me classes in nutrition and the machine to check my sugar. And now that there are so many opportunities with Medicare there are many people on that diabetes program. We need to educate ourselves more, teach people and now how good it is that my daughter is involved in this because there aren't enough nurses who practice with Hispanic families. And they don't go to the doctor because the doctor doesn't understand them, or the patients, the patients don't understand the doctor and this is a big problem also. When I was going to the Virginia Garcia I wanted to volunteer to educate people, to teach them a little about my experiences right, but no. Even now, now that there are more facilities which have bilingual personnel and they are helping more, even with all this I know of some people who still have this problem. I am trying to make them go to the doctor, take their medicines, check their sugar to see how it's doing. I don't know, nobody chooses this illness. Diabetes is a very serious problem I tell you because I saw it with my mother. They cut off her 2 legs up to here. She couldn't sit down because they had to hold her up With a belt. She had no balance in her body. And my mom said "look, daughter, learn about this disease from your mother. See how I have ended up." And these are my experiences.

Ah, La Comida Mexicana-Tale of the Tortilla

Family 01 PWD

But its very hard. It doesn't. The way we work cook. It's very different. It is very hard to get it to change it. Because of the way we were brought up and how we learned how to cook. It is a very hard change and I still don't follow it by the books. But we try on more... more how to cook more healthier. Because it is very hard for us. Just..We use a lot of oil a lot of lard when we cook. Uhm I think that would be helpful And a lot more information out there in Spanish and how we could get you know everyone involved, you know the whole family Uhm hmmm

*Okay, I can't get use to the diabetic way that I should eat. Because well of course they tell your Salt... cut back on salt. Cut back on oil, lard, don't fry your foods. That's really what we do. So now, the one thing that I have changed in my family. The way that everything uhm really would get fried, but now we put things in the oven. So we don't have use oil and also like when I make like enchiladas. I try I don't Because when you make them, you dipped them in oil and then put in the sauce and then make them. I don't do that anymore. I just put the **tortillas** in the microwave now. They come out, they taste the same. Try to cut back on that. Uhm.... I buy diet coke now for me and my family. No one buys diet coke in the Hispanic. My parents are both diabetics and they both don't buy diet coke. So I tried to get them to drink diet coke and my dad does now. So.... So the way we eat. When we cook rice, Spanish rice uhm...I try not to use so much oil when you fry it up and thats you know basically it. So then when I cook the meals I don't have to use so much lard.*

So when I wake up in the morning I try to eat something in the morning but I am not much of a breakfast person. So I can tell by I would say by 11:00, 10:30 if I haven't eaten something while I'm at work. I can tell that, I start getting kind of nervous, kind of shaky. So I need to go get something. I know I don't eat the vending machines, there is nothing really healthy in there. So, I eat the chips and pop. I mean, I drink diet pop now I wasn't doing that last year.

*I clean a little bit and then we make food. Uhm I am trying to give my husband **more tortillas, corn tortillas**. Cause, the nutritionists said that was better than **flour tortillas** because with flour tortillas you have to use lard.*

Okay, like, lets say when we make tamales on Christmas. And it's very hard because they're really good.

Family 01 PWD (continued)

And when I went to the nutritionist they told me you should have at least two. And that's it.....that's not going to happen.

It does not happen (laughing). When I sit down and eat tamales, it's like six, seven. And It's just the lard. You have to put so much lard in the dough to make the tamales. So what's bad in them for them to taste so good. So...

*So the cooking part is very hard. Anything you eat its fattening. The beans, you use the lard out of the bacon, you save it to make the beans, to make refried beans. Uhm Just everything The way we eat tortillas. **Tortillas** are eaten with every meal. So It is either corn or flour. I really don't like corn. I'll eat more flour, I'll eat two or three when I make them but I'm not a that big of a **tortilla** eater. The more is basically the food. I/We eat a lot out, especially here at work. But that's going to stop. (laughs) But we do eat a lot out and I know that's not good for us either but the cooking has been the hardest on what to do, cause everything is fattening in the Hispanic, the way we cook the Mexican food. So, its harder.....*

Familia 04 PWD

En México uno allá se pone a echar tortillas y este hacer comida mexicana y lo que yo pare de las tortillas de mana,

Si, me gustaba mucho comer tortilla así con sal y calientitas y ya así nada mas esta decía, y después ya nada mas las veía.

Ya ahora era difícil. Ahora yo digo no lo tengo que comer porque me hace daño y eso tampoco me hace daño.

