

EXPERIENCES OF LATINOS WITH DIABETES IN THE
CENTRAL SAN JOAQUIN VALLEY

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Thesis Prepared for the Degree of
MASTER OF SCIENCE

UNIVERSITY OF NORTH TEXAS

May 2018

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Cortez, Jacqueline Nicole. *Experiences of Latinos with Diabetes in the Central San Joaquin Valley*. Master of Science (Applied Anthropology), May 2018, 58 pp., 4 tables, references, 40 titles.

Embarking on a quest to uncover the shared experiences of Latinos with diabetes in the Central San Joaquin Valley is the principal issue discussed in this body of work. Diabetes is estimated to become a serious public health problem, with a current estimate of more than 30 million already afflicted. Engaging in participant-observation at a local clinic serving patients in a diabetes education program and semi-structured interviews with Latinos attending the program, this research explores cultural experiences of diabetes. The primary aim of this research is to answer how health education information is accepted and interpreted based on cultural definitions of diabetes to inform diabetes management strategies.

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ACKNOWLEDGEMENTS

I would like to show great appreciation and express a special thanks to my committee chair and advisor, Dr. Beverly Ann Davenport for her continued encouragement and guidance throughout this experience. Dr. Davenport's support and patience guided me through the highs and lows of graduate research. I would like to thank my employer, Central Valley Health Policy Institute for granting me the opportunity to develop into a professional researcher. I also want to thank Dr. Marlene Bengiamin and Dr. John Capitman of Central Valley Health Policy Institute for their mentorship and belief in me. To Dr. Bengiamin who has been a pillar of strength and support, thank you for your faith and welcoming me into the Central Valley Health Policy Institute. A special thanks to Dr. John Capitman who facilitated the introduction between myself and Clinica Sierra Vista.

My sincerest gratitude is extended to the University of North Texas and University of North Texas Health Science Center for the opportunity to develop and prepare for a thrilling career in health research. To the professors and administrators who made my educational experience a success, I thank you. Saludos a Clinica Sierra Vista whose openness and approval to conduct research at their facility made this possible.

Finally, I would like to thank the men and women of the Central San Joaquin Valley who welcomed me into their homes, shared their life histories, and opened their hearts. Your honesty and your experiences are now recorded for others to read, to learn from and continue the fight for healthier lives for Central San Joaquin Valley residents.

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CHAPTER 1

INTRODUCTION

This master's thesis is the product of more than two years' planning and execution, an idea originally conceived in my first year of graduate studies. This study is a presentation of the daily efforts associated with caring for a chronic disease like diabetes. It is also a reflection of my personal journey to discover the histories of persons whom could easily be my mother, sister, father, brother, cousin, or grandparent because being Latino in the Central San Joaquin Valley means we are all connected by this shared place that is rich in history and poor in resources. Embarking on a quest to uncover the shared experiences of Latinos with diabetes in the Central San Joaquin Valley is the principal issue discussed in this body of work. What follows is their stories of shared barriers, fears, victories, and hope.

Study Purpose

The purpose of this study is to examine the chronic disease management strategies of Latinos with diabetes in the Central San Joaquin Valley. Examination of the social and economic circumstances surrounding research participants also contributes to a holistic understanding of the negotiations necessary to implement the adoption of newly acquired health information. I was also curious to learn how health beliefs influence the adoption, acceptance, and practice of health education information. Health beliefs strongly influence the adoption of recommended therapies, but knowledge based on beliefs and informal education, resulting from everyday interactions informs the cultural construction of illness and ultimately informs health behaviors. Acknowledgement of the lay health beliefs as a factor of health-seeking behavior among Latinos

with diabetes could be of benefit to current Diabetes Education Program information being disseminated. Therefore, the following research questions are explored in this paper:

1. How does the patient describe their chronic illness?
2. Are patients comfortable speaking to their provider?
3. Where are patients seeking information about diabetes?
4. How is identity influenced by the sick role?

Research Site

The client for this thesis project is Clinica Sierra Vista (CSV), a large Federally Qualified Health Center (FQHC) in California serving the counties of Fresno, Kern, and Inyo. CSV is dedicated to providing medical, dental, and behavioral health services to residents of the San Joaquin Valley with 31 sites and 2 mobile units capable of serving a diverse patient population. Created in 1971 as a small, rural outpost in Weedpach, California, CSV has grown into one of the largest FQHC systems operating in California. CSV primarily serves patients from low to moderate fixed income households, individuals who are homeless, and migrant families that traverse the San Joaquin Valley (Clinica Sierra Vista, n.d.).

Assuring care is not denied based on a patient's inability to pay, promoting the well-being of its patients, and continuing to serve the community as a non-profit entity are some of the goals CSV aims to promote in its delivery of healthcare. As a product of its success and growth, CSV has had the opportunity to expand beyond the needs of primary care and create health education and health promotion and prevention programs tailored to serve the San Joaquin Valley.

