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The etiological role of susto in diabetes among Hispanics in southern Nevada

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THE ETIOLOGICAL ROLE OF *SUSTO* IN
DIABETES AMONG HISPANICS
IN SOUTHERN NEVADA

by

Carin K. Wallace

Bachelor of Arts
Northern Arizona University
2001

A thesis submitted in partial fulfillment
of the requirements for the

**Master of Arts Degree in Anthropology
Department of Anthropology
College of Liberal Arts**

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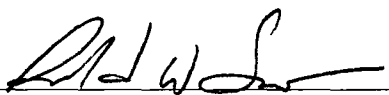
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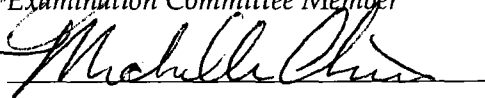
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ABSTRACT

The Etiological Role of *Susto* in Diabetes among Hispanics in Southern Nevada

by

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This thesis explores the association between *susto*, a Hispanic folk explanation of disease, and type 2 diabetes. This association is explored through a focus group and semi-structured interviews, with participants recruited from a population of 300 diabetes patients under treatment by a local non-profit group. Results show that not only is *susto* thought to be an important cause of diabetes among Hispanic diabetics and their family members, but that the meaning of *susto* may be changing; no longer thought of as solely a frightful event, it is a description of the resulting emotions as well. The role of emotions such as anger, sadness and stress in the etiology of diabetes is also explored. Implications of these results for health care providers working in Hispanic communities are discussed.

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CHAPTER 1

INTRODUCTION

This is a study of how Hispanics in Las Vegas think and talk about the intersection of type 2 diabetes and a folk illness called '*susto*.' Hispanic explanatory models for diabetes have been explored and attempts have been made to explain *susto*; however, little work has been undertaken to understand how these illnesses are related. The dearth of such explanation makes emic perspectives imperative for anthropological study. As diabetes rates increase worldwide and as the disease affects more people, emic explanatory models for illness allow for people diagnosed and living with diabetes to "make sense" of their illness experiences, and have been shown to have clinically applied value.

Type 2 diabetes, formerly known as non-insulin dependent diabetes mellitus (NIDDM), is on the rise internationally. A type of diabetes in which the body does not produce enough insulin or cannot use the produced insulin effectively (National Diabetes Education Program 2005), type 2 diabetes puts patients at risk for kidney failure, amputations, retinopathy, and cardiovascular problems (National Diabetes Fact Sheet 2005).

Worldwide, an estimated 171 million people suffered from diabetes in 2000 (Wild *et al.* 2004), and in 2001, over 90% of cases were type 2 (Zimmet *et al.* 2001). By 2010, the estimates rise to 220 million (Amos *et al.* 1997), and then to 366 million in 2030 (Wild *et al.* 2004). Prevalence rates are rising fastest in developing countries, where high

caloric/high fat diets, and sedentary, low-physical activity lifestyles, facilitated by an increase in computerization and mechanization, as well as improved transportation, are leading to ever higher rates of obesity and diabetes. (Zimmet *et al.* 2001). In developing countries there will be an estimated 170% increase in diabetes by 2025, whereas developed countries will see a 42% increase (King *et al.* 1999).

In the United States, 7% (20.8 million) of the population had diabetes in 2005, including 6.2 million people who remained undiagnosed (American Diabetes Association 2005). An estimated 14% of Hispanic/Latino Americans had diabetes, while 8% of the Non-Hispanic white population had the disease (National Diabetes Fact Sheet 2005).

Census data from 2000 shows that persons of Hispanic or Latino origin made up 25.2% of the Clark County population (US Census Bureau 2000). In a 2005 American Community Survey, persons of Hispanic or Latino origin made up 26.2% of the Clark County, Nevada population (US Census Bureau 2005). As prevalence rates continue to skyrocket, competent diabetes care for Hispanics is in increasingly high demand. This has heightened the need for more details on what might be unique “Hispanic” beliefs and attitudes about diabetes. Preliminary studies have shown that in these learned folk ideologies, emotional states are closely linked to the causes of diabetes for many Hispanic diabetics, and are seen as equally important factors to these patients as the biomedical etiological factors their doctors espouse.

Diabetes

As a group of diseases diabetes is characterized by defects in insulin production or action resulting from high levels of blood glucose (National Diabetes Education Program

2005). The most common forms of diabetes are type 1, type 2, and gestational diabetes, as well as related disorders such as the ‘metabolic syndrome’ (a combination of health factors that increase the risk for heart disease) and prediabetic conditions (impaired glucose tolerance and impaired fasting glucose).

Type 1 diabetes accounts for 5% to 10% of diagnosed cases of diabetes. It results when the body’s immune system attacks the pancreatic cells producing insulin, and insulin must then be injected or pumped into the body. Type 1 predominantly targets children and young adults. Risk factors may be autoimmune, genetic, or environmental in nature (National Diabetes Education Program 2005).

Type 2 diabetes accounts for approximately 90% to 95% of diagnosed cases of diabetes. Risk factors include a family history of diabetes, affiliation with a high risk ethnic group, being overweight or obese, having had gestational diabetes, high blood pressure, abnormal cholesterol levels, and a lack of physical activity (National Diabetes Education Program 2005). It often begins as insulin resistance, when the cells do not utilize insulin—a hormone essential in the metabolism of blood sugar—efficiently. (National Diabetes Fact Sheet 2005). Those US ethnic groups at high risk for developing type 2 diabetes include African Americans, Hispanic/Latino Americans, American Indians, as well as some Asian Americans, and Pacific Islanders (National Diabetes Fact Sheet 2005).

Gestational diabetes affects women during pregnancy. In the 5-10 years following the development of gestational diabetes, women have a 20% to 50% chance of developing diabetes, most likely type 2 (National Diabetes Education Program 2005).

While there is no cure for diabetes, treatments include an emphasis on prevention and disease management through diet and exercise, medications, and insulin injections.

Glycemic control (keeping blood glucose in a normal range) positively affects people with type 1 and type 2 diabetes. For every percentage point reduction in glucose (A1C blood test results), the risk of microvascular complications affecting the eye, kidney, and nerves, is reduced by 40% (National Diabetes Fact Sheet 2005).

Among diabetic adults, 15% do not take insulin or oral medications, 12% take both insulin and oral medication, 16% take only insulin, and 57% use only oral medication (National Diabetes Fact Sheet 2005). Patients with prediabetes (higher glucose levels than normal) can often delay diabetes or return to normal glucose levels with weight loss and increased physical activity. Doing so also reduces their risk for heart disease and stroke (National Diabetes Fact Sheet 2005), the very afflictions for which the likelihood is increased by contributing factors of the metabolic syndrome, such as diabetes, obesity, and unhealthy lipid levels (American Diabetes Association 2005).

U.S. Hispanics and Diabetes

While many terms exist for the focal group of the present research, this thesis will refer to the targeted population as Hispanic. 'Hispanic' describes persons of both Latin American and Spanish descent. Additionally, in the year 2000, a polling firm called Hispanic Trends, Inc., asked registered Hispanic/Latino voters which term they preferred. The outcome was that the majority preferred 'Hispanic' (Granados 2000).

A study of the prevalence of type 2 diabetes among Hispanics in selected areas (with proportionally higher Hispanic populations) conducted between 1998 and 2002 found

that the "...age-adjusted diabetes prevalence among Hispanics was approximately twice that among non-Hispanic whites (9.8% versus 5.0%)" (National Center for Chronic Disease Prevention and Health Promotion 2004:942). These prevalence rates are higher than those of the Third National Health and Nutrition Examination Survey, dating from 1988 to 1994. In that survey, prevalence rates were 5.0% for non-Hispanic whites and 5.6% for "Mexican Americans" (Harris *et al.* 1998:520). While different methodologies and study populations may make exact comparison difficult, these statistics do illustrate a growing trend toward an even higher prevalence of type 2 diabetes among US Hispanic groups, especially when compared to other US populations.

Hispanic Ideologies about Diabetes

As prevalence rates increase, the Hispanic population will only become more aware of diabetes and its impact in their lives. An in-depth understanding of beliefs regarding this disease among Las Vegas Hispanics is firmly within the scope of medical anthropology. It is likely that multiple Hispanic ideologies of diabetes are present, given the diversity of the Hispanic population in the U.S. Nevertheless, common themes may exist across the country. This is true for the local community as well, where common threads may run through ideologies that differ based on an array of national and regional origins and identities. Once understood, medical anthropologists have been able to communicate culturally shaped beliefs and the possible need for alternative approaches to the biomedical and public health communities. The formation of the Hispanic Health Council in Hartford, Connecticut, is an excellent example of anthropology and community working together. Founded in 1978 by members of the Puerto Rican

community of Hartford and university anthropologists, the council focuses on community-based research that positively affects the health care of the local Hispanic community (Singer 1990).

Medical anthropological research has shown that patient ideas about what causes illness, its timing and onset, and likely effective treatments, are culturally shaped (Johnson & Sargent 1990). How Hispanics perceive etiological factors for type 2 diabetes has been documented and studied by researchers from an array of disciplines. Members of the nursing, anthropological, and psychiatric communities have investigated the topic in efforts to positively affect healthcare in this population (Poss and Jezewski 2002; Jezewski and Poss 2002; Rubel 1964; Bolton 1981; Gobeil 1973; Trotter 1982). Research thus far among Hispanics highlights a common belief that diabetes is triggered by a single event. Jezewski and Poss took note of this in their work on the Mexican American explanatory model for type 2 diabetes (2002:843). Such a single event is usually one of *susto*. The word, '*susto*' translates to the English noun, 'scare,' or 'fright.' *Susto* is defined comprehensively by Andrews and Boyle as a folk illness occurring throughout Latin America that is caused by anxiety, a frightening experience, or soul loss. Its symptoms are a loss of appetite and sleep, as well as nervousness and social withdrawal (1999:45, 133, 230, 232). Foster and Anderson note that Hispanics correlated it with a "...sudden start or sneeze" (Andrews and Boyle 1999:230). When hearing of their diagnosis, participants were able to think back and identify a past frightful or startling experience that caused their diabetes. An interesting note by Jezewski and Poss is that such a causal concept is different from the traditional anthropological concept of *susto* (Simons 1985 & Hughes 1985), that of an illness found in a specific culture and treated in culturally

prescribed ways (i.e. a “culture-bound syndrome”). Rather, the participants viewed *susto* as a precipitating condition causing diabetes instead of an illness in and of itself (2002:848). This causal concept linking diabetes and *susto* is further described in another 2002 article by Poss and Jezewski, in which *susto* was found to be an event that occurred unexpectedly, causing an increase in susceptibility for type 2 diabetes (Poss and Jezewski 2002:369). In that study, the authors refer to *susto*, anger and other “powerful emotions” as the causes of diabetes for their subjects, along with other commonly cited biomedical factors. The object of their study is the role of *susto* in Mexican Americans’ explanatory models for diabetes, however, and the roles of the other emotions are not developed. The amount of literature surrounding the relationship between diabetes and *susto* from an emic (insider) perspective is sufficient enough that further investigation is warranted. More knowledge is necessary about the factors that surround the relationship between *susto* and diabetes and the explanatory nature and context of that relationship to positively affect healthcare for Hispanic diabetics.

Such investigation is necessary due to the difficulty of pinpointing the characteristics and role of *susto* in the Hispanic community, and the regional or local differences in its conceptualization and characterization. In a 1993 study, it was found that Hispanic mothers living in Florida were reluctant to bring their children stricken with *susto* to see a physician and preferred folk healers. The authors describe folk healers’ lack of faith in the ability of biomedical practitioners to care for these illnesses and the congruent belief of biomedical healers that these illnesses are simply “culture bound syndromes” and not to be seriously considered (Baer and Bustillo 1993). The present study, conducted in the Las Vegas Hispanic community, is of value regarding improved patient/practitioner

interactions, patient well-being, and the improved understanding of the explanatory relationship between diabetes, *susto*, and emotions.

CHAPTER 2

STUDY AIMS AND RESEARCH QUESTIONS

This project explores how Hispanics living in the greater Las Vegas, Nevada area view the explanatory relationship between *susto* and biomedically diagnosed diabetes. The purpose of this research is to better understand the relationship between Hispanic ideologies of *susto* and other powerful emotional states that may be intimately connected to diabetes. Should any common themes regarding *susto* and diabetes be present among sampled Hispanics in Las Vegas, physicians and other health care providers may be able to add that information to their toolkit for patient care, and as a result, improved communication between health care professionals and patients may result, leading to better care and improved health outcomes.

Such knowledge on behalf of physicians is one of biomedicine's main, far-reaching goals – that all patients will feel comfortable in the presence of their physician and will not feel inhibited as they explain their symptoms. This requires a sensitivity and awareness on the part of physicians that other explanatory models besides their own are equally valid, making communication key for successful clinical negotiation.

The present study was guided by the following research questions:

- What are the explanatory models regarding the role of *susto* in diabetes among Hispanic diagnosed diabetics and their family members in southern Nevada? Do these differ across generations and genders?

- Which symptoms (if any) of *susto* are also considered symptoms of diabetes?
- Do family histories of *susto* and diabetes predispose patients to these same illnesses?

- Are patients reluctant to discuss *susto* with their biomedical providers (when discussing general health problems or diabetes specifically)?

- Is there is a stigma associated with having *susto* and/or diabetes?