Pues hacia yo lo comida para mis hijos y eso si me sentía como desesperada porque yo quería comer, yo quería comer y lo que hacia es que comía ensalada de nopales .eso si me servia hasta comía y comía y con eso. O las tortillas bien doradas, bien doradas así me mataba poquito porque mucho hambre, ya después poco a poquito se fue quitando todo esto o que ya les hacia enchiladas. Yo nunca hice tamales porque nunca supe hacerlo, mi mama como yo vivía cerca de mi mama, a una cuadra, mi mama seguido hacia los ollas de tamales, y vénganse a comer tamales, y vamos a comer pero poquito. Antes yo comía mucho con leche o atole pero a horita ya no, mi mama hacia enchiladas pero ya no. También seguido hace taco como hace muchos anos vendieron ellos, tenían su puesto de tacos de cabeza de lengua de todo eso, y a horita pues ahora ya no tienen nada de eso, yo no lo hacen para vender solo para ellos y a veces que les digo, denme cinco pero con una tortilla y solo dos o tres y no mas, el mismo cuerpo se va imponiendo a estar comiendo poquita cosa.

El dulce casi no, lo que si me gusta mucho es el alfajor, el dulce que es mucha azucar como una barra, pura azucar ese si me gustaba mucho y tiene coco, y me gusta pero solo me como un poquito pero por alla , es pura azucar pero esta como comprimido ese si es veneno para los diabéticos) y vienen de México y como mi suegro llevo el viernes y digo siempre , no traerá dulces, pero si trajo para que

Familia 04 PWD (continued)

quiero, si los trae, trae tentación mejor no, y aquí lo venden en las carnicerías mexicanas. Luego mi esposo trae pero solo le pellizco un pedacito chiquito, poco a poquito se va imponiendo uno,

In Mexico you start making tortillas and Mexican food and I gave up tortillas,

A: by hand?

P: yes, I really liked to eat tortillas made like that with salt and nice and hot and she'd say no more and afterwards I'd just look at them.

Well I used to cook for my kids and it like drove me crazy because I wanted to eat. I wanted to eat and what I did eat was prickly pear salad. I fixed this and ate it and ate it and that had to do. Oh nicely browned tortillas, well browned I was dying for them because I was very hungry. Then afterwards all that gradually went away and then I made them enchiladas. I never made tamales because I never knew how. My mom, I lived close to my mom like a block away, my mom used to make pots full of tamales all the time and 'come over here for tamales' and we'd go and eat but just a little. Before I used to eat a lot with milk and corn flour soup but not any more. My mom used to make enchiladas but not any more. She used to make tacos all the time as well because many years ago they used to sell them. They had their taco stand but now they don't have any of that any more. They don't make them to sell, just for themselves and sometimes for me when I say give me five but with one tortilla and two or three, no more. Your own body starts to tell you to eat less.

Sweets almost none, the one I like most is *El Alfagor*, this sweet is very sugary like a bar, pure sugar that yes, I like a lot y it has cocoa, and I like (cocoa) but I only eat a little but for it is pure sugar and that is a tablet of venom for diabetics. And when they come from Mexico like my sister-in-law who arrives Friday and I say always, don't bring sweets, but bring what you want, brings what will better us. And here it is sold in the Mexican meat markets. Then my husband brings me some, only a little tiny piece, little by little I go on to eat one.

Preocupaciones por el futuro (Worries for the Future)

Family 01-02

Me preocupa el futuro porque yo no pienso que ella va estar en mi futuro. Porque a la manera que va no pienso que la va a hacer. Porque le digo "no vamos a llegar hacer bien a tu" Y luego me molesta porque las muchachas son parte de esa familia, y de ellas y no van a querer mirar a su grandma, no van a tener grandma, y duele verdad.

Que vamos a hacer? Que vamos a hacer yo solo aca? Me duele mucho. Me duele bastante. Las muchachas tambien. "No vas a vivir tu" y pues duele. No se, no se que hacer. Por eso le digo pues "cuidate, cuidate, cuidate, cuidate, queremos vivir contigo muchos mas anos". Pero a ella no le entra nada a la cabeza. Si le duele a todos, me imagino yo que asi como me duele a mi, tambien a mis hijas. Si esta duro todo eso. Y luego tambien le digo "yo he sabido de gente que le cortan los pies o le cortan un pie porque el diabetes le llevan los pies, y luego como va estar en una silla de ruedas? Como te vas a sentir? Lo voy a sentir yo peor con tigo viendote asi y no mas sufriendo y sufriendo porque no te quieres cuidar". Y le trato de decir porque como mi papa es diabetico. Yo iba con el al hospital y todo cuando era mas joven y miremos las cosas que le afectaron a todos desde entonces. Y ahora gracias a dios, ya esta mas viejo pero se cuida y le digo "(Name) esta duro pero tu puedes hacerlo" y no, pues, no se, no tiene control de si misma. I don't know. Yo no se. Yo no se que hacer Esta muy dificil. Tan dificil. Pero cuando alguien dice algo pues le digo "dame sufferencias porque yo no se como vivir, como tratar de llegar a la cabeza de ella". Ya dije todo lo que puedo decir. Me pongo todo a sudar en la cara diciendole y no hace caso. Como le gusta unas cosas que yo creo que le afecta mas. Es que se compra como uno o dos 2 litros, two litres de soda y se acaba como dos al dia y yo creo que este es bastante azucar, bastante. Le digo "si no mas corta esa colas.