This thesis project concerns itself with the Diabetes Education Program offered to patients at one of Clinica Sierra Vista's Fresno locations. Communication was initiated with the Deputy Chief of Programs of Clinica Sierra Vista in July of 2015. I was introduced to CSV and the former Deputy Chief of Programs, Kevin Hamilton by the Executive Director of the Central Valley Health Policy Institute at California State University, Fresno, Dr. John Capitman. Upon hearing my interest in pursuing a qualitative study of patients with chronic conditions, Mr. Hamilton facilitated an introduction to meet the health educator, Ms. Elena Márquez, for the Diabetes Education Program. An agreement was reached in August of 2015 between the health educator, the Deputy Chief of Programs and me to engage in a qualitative observational study of CSV patients with diabetes. I met once more with Ms. Márquez in November of 2015 to review expectations of the research project and discuss the structure of the program. Upon receiving IRB approval in late 2015, I began observations of the Diabetes Education Program in January 2016.

Study Limitations

This study is the result of data collected from a limited sample of patients attending one program offered by CSV and is not representative of the general population. While the data contained within this study may elucidate the experiences of residents of Fresno, California who are predominantly non-native and Spanish speaking, my research did not result in practical applications for patients of CSV. Limitations were also experienced in the form of practical and logistical application: (1) Attendance. The Diabetes Education Program enrolls 30-40 patients per program cycle, however during the research period attendance in the program ranged from 3-22 patients (excluding family, friends attending for support). (2) Inclusion Criteria. Participants were included in this study if they self-identified as being of Latino background, therefore

patients attending the Diabetes Education Program who were non-Latino were excluded from the study.

Deliverables

Deliverables to Clinica Sierra Vista will include a formal presentation with research findings.

CHAPTER 2

LITERATURE REVIEW

Here I detail influential works found in the literature that contributed to the development of my research. While the works presented in this section do not intend to serve as a compilation of all work contributed to the field of diabetic research and education; it does present referential ideas and studies that contribute to the conceptual underpinning of my research observations. The literature presented contextualizes the Diabetes Education Program I observed into a wider, social perspective.

The chapter is organized to first provide the reader with a cursory understanding of diabetes, a chronic condition affecting millions nationally. Focus is then placed on theoretical frameworks that classifies my research observations into three broad categories of individual, interpersonal and ecologic perspectives. Much of the literary emphasis examines how health information is defined, perceived, and adopted in social contexts. Using works by authors in anthropology, public health and other social sciences, I seek to demonstrate how these frameworks cannot sufficiently explain behavior change independently.

Diabetes: A Chronic Condition

Diabetes is the inability of the body to make or properly absorb the hormone insulin. Insulin aids in digestion of foods into basic sugars and carbohydrates for biological functioning. There are three classifications of diabetes: Type 1, Type 2, and Gestational. Persons diagnosed during childhood or in their early teens are often diagnosed with having Type 1 diabetes. Type 1 is characterized by the pancreas's inability to manufacture insulin. This disease usually begins in childhood; the American Diabetes Association calculates that approximately 5% of adults living

with diabetes are diagnosed as living with Type 1 (American Association, 2011). Expectant mothers who develop diabetes during pregnancy are classified as having gestational diabetes. Affecting nearly 18% of pregnancies in the United States, the onset of gestational diabetes poses an increased risk of the mother developing Type 2 diabetes postpartum (American Association, 2011).

Non-insulin dependent diabetes mellitus (NIDDM), or Type 2 diabetes, affects many across age, race, gender, and class; and is the primary focus of my research. This disease is characterized by the body's resistance to insulin, the primary hormone that carries glucose from the bloodstream into cells where it is used for the production of energy in the body. Over time, the pancreas may stop insulin production altogether. Insulin resistance causes individuals with diagnosed Type 2 diabetes to experience elevated levels of glucose, a simple sugar, in their blood. The long-term consequences of elevated glucose are severe: cardiovascular disease and blindness are the major risks. Type 2 is the most common form of diabetes and accounts for an estimated 95% of diagnosed cases (American Association, 2011). Diabetes is listed as the seventh leading cause of death for the year 2015; with 30.3 million people, or 9.4% of the U.S. population living with diabetes during the same year (CDC, 2017). The Centers for Disease Control and Prevention estimate in their 2017 statistical report that 1.5 million Americans were newly diagnosed as of 2015. An additional 7.2 million people or 23.8% of adults 18 years of age or older are estimated to be undiagnosed (CDC, 2017). Reflecting on these estimates, it is clear that diabetes is a pressing public health concern.

In the state of California, many are affected by diabetes. The California Department of Public Health cites that 2.3 million individuals are living with the disease, those with diagnosed Type 2 diabetes account for 1.9 million of the total state estimate. Diabetes is listed as the

seventh leading cause of death in the state of California for the year 2013. According to recent data from the California Health Interview Survey (CHIS) Neighborhood Edition, trends for Fresno County, depicts a rather vivid portrait of the population characteristics which contribute to poorer health outcomes (Table 1). Although the Fresno County prevalence for diabetes is lower than to the statewide statistic, other factors that affect health outcomes like education level and income synergistically amplify barriers to living with a chronic disease. In addition, the count is based on “ever diagnosed with diabetes,” and given the lack of access to care, it may underrepresent the actual prevalence of people with diabetes in Fresno County.