The chapters that follow are organized in the following manner: previous literature, methods, results, and discussion and conclusions/recommendations. The *Literature Review* chapter will include a background on *susto*, related illnesses and theory. *Methods* will include data collection and analysis. *Results* will report that data, and it will be interpreted in light of other research in *Discussion*. Finally, clinical and public health recommendations will be made based on the study findings and analysis.

CHAPTER 3

LITERATURE REVIEW

Applied Medical Anthropology and the Explanatory Model

Medical Anthropology is the study of illness, health, and health care in terms of anthropological theory and research (Johnson & Sargent 1990). Medical Anthropology, more than any other discipline, examines the social and environmental contexts of disease. It draws on the biological and social sciences, in addition to clinical medical practice, in efforts that may contribute to improved health status worldwide. This is accomplished increasingly through interdisciplinary interactions and with an applied focus (Johnson & Sargent 1996).

Applied Medical Anthropology has its roots in mid twentieth century public health work (McElroy & Townsend 2004). Theories and ideas are put into practice in efforts to seek out and understand issues of disease and illness, and in turn positively affecting poor health. Concepts necessary to do so include understanding how an individual views disease. Such a concept is referred to as an explanatory model, or EM.

Explanatory models are dynamic beliefs about illness held by patients and practitioners. Arthur Kleinman pioneered work on explanatory models. He, along with Eisenberg and Good, focus on a clinical strategy to elicit a patient's explanatory model. Five issues of an explanatory model are critical: etiology, onset and mode of symptoms,

pathophysiology, course of sickness, and treatment (1978:256). EM's reflect general belief systems, but are employed specifically in order to cope with a particular health problem. They must therefore be studied in that particular setting (Kleinman 1980).

Research has shown that differences between EMs of patients and providers increases the likelihood of patient non-compliance with clinical recommendations (Cohen *et al.* 1994).

Cultural or “ethnic” ideologies about disease are often referred to as “folk models” of illness. Recognition of a folk illness is how a social group expresses the absence of health (Rubel 1993). The folk model of illness is beliefs about the expression of health that are held throughout the social group.

Other models of individual and community health beliefs exist as well, such as the “health belief model” and the “theory of planned behavior”. While these are applicable tools in anthropology, these models were not deemed appropriate for this project. Using the health belief model, researchers seek to explain and then predict health behaviors (Sheeran and Abraham 1996). Additionally, the theory of planned behavior focuses on the decisions people make based on available information (Conner and Sparks 1996). However, predictions and data on the decisions people make are beyond the scope of this research; the project at hand is concerned with beliefs, not behaviors. The goals of Kleinman’s explanatory model are to simply learn and attempt to understand how people think about illness.

Explanatory models and folk models of illness are both tools for understanding how people think about illness. Applied to the same research topic, these tools can provide anthropologists and biomedical practitioners with data important in the provision of medical care and health education. These constructs, therefore, represent a window on

culturally shaped beliefs about illness. These beliefs constitute the main focus of this study.

Patient/Provider Models

As Kleinman *et al.* (1978) and others note, (Eisenberg 1976, Engel 1977, & Feinstein 1967) a distinction between patients and providers exists in terms of how they view ill-health. Kleinman and colleagues note, “Modern physicians diagnose and treat *diseases* (abnormalities in the structure and function of body organs and systems), whereas patients suffer *illnesses* (experiences of disvalued changes in states of being and in social function; the human experience of sickness)” (1978:251). Biomedicine is interested in curing (recognizing and curing disease), while traditional care is interested in healing (providing meaningful explanations for illness and responding to personal, family, and community issues surrounding the illness) (1978:252). Biomedicine’s inattention to illness (Stimson 1974; Kleinman 1975; Davis 1968; Frances *et al.* 1969; Haefner & Kirscht 1970; Kazare *et al.* 1975; Lipsitt 1968) “is in part responsible for patient noncompliance, patient and family dissatisfaction with professional health care, and inadequate clinical care” (Kleinman *et al.* 1978:252). Patients with chronic medical problems may fare better with improved conditions (Kleinman 1976) after encounters with folk or marginal practitioners, due to fewer differences in social class, the similar explanatory systems of patient and provider, and a greater emphasis placed on ‘explanation’ (Kleinman *et al.* 1978:252).

A “cultural construction of clinical reality” is made through negotiations between patient and provider and becomes the object of medical intervention and therapies

(Kleinman *et al.* 1978:254). However, the clinical reality is often viewed differently by the doctor and the patient, leading to inadequate or poor care (Kleinman *et al.* 1978:255). Patient explanatory models, like clinical models, attempt to explain clinical phenomena. “Such models reflect social class, cultural, beliefs, education, occupation, religious affiliation, and past experience with illness and health care” (Kleinman *et al.* 1978:256). The patient’s model encompasses one of the four psychosocial meanings of illness (Lipowski 1969): i) threat, ii) loss, iii) no significance, or iv) gain (Kleinman *et al.* 1978:256), and the psychosocial meaning of an illness should be elicited from the patient by the provider, if possible, in order to identify major differences between their explanatory models that may cause difficulties for clinical management (1978:256).

In terms of diabetes, these concepts are substantiated by a variety of sources. In a study of the differences in the ways providers and patients from a range of ethnic backgrounds experience and think about diabetes in regards to etiology, symptoms/signs, factors which affect blood sugar, ideal blood sugar, and future prospects, it was found that differences exist across all five of those dimensions (Loewe & Freeman 2000). The study by Baer and Bustillo of emic and etic perspectives regarding *susto* and *mal de ojo* (evil eye) among Mexican farmworkers in Florida documented the difficulties of communication among biomedical practitioners, patients, and folk healers with their differing explanatory models (1993). They conclude:

The best outcome for patients with these illnesses is likely to be achieved by having the services of sensitive biomedical practitioners, who are widely recognized as experts in the treatment of microorganisms (Foster and Anderson 1978), to address the symptoms and proximate biological cause of the illness. It is also necessary, however, to have available the services of folk healers to provide and create social and psychological support and address the emically determined, ultimate social cause of the illness. The persistence of the attitude among physicians that folk illnesses are merely old-fashioned superstitions will only

increase morbidity and mortality among Mexican and Mexican American populations from a series of life-threatening conditions they have learned to recognize and label in their own fashion [1993:99].

Effective communication will result when biomedical practitioners leave ideas and attitudes as described by Baer and Bustillo behind, and embrace a more holistic outlook, understanding that folk explanations are as equally valid as biomedical explanations.

In their study on “Latino” beliefs about diabetes, Weller *et al.* suggest an approach that seeks to obtain the support of the patient’s family utilizing the key role familial support plays in compliance. They suggest “...using the knowledge of the various aspects of this disease as a source of support for patient compliance with practitioner treatment regimens” and educating the patient and family regarding their beliefs that are not in concordance with the biomedical model (1999:726). A study of San Diego County physicians and their care of Mexican Americans with diabetes determined that all physicians can take steps to increase their “cultural competence,” becoming culturally aware. Culturally competent care is a result of recognizing that cultural aspects and awareness of personal prejudices and inclinations are important (Reimann *et al.* 2004). Mexican Americans have their own perceptions of culturally competent care, as described by Warda. She finds that many Hispanics view the medical system as unresponsive (2000:205), that personal processes are important to them, and the themes of respect, caring, understanding, and patience are invaluable in their healthcare encounters (2000:203). Ultimately, culturally-based patterns of social behavior are critical to Mexican Americans’ perceptions of competent care (Warda 2000:218).

Diabetes

Only a few authors have discussed the Hispanic EMs for diabetes. “Mexican American” patients have been described as speaking of their diabetes in terms of cause, symptoms, treatment, and social significance (Jezewski & Poss 2002). The patients consider the cause to be a combination of a single event (usually *susto*), unhealthy eating habits, heredity, being overweight and lack of exercise, and not taking care of oneself (Jezewski & Poss 2002). Patient symptoms of diabetes are visual problems, fatigue, weakness, headaches, thirst, increased urination, dry mouth and skin, and losing weight (Jezewski & Poss 2002), as well as complications such as circulatory problems, kidney problems, and eye problems (Weller *et al.* 1999). Effective treatments are thought to be herbal remedies and biomedical prescriptions (Jezewski & Poss 2002), in addition to prayer (Hunt, Arar & Akana 2000). Many Hispanics feel they have the support of their families (Jezewski & Poss 2002), whereas others feel a sense of stigma associated with their diabetes and may be unwilling to discuss their illness with family and friends (Jezewski & Poss 2002; Lipton *et al.* 1998). Others feel concerned about issues of body image instead of the effects on internal organs (Loewe & Freeman 2000).

Compliance with physician recommendations for many Hispanics is often related to social support. Two out of three focus groups in a 1998 study (Lipton *et al.*) felt that patients who have been in the United States for a long period or have had the support of a family member who was acculturated are more likely to accept biomedical treatment. Also, although family is often a positive factor, it can also impede compliance. Women especially consider their needs secondary to the benefit of the family and consider family necessities more important than diabetic medications and supplies (Lipton *et al.* 1998).

When it comes to social support, patients sometimes feel dissatisfied with support involving daily diabetic care such as preparing the appropriate diet, foot care, and personal hygiene (Gleeson-Kreig *et al.* 2002:221).

Susto and Other Hispanic Popular Illnesses

Studies of *susto* and related illnesses trace back to the mid-twentieth century. Related illnesses include *mal de ojo* (evil eye), *embrujado* (witchcraft sickness), *ataque de nervios* (hysterics), and *fallen fontanelle*. This is due to their inclusion, along with *susto*, in the “culture-bound syndrome” category. Since similarities among descriptions of these illnesses are so great, and because the culture-bound syndrome debate is more clearly “illustrated”, these illnesses are included in the following discussion.

The Hispanic EM for *susto* involves the same clinical topics as that of diabetes. For some *susto* sufferers, *susto* refers to both cause and effect. In these cases, the illness of *susto* may be the result of soul-loss while the experience of a *susto*, or fright, may in turn cause soul-loss (O'Neill 1975). Such a frightening event may occur immediately prior to, or twenty years before, the onset of symptoms. The symptoms of *susto* are loss of appetite, nervousness, social withdrawal, and sleeplessness (Andrews & Boyle 1999). If not treated, *susto* is believed by some to be potentially fatal. A family member or folk healer often treats *susto* using magico-religious techniques (Rubel 1960) in which the soul is returned to the body, or through ethnopharmacological techniques in which *susto* is cured, for instance, by taking indigenous medications to treat *susto* and/or its symptoms (Trotter 1982). A case of *susto* often requires social support from friends and family, as *susto* sufferers may feel overwhelmed and are often unable to fulfill their usual social obligations (Bolton 1981).

Since the early 1980s, literature on *susto* has centered loosely around four differing viewpoints: first, that *susto* is a socio-psychological illness; second, it is a physiological/biological illness; third, it is a psychiatric illness; and fourth, that multiple factors contribute to *susto*.

In terms of socio-psychological illnesses, several authors have suggested social factors that contribute to *susto*. In 1964, Arthur Rubel suggested that *susto* was based on sociocultural factors – some segments of the population are more likely to experience it than others. Since then, several authors have similarly suggested the importance of social stress in the etiology of *susto* (Castro & Eroza 1998; Houghton & Boersma 1989; Green 1994; O’Neill 1975; Uzzell 1974; Logan 1979). Different types of social stress, as described by the authors, may be at fault. Castro and Eroza, for example, cite social stresses such as oppression, violence, and unexpected events in a town in Central Mexico. The diagnosis of *susto* allows for a sense of causality, a chain of events that is meaningful to individuals. This is preferred over biomedical diagnoses sometimes handed to individuals, such as general weakness (1998). In another interpretation of social stress, Houghton and Boersma seek to prove that *susto* is a Hispanic-American form of grief. Caused by a loss of some kind (the ending of a relationship, or in the case of the Zapotec Indians, a stillbirth) a diagnosis of *susto* allows for public acknowledgement of grief when it otherwise would not be (1989).

Social stress has also been cited in the etiology of other traditionally Hispanic illnesses, such as *ataque de nervios* and *embrujado*. Oquendo *et al.* (1992) examine *ataque de nervios* and suggest that cultural influences and spiritual beliefs play roles in how symptoms are formed and how perceptual experiences are expressed, in addition to

influencing how a person responds to stress. *Ataque* is a condoned, maybe even expected response to stress that is often cured when the family helps to relieve the stress by removing the offending agent or repairing a stressed familial relationship. In a study on *embrujado*, Koss-Chioino *et al.* (1993) similarly find that bewitched male patients were those that managed to function until their feelings of ‘manhood’ were threatened. The authors find that *embrujado* is due to feelings of helplessness brought on by a social marginality and struggle over power.

In the case of *susto* as a physiological/biological illness, Ralph Bolton states in a 1981 article that physiological aspects of *susto* have largely been ignored. He suggests that *susto* is not a “‘folk illness,’” as he writes, because an equivalent biomedical syndrome exists – hypoglycemia. He explains that social and psychological stressors produce *susto* through physiological mechanisms. Role stress is one of many types of stressors (environmental, psychological, etc.) that “may lead to difficulties with glucose homeostasis and hence to *susto*” (1981:262). Bolton notes that his hypothesis is not solely based in biology. In his article, he emphasizes how he tests hypotheses from both the role-stress approach and the hypoglycemia approach, remarking that from his point of view, they are not separate – both are part of biological theory.