The future worries me because I don't think she's going to be in my future. Because the way she's going I don't think she's going to make it. Because I tell her "we're not going to manage to make you better." And then it bothers me because the girls are part of this family, and theirs, and they aren't going to want to see their grandma, they're not going to have a grandma, and it hurts right.

What are we going to do? What are we going to do with me alone here? It hurts me a lot. It really hurts me. The girls also "you are not going to live" and well it hurts. I don't know, I don't know what to do. Then because of this I tell her "take care of yourself, take care of yourself, take care of yourself, take care of yourself, we want to live with you for many more years." But nothing gets through to her. Yes it hurts everyone; I imagine that it also hurts my daughters as much as it hurts me. Yes all this is hard. And then I tell her "I've known people who have had their feet cut off or a foot because diabetes takes away the feet, and then how are you going to be in a wheelchair? How are you going to feel? I'm going to feel worse than you seeing you like that, and only suffering and suffering because you don't want to take care of yourself." And I try to tell her because like my father is diabetic. I used to go to the hospital with him and everything when I was younger and since then we've seen the things which affected everyone. And now thank God, now he's older but he took care of himself and I say "[name] it's hard but you can do it" and no, well I don't know, she doesn't have self control. I don't know. I don't know. I don't know

Family 01-02

what to do. It's very difficult. So difficult. But when someone says something, well I tell them "give me suggestions because I don't know how to live through this, how to try and get through to her." Now I've said everything that I can say. I get red in the face talking to her and she doesn't listen to me. Like she likes some things that I think affect her more. It's that she buys like one or two 2 liters, 2 liters of soda and she finishes about two a day and I think that's a lot of sugar, really a lot. I say "if you could just cut out those colas"....

Familia 07-PWD

Si las hay, antes no las había y hoy la reflexión es tratar de vivir el día como es de mejor calidad, mejor hábitos, pensar un poquito mejor que esta bien, que esta mal y trato de, para el punto mas importante es en el momento que yo despierto, la primera palabra es gracias al señor por un día mas y ya de ahí viene que lo tengo que vivir mejor, ese es.

Mi preocupación es no poder controlado, porque, porque mi preocupación es mi hija, entonces si no la puedo controlar, mi hija va a sufrir si la controlo voy a estar un poco mas de tiempo con ella, entonces eso que me preocupo, entonces trato de seguir las indicaciones que me da el doctor. Mi preocupación mas grande es ella mi hija, y es feo decirlo, mi esposa no esta, no le gusta que lo diga y se los voy a decir a ustedes, si algún día yo llego a faltar, yo le pido a dios que primero recoga a mi hija y luego a mi, porque es mi preocupacion, si me preocupo, y es no poder controlar esto, mi hija me necesita, mis hijos me necesitan, pero gracias a dios ellos pueden salir adelante, mi esposa me necesita, pero ella puede salir adelante, eso es lo que me preocupa, mi hija, porque para ella mama y papa son pies y manos para ella, eso es lo que me preocupa.

Yes there are, before there weren't and today the idea is to try and live the day better, better habits, think a little more about what's good, what's bad and I try; so the most important thing is that the moment I wake up the first words are thanks to God for one more day and from then on I have to live better, that's it.

My worry is being unable to control it because, because my concern is my daughter. If I can't control it my daughter is going to suffer. If I control it I'm going to be around for a little longer with her, so because that's what worries me I try to follow the doctor's instructions. My biggest worry is her, my daughter and it's horrible to say it. She doesn't like me talking about it but I'm going to tell you; if some day if I falter and end up unable to carry on, I ask God to take my daughter first and then me, because this is my concern. I worry, about being unable to control it. My daughter needs me. My sons need me but thank God they are able to move ahead. My wife needs me but she can move ahead. This is what worries me, my daughter, because for her, Mom and Dad are her feet and hands. This is what worries me.