Table 1

Demographics: California vs. Fresno County (2014)

Indicator^a	California^b (%)	Fresno County^c (%)
Ever Diagnosed: Diabetes	8.8*	8.00**
Hispanic or Latino	33.9	46.4
Born U.S. citizen	66.1	71.1
Non-Citizen	17.2	18.1
Less than High School	18	25.5
Living in Poverty ^d	14.1	22.0

Note. *a* Adults 18+. *b* Population 28,539,200. *c* Population 669,800. *d* FPL = Federal Poverty Level. U.S. Department of Health & Human Services defines FPL as \$12,140 for an individual and \$25,100 for a family of four as of January 23, 2018. *(8.2-9.3, 95 CI); **(5.4-10.6, 95 CI). *Source.* AskCHIS Neighborhood Edition

The statistical snapshot of Fresno County contrasted against the state of California demonstrates that there is a concentrated density of fewer adults with formal education (25.5% compared to 18%) with nearly one third more experiencing poverty in Fresno County compared to the California average (22.0% compared to 14.1%). Research on the social determinants of health has indicated that these factors which are beyond individual control such as environmental, social, and political pressures greatly increase an individual’s risk of developing

a chronic disease like diabetes as well as exacerbate health outcomes (Heiman and Artiga 2016; Marmot 2005; Walker et al. 2014). Therefore, educational attainment, transportation and the built environment, access to health care, housing conditions, income stability, and many other factors are greatly influenced by the individual's environment and access to resources (Remington, Brownson, Wegner 2010).

Considering that diabetes is much more prevalent among Latinos compared to non-Hispanic whites, 12.1 % and 7.4% respectively (CDC 2017), the unfortunate reality is that many adults living in the Central San Joaquin Valley will likely develop diabetes during their lifetime. Fresno County has a much higher population of adults identifying as Hispanic or Latino compared to the rest of California; one can reasonably conclude that individuals currently living with diabetes are doing so with fewer resources (poverty, education, access to healthcare) and attempting to manage complications arising from diabetes with limited capacity to overcome social and environmental factors. These conclusions are further verified with a snapshot report of health, education, and earnings of Central San Joaquin Valley residents (Lewis and Burd-Sharps 2014). According to this report, stress concerning employment, affordable and reliable childcare, experiences with segregated housing, neighborhood safety, and lack of financial resources strain families who are unable to adequately exist on their median income earnings. When contextualized within the social determinants of health, one can conclude the population of Fresno County and greater Central San Joaquin Valley is a product of too few resources and opportunities for residents to live healthy, prosperous lives.

Therefore, it is crucial to examine these factors and place them within the context of Fresno residents living in reduced circumstances to fully appreciate the lived experience of managing a chronic condition like diabetes. The section titled "Intrapersonal Considerations"

conveys the reality of the twenty participants kind enough to allow me to glimpse into their daily struggles and triumphs. While the analysis presented below cannot be generalized to the whole of Latinos living in Fresno County, it does serve to enlighten the reader of the daily experiences of the few courageous folks who invited me into their homes and voiced their stories.

Intrapersonal Considerations

In this section I introduce some of the tenets used in the field of public health, specifically as they apply to the areas of health education and health promotion. Theories that are well-known and discussed include the health belief model, the theory of reasoned action, and theory of planned behavior. These theories of behavior change aid public health interventions, such as health education and health promotion efforts by explaining how change occurs. Intrapersonal characteristics are those factors which, "...influence behavior, such as knowledge, attitudes, beliefs, and personality traits" (McKenzie, Neiger, and Thackeray 2013, 167). The public health theories I discuss fall within the realm of describing these intrapersonal characteristics. These important frameworks are pivotal to understanding the application of disease management strategies.

These three behavior change theories (health belief model, theory of reasoned action, and theory of planned behavior) have been selected for two purposes. First, each theory contributes to an understanding of behavior change according to varying motivations or beliefs of efficacy—which is important for understanding for the delivery of health promotion and education; such as the CSV Diabetes Education Program. Secondly, these theories are instrumental to public health efforts, particularly in health education, with the addition of an anthropological lens, these

behavior change theories could be applied in such a way as to further succeed in improving the health of patient with diabetes.

Health Belief Model

Certainly, the most popular and widely used theory in the field of health education and health promotion is the health belief model (Rimer and Glanz 2005). This model was developed in the 1950s by social psychologists at the United States Public Health Service seeking to understand why screening rates for tuberculosis were unsuccessful (Janz and Becker 1984). The basic principle of the health belief model according to Hayden (2014) is that, "...health behavior is determined by personal beliefs or perceptions about a disease and the strategies available to decrease its occurrence" (2014, 31). There are four constructs to be aware of when applying the health belief model. These include: 1) perceived seriousness, 2) perceived susceptibility, 3) perceived benefits, and 4) perceived barriers (Hayden 2014). The amalgamation of these four constructs is what informs an individual's actions with respect to a particular disease or ailment.

A summary these four constructs are provided within the text by Hayden (2014):

- 1) Perceived severity of a disease is most often informed by medical knowledge; although it can also include one's beliefs about the difficulty said disease places on the quality of life.
- 2) Perceived susceptibility is the direct relationship between risk and engaging in behavior to reduce risk. The health belief model also argues that the higher at risk an individual is for disease, the more likely the individual will act to prevent its onset.
- 3) Perceived benefits relate behavior with risk of developing a disease. Should an individual believe engaging in a behavior will minimize risk, they are more likely to adopt the behavior.
- 4) Perceived barriers are the factors an individual has identified as preventing them from adopting a new behavior. These barriers, whatever they may be, are cited as being the, "most significant in determining behavior change" (Hayden 2014, 33).