Susto has also long been considered a psychiatric illness by some theorists. Gillin (1948) was first to interpret *susto* as a culturally appropriate manner in which to express hysterical anxiety. Other authors followed suit with further psychiatric analyses of *susto* (Gobeil 1973; Kiev 1968; Salman *et al.* 1998). Gobeil explains that *susto* is masked depression, categorized along with other neuroses by fear and anxiety. Such depression leads patients to think about soul loss and death, and they ultimately develop *susto*

(1973:40). She suggests that *susto* is a reaction to culture change and cultural stress for Peruvians, and that "...it may be said that *susto* plays a definite role for an insecure person in re-establishing his contact with society and permitting him to feel wanted and appreciated" (1973:42). This is especially important for migrants, who after being diagnosed with *susto* and cared for are better able to cope with new structures and settings. Kiev's findings are similar. He writes that *susto* gives people who cannot cope with certain situations the option to be sick and culturally recognized as such (1968:170-171).

Ataque de nervios has also been considered a psychiatric illness. Salman *et al.* attempt to align *ataque de nervios* with psychiatric categories. The authors find that *ataque de nervios* is a broad, general condition, which can be categorized according to the symptoms expressed. It can be diagnosed as three types (and subtypes) of psychiatric conditions: panic disorder, affective disorder, and anxiety disorder (1998).

The more recent research on Hispanic illnesses has focused on more of a multi-factor, holistic etiology. Several authors have considered elements of the social, economic and political environments as well as organic elements responsible for these illnesses. Simons writes generally of culture-bound syndromes (further discussion will follow). He believes that the debate between nature and nurture is central to the examination of culture-bound syndromes. Citing Daniel Lehrman's 1970 classic work, he stresses that "...*biology and experience are always equally important in shaping any single instance of behavior but that differences between two instances may be attributable to one or the other*" (author's emphasis) (1985:29). In a 1993 article, Rubel considers the overall issues of studying Latino (Hispanic) folk illnesses. He states that three organizing procedures clarify

comparative studies of folk illnesses and comparisons of folk illnesses with biomedical disease. First, an emic discussion of the illness including the most susceptible populations, the etiology, and preferred treatments. Second, an assessment of how much the emic etiology is consistent with biomedical understanding of the human body. Third, the characteristics of a folk illness can be compared to those of biomedical nosologies after the first two procedures are implemented. He states that inquiries should look at emic descriptions, demographic characteristics, and overlap between folk symptoms of distress and biomedical symptoms of distress (Rubel 1993).

In terms of *susto*, Libbet Crandon's work contributes a model combining sociocultural anthropology and physiology. She argues that there are several physiological diseases that can account for the symptoms of *susto* (such as iron and folate deficiencies), both for the progression of its symptoms and its variations (1985:158). The key, however, is to combine such environmental causes as well as *susto*'s "...underlying meaning, and...the relationship between its meaning and its sociocultural context which leads people to diagnose symptoms as *susto*" (1985:154). These three levels of analysis, Crandon explains, should form the study of *susto* in any location. Rubel, O'Neill and Collado explain *susto* in a slightly different vein, suggesting that *susto* is the result of a combination of social stress (not meeting role expectations) and organic disease. This combination, they write, leads to an early death (1985).

In the most recent research on *susto*, as previously mentioned, Poss and Jezewski (2002) conducted focus groups and interviews to learn about the Mexican American explanatory model for diabetes. In a separate study (2002) focusing on *susto* and diabetes, they find that their subjects believed *susto* to be a "...severe fright caused by a

sudden, unexpected, and very unsettling event.” However, while the Poss and Jezewski article does discuss *susto*, subjects’ ideologies for how *susto* and diabetes interact were not developed. They write, “Participants in the study could not explain why or how *susto* caused diabetes.”

The Culture-Bound Syndrome Debate

As mentioned above, authors writing about *susto* often refer to it as a “folk illness” or a “culture-bound syndrome.” In relatively recent years, however, the use of these terms has been criticized; not just in the case of *susto*, but in the case of all so-called “culture-specific illnesses.” Several authors have found fault with the “culture-bound syndrome” label (Simons & Hughes 1993; Guarnaccia 1993; Rubel 1993; Kay 1993). Simons and Hughes, for example, argue that syndromes labeled as “culture-bound” are referred to as such only because they are different from cultural expectations of the Western medical practitioner, and in addition, symptoms of culture-bound syndromes occur in many culturally unrelated settings but may be simply interpreted in different ways.

There are also debates regarding whether Hispanic folk illnesses are culture-specific at all. In her study of *fallen fontanelle*, Kay takes the concept of the illness as a culture-bound syndrome of Hispanic tradition and proves that it is not culture-specific. She traces the root of the disorder back in time to the first and second centuries and finds references to it in Northwestern New Spain, Rome, and contemporaneously in Pakistan and Africa (among other locations). Kay cites Werner (1997) to make her point: “Mothers in different lands realize that when the soft spot sinks inwards, their babies are in danger. They have many beliefs to explain this...A sunken soft spot is really caused by

dehydration” (1993:151). The etiology of *fallen fontanelle* has a physiological component, but is explained differently in different cultures.

Guarnaccia questions the use of the term “culture-bound syndrome.” He writes that the use of the label “Puerto Rican Syndrome” implies the presence of a defect in Puerto Ricans. “Culture-bound syndrome,” while perhaps not explicitly conveying negative implications, is being used in reference to cultures not including those of North America and Europe. In response to these concerns, Guarnaccia prefers the term “popular illness.” Used as a category, he states that such an illness is not recognized in professional nosology, but is recognized in the community.

Rubel also mentions the categorization of “Latino folk illnesses.” He states that there is a lack of consistency among authors, some of whom refer to these Latino illnesses as “folk illnesses” and others who refer to them as “culture-bound syndromes.” He argues that criteria are necessary for determining which is which and where illnesses should be categorized. Agreements as to what is being analyzed must exist before conclusions can be made regarding the “cross-cultural comparability of illness concepts or their generalizability...” (1993:209). Simons (1985) similarly suggests the sorting of culture-bound syndromes into taxa. Such taxa might include *Sleep Paralysis* and *Fright Illness*. Formulations that explain taxons can be compared to each other in two ways: validity and consequence. A formulation is valid if its descriptive data are consistent. The questions of consequence must also be raised. These syndromes often include suffering, and if an explanatory formulation becomes widespread, the likely consequence - such as involuntary hospitalization or political consequences - must be considered.

While differing opinions among the aforementioned authors are debated, the biomedical point of view is less complicated. In *Alternative Therapies*, Lee and Balick express to their fellow biomedical practitioners the importance of cultural understanding and describe the benefits to understanding cross-cultural medicine. They appreciate the inclusion of culture-bound syndromes in the DSM-IV and write, "...it is wise to remember that, wherever we come from, our ancestors recognized disease conditions and folk therapies unique to our own cultures" (Lee and Balick 2003:109). Other authors contend that culture-bound illnesses are just other names for familiar biomedical diseases (Horbst 1997; Lux 2001; Salman *et al* 1998). In particular, Salman *et al.* (1998) (as mentioned earlier) attempts to align *ataque de nervios* with psychiatric categories, fitting them into three types of Western psychiatric conditions.

As mentioned above, the term "culture-bound syndrome" is argued to attach negative significance to the population being described. A couple of authors have found methods for working with popular illnesses. Weller *et al.* mention the problems in using different methodologies to compare illnesses across cultural groups. The authors suggest the use of a common methodology in all locations and with all groups. Comparisons, they write, can only be made if all the informants are asked the same questions, and a "comparative study based upon standard protocol is one of the most powerful methodological tools there is" (1993:123). Pachter also illustrates the need for appropriate methodologies and technologies in the study of "folk illnesses." He writes that combinations of quantitative and qualitative techniques lead to reliable and descriptive data. "Latin American folk illnesses" can be studied using multidimensional scaling, cluster analysis, factor analysis, and consensus analysis. Pachter suggests that cultural differences between groups can be

measured, and the assessments can be used to support or refute hypotheses regarding the diffusion of ethnomedical beliefs. Integrative methodologies, the author concludes, should lead to studies of folk illnesses that are “predictive and theoretically generative” (1993:107).

The debate over the relevance and meaning of so-called “culture-bound syndromes” such as *susto* is significant because *susto* and other illnesses such as *embrujado* and *ataque de nervios* affect a population in the United States that is constantly growing. *Susto* may be a culture-bound syndrome or perhaps an illness with which the Western world is familiar, but differently named (Kay 1993, Rubel 1964, Simons & Hughes 1993). It may also be an illness that Hispanic populations in the U.S. endure due to an increased level of stress or cultural strain (Gobeil 1974, Kiev 1968).

These considerations may be applicable to the current study, as participants describe their beliefs about diabetes and *susto*. How they think about the connection between the two illnesses may affect how health care professionals are recommended to interact with their Hispanic patients.

CHAPTER 4

METHODS

Qualitative Methods: Background

Both focus group and interview methods were used in this study, and are qualitative in nature. While a combination of qualitative and quantitative methods would have been preferable, time constraints and the level of work required for a master of arts project limited the extent of the study.

Qualitative methods are generally those that are nonnumerical (Spradley 1979). Ethnographic research, as Spradley writes, "...alone seeks to document the existence of alternative realities and to describe these realities in their own terms" (1979:11). Focus groups and ethnographic interviews are becoming increasingly popular (Krueger & Casey 2000). The goal in ethnographic interviewing is to learn about realities from the insider, or emic, perspective. The "essence" of ethnography is to be taught, to become a student, as the interviewee becomes the teacher (Spradley 1979: 4). A focus group is similar.

Focus group research is based on extended mutual discussion with a compelling selected set of individuals. A practical definition is "...an interview style designed for small groups" (Berg 2004:123). The purpose of a focus group is to understand how people think or the feelings they have about a specific issue. They are carefully designed in terms of size, participant composition, purpose, and procedures (Krueger & Casey 2000:4). It should be a relaxed environment where participants feel at ease, and the

interviewer can guide them through planned discussion topics to draw out participants' thoughts and feelings. Focus groups can become quite dynamic, where a "brainstorming" effect occurs as participants bounce ideas off one another (Berg 2004: 124). A distinction separating one-on-one interviews with focus group interviewing is that the interviewer is able to observe interactions regarding attitudes, opinions, and experiences as participants discuss the issues (Berg 2004:127). Focus groups also require lesser amounts of time than traditional interviewing.

Data Gathering

Study Approval

This study was approved before implementation by the Institutional Review Board at the University of Nevada, Las Vegas, protocol #0510-1784. Approval for the focus group was granted 22 February 2006 and approval for the ethnographic interviews was granted 23 May 2006.

Participants

Participants in this study were drawn from participating members of the Nevada Alliance Against Diabetes, or *la Unión Contra la Diabetes*, a registered non-profit organization targeting Hispanic diabetics. Patients receiving care range in socioeconomic status from middle class to low-income, the majority being middle class. The Alliance focuses on diet and preventative care, in addition to medications. A focus group of five participants was conducted, followed by nine ethnographic interviews. Particular care was taken in order to assure responsible work with human subjects during the project. Project participants included in the project met three criteria:

(1) Hispanic; either born in a Latin American country or born to Hispanic parents in the U.S;

(2) Age 18 or older; and

(3) Diagnosed with type 2 diabetes or family member of a diabetic.

Project recruitment took place in the form of announcements made during the monthly diabetes support group held by the Nevada Alliance Against Diabetes, and also via telephone. Pedometers were promised and provided to all who participated, in an effort to encourage exercise as part of a healthy lifestyle.

Data Collection

The focus group and interviews were conducted at the Rafael Rivera Community Center in Las Vegas, Nevada. A professional health educator from the Nevada Cancer Institute, fluent in both English and Spanish, assisted in facilitating and translating the focus group, which totaled five participants. Technology used included an audio mixer, two microphones, and a tape recorder. The focus group ran two hours. Audiotapes were transcribed verbatim in Spanish. Interviews were conducted in venues most suitable to participants, which included the Rafael Rivera Community Center, local libraries, and participants' homes. Assistance in facilitating was provided by a native Mexican with a degree in anthropology. Interviews were recorded using a handheld tape recorder and attached microphone, and ran from half an hour to two hours in length. Audiotapes were transcribed verbatim in Spanish.

Upon arrival, participants learned about the project and were allowed time to answer questions and sign informed consent forms for the focus group and interviews, and for

the use of an audio recorder. Questions asked in the focus group and interviews were designed to be open-ended and to encourage conversation (Appendix). In the focus group, most of the prepared questions were answered without needing being asked, as conversation moved among the participants.

Analysis

Kleinman's EM concept was used as the foundation in the development of categories. Data in the focus group transcript was coded and sorted by relevance to the research questions and by participant, noting things such as denial, family involvement and causal beliefs. Categories were formed based on patterns in the data that would possibly elucidate explanatory and folk models of illness. Resultant categories were "Cause", "Response to Diagnosis," and "Other Players". The resulting data was then used to help formulate semi-structured interview questions.

The interview transcripts were coded and sorted. While separate categorization of diabetes and *susto* was considered, it was decided instead to interpret the interview responses to both features as an integrated whole. This was due to the complex nature of their responses (*susto* and diabetes were intimately connected) and the added questions about *susto*, making the interviews equally about both conditions, instead of an emphasis on one, as was the case with the focus group. In the interviews, descriptions regarding "other" emotional factors (in addition to *susto*) involved in explanatory model causal factors were made more explicit by the participants.

In coding the focus group and interviews, themes that were identified included social support, stigma, stress, family histories of *susto* and diabetes, response to diagnosis,

issues of emotion including depression, sadness, joy, grief, and anger, as well as denial, participant definitions of *susto*, patient/practitioner interactions and symptoms of *susto* and diabetes. Also coded were responses that were unexpected or not part of the research design, such as “impressions” (elaboration provided in Results), and the interrelatedness of emotions.

CHAPTER 5

RESULTS

Participants

Focus group participants included two men and three women. Their ages ranged from 21 to 49, the average being 38. Their places of birth were Mexico (three) and Guatemala (two). The primary language of all five was Spanish, and one was bilingual. One participant had health insurance. The number of people in their households ranged from one to seven, the average being 4.2. Household income broken down into 2003 Poverty Thresholds indicates that all but one participants' households live below poverty thresholds. All participants were diabetic.

Interview participants included four men and five women. Their ages ranged from 25 to 71, the average being 52. Their places of birth were Mexico (8) and Guatemala (1). The primary language of all nine was Spanish. None of the participants had health insurance, making any connection between having *susto* and not having insurance difficult to determine. The number of people in their households ranged from two to ten, the average being six. Household income broken down into 2003 Poverty Thresholds indicates that three participants households' live above poverty thresholds while four live below. Five of the participants were diabetic, and four had diabetic family members.

Focus Group

The purpose of the focus group was to determine what type (e.g., causal), if any, relationship between diabetes and *susto* existed for participants, to gather any main themes or issues, and to learn how people talked about diagnosed diabetes and *susto*. Learning of any perceived relationship and uncovering the nature of that relationship was imperative for the study to continue. The overriding theme of the focus group questioning route, therefore, was the cause of diabetes. During coding of the focus group transcript, several ideological patterns emerged which fell naturally into the three following categories:

Cause

Causes of *susto* for participants were *susto* (a scare), *coraje* (anger), *tristeza* (sadness), stress, diet, heredity, and obesity. The three definitions of *susto* explained in the focus group had a common theme, that of a sudden impression or action that led to a physical response. Examples included a car accident, an earthquake, a mugging, a child falling down, and a sibling's diagnosis with a brain tumor. A description of a physical response included panic with heart palpitations and trouble breathing. *Susto* was not described as an ongoing condition, but one of suddenness caused by an unexpected event. All the participants believed that *susto* plays a role in causing diabetes. However, *susto* was not solely to blame. While it was considered by one participant to be the most important cause of diabetes, it was described as one factor in diabetes etiology in combination with *coraje* and *tristeza*, and sometimes being *enojado* (angered), as well.

Susto and *coraje* were often mentioned in the same context. One participant expressed deep displeasure with her husband's frequent drinking and car accidents. Her

reaction when arriving at the scene of the accidents has been a combination of *susto* and *coraje*. She noted that when having a *susto* or *coraje*, her sugar levels rose as a result. Another participant explained that his brother had been diagnosed with diabetes three months after experiencing *corajes* and *susto* due to business problems. The participant later explained that, “...*del susto viene coraje*” (from *susto* comes anger). He credited his own case of diabetes to the *corajes* he endured while having trouble finding a home loan and problems he experienced with a realtor. He later said, “It’s like a combination, a *coraje* is mad, you know, and *susto* is when you get scared, when you are scared of something...” While the two were frequently mentioned in the focus group, *tristeza* was an integral component as well.

Two participants pointed to *tristeza* as the primary cause of their diabetes. *Tristeza* was described as a long-term condition. One participant had felt sad because her daughter and grandchildren were going to move away to the United States. Another felt an intense sadness because he was forced to separate from his mother and move from Guatemala to the United States at the age of 15. He was unable to join his mother when she was dying. He also noted that when he experienced a depression in August of 2005 following a romantic separation, his sugar levels rose from a healthy 100-120 to 155. He credited this change to that depression and his diabetes to a “*tristeza grande*,” or great sadness.

Stress and *enojado* were mentioned less frequently in the context of personal causes of diabetes, but were mentioned generally as causal factors. When considering causes of diabetes, stress was named but not elaborated upon. In the interview results, however, participants spoke about stress in greater detail. While describing the experiences that led to his development of diabetes, one participant described an intense situation due to

which he had many *corajes*. As he discussed other cases of diabetes in his family and the reasons for those cases of diabetes, he said, “I think that *susto* and *coraje*, stress, have much to do with diabetes.” He reiterated this opinion two more times over the duration of the focus group. *Enojo* was also brought up, but without the emphasis afforded to *susto* and *coraje*. In the context of explaining an event that led to their cases of diabetes, two participants described themselves as being angered. The difference lies in the use of *enojo* for mild irritation and anger and *coraje* for strong feelings of anger. Participants were more likely to say that they had a *coraje* or a *susto*, than to say that they felt mildly angered.

The group came to a consensus at the end of the focus group, explaining that while *tristeza*, *coraje*, *enojado*, and *susto* were different, all were related causally and each can cause diabetes. For example, being sad was part of feeling angry, and from anger came *susto*. This relation was evidenced through the context of the focus group. For instance, participants tried to convince a fellow participant that it was not sadness that he was feeling, but anger instead. Participants held up their hands with fingers intertwined to illustrate their point that those factors were interrelated.

The biomedical factors: diet, heredity, and obesity, were discussed in response to a question regarding whether some people were more likely to be diagnosed with diabetes or blood pressure problems than others. Those factors were listed, but not in connection with any participant’s personal experience. Additionally, having “fat in the blood” was considered a risk factor, since it is converted to sugar. The participant who felt *susto* was the most important risk factor explained, “An impression, the first one it gives you or

susto, bam! And already the development of diabetes, for me the most important is *susto*, the cause of diabetes.”

Response to Diagnosis

All of the participants described their reactions to being diagnosed. Two were in denial for a time after diagnosis, continuing to eat unhealthily and to drink alcohol. Another two experienced an intense depression. One called it “la gran depresion” and a second thought of her body as decaying. Their thoughts included asking how diabetes could happen to them, wondering what they would eat, and not wanting to die.

Other Players

Other players were involved in the health of the participants. These were doctors and family members. Participants noted a difference between Latino doctors and American doctors. One participant received care at a clinic on Fremont Street, in downtown Las Vegas, but he did not feel he was getting enough attention and the doctors only spoke English. He then drove to Tijuana and saw a doctor there. The doctor attended to him for two hours, explaining that diabetics sometimes have problems with nerves and can have stress. He then suggested that there was something negatively affecting the participant at work or at home. While describing this, the participant explained, “Imagine a doctor here in the United States, he will not lose two hours on me, and you are always waiting!” Now he sees a Guatemalan doctor in Las Vegas.

Another participant described a visit to the clinic run by the Nevada Alliance Against Diabetes. While waiting for her appointment another doctor came up to her and said, “I can see you are very depressed, you have problems in your home.” The doctor proceeded to talk with her about her husband and whether he supported her by accompanying her to

medical appointments. When speaking of *susto*, another participant exclaimed that no American doctor had ever said anything to him about *susto*. He always goes to laboratories, and is told the results but nothing more.

Participants' family members played significant roles in their diabetes. The participant who told of her grandchildren's move to the United States experienced the *tristeza* that caused her diabetes. Family support mattered greatly to one participant who could not count on her husband or her children. Her children could not be bothered to take her to medical appointments most of the time, and when they did, it was with reluctance. She exclaimed that instead of helping, her husband worsened things. He was constantly drunk, and would wake her up just to talk with her about a television show on in the middle of the night. She rarely had enough sleep. The participant explained that she had moved to the United States a year before her husband. In the year before he joined her, her sugar levels were good. Afterwards, they rose to dangerously high levels and she risked being placed on insulin. That participant felt the absence of her family's support keenly, and the focus group sympathized with her plight. Another participant had the support of his wife, who was told by the doctor when he was diagnosed, "you must take care of him, and make the food, and all of that." In this instance, the participant felt he had the support of his wife.

Interviews

The purpose of the semi-structured interviews was to learn about the relationship between diabetes and *susto* in an in-depth manner and to learn more about *susto*. It was thought that interview participants might be more willing to say things in private than in

front of their peers, and that the interview results might therefore prove to contain more nuances and subtleties than the peer-oriented focus group.

The results of the interviews did indeed prove far more complex than those of the focus group. Not only was the cause of diabetes a major topic of conversation, as in the focus group, but the cause of *susto* was discussed more thoroughly as well. The two illnesses, along with the relationship they shared, were discussed. As in the focus group, interview participants combined causal factors as they spoke about diabetes etiology. *Susto* immediately emerged as a causal factor, along with *coraje*, stress, *gusto*, *enojo*, diet, obesity, and heredity. One would be tempted to consider all of these factors separately, but doing so would prove unfair to the participants' ideologies. From their points of view, many if not all of the factors were related. In the following description of interview results, the aforementioned factors are described in an interlinked manner, as accurately as possible with respect to the participants' viewpoints. Results will begin with *susto*, with the goal of maintaining a descriptive progression from *susto* to diabetes.

Definitions and Causes of *Susto*

Definitions and thoughts on the causes of *susto* were mixed. Causal factors of *susto* were ongoing exposure to abuse and sudden traumatic events, or events causing excitement or joy. One participant (1) thought that *susto* was a lasting condition. She responded to the question, "Please tell me about *susto*. What is it?" by answering that for her, *susto* was when her husband routinely arrived home drunk and beat her. She would hide in the house with her children, and her mouth would always become dry. When he'd find her, he'd accuse her of doing something and beat her for it. If she didn't hide, he would invent something and hit her for that. Her final response was that *susto* is always

living in tension and fear. Another participant (2) also mentioned that *susto* is a reflection of fear. Other participants were of the opinion that *susto* was a phenomenon with a quicker or more abrupt onset.

In those cases, *susto* was described by participants as something sudden; a shock, or an impact. These definitions included, “*Susto* is when they frighten you...when they scare you” and *susto* was “...when you were frightened.” One participant (5) gave the example of choking; two more (3, 4) gave the example of their niece’s rape, one (8/9:JM) told of his nephew’s death as a passenger in his car, and yet another (6) described a realistic dream that caused a *susto* and changed his life. In those cases, diabetes might follow months later or the onset might be immediate. No examples were given of instances when a *susto* worsened a case of diabetes. A participant (2) explained that other people talked about *susto*, *coraje*, and *gusto* causing diabetes, but she believed it was really heredity. However, she later said that a case of *susto* caused diabetes for her: one of her sons was in a car accident and died, she felt something, and it was a *susto*. Eight months later, she was diagnosed with diabetes. Another (8/9:JM) worried about his wife, and said, “She can get diabetes overnight through a *susto*...it can be a strong distraction of a car rushing on top of you or there are shots...you see right now it’s fine, and you get scared and everything and another day you feel bad...”

“Other People” and Support: Doctors, General Public, U.S. and Hispanic

Participants were asked about how they thought other people would respond to *susto*. In terms of family support regarding a case of *susto*, one participant (3/4:J) felt his family would be supportive. He said, “Well, you have to look for support, a consoler with the family. We have a united family... If something happens, we talk.” Seven felt (2, 3, 4, 5,

7, 8, 9) felt they would have their family's support if they had *susto*, and two (1, 6) did not. A woman (1) who felt she was without her family's support of her *sustos* explained:

Sometimes I feel they are cruel with me. Because sometimes I am sensible, like now, but I think a problem one with diabetes has is that sometimes you feel that way, but sometimes very fragile and emotional. My youngest son supports me, but my daughter is not, is angry, tells me to be stronger.

Another participant (6) who did not have any family support explained that he had lived with his girlfriend and her kids. However, family life with them was not tranquil, and living with them made him feel worse. He had chosen to move away from them. One of the two married couples (8, 9) explained that while her children were supportive, his were not. They did not help him, and would only ask him for money.

There was consensus among participants that the meaning of *susto* was the same for everyone, regardless of generational differences. As one (2) said, "*Susto is susto.*" Relatedly, most participants believed that if one family member had *susto*, they would be more likely to acquire it themselves. One participant (2) thought that when people in her family experienced a traumatic event, she experienced a resulting case of *susto*. Another (3/4:J) whose family experienced 10 or 11 deaths in the year 2000 stated that he was going to get diabetes through a *susto*. There was an array of opinions surrounding the concept of how others, either American or Hispanic, would view *susto*. One participant (1) stated she would never tell anyone about her *sustos*, another (2) thought that people in her native country would believe in *susto* but Americans would not, and yet another (5) thought that no one would "...support the theory of *susto*," American or Hispanic. The last participant was the youngest, at 25, and her feelings might be due to changes in folk ideology or a recognition that more educated people such as doctors would not believe in

susto. Opinions were also mixed regarding whether participants would willingly speak of *susto* with anyone, and they were similarly mixed regarding whether participants would mention *susto* to their doctors. A married couple (8, 9) felt that their American doctor (who had been born in Peru and spoke fluent Spanish) understood *susto*. One participant (5) did not believe that any doctor, American or Hispanic, would understand *susto*. Conversely, another (2) thought American doctors would understand. Neither participant thought they would have a problem speaking of it to anyone at all, even doctors, although one (6) said, “In reality, I have never been to a doctor who has mentioned the word ‘*susto*....’ For doctors, *susto* is not in their books or their theories...Doctors do not believe in *susto*.”