Importantly, these constructs are also affected by additional factors unique to each individual such as education level, cultural background, skills, and others (Hayden 2014). Described as modifying variables, the health belief model also considers what it terms ‘cues to action’ and ‘self-efficacy.’ Cues to action are motivators for behavior change, and according to Janz and Becker (1984), are either external (social) or internal (symptoms) motivations. Self-efficacy is defined by Albert Bandura (1977) as, “the conviction that one can successfully execute the behavior required to produce the outcomes” (1977, 193). Bandura also posits that self-efficacy explains how people’s behavior change moves beyond the mechanistic conditioning process of behaviorism and gives individuals a role in their own process of change, or simply rephrased, it gives an individual the perception of agency to enact change.

Theory of Reasoned Action

The theory of reasoned action (TRA) was developed as a model for explaining human behavior change, in particular health behavior and an individual’s attitude toward behavior (McKenzie, Neiger, and Thackeray 2013). Citing work by Martin Fishbein and Icek Ajzen (1975), McKenzie and colleagues (2013) review key features of this theory —the fundamental framework posits that attitude, belief, intention, and behavior contribute to behavior change. Ajzen (2012) wonderfully summarizes Fishbein’s theory of reasoned action (Fishbein 1967). The motivation for behavior change according to TRA is the individual’s intention towards change based on beliefs, particularly beliefs informed by subjective norms; much like the HBM which posits behavior change is motivated by an individual’s personal beliefs about their susceptibility to a disease or other health risk.

An attitude is formed when an individual assesses an object based on subjective beliefs already in their possession. These subjective values placed on the object can be positive or negative, and ultimately is associated with the object (Ajzen 2012). For example, if a participant of a health education course believes strongly that taking medications as prescribed by their doctor will help stabilize blood glucose levels, this participant will be more inclined to have a positive attitude towards prescription medications. Said another way, what I'm saying is that this participant would already have this belief before they participated in the health education program in the first place and the program would merely reinforce their existing ideas.

A subjective norm describes the individual's perceived social pressure to participate or refrain from a behavior. These normative beliefs are amassed by multiple interactions an individual has within their social spheres; family, friends, co-workers, medical professionals, and others can influence the subjective beliefs of an individual and combine to form a subjective norm according to the TRA (Ajzen 2012). These subjective norms are also influenced by the strength of each belief with its associated broadcaster (i.e. family member, co-worker, medical doctor). That is to say, the more motivated an individual is to meet the expectations of broadcasters, the stronger the desire to engage in behavior change. The desire for acceptance and inclusion is a strong modifying factor that is calculated into the equation of behavior change (McKenzie, Neiger, and Thackeray 2013). Lastly, subjective norms and attitudes can only be catalysts for behavior change if the individual is ready to make such changes. This condition of the TRA, much like the HBM, requires that an individual be aware of the health risks and be motivated by their belief to accomplish and to enact behavior change(s) to prevent the onset of disease or illness. Intention of behavior change is, "...a joint function of a favorable or

unfavorable attitude toward the behavior and of a subjective norm that encourages or discourages its performance...” (Ajzen 2012, 17).

Therefore, it is the interaction of these modifying factors: intent, subjective norms, attitudes, and beliefs that contribute to an understanding for behavior change motivations among individuals. Placing TRA into the context of the health education course I observed in Fresno County, it is evident that this model is appropriate for describing the interaction of these factors. Patients of CSV enter the conference room with previously held beliefs and attitudes about their disease(s), which in turn affect how the health education information presented will be received and interpreted. If this newly amassed health information is interpreted and accepted positively, a new subjective norm will be formed. I caution the reader to note the conditions required for these behavior changes to actually take place.

Theory of Planned Behavior

Created and built as an expansion of theory of reasoned action, the theory of planned behavior (TPB) adds to its framework the construct of perceived behavioral control. Ajzen (2012) states that while developing the TRA to only include behaviors under willful control, “...it soon became apparent that this formulation imposed too severe a limitation on a theory meant to predict and explain all kinds of socially significant behavior” (2012, 17). Therefore, to include a framework to aid in contextualizing human behaviors that are perceived to be out of the individual’s control (loosely or strongly), the TPB was created to supplement this limitation.

According to TPB, perceived behavioral control, “...refers to the perceived ease or difficulty of performing the behavior and is assumed to reflect past experience as well as anticipated impediments and obstacles” (McKenzie, Neiger, and Thackeray 2013, 172).

Therefore, the proposed TPB model takes into account the level of control an individual perceives to possess. When defined within the bounds of the TPB, perceived behavioral control is assumed to be derivative of, "...readily accessible beliefs...about resources and obstacles that can facilitate or interfere with performance of a given behavior" (Ajzen 2012, 18). For example, a patient attending the CSV Diabetes Education Program will find behavior change more difficult to accomplish if income prevents purchasing the necessary ingredients to make the appropriate diet changes; this real-life obstacle can influence the patient's overall lack of perceived behavioral control. This lack of control also effects a patient's behavior and attitude towards an intended behavior change.