Multiple Causal Factors

It was common for participants to cite multiple causal factors for diabetes. All but one participant felt that multiple factors contributed to diabetes. In fact, five (1, 3, 4, 8, 9) thought that everything, factors such as *coraje* and *susto*, as well as biomedical factors such as diet and heredity, contributed to diabetes. One of these participants (1) said, “I believe that one triggers everything. The fear, the sadness come together and you are tense, there are many things.” Others were more selective. For example, five (1, 3, 4, 5, 6) of the same people who thought that stress was a causal factor also believed that *coraje* caused diabetes, and six (3, 4, 5, 6, 8, 9) of them additionally thought that diet and heredity played roles as well. For one participant (5), *corajes*, *sustos*, stress, fat, and lots of sugar caused diabetes, but *enojo* was the most important factor. She also thought that *enojo* and stress could worsen diabetes. Two (2, 6) said that both *corajes* and *sustos* would worsen a case of diabetes. One (6) thought that heredity was the most important

factor. Yet another participant (3/4:J) ardently supported *coraje* over *susto* as the more important cause of diabetes, and also thought *gusto*, diet, and heredity were factors. His wife (3/4:ME) said that the diabetes in their family was due to *sustos*, along with diet and heredity. She explained that, “We don’t take care of ourselves”...and “We don’t understand how what they say not to eat is what we want the most.” A participant (7) thought that diet was the most important causal factor, and believed that *susto* and *corajes* were factors as well. He said, “The diet causes diabetes, one can’t drink sodas or beer.”

Emotions

Aside from diet and heredity, all but one participant (2) thought or expressed in the contexts of the interviews that “The emotional state contributes much,” as another (1) said. This was reiterated later, as yet another participant (3/4:EM) said, “...like what has happened in our family through emotional problems that are detected, I say the same, we say through this comes diabetes.” A third (7) also thought that problems caused *susto*. The participant (2) who disagreed said, “I don’t think those [negative] feelings cause diabetes,” and later attributed her diabetes to a *susto*. A fourth (6) explained the effects of positive feelings “Feeling can affect diabetes a lot. A sincere hug gives me more feeling than miles of words. Because sometimes our bodies say more than words.”

Stress

Seven participants (1, 3, 4, 5, 6, 8, 9) felt that stress was a cause of diabetes. Asked if *susto* and stress were the same or similar, all participants answered that the two were different. Stress was caused by work or fatigue, explained one participant (5), and could worsen a case of diabetes. A married couple (3, 4) stated that *susto* was different than

stress, that "...stress is very depressing, a person who works a lot and does not rest or has many worries....[who] is very sad about life." The wife (3/4:ME) said, "I have seen how they say that stress is worse than any illness" and her husband (3/4:J) said, "With stress, you lose the love for life." Another participant (1) explained that while the two were different, they were related to one another and to diabetes. She said:

...you have *susto* some time and that's it. But from the same scare can come stress. This happened to me. I no longer liked my job, and I felt it was hurting me and I left. But there I had a tension that contributed to my body hurting so. I felt tired, bad, I couldn't work. I think feeling tense contributed to the illness.

This participant had made an ideological connection between the two. In answer to which factor caused diabetes more quickly, another married couple answered that such a factor was stress. The husband (8/9:JM) said, "The stress [pause] is a depression that one has all the time because of the burden here." However, the most common answer was similar to one participant's: "*Susto* is spontaneous. Stress is constant." Even the same couple (8, 9) explained that *susto* is momentary and fast. Relatedly, another participant (6) described how the body is affected by worries:

Heredity is most important. *Susto* also gives you diabetes...it has to be a strong *susto*...the *coraje* also has to be strong to affect you. And supposing that you already have diabetes and you get *coraje*, you can get worse, you can die, because the sugar has gone up. Also, if you have diabetes a *susto* can harm you more...All of our worries are in the brain, and the brain manages the body. Like a bomb happens in the body and it harms you in many ways.

Although he did not mention the word, "stress" in this context, the relationship he placed between *susto* and *coraje* with worries, along with how worries affected the body, was evident.

Different *Sustos* and Personality Types

One participant thought that a small *susto* would not cause diabetes, but that a larger one would. This was alluded to as well by another participant (2), who pointed out that there are different *sustos*. Participants (1, 2, 3, 4, 5,) agreed that some people get *susto* more easily than others. This depended on personality type; some people were described as naturally more nervous than others. Instead of taking things calmly, they would take an event or encounter and make it into a larger issue than necessary. One participant (1) described herself as just such a type of person, as someone who was scared easily and tried to control her feelings of panic. The youngest participant (5), at 25 years of age, explained that some people were more sensitive than others. Another (6) said that “..I have problems and that also affects me, mentally and psychologically...Our body is like we say, very sensitive to things. One day you feel well and the other you don’t know what happened. You feel bad, a headache, or you feel nostalgic, a sadness.” Another (3/4:J) said that some were more despairing. The husband in a couple (8, 9) was worried that his wife, a non-diabetic, might get diabetes. He (8/9:JM) said, “We are all exposed to a *susto* and anyone can get it,” and later said, “She gets scared over everything” and “Well, I fear that she will get diabetes through the tension we have right now. Understand? Because the kids are in Mexico, and are not stressed. But we are. And there is the probability that she will contract diabetes through the same depression she has for everything else.” His wife (8/9:M) described how having a *susto* felt: “I feel a very bad thing. It enters me later, later, a cold thing...My hands become numb...later it hurts my head and in another hour I feel...tired.” The participant (2) who believed in different types of *sustos* told a story from her childhood, of an ill man who lived nearby. She said,

“When he wasn’t sick, he was educated and a good man. But when ill, he had a madness and panics. That is *susto*, and others are when you see someone get run over.”

Ideological Link between *Susto* and Diabetes

One way in which *susto* and diabetes were linked in participants’ minds was in broad definitions or statements. They were asked to explain *susto*, and were also asked if there was a cause of diabetes that people in their communities spoke of but their doctors didn’t. Asked to explain *susto*, one said (5) laughingly, “Well, when you have *susto*! It is said diabetes comes from *susto*...It’s a myth, right? All the people say that when you begin to have *susto* you get thirsty and then get diabetes. I don’t know.” Another (8/9:JM) said, “They say it is because of a *susto* or a very strong emotion...various accidents and with much tension, and I believe through this I suffered from diabetes.” Yet another (1) said, “It is clear there is a relationship...They [people] talk of *susto*, and yes, it could be. I think everything contributes...I think you have *susto* and then also tension and then, something happens. I believe that contributes, I feel it’s what happened to me.” Still another (6) explained that, “I have heard it can be because of a *coraje* or a *susto*. Someone dies, there is an accident or something scares you and it can affect the blood system, there these kinds of illnesses [diabetes] can develop.” He later added, “One says that you have *susto* and your blood goes to your feet and you look wan...I imagine that with a *susto* the blood goes, it blocks...and the body does not run...more than anything regarding diabetes, I imagine that a person with *susto* is affected by getting diabetes.”

A married couple (3, 4) stated that there was a third factor involving *susto* and diabetes (although they also thought *coraje* and stress played roles, as well). This was a strong impression. Impressions were described as “of the moment” and could consist of

watching a car crossing lanes dangerously close, or of running someone over in a car. An impression is stronger than a *susto*, and *susto* is just part of the stronger impression. The couple clarified that when having experienced an impression, a person would say it was a *susto*. If that person were later diagnosed with diabetes, the blame would be placed on the case of *susto*. However, they stressed it was actually the impression that caused the case of diabetes. The wife explained, “More like a person has a strong impression, and they say it is *susto* in the manner, ‘Oh, I have a *susto*!’ and later diabetes is detected ‘ah! It was because of the *susto*’ is what one says. But sometimes I say it’s the strong impression that the person has in that moment.” An example given was that of the husband’s niece, who was raped at the age of seven. By the time she left the hospital after treatment, she had diabetes. Her aunt explained, “Well, I think the sugar rises, from the impression or I don’t know, the glucose rises from the impression.” The other husband and wife also spoke of impressions. He (8/9:JM) explained that “Seeing a spider would cause a *susto*, but separating from a spouse would not. It is an impression, not a *susto*. The result of the impression is a sadness, a depression. It’s a strong emotion.”

In the above paragraphs it was shown that participants linked *susto* and diabetes ideologically. As participants answered questions about *susto* and how they linked it to diabetes, they also answered similarly phrased questions about diabetes itself. In the following paragraphs, participant beliefs regarding diabetes diagnosis, family support, and patient/practitioner interactions are described.

Diagnosis of Diabetes

It was not uncommon for participants to experience a sense of depression after diabetes diagnosis, or to feel that if they were diagnosed with diabetes in the future,

depression would result. One (1) participant exclaimed, “I was badly depressed. I cried because I thought I was going to die.” Another participant (2) first said she had not been depressed, but then said, “...well yes, a little sadness, right? But if you have the illness, what are you going to do?” A third participant (3/4:ME) thought, “I think first you get used to the idea and then you accept it.” A fourth (6) participant lost weight after his diagnosis. He had a *susto* because he found out he had diabetes. Finally a fifth (5) whose grandmother had diabetes thought that her grandmother experienced depression because many things were prohibited from her. More positively, the participant (2) who felt a “little sadness” might result said later:

Many times people are depressed when they are ill. But I say whatever the illness is, one doesn't have to feel bad. Because many times God sends us things because we are disobedient and in some manner God says, 'No, I'm going to send this to you so that you put yourself right with me. But still, one is very rebellious with God. And he is good because he always has waiting open arms for one who is looking for him.'

Many participants had definite opinions as to how long they had diabetes before being diagnosed. One (1) felt sure it had been ten years. Another (8/9:J) explained, “I suffered some time without knowing until one time in California that I felt a little tired” and later said, “It's a silent illness that you don't know if you have or not.”

There was an array of opinions among participants regarding whether they felt supported by their families or would be supported if diagnosed. One (1) woman felt unsupported. Her family did not come to the diabetes support groups with her, and they encouraged her to make meals they preferred, but were unhealthy for her.. She explained that if she made the food, then of course she would eat it. Another (2) felt that her family supported her more or less well. They took her to doctor appointments. But since she

lived with her son and his family, it was clear she was also dependent on them. Her explanation was that they want to eat what she eats and sometimes she eats what they eat. The participant was obviously reluctant to say anything negative about her family, but the implication was that she sometimes made things easier on them by eating as they did. A married couple (3, 4) with diabetic family members felt very supportive of each other, and if the husband were in fact diagnosed, they would try to have a healthy diet together. The husband (8/9:JM) of another married couple remarked, "Thanks to my señora I have a good diet." A man (7) living with diabetic roommates explained that, "If one is sick, we care for him."

Doctors and Diabetes

Participants reflected on interactions with doctors, based on a variety of questions. The participant (1) who felt she had had diabetes for ten years before diagnosis told a story of seeing a doctor in Mexico a total fifteen years beforehand, who told her to take pills. She took them for a day, and became physically ill as a result. She went to the scheduled return visit with the doctor, but didn't tell him she had stopped taking the pills. The doctor thought she was doing badly, and gave her more medicine. At that point, she began taking the pills when she remembered to. At the time of the interview, she explained that she had not realized the gravity of the situation. The doctor had not explained her condition to her, and she thought perhaps she had had diabetes since then. Another (2) participant told a story of seeing an American doctor about three or four years ago. She said:

They took me to a doctor and he made me part of a study about diabetes. Even today I do not know the results, because they did not tell me anything. They only told me to take these pills. I felt bad and stopped taking them. Always a Latin

person will look for someone who understands, or one will not understand the seriousness of the illness.

Yet another participant (3/4:J) explained that sometimes diabetes moves fast, like in the case of his brother, who died less than a year after diagnosis.

Some participants were able to reflect on differences or similarities between experiences with American doctors and doctors from their native countries. Some thought that appointments with American doctors were longer than those with Latino doctors in their home country, and vice versa. For instance, one (1) said that her appointments with American doctors have been about 10 minutes, because a person is not equal if they don't speak English. Conversely, another (2) thought that visits in her home country lasted fifteen minutes, while appointments in the U.S. were a little longer. She also stated that when she lived in her home country, she had discussed *susto* with her doctor. She also felt no problems would arise if she told her present doctor, originally from El Salvador, about a case of *susto*. She remarked, "I think the doctor is authorized to answer any question. And one has to ask questions because it is one's health. Many people don't ask, 'what is my illness?'" Another (3/4:ME) woman had not seen many American doctors, but thought that while appointments in Mexico were half an hour or twenty minutes, appointments with American doctors would be longer, with more questions asked.

On the other hand, another participant (6) thought that appointments were longer with Mexican doctors, and that Mexican doctors emphasized talking about things like foot care while American doctors asked which medications he took and how many times he took them a day. A husband and wife thought that the visits were longer in Mexico than in Las Vegas, and the wife (8/9:M) explained, "In Mexico, I felt and they had me lie

down and they checked my mouth, hearing, and everything and here they don't. It's rare that the doctors does that here." The participant (1) who thought not speaking English affected medical visits explained that doctors could be confusing – some were nice and others were not. She described an experience when the doctor said, "But as you don't have money, you are not going to be able [to have an appointment]." Her conclusion was that having money affected how doctors attended to her. A participant (7) from Oaxaca, Mexico, explained that while he rarely saw a doctor in his country, when he did, appointments lasted an hour or an hour and a half. He saw doctors much more frequently in Las Vegas, but remarked, "We don't know if they'll be late. Because sometimes they are half an hour, an hour late."