The TPB, as explained by Ajzen (2012), constructs its guiding principles about behavior in three categories: behavioral, normative, and control beliefs. Behavioral beliefs are those considered by an individual with respect to likely outcomes and evaluations of the behavior; these can be positive or negative. Normative beliefs are generally occupied with the expectations and motivations to comply with actions deemed valuable by important referents; or stated another way, the perceived social pressure or subjective norm that result from these expectations. Finally, control beliefs are primarily concerned with the identified impediments or enabling factors and the level of control over these factors by the individual. Further, the TPB assumes that an individual's intent is positively associated with stronger, positive attitudes and subjective norms. Therefore, it is presumed that an individual will seize the opportunity to enact behavior change as soon as it is presented; facilitated by the individual's perceived control (Ajzen 2012).

Interpersonal Considerations

The discussion that follows reviews select theoretical frameworks that turns attention

towards interpersonal concepts pertaining to health. The tenet of theories used to explain interpersonal characteristics, "...assume individuals exist within, and are influenced by, a social environment. The opinions, thoughts, behavior, advice, and support of the people surrounding an individual influence his or her feelings and behavior, and the individual has a reciprocal effect on those people" (Rimer and Glanz 2005, 19). Discussion pertaining to explanatory models, Funds of Knowledge, and works from the field of anthropology showcase the cultural resources available to the masses that is not always included in clinical decision-making.

Explanatory Models

The construction of what diabetes *is*, ideas and beliefs surrounding this disease are culturally based and contribute to the explanatory model of disease that then determines appropriate behavior and treatments. Therefore, it is critical to examine these explanatory models of diabetes to learn how this disease is understood by individuals within the community and how to better create access and programs that will enhance the knowledge being produced between patient and the clinical setting.

Arthur Kleinman, Leon Eisenberg, and Byron Good (1978) have collaborated on important and seminal work to convey the cultural construction of health and illness. In, "Culture, Illness, Care: Clinical Lessons from Anthropologic and Cross-Cultural Research" (1978) a clear distinction is made between *disease* and *illness* that subsequently characterizes actor roles, requirements, actions and expectations. The distinction between the two lies in the physical and biological versus the social and psychological. Disease is therefore characterized as a, "...malfunctioning or maladaptation of biologic or psychophysiologic processes in the

individual; whereas illness represents personal, interpersonal, and cultural reactions to disease or discomfort” (1978, 252).

The construction of *illness* is the earliest function of the healing process. Construction begins with the placement of symptoms into categories based on perceptions and expressions that are individual and social responses. Kleinman (1978) also delineates between *illness* and *disease*, a dichotomous element studied in medical anthropology, *disease* refers to a malfunctioning of biological and/or psychological processes where *illness* is viewed as a psychosocial experience and meaning of perceived disease.

Patient perspectives remain an important research topic in medical anthropology. Mendenhall et. al (2010) examine the “idioms of distress” narrated by Mexican Americans as they sought diabetes care at a public Chicago hospital. What was discovered were the manifestations of social/psychological/emotional/structural violence representing the distress and collective “explanatory models” for the onset of diabetes. This article further demonstrates the need for lines of communication to be opened between medical and clinical staff with patients regarding illness. Voiced through the narratives of the participants is the need to not only aid diabetes management through clinical avenues (medications, nutrition counseling, etc.); there also exists a need to provide social and mental health services to low-income, underserved populations to supplement clinical management therapies.

Incorporating diabetes narratives and experiences into chronicity discourse as an idiom of distress enables patients and health researchers the ability to pursue further states of being than are currently explored. A new level of understanding can be obtained by contextualizing diabetes as an idiom of distress providing patients an outlet for communicating social frustration and distress while also validating these stressors in the medical literature associated with diagnosis.

The political and socioeconomic conditions that Latinos must operate in are also descriptive of the daily living and coping mechanisms that must be evaluated to complete the holistic nature of the anthropology that is diabetes. Structures at play, from the social class structures, the roles of authority that are produced in the work environment; the social environment and so on can further contribute to a deeper level comprehension of Latinos with diabetes.

Creating an understanding of Latino experiences with diabetes, their explanatory models and beliefs about how one becomes diabetic, the boundaries that are faced in reaching access to care, goods, and services will inform the research aims and direct new pathways. Learning the explanatory models will be very fruitful for developing new theory as much of the literature already points to supernatural and traditional ‘folk’ conceptualizations of diabetes, particularly *susto*. This culture bound *symbolology* can create a very rich interpretation of diabetes that is currently unrecognized in biomedical frameworks.

Susan C. Weller and colleagues (1999) address this very focus. In “Latino Beliefs about Diabetes”, Weller et al., set out to discover the degree of similarity of explanatory models, beliefs and knowledge, among four different groups of Latinos. Respondents from Connecticut (Puerto Ricans), Texas (Mexican-American), Mexico, and Guatemala were sampled to learn of the local diabetes “attitudes”. Themes were focused on the causes, symptoms, and treatment methods. Researchers utilized the Cultural Consensus Model to analyze and measure participant responses and similarity. This theoretical framework enables regional explanatory models to be compared between and across each population group regarding beliefs and appropriate behaviors and treatments. Explanatory models and beliefs were found to be consistent across all four sites,

leading the researchers to conclude that cultural understandings could be easily translated for clinical purposes (health education programs, doctor/patient interactions, etc.).