A married couple explained (3/4:M), "We have had luck that there are things that they don't understand about us but they have a person who..." (3/4:JM) "But there are doctors that we like who talk with one...He sits and listens to me word for word and talks to me about what I don't understand. But to me I like it because I'm going to sit and listen and you find very few doctors who pay attention. And I'm delighted with him." This couple felt lucky, because while they considered their doctor to be American, he was actually born in Peru and spoke Spanish fluently. Judging from such remarks, how doctors attended to participants mattered in terms of how they framed competent care. The amount of time spent on them mattered, as well as how the doctor interacted with them.

Focus Group and Interview Results, Per Research Questions

Definite themes emerged that mattered to participants and were integral parts of how they thought about the relationship between the two illnesses, as well as patient/practitioner interactions. In relation to the research questions, these were causal factors in participants' explanatory models for *susto* and diabetes and demographics, symptoms, and issues of stigma and support from family and doctors.

Causal Factors

One of the anticipated results of this study was how participants thought of family histories affected the likelihood of having *susto* and diabetes. In terms of diabetes, participants pointed to a hereditary component. A genetic predisposition mattered to participants, and "heredity" as such, was a distinct causal factor. In terms of *susto*, participants also thought that if other people in their families experienced *susto*, then they were likely to get it. The difference, however, is that this likelihood was not due to a genetic component, but rather to an experiential component. If something unpleasant happened to a participant's child, for instance, then the participant was likely to have *susto* from watching that child suffer. Living in the same house and being exposed to the same problems mattered as well.

Demographics and Ideologies

One of the goals of this study was to determine if any differences regarding ideologies of diabetes and *susto* existed between different groups of Hispanic people. Generational differences were difficult to determine, and results from a study of this size are only suggestive for further research. Two participants were in their 20s, three were in their 30s, and the rest ranged from the 40s to the 70s. Only one slight difference in

ideologies emerged along a generational axis. A young woman of 25 first questioned the existence of *susto* (“It’s a myth, right?”) but substantiated its relationship to diabetes and her belief in it throughout the interview. She may have done this because of an awareness of how other people view *susto*, or perhaps because she had been more exposed to other influences than the other interviewees. Aside from that remark, however, there were no clear generational differences between participants of varying ages. Interview participants reinforced this finding when answering whether different generations thought of *susto* in a similar manner. Participants did not think that beliefs about *susto* varied on a generational basis. There was a general consensus that everyone thought about *susto* in the same way.

In terms of ideological differences between men and women, a noted difference was the emotional component women expressed. Female participants were much more likely to mention emotions, exhibit emotions during the focus group and interviews, and to reflect on the emotions they had felt during an event. While causal factors were mentioned no more by one gender than another, men did not elucidate on emotions any more than necessary. One participant (7) may have felt uncomfortable discussing emotions, and tended to answer those questions in a roundabout manner. When asked about feelings (*enojo*, *coraje*, *tristeza*, and stress) he spoke about *coraje*. It is possible that anger was a feeling more easily spoken about and more readily accepted by two of the male participants (3/4:J, 7).

Social class and any differences in ideologies, as well as the prevalence of *susto* among social classes, were initially an aim of this study. Differences in social class between participants were few, however. Most study participants’ household incomes fell

below poverty thresholds. Learning of any differences in *susto* prevalence along class lines, therefore, was not possible due to the socioeconomic homogeneity of the participants.

Analysis of data based on country of origin fell short of anticipated goals. Purely by chance, focus group and interview participants were from two different countries: Guatemala (3) and Mexico (11). This also made for a rather homogeneous participant group. No significant differences were noted, however, between Guatemalan and Mexican participants. The two men who spoke the most about *coraje* came from Mexico, and the participants in the focus group from Guatemala spoke about *tristeza*, as well as *coraje* and *susto*.

Symptoms

Interview participants were asked about whether they thought the symptoms of diabetes and the symptoms of *susto* were similar. Most participants found this question difficult to answer. One (5) understood the intent of the question, which was an attempt to understand if one might feel much like the other, and immediately responded, “There isn’t a similarity between the two. There isn’t any similarity because *susto* is a factor of diabetes, it’s supposed...” As the interviews continued, however, participants were asked separate questions, first about the symptoms of one, and then the other. Toward the end of the research, a married couple (8, 9) was quite helpful. She (8/9:M) explained how she felt when having a *susto*, as previously mentioned, “My hands become numb...later it hurts my head and in another hour I feel...tired.” Her husband (8/9:JM) agreed that the symptoms of *susto* in the days following his nephew’s death were the same as his current diabetic symptoms. Those participants (6) that felt *susto* was a spontaneous event were

more likely to feel that *susto* had no symptoms, and other participants (2, 3, 4, 5) felt that the symptoms of the two were dissimilar. A participant (1) who felt that *susto* was an ongoing condition, always living in tension and fear, said, “I had not thought of that...can it be there is a connection?” She explained, “When I was pregnant with my youngest son, (and even now sometimes I don’t laugh much and I’m tired,) I did not laugh much, because I was tired...But apart from the fatigue, I was in pain, I hurt everywhere. I remember much of the pregnancy with my son because it was like that, and I...sometimes we were laughing with my cousins or something or I got an equal *susto* and the laughter took hold of me and I was equally tired.” Interpretation of this story was difficult. The participant may have had gestational diabetes while pregnant with her youngest child without knowing. She was describing how she had *sustos* in relation to how she felt about those of diabetes. Results regarding ideologies of the symptoms of diabetes and *susto* were mixed and without pattern or theme.

Stigma and Support

The presence of support, lack of support, or even antagonistic or negligent attitudes and behaviors mattered to participants with respect to social interactions. This was true in cases of both family and doctor support. There were several examples of how support or lack of support mattered to participants. First, other focus group participants empathized with a diabetic woman who was without her husband’s support. She was fully aware that her husband’s joining her in Las Vegas raised her blood sugar to alarming levels. Second, an interview participant knew that her *sustos* and subsequent dry mouth were due to the beatings inflicted on her by her husband. Third, another interview participant explained that without family support, the *susto* would remain with the sufferer. Participants were

keenly aware of the value of a doctor attending to them, and two remembered particular encounters with Hispanic doctors who took particular interest in how their patients' personal lives might be affecting their health. Participants' awareness of their need for support suggests the importance they place on the role social support plays in their health. This importance highlights how participants thought a sense of support and caring mattered in patient/practitioner interactions, as well as how a family could negatively or positively affect the health of their loved one.

Generally, participants felt comfortable speaking of *susto* and diabetes with anyone in their communities. The one exception was a woman embarrassed by the cycle of violence she could not escape – this was her ongoing *susto*. In defining *susto* in such a personal manner, she denied herself the opportunity to speak with others about *susto* in general terms or her personal experiences out of feelings of shame. Some participants might speak of *susto* to their American or Hispanic doctors, while others would not, thinking that the doctors would not know anything about it. Those feelings suggest that participants did not associate *susto* with any stigma, but rather had a “why bother” attitude toward speaking about something which the doctor would not understand. There were participants that definitely felt trying to receive adequate care from an American doctor was a challenge. Not enough time was spent with them by the doctors, care was sub par if participants could not speak English, and even impossible to receive without money. Additionally, participants had experiences with Hispanic and American doctors in which the patients did not understand their conditions and had never learned of their test results. As one participant explained, she stopped taking the pills prescribed for her, sure evidence of noncompliance. However, she had not understood the severity of her

condition. All this highlights communication problems between participants and doctors, both from Latin American countries of origin and American.

CHAPTER 6

DISCUSSION

In Chapter 5, participant beliefs regarding *susto* and diabetes were summarized and detailed. In the following discussion, the results of this project are further interpreted and compared to the findings of other relevant studies, including those focusing on Hispanic health beliefs, patient/practitioner interactions, and the suitability of calling *susto* a “culture-bound syndrome.”

Diabetes and *Susto*

We begin by discussing the present findings in light of other research focusing on Hispanic “beliefs” about diabetes. In 1999, Weller *et al.* published an article entitled, “Latino Beliefs About Diabetes,” in which they examine a total of 161 (diabetic and nondiabetic) Latino adults from four communities in Connecticut, Texas, Mexico, and rural Guatemala for a sense of community-held beliefs. Participants filled out a quantitatively-analyzed questionnaire (Anthropac: Cultural Consensus Model) on the causes, symptoms, and treatments for diabetes. The authors find that while the response variation increased from Connecticut to Guatemala, sample answers showed significant agreement. They find that 56% of the beliefs were shared among the samples. The authors conclude that Latino beliefs about diabetes largely converged with those of the biomedical model, and that differences in question responses were due to varying levels

of experience subjects had with diabetes, not to different Hispanic regional beliefs. They submit:

The high levels of correct knowledge within and between Latino groups suggest that practitioners need not be overly concerned with potential ethnic variations in the perception of the disease. Rather, the focus should be on obtaining the support of the patient's family and using the knowledge of the various aspects of this disease as a source of support for patient compliance with practitioner treatment regimens [Weller *et al.* 1999:726.]

Knowledge regarding the biomedical model of diabetes was also evident among the participants in this study. All of the participants in the current study knew of the basic etiological or causal components of the biomedical model of type 2 diabetes, that diabetes could be hereditary and was usually associated with high calorie/high fat diets. While participants in the present study were queried specifically about the relationship between *susto* and diabetes, nearly all of them emphasized the primary causal role of *susto*, and other emotional states, in the development of their own or a family member's diabetes. Because study participants were all either biomedically diagnosed diabetics, or had a diagnosed diabetic family member, comparisons of knowledge based on the amount of experience participants had with diabetes called for by Weller and colleagues are less appropriate among these individuals. Weller *et al.* recommend adapting treatments to Latino values, such as the importance of family, and as such, recognize the importance of family support in the treatment of Latino diabetics. The Hispanics in the current study also expressed the importance of family. Participants with support were grateful to their families and verbally expressed their contentment, whereas those without support were sympathized with by focus group participants and expressed being frustrated with their unsupportive families and spouses. Weller *et al.* write that beliefs that were not in

concordance with the biomedical model were those regarding some of the symptoms of diabetes and "...the role that emotions may have." While the authors mention emotions, their research focuses on beliefs that affect the *management* of diabetes rather than an in-depth understanding of participants' explanatory models. The current study focuses more on the perceived role of emotions insofar as they affect the etiology of diabetes for Hispanics. While the goal of the Weller *et al.* article is diabetes management, the goal of this study is to provide more information about common themes in Hispanic explanatory models regarding emotions and diabetes, and their potential value in clinical and public health preventive and management efforts.

A 2002 study by Jezewski and Poss examines the Mexican American explanatory model for type 2 diabetes. Using qualitative methods among Hispanics in El Paso, Texas, the authors describe how their Mexican American subjects construct their explanatory models in terms of cause, symptoms, treatment, and social significance. In their results, as in the results of the current study, Jezewski and Poss find that their subjects make use of both biomedical and folk components in the explanatory models, and conclude this is most likely due to their subjects' attendance at diabetes education classes. They also find that *susto* is considered the primary cause of diabetes by their subjects, a central finding of this study as well. While they mention that "stress," "worry," or a "strong emotion" are also thought of as causes of diabetes, the examples given are mostly of *susto*, and *susto* is the condition about which participants elaborated most.

One of the main points of Jezewski and Poss' research is that subjects in their study regarded *susto* as a previous single event that caused diabetes, not as an illness itself. Dissimilarly, in the current study, some participants believed that *susto* was an "ongoing"

condition rather than a one-time occurrence with lasting consequences. Whether the results of this study support or refute Jezewski and Poss' conclusion is difficult to ascertain due to the smaller, more homogeneous sample used in this project. Poss and Jezewski back up their conclusion by mentioning that while they found no specific treatment for *susto*, their subjects knew of biomedical and folk treatments for the disease that *susto* caused -- diabetes. However, results from the current study suggest that participants were aware of how to treat *susto* in at least one respect. Participants were asked if they had the support of their families and if their families helped them to feel better when having a *susto*. A participant answered, "Well, you have to look for support, a consoler with the family....We have a united family...Because perhaps if one is not sick, he may have a *susto*, right? ...soon they will try to ask him about the *susto*. It's what one looks for, because if one has support, at least like us, if something happens we talk." His family could effectively treat *susto* by acting supportively and by talking about it.

This emphasis on family support is substantiated by two participants' ardent expressed unhappiness with their situation, when they lacked support from their spouses and from most of their children. The amount of emotion expressed by them, combined with the great amount of sympathy the other focus group participants shared with one emphasizes the importance placed on such support. Family support was emphasized by two Spanish-speaking doctors as well, who could tell if participants' family life was problematic or unsupportive. The seriousness afforded family support by project participants suggests that such support is not just a considerateness on the part of family but a component of the treatment process that is vitally missed and that might improve

patient well-being. It suggests that *susto* sufferers are aware that they need the support of their family to overcome and deal with a scare, as well as other life issues.