Further research has been undertaken to assess levels of health literacy with recognition of diabetes symptoms and its effects on health-seeking behaviors. Coffman and associates examined these topics in their publication, “Diabetes Symptoms, Health Literacy, and Health Care Use in Adult Latinos with Diabetes Risk Factors” (2012). Researchers attempted to create a descriptive and correlational depiction that was informed by the Symptom Interpretation Model. This framework allows measurement of the individual’s reaction(s), experiences and health literacy to determine how the explanatory model is used to gauge symptom severity, interpretation of symptoms and subsequent actions or behaviors.

Findings show poor understandings of diabetes and subsequent symptoms are reflected in management practices. Symptoms are likely to go unrecognized or considered mild; many participants lacked health insurance and resorted to emergency services for treatment. Most of research participants tended to be female, of middle age (44 median age), uninsured and recently immigrated (<10 years in country). As demonstrated by the work of Weller, et al. (1999), diabetes symptoms tended to be constructed out of personal and cultural interpretations. Past experiences tend to inform measures taken to treat and manage diabetes. Even though an overwhelming majority of participants were diagnosed with diabetes, many had not received or attended diabetes education counseling. Further, a high percentage of diagnosed diabetics in the study had the disease for less than five years, contributing to low health literacy.

The duality of being chronically ill and having immigration status has also been worked into the explanatory model, construction and understanding of Latino diabetes. Mendenhall et al. (2010) have shown case histories of what it’s like being vulnerable as an undocumented

immigrant in a host country where the medical system also makes it difficult to receive medical care. Chronic disease is not a biological or physiological experience, rather it becomes part of the individual and restructures perceptions of self; the diabetes narratives presented within the pages of *Speaking through Diabetes: Rethinking the Significance of Lay Discourses on Diabetes* proves that people tell their illness narrative to make sense of their experiences for themselves and communicating these experiences to others.

Funds of Knowledge

Anthropologists Carlos Vélez-Ibáñez and James Greenberg (1995) used the term “funds of knowledge” to describe gathered household knowledge from daily lived experiences, educational or workplace environments, and activities. According to the works of Vélez-Ibáñez, families possess specialized facets of knowledge and skills that is through experience or within the context of social networks that contributes to the resourcefulness of the family unit. Information is also a currency that can be used to assist other family members or acquaintances in the social network that can be exchanged reciprocally or as an exchange bartering system (1992, 1995).

Specifically discussing the education of young Latino groups in the United States, Vélez-Ibáñez (1995) reports funds of knowledge are a yet unrecognized resource, “...in creating intervention programs that enhance the learning relationship between educational institutions and the constituent households they serve” (1995, 253-4). While originally written in terms of formal education systems, it is not so implausible to adopt his sentiments in the application of health education courses or programs. Chronicling an impoverished Mexican population in the southwest United States, Vélez-Ibáñez and Greenberg (1995) argue that while families may be

economically burdened their accumulation of knowledge resulting from occupations held in various industries or domestic skills implemented to reduce household costs has allowed these families and communities to become incredibly resourceful. While formal education is at times elusive for some members living in Mexican households, the funds of knowledge framework serves to draw focus to the resiliency, potential, and wealth of knowledge for learning that these families and communities have. A message that would prove to serve these families as they engage in health education programs and interventions.

Ecological Considerations

Socio-ecological perspectives posit that human behavior is influenced and affected by multiple contexts simultaneously (McKenzie, Neiger, and Thackeray 2013). Further detailed by Rimer and Glanz (2005), ecological perspectives in health education, "...highlights people's interactions with their physical and socio-cultural environments" (2005, 10). According to this school of thought, human behavior is influenced by 'multiple levels of influence' and 'social environments reciprocally affects individual behavior' (2005, 10). The levels of influence are classified as: 1) intrapersonal 2) interpersonal 3) institutional/organizational 4) community and 5) public policy. I have detailed at length the first two levels previously in this chapter, this section emphasizes the latter three levels; particularly as they concern diabetes outcomes.

Community level influences are associated in public health as physical spaces, organizations, and networks that affect health outcomes. The field of anthropology also takes into account the organizational impacts on health. Claudia Chaufan (2004) presents a thorough literature review evaluating the social and political framing of the diabetes epidemic claiming health care policy and health care practices have hindered the appropriate treatment for the most

disadvantaged and ‘high-risk’ patients in the United States in, “Sugar Blues: A Social Anatomy of the Diabetes Epidemic in the United States”. Chaufan gives strong testimony for the structural violence and disparities experienced by diabetes patients who are also socially and ethnically disenfranchised. Calling for action by framing discourse and public awareness to enact change at the structural level, policy will reshape how diabetes care is managed and approached. Chaufan argues that changing the landscape by which structural violence is played out, through policy, can make a positive difference and begin to improve the quality of care experienced by those who are currently unavailable to it.

When evaluating the public policy implications of health and disease, an anthropologic framework is a useful lens for examining such factors. Critical Medical Anthropology (CMA) draws attention to the macro-level processes that affect the daily lives of the human population. Use of a CMA framework in anthropological literature and methods have produced some great literary works that indicate that these hegemonic powers and policies are negatively impacting certain populations in every corner of the planet and show that interconnected nature of human thought and action. An advantage to this approach is the recognition that there are sources of disparity and inequality that can be changed or transformed so as to ameliorate the pain and suffering of many marginalized communities. The Political Economic framework that influences many ethnographies and researchers in CMA and anthropology can show that funding dollars may be wiser spent on eliminating the structural barriers like access to clean water and reliable food sources.

Diabetes: Other Anthropological Perspectives

The discipline of anthropology has much to offer for the benefit of public health. The

increasing transdisciplinary collaborations between the two disciplines provide substantial evidence for the merit each field contributes to the identification and amelioration of health issues. The presence of anthropology in public health efforts can further the advancement of health initiatives, inform policy and eradicate barriers that are currently preventing efficient allocation of funds and program directives. Anthropology can be used to assist in further understanding how diabetes creates an alternate reality for Latinos in the United States, in much the same way I implemented anthropological perspectives in capturing lived experiences in Fresno, California. Uses of CMA provide a framework from which to assess the larger socio-political environments that shape the illness experience such as the built environment, accessibility to food, medical and social services. Influential works by Arthur Kleinman and Hans Baer are also presented to illustrate the cultural construction of illness and disease could provide further knowledge about the practices of medical pluralism as related to diabetes treatment and health-seeking behaviors among Latinos.

Cultural relativism is a key tenet of anthropology that assumes beliefs, values, and norms practiced in each society are logical within their respective contexts. The cultural environment that one is raised in has influence on the beliefs and attitudes about health and illness, these must be understood in context should interventions, programs, and relief entities from outside the community be successful. Robert Hahn and Marcia Inhorn index an interesting point regarding cultural relativism and its function within the biomedical system, “A question of relativism critical to the role of anthropology when working with public health is whether the predominant medical system of Western civilization, *biomedicine*, is superior entirely, in general, or in specific aspects –to the *ethnomedicines*, or indigenous health systems of non-Western societies.” (Han and Inhorn 2005, 9).

This is an essential ideology that must be addressed in public health and anthropology discourse. Recognizing biomedicine as *ethnomedicine*, a culturally bound framework for understanding and interpreting health and illness could strip away the tensions and frayed connections that occur at cultural intersections. Hahn and Inhorn further detail the disconnect that is often made as public health interventions have traditionally operated under assumptions that communities were simply in need of information and knowledge, “empty vessels” to be filled and accepting of health promotion efforts (Hahn and Inhorn 2009, 10). This model of intervention has not produced very efficacious programs and use of local contextual knowledge demonstrated by anthropology can improve program outcomes.

Sara H. Cody and colleagues provide an illustrative example of utilizing information about local health belief models to inform improved intervention strategies in, “Knowing Pneumonia: Mothers, Doctors, and Sick Children in Pakistan” (1997). The research aim of this study was to improve diagnosis and treatment for acute respiratory infection (ARI) among third world nations by the World Health Organization (WHO); which stressed breathing rate assessments as its method of diagnosis. Through discussions, health seeking practices and preferences revealed that WHO clinical training may not be as effective in reaching target groups or match cultural beliefs of Pakistani doctors and patients. Researchers uncovered the humoral ‘hot/cold’ explanatory models used to assess and determine the presence of illness and pneumonia; which were unaccounted for in the WHO programs administered by local hospitals. Cody and colleagues also discovered that home remedies (teas, ointments, wraps, etc.) were used before proceeding to a local bazaar practitioner or clinical doctor. Rejection of biomedical sites and explanations for ARI in favor of culturally produced humoral models reveal that recognition of signs and symptoms may differ from Western prescribed etiology.

The information learned and presented by Cody (1997) was made possible by use of anthropologic methods and theory to produce relevant qualitative information about communities under research. Anthropology can provide much richer descriptions and provide detailed information that may go missed and undiscovered in research undertaken by other disciplines that focus more on quantitative data collection. Like the Cody publication mentioned above, anthropologic fieldwork in public health settings focus on cultural explanations, belief models and illness narratives to gain a holistic interpretation of the phenomena that is occurring locally.

The ethnographic data collected during the course of this research project reflects the pertinence of the public health theories of change presented earlier. The Health Belief Model, TRA, and TPB as implemented into public health interventions, health education and prevention efforts are not holistically effective at aiding populations if consideration of individual and cultural behavior are unaccounted for. Behavior and beliefs held by the individual and group are complex intersections to navigate. As the details of the research participants' narratives show that behavior cannot be considered outside of a cultural and social context. Therefore, it is incumbent upon designers of health intervention to consider the capability of those all-too-often overlooked individuals overlooked due to lack of education or income.

CHAPTER 3

METHODOLOGY

Presented here is a detailed account of the process undertaken to engage in research with human subjects, secure a research site, observe and interview participants with the intention of learning about diabetes in Fresno County.