In another 2002 paper by the same authors, these investigators provide an extension of their earlier study. In this second study, emotional causes of diabetes aside from *susto* are not explored. Instead, *susto* is described as a specific episode of fright, whereas in the current study, *susto* was found to be an event or emotions, and sometimes a following condition, as well. Poss and Jezewski write, “*Susto* was not conceptualized as the everyday occurrence of being momentarily startled by a particular situation; rather, it was felt to be a severe fright caused by a sudden, unexpected, and very unsettling event” (369). The results of this project support the idea that *susto* was a sudden event – many participants thought that was the case. However, a finding not arrived at by Poss and Jezewski was that *susto* could be “always living in tension and fear.” Poss and Jezewski’s conceptualization of someone experiencing a lot of *sustos* was that they might experience a specific frightful event frequently, perhaps everyday. But in the current study, *susto* might be an ongoing condition. While Poss and Jezewski’s subjects talked about an event, some participants in the present study spoke about “impressions” and how impressions interacted with, and were related to, *susto*. In their focus groups, Poss and Jezewski found a consensus for the cause of diabetes; “heredity”. However, focus group participants in the current study agreed that there were many interrelated causes of diabetes. Current study participants stated that while causes such as diet and heredity were certainly partially to blame for diabetes, so were anger, sadness, stress, and *susto*. Poss and Jezewski chose not to expand on the other emotions aside from *susto*. However, in this study, it is clear that these other “powerful emotions” are of equal etiological

importance as *susto*. While the word “*susto*” has an innately exotic quality – and because of its association with so-called “culturally-bound syndromes”, the “emotions” participants called on as causes of diabetes deserve more focus. Participants saw these emotions as being linked to *susto* in that one could cause another, and then another, and were very similar. However, one was still sufficiently different from another. One participant explained that they were related in a union, but different. Another used the example of his brother’s death. While he was sad that his brother died, he was also angry that he could not go to his brother beforehand. All these emotions were said to be equal, and each was equally effective at causing diabetes to develop. Participants would correct any misperception on the part of the researcher, as in the case when two participants explained “impressions.” When asked if the progressive events were first an impression, then a *susto*, and then the development of diabetes, they were quick to explain that what truly happens, and how people talk about what happens, are two different matters: a person would have strong impression and then say “Oh, I have a *susto*!” Later, when diabetes was detected, they would say “It was because of the *susto*.” Explaining exactly how emotions, *susto*, and impressions were related and worked mattered greatly to participants.

In their conclusion, Poss and Jezewski suggest that the meaning of *susto* has changed from Central and South America to the U.S. – Mexico border. Following in the same vein, the findings of the current study suggest that the meaning of the word is undergoing another metamorphosis: the extension of the meaning of the word from describing an event to describing a condition as well.

Support: The Role of Practitioner and Family

How participants viewed competent care and the interactions with their medical providers supported the literature on the lack of attention paid by biomedical practitioners to illness as understood and experienced by patients. Kleinman wrote that patient noncompliance and dissatisfaction are due to that lack of attention by physicians. Patients with chronic medical problems would fare better (Kleinman 1976) if they received care from folk practitioners and experienced fewer differences in social class between themselves and their medical providers. They would also fare better if the explanatory systems between patient and provider were similar, as well as if 'explanation' on the part of the provider received greater emphasis (Kleinman *et al.* 1978:252). Participants in the current study described situations in which communication between themselves and their doctors was lost or confused. They never learned of their test results or they were uninformed about or underestimated the severity of their illness. Only one participant spoke about how patients must ask questions of their doctors. None of the others mentioned that they conversed in this manner with their health care providers.

Warda (2000) wrote that many Mexican Americans view the medical systems as unresponsive, and that the themes of respect, caring, understanding, and patience are invaluable in their healthcare encounters. The current study supports those conclusions. As diabetics, many participants in this study had attempted to find medical care. They felt dissatisfied with the care they had received, and had gone to great lengths to find health care they deemed acceptable. The doctors with whom participants were satisfied were most often, although not always, Hispanic. Since personal interaction mattered so greatly

to them, participants who had not experienced a personal responsiveness from doctors might be even less likely to mention *susto* in a medical visit.

As Lipton *et al.* (1998) found in their 1998 study, participants in the present research reported that family was not always a positive supportive factor. In fact, not only might family fail to provide support to a diabetic parent or spouse, family matters could actually *impede* compliance as well, as women in the current study seemed more likely than men to live in family situations that were not as supportive as they would have preferred. Maintaining a healthy diet was a problem, as well as family that did not seem to acknowledge the illness or respect their mother or partner. This increased the difficulty for diabetics trying to control their diabetes through behaviors such as diet and exercise, and may have increased stress levels for some of the participants as well.

Stress and Physiology

In this project, focus group and interview participants refer to “stress” as one of the interlinked causes of diabetes, along with emotions and *susto*. In the following pages, the link between these findings and the physiological effects of stress on blood sugar is explained, in support of the folk model held by many of the participants.

In biological terms, “stress” is defined as any event that challenges homeostatic mechanisms (Bjorntorp *et al.* 2000,) and in terms of “defense-defeat” reactions, it is defined as any stimulus that causes exaggerated reactions in the limbic-hypothalamic portions of the brain, or any environmental event that leads to arousal of those centers (Bjorntorp *et al.* 2000). “Defense-defeat” reactions have been well defined by Henry (1977, 1990, 1988, 1993) in animal models and are built on the more popularly known

“fight or flight” response. “Defense-defeat” reactions are responses with neuroendocrine consequences including somatomotor behavior responses, autonomic-nervous adjustments of inner organ systems, and hormonal adjustments of metabolism and electrolyte-water balance. Such responses are found in all mammalian species, assisting in the maintenance of safety and survival. Bjorntorp *et al.* explain that the human species is the one exception: “Once an emotion is elicited, man can far better than animals – for social reasons – voluntarily suppress the somatomotor behavioural link, but not the autonomic-nervous and hormonal links” (Folkow 1982, Folkow 1987, Folkow *et al.* 1997) (2000). In other words, while the effects of stress might not be evident in a person’s behavior, they would be evidenced through abnormal endocrine changes. In humans, intense “defeat” reactions are characterized by a depressing sense of “helplessness” in reaction to overwhelming external pressure (Henry 1977, 1990, 1988, 1993; Chrousos and Gold 1992) (Bjorntorp *et al.* 2000).

A dialogue on the physiological effects of stress began in earnest in 1929, when Cannon published his work suggesting that a condition of homeostasis can be overwhelmed. He wrote, “...any high degree of excitement in the central nervous system, whether felt as anger, terror, pain, anxiety, joy, grief or deep disgust, is likely to break over the threshold of the sympathetic division...(344-345). He explained that compensatory responses for homeostasis are mediated by the autonomic nervous system, and other secondary responses are mediated by the adrenal medullary hormone, epinephrine (24-25). He also described the “fight or flight” response that is part of human behavior (195). In 1956, Selye began adding to the research by extending this concept to include the responses to stress of other hormones, especially the hypothalamic-pituitary-

adrenal axis (HPA). Stress for Selye was a state in which these responses had been evoked (Selye 1976:1), and he “popularized the notion that a variety of diseases are produced as a result of excessive or deficient adaptive processes during the stress response” (Kopin 1995:19). Cannon and Selye contributed the concept that when exceeding a critical level, demands upon the body elicit many complex neuroendocrine responses, and that such responses may result in harmful effects (Kopin 1995:19).

More recently, efforts have continued to focus on discovering the exact relationship between stress, physiological reactions, and disease. In 2000, Bjorntorp *et al.* published an article illustrating the connection between hypertension and the metabolic syndrome, suggesting that both are “ ‘disorders of civilization,’ ” and “long-term consequences of the arousal of hypothalamic centres, with background factors in the competitive, complex, and hectic environment of today” (79). They base this conclusion on a study of 284 middle-aged men, in which 25% were found to have elevated cortisol, and determined from reports of perceived mental stress that were recorded before each saliva sampling. This stress-related cortisol elevation only occurred early in the day, when the hypothalamic-pituitary-adrenal (HPA) axis is most active. Bjorntorp *et al.* point out that such a pattern has been observed in animals exposed to chronic stress, and make the case that the 25% of study participants exhibiting that pattern were being subjected to chronic stress as well. They explain that stressors activate centers in the hypothalamic region of the brain, and that three main pathways are activated. One of these pathways is a corticotrophin releasing hormone that stimulates secretion of adrenocorticotrophin from the pituitary and cortisol secretion from the adrenals, in what is considered a “defeat reaction.” Cortisol elevates blood sugar levels. Bjorntorp *et al.* suggest that while

“defense” reactions may lead to hypertension, “defeat” reactions may lead to the metabolic syndrome. They go on to suggest that the metabolic syndrome “...can be derived from stress-related cortisol secretion” (76). The study participants with elevated cortisol levels had an increased mass of intra-abdominal fat, insulin resistance, dyslipidaemia (abnormal levels of lipids in the blood) and elevated blood pressure, all of which Bjorntorp and colleagues consider to be characteristics of the metabolic syndrome. They go on to write, “A position at the low end of a socioeconomic gradient is associated with elevated stress-related cortisol secretion and malfunction of the HPA axis, which is accentuated with time of exposure to socio-economic handicaps (Rosmond and Bjorntorp 1999), and reflects the social inequality of disease” (78).

People with the metabolic syndrome are considered at increased risk for coronary heart disease and diabetes. The metabolic risk factors include abdominal obesity, blood fat disorders (atherogenic dyslipidemia), elevated blood pressure, and insulin resistance or glucose intolerance (American Diabetes Association 2006).

Insulin Resistance Syndrome (IRS) has been linked to stress. Bjorntorp (1997) explains the chain of events, beginning with endocrine perturbations, followed by visceral fat accumulation, insulin resistance, and other risk factors (144). Raikonen et al. also find that psychosocial stress is related to IRS (1996). They suggest that a struggle for control elicits a defense, or “fight or flight” response (Cannon 1929 and Henry and Stephens 1977,) and that loss of control elicits a defeat or “withdrawal reaction” (Selye 1946 and Henry and Stephens 1977) (1996:1537). Exhaustion, along with loss of control and helplessness, may be comparable with the defeat response pattern (Appels 1989) and may reflect a response to chronic stress after a loss of environmental control (Raikonen

et al. 1996:1537). Depression, anxiety, alcohol consumption and smoking are also linked to a defeat reaction (Bjorntorp 1997:144), characterized by a change in activity of the pituitary-adrenocortical axis, metabolic changes and signs of IRS (Raikkonen *et al.* 1996:1537). On the other hand, a struggle for control may be reflected in hostility (Williams 1989), driven by a heightened insistence on unceasingly observing the environment (Raikkonen *et al.* 1996:1537). Chronic activation of the defense reaction makes the metabolism difficult to control, and insulin resistance may result (Julius 1992) (Raikkonen *et al.* 1996:1537).

Insulin resistance is often the beginning of what becomes type 2 diabetes. Insulin is a hormone that tells other cells when to convert glucose into energy. Insulin resistance results when the body is unable to respond to and use the insulin that it makes (American Society on Aging 2005). Type 2 diabetes results when cells become resistant to insulin, often as a person ages. As this process occurs, blood glucose levels rise. The pancreas is less able to produce insulin and eventually halts production altogether (American Society on Aging 2005).

The dialogue on stress, insulin resistance, and the metabolic syndrome highlights the relationship between stress and diabetes. Stress is shown to put people at a higher risk for conditions that make them susceptible to diabetes. Several factors are included in the risks for the metabolic syndrome, such as family history, physical inactivity, aging and hormonal imbalance, suggesting that stress interacts with several other factors that affect health.

Several studies have been conducted on how the stressors diabetics face may affect their glycemic control and compliance. In a study on life stress and social support for

diabetics, Griffith *et al.* found that when faced with high stress levels, patients with little social support had higher glucose levels than those with substantial social support. They suggest that during times of high stress, social support may insulate diabetics from "...the adverse physiologic and behavioral consequences of stress and thereby foster glucose control" (1990:365). In the same vein, a study on the psychosocial predictors of self-care behaviors and glycemic control (Wilson *et al.*) found that measures of health beliefs and social support were the strongest predictors of self-care behavior (1986:614). These findings indicate that even after diagnosis, perceived stress on the part of diabetic patients may affect the severity of their illness and their ability to control it. Without social support, diabetic patients may have more difficulty coping with stress and their health may suffer as a result.

In the medical anthropology literature, where emphasis is generally placed on how health and illness are culturally patterned and shaped, diabetes has been tied to stress on multiple levels. These studies include the relationship between diabetes on the one hand, and socio-historically situated "social suffering" (Rock 2003), nutritional distress (Benyshek *et al.* 2001), and socio-economic stress (Scheder 1988), on the other.

To summarize, the demonstrated physiological linkage between stress and diabetes is well established in a variety of health-related disciplines. In a classic "defeat" response, characterized by a sense of helplessness and exhaustion, cortisol is secreted from the adrenal glands, which, in turn, causes an elevation in blood sugar. In the case of insulin resistant individuals, cells that would normally admit glucose do not, and gradually the pancreas becomes unable to produce a sufficient number of insulin cells. Individuals with insulin resistance may also be more susceptible to the metabolic.

syndrome, a combination of conditions that makes them at increased risk for coronary problems and diabetes.

As participants of this project discussed etiological factors for diabetes, they routinely mentioned stress, *susto*, sadness, and anger. Whether these findings reflect a relatively greater amount or degree of psycho-physiological stressors in their lives, is unknown. What is clear, however, is that susceptibility to diabetes is at minimum exacerbated by stress, and the participants of this study seem keenly aware of this in their emphasis on its culturally coded expression – the idiom of *susto* and other strong emotions. This risk is further exacerbated due to the fact that participants are members of a community that is already at high risk for diabetes, and who possess relatively meager economic resources to prevent or manage the disease. If increased susceptibility to diabetes is due, at least partially, to less support (social and financial), as well as a sense of “defeat,” and/or a sense of “defense” (Henry 1977, 1990, 1988, 1993), these reactions may not provoke pathophysiological metabolic differences in a short-term emergency situation that protects the body (Raikkonen *et al.* 1996), but instead lead to insulin resistance. Participants in this study were either “always living in tension and fear” or had experienced a significant number of tragic emotionally draining situations. The study by Raikkonen and colleagues centered around a healthy population, but they write, “...in a less-fit population, psychosocial factors and IRS risk-factor clustering may be even more closely correlated” (1996:1537). I suggest that many of the participants in the current project were “less fit”, living closer to the edge socially and economically with little or no sense of a social or economic safety net. Participants made it clear to me that they had little or no idea how to access services available to them, or how to “navigate” the

systems in the way that many Americans take for granted. This may add to a sense of helplessness and defeat, and keep many at a chronic level of defense.

Project Results and Culture-Bound Syndromes

As explained in Chapter 2, *susto* and related illnesses have long been considered culture-bound syndromes. In light of the results of this project, I argue that *susto* is not a “culture-bound syndrome.” *Susto*, far from an “exotic” illness experienced by the “other,” is simply a widely shared cultural idiom in Hispanic cultures for the type of emotions usually associated with frightful or anxiety-promoting experiences, and that for many, has come to mean the condition that follows such an experience as well. The “condition” of *susto* is the experience of the emotions that result from such a traumatic experience.

I do not suggest that the term “culture-bound syndrome” should not be used at all, but that it be used with caution. In the case of *susto*, I agree with Simons and Hughes (1993), who suspect that syndromes labeled as “culture-bound” are referred to as such only because they are different from cultural expectations of the Western medical practitioner. I argue that “*susto*” is the translated “fright/scare” and that feeling scared is part of the human condition, in the vein that Kay wrote about *fallen fontanelle*, and how its physiological component has different interpretations in different cultures.

The differentiation between a fright for those individuals who experience *susto* and a fright for people in non-Hispanic American society may be the emphasis that those who believe in *susto* place on social support and cohesion. This aspect of Hispanic culture, which stresses values and the active support of family members and friends, should be

seen as a valuable asset. When *susto* sufferers are having problems living in their realities (e.g. after a child's death or witnessing a tragic event), I posit that identifying their condition as "*susto*" is a culturally condoned way to ask for help from their support system. (Such a conclusion is similar to those reached by Oquendo *et al.* 1999, concerning *ataque de nervios* and stress from an offending agent or strained familial relationship; O'Neill and Selby 1968, concerning *susto* and stress resulting from failure to fulfill sex roles; Houghton *et al.* 1989, concerning *susto* as a socially accepted expression of grief; and Koss-Chioino *et al.* 1993, concerning *embrujado* and overcoming feelings of helplessness). If a sufferer is fortunate enough to have such a support system, friends and family rally around him or her with the understanding that their support is an integral component of the sufferer's recovery. For the Hispanic community that believes in *susto* and uses the word to describe more than just a little scare, *susto* carries no stigma. This differs from mainstream American culture, where an individual suffering with an emotional or mental breakdown may feel a sense of stigma regarding their condition. I argue that the condition of *susto* (the complex of emotions felt by sufferers following a traumatic event) is very real to those who have it, comparable to the breakdowns Americans have after tragedy.

Current project participants reported no sense of stigma when it came to talking about *susto* with friends and family. In the focus group, participants spoke openly with one another about *susto*, and sympathized with one another over stories of tragedy and any lack of support in their lives. Family members who were said to show little regard or respect for their wife and mother were frowned upon by fellow focus group participants, as though such a dearth of support was a tragedy in and of itself. There was a distinct

sense that without family support, that person was at a disadvantage when it came to managing and maintaining her health. Without family support, as one interview participant explained, *susto* remained with the sufferer. In other words, people dealing with *susto* had little chance of recovering without family intervention. Project participants described extremely traumatic events: a car accident that killed a man's nephew, a drunken husband's multiple car accidents and resulting financial fallout, and the shooting of a son and the loss of his leg. The emotions participants felt were what anyone might feel in those situations. After her mother's death, a participant said, "I felt like I was walking in the wind," and "...purely ugly things." Another described the physical results of a *susto*: a bad thing, a cold thing, that caused her hands to become numb, hurt her head and caused tiredness. The emotional and physical results of a *susto* were very real to the participants that experienced them.

Pachter's 1993 article on folk illnesses states that quantitative and qualitative techniques are desirable for reliable and descriptive data. While quantitative data was beyond the scope of this project, from the derived qualitative data we can see that referring to *susto* as a culture-bound syndrome is likely of limited theoretical and practical utility. Medical anthropology should not be seduced by the exotic-ness of such a cross-cultural medical classification, but instead should endeavor to understand the meaning of the term and its effects (i.e., social, psychological and physiological) as a real-life, lived experience of those who recognize it. Additionally, as believers in *susto* connect it to diabetes, anthropologists should be concerned with seeking out any physiological mechanisms that support such a connection. Health patterns noticed by people and included in their belief systems may be more than they seem.

CHAPTER 7

CONCLUSIONS AND RECOMMENDATIONS

The ideologies of the Las Vegas Hispanics studied in this project were complex, with differing views of the ultimate causes of diabetes (e.g. heredity, *coraje*, *susto*, *tristeza*) and with layered meanings of the word *susto* (e.g. event or condition, or both). In comparison with the most recent and applicable literature on *susto*, the current study revealed that *susto* should not be described as a single ideological cause of diabetes, but rather should be considered as a component of a more complex ideological constellation, that also includes other strong “emotions” and “stress”. The effects of this complex may affect the body physiologically through “defense” and “defeat” reactions that cause a heightened release of cortisol into the body, and likely exacerbating features of the metabolic syndrome and diabetes among susceptible individuals.

This linkage is possible when participant factors are considered: many participants were living in the lower end of the socioeconomic spectrum, had experienced many distressful life events and traumas (or felt they were always living with a level of tension), or may have felt a lack of support from family. Emotions such as anger and sadness, along with *susto* and stress, are components of participants’ causal ideologies of diabetes. One participant in particular was aware of the stressful effect her abusive husband’s presence had on her health: she found that the effects of his presence

correlated with elevated blood sugar levels. It is only commonsensical that repeated or constant exposure to elements such as anger, sadness, *susto*, and stress would cause physiological responses such as high blood sugar.

It has been shown that patient views and understandings of their illness may affect their compliance with biomedical recommendations, and may affect the patient's health, quality of life, and life expectancy (Lowe and Freeman 2000). Practitioners with an added understanding and sensitivity to possible differences and nuances in patient ideologies are able to provide better care for their patients, as well as prevent or delay more intensive medical care.

It is in the interest of both Hispanic diabetic patients and their biomedical practitioners for the data from this study to be disseminated to biomedical practitioners in the Las Vegas area. In addition to dissemination of the data, it is the recommendation of this author that practitioners express an acknowledgement of the connection between *susto* and diabetes, as well as the need for social support, and ask their Hispanic patients if they have the help they need to deal with their problems and to get better. Patients in this study were overwhelmingly unlikely to bring a case of *susto* to their doctor's attention. However, acknowledging the relationship between diabetes and *susto* and inquiring about patient support may be interpreted by Hispanic patients as signs that their doctors care about them. They may then be more inclined to speak openly with their doctors about those issues that impede positive health outcomes. This communication between patients and practitioners is crucial. The Hispanic doctors described by participants of making efforts to communicate with patients about their problems were thought of as sympathetic

and provided care needed by patients, going out of their way to express an understanding that patients' personal lives affected their health.

Dissemination of the data from this project will begin with doctors from the Nevada Alliance Against Diabetes, the non-profit organization from which project participants were drawn. Desert Springs Hospital will also be contacted. If dissemination at the hospital is successful, data results may be further disseminated to hospitals across the Las Vegas valley.

APPENDIX

FOCUS GROUP/ETHNOGRAPHIC INTERVIEW QUESTIONS

FOCUS GROUP QUESTIONS

Questioning Route

Opening Questions

1. Please tell us your names and explain to us when you were diagnosed with diabetes.
2. How long do you think you had diabetes before you were diagnosed?

Introductory Questions

1. When did you first feel the symptoms of diabetes?
Prompt→ Did you feel the symptoms of your diabetes two years before you were diagnosed? Or was it after the doctor told you that you have diabetes? When did you start feeling badly?

Key Questions - Symptoms

1. What sorts of things have you all heard doctors, nurses and other people at the clinic say about what the symptoms of diabetes are?
Prompt→ What do they tell you about diabetes symptoms? What sorts of symptoms?
 - a. Are there other symptoms of diabetes that doctors don't usually mention but family members and friends talk about?
Prompt→ When you talk with one another, are there other things that you suspect are symptoms too?

Key Questions - Causes

2. What sorts of things have you all heard doctors, nurses and other people at the clinic say that leads to diabetes?
Prompt→ What do they tell you about that causes diabetes? Things you eat? Or inherit from your parents?
 - a. Are there things besides these that family members, friends and other people in the community say about why people have diabetes?
Prompt→ When you talk with one another, do you ever talk about anything else that you think might cause diabetes?

- b. Are there things that might make someone's diabetes worse that doctors and nurses don't usually talk about?

Prompt→ Do you know of anything that can make your diabetes worse, but your doctors don't talk about it?

Ending Questions

1. Is there anything else you'd like to add?

Follow-Ups

On Diabetes:

1. If people in your family have diabetes, is there more of a chance that you'll have it too? Or is it more a matter of chance?

Prompt→ Can diabetes run in families, or can it happen to anyone?

On Susto:

1. Please tell me more about susto. What is it?
2. What happens to you when you have a susto? Please give me an example.
3. Are there times when you might feel uncomfortable talking about susto? Can you talk about it with anyone?
 - a. When you are with a doctor who is not Latino, are you less likely to tell him about susto?
 - b. What does your doctor think about susto?
 - c. Where is your doctor from?
4. What do other people think when you tell them you have susto?
5. If people in your family have susto, what are the chances that you'll have it too? Does it run in families, or can it happen to anyone?
6. Are there people who are more likely to get susto than others? Why?
 1. Who gets diabetes or high blood sugar due to susto?

Prompt→ Are some people more likely to get diabetes from susto?

ETHNOGRAPHIC INTERVIEW QUESTIONS

Questioning Route

Opening Questions

1. Please tell us your name and explain to us when and where you were diagnosed with diabetes.
2. How long do you think you had diabetes before you were diagnosed?

Key Questions – Symptoms, Diabetes

1. Are there symptoms of diabetes that doctors don't usually mention but family members and friends talk about?
Prompt→ When you talk with one another, are there other things that you suspect are symptoms too?

Key Questions – Causes, Diabetes

1. Are there causes of diabetes that family members, friends and other people in the community talk about but doctors don't?
Prompt→ When you talk with one another, do you ever talk about anything else that you think might cause diabetes?
2. Are there things that might make someone's diabetes worse that doctors and nurses don't usually talk about?
Prompt→ Do you know of anything that can make your diabetes worse, but your doctors don't talk about?

Key Questions – Additional, Diabetes

1. Did you feel seriously depressed after you were diagnosed with diabetes?
2. Does your family support you? Take you to the doctor? Help you to eat well?
3. If people in your family have diabetes, is there more of a chance that you'll have it too, or is it more a matter of chance?
Prompt→ Does diabetes only "run in families," or can it happen to anyone?

Key Questions, Susto:

4. Please tell me about susto. What is it?

5. What happens to you when you have a susto?
6. Are there times when you might feel uncomfortable talking about susto? Can you talk about it with anyone?
 - a. When you are with an American doctor, are you less likely to tell him about susto? Do you think an American doctor would understand susto if you did tell him?
 - b. Have you ever mentioned susto to your doctor?
 - i. (If yes) What did he say about it?
 - ii. (If no) Why not?
 - c. Where is your doctor from?
 - d. How long were doctor visits in your home country?
 - e. Are visits with American doctors the same length as with Latino doctors?
 - f. Did you ever discuss susto with your doctor in your home country?
7. What do you believe "other people" might think if you told them you had susto?
 - a. People from your home country?
 - b. People from the United States?
8. If people in your family have susto, what are the chances that you'll have it too? Does it run in families, or can it happen to anyone?
9. Do you think about susto differently than your parents or your children do?
10. Does your family support you when you have a susto? Do they help you to get better?
11. Are there people who are more likely to get susto than others? Why?
12. There are certain emotions that people sometimes say cause diabetes?
Prompt→ sadness, anger, susto, stress....please tell me your opinion of them.
 - a. Do any/all four influence getting diabetes equally? Is there one that is more likely to cause diabetes? When it comes to getting diabetes, are these factors equally influential as things like heredity and diet?
 - b. Is susto the same as stress or different?
 - c. Do you think having serious emotions and problems in life with relationships and jobs can cause diabetes?
13. Are there any symptoms of susto that are similar or the same as symptoms of diabetes?

Ending Questions

1. Is there anything else you'd like to add?

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