Ethical Research Considerations

The Institutional Review Board (IRB) at the University of North Texas reviewed and approved this research; ethical clearance and research permission was granted in December 2015. Research materials including English and Spanish language informed consent, interview schedule, and research guide was submitted and approved. In accordance with the study involving private community members, anthropology and public health research assures privacy and confidentiality to research participants. To assure the privacy and anonymity of research participants, pseudonyms have been assigned and any personal or identifying information has been generalized or obscured. Prior to the commencement of an interview, I reviewed the informed consent document pausing throughout to provide further clarification of participant rights and to explain the intentions of the research study. Participants signed and received a copy of the informed consent with contact information should questions arise at a point after the scheduled interview. To reduce ethical concerns concerning research with minors, only individuals eighteen years of age or older were considered for inclusion into this research project.

Preliminary Investigation

Prior to beginning my field observations of the health education courses offered at CSV, I met in late November of 2015 with the health educator, Ms. Elena Márquez, at one of her office locations in Fresno, California. The purpose of this meeting was to introduce my research plans to her. Our discussion during this meeting included a brief overview of my research intentions: to learn the lay health beliefs of Latino patients and how these beliefs influence the adoption of health information. I also explained during this meeting that I also intended to learn the established practices, structure, and goals of the health education course. Discussion during this late November meeting yielded some insights into Ms. Márquez's experiences with patients living with diabetes. From this conversation, I gleaned preliminary ideas concerning health-seeking behavior, beliefs, and knowledge about the patient population.

Study Site

CSV is a Federally Qualified Health Center (FQHC) with 77 sites located across 3 California counties: Fresno, Kern, and Inyo. The patient population served by CSV are primarily individuals with a low to moderate income who qualify for public insurance such as Medicare or Medi-Cal, and/or racial minorities. For patients presenting with chronic morbidities CSV offers health education classes hosted by a trained health educator. The course is intended for persons with chronic diseases and the consequences that arise from those diseases. The course is offered to patients with diabetes, hypertension, hyperlipidemia, or are in need of weight management. Health education is presented as a six-hour course broken into two-hour classes taken for three consecutive weeks. It's available in English or Spanish. Patients are enrolled via their providers. The class I observed took place in southwest Fresno at the Elm Dental Center inside a large

conference room on the premises. This particular class location was recommended by former CSV Deputy Chief of Programs, Kevin Hamilton, as it would allow the researcher ease of access to its patient population with the intended study focus, Latinos with diabetes.

Armed with over 14 years of CSV experience and a chalk board, Ms. Elena Márquez sets out to educate patients entering the conference room. The front of the room is adorned with hands-on learning aids like food labels of diabetic friendly items (cooking oils, dairy products, beverages, snacks, and other pantry items). There are also on display test-tubes filled with various volumes to indicate amounts of oils, fats, sugars found in common food items, and other health props to help patients visualize how food impacts the body. In her delivery of health information and interacting with patients in conversation during class, Ms. Márquez attempts to treat each patient equally so that all have an opportunity to learn and access information.

Once patients attend the three required courses, they are eligible to schedule individual consultations with Ms. Márquez to receive a tailored health plan; including nutritional recommendations and regular monitoring of their chronic condition (HbA1c, cholesterol). Patients can schedule consultations on Fridays. Consultation appointments take place at one of CSV's downtown Fresno facilities or on Thursdays in the hours between the scheduled health education class sessions. Due to HIPPA (Health Insurance Portability and Accountability Act) regulations, I could not attend these consultations.

Data Collection

Participant observation, is defined by H. Russell Bernard as the "...the foundation of cultural anthropology" and is a strategic method that allows the researcher to, "...collect life histories, attend rituals, and talk to people about sensitive topics" (2009, 256, 258). Starting in

January 2016, I attended weekly rituals known as a health education course. The strangers whom I met there invited me into their homes to discuss sensitive topics about their lives, their worries, and their fears. Participant-observation of the class was essential for developing rapport with Ms. Márquez, enrolled participants and clinical staff at the study site. In addition, I was able to gain familiarity with the topics and lessons presented during the health education course.

Observations made about the health education course and its participants informed future literature searches. The life histories I have collected deal with the burdens of managing diabetes,

During the study observation period, I attended the health education course scheduled weekly on Thursdays. English language courses were scheduled in the mornings and Spanish language classes were held in the evenings. I was present for both English and Spanish language sessions between the months of January and May 2016. Each class is two hours long. Ideally, enrollees come to three consecutive sessions over the course of a three-week period. Class one introduces patients to basic concepts in diabetes, physiology, the effects of carbohydrates, proteins and fats on the body, cholesterol, hypertension, and weight loss. Class two involves meal planning and nutrition information; class three ends with eye and skin care, hygiene best practices, and how to keep insurance coverage up to date. I recorded my observations of the course materials, patient behavior, and interactions between patients and Ms. Márquez.

Recruitment

The target sample population (n=30) was initially scheduled to include (n=15) Latino/a patients with diabetes and (n=15) Latino/a participants without diabetes. Time constraints limited the final sample population (n=20) and included (n=16) participants with diabetes and (n=4) participants without diabetes (Table 2). Basis for inclusion was also contingent upon participants

completing the three-session course offered by CSV (Table 3). I introduced myself to the enrolled patients at the start of each new course cycle; information about my personal and educational background was provided as well as my research study goals to explain my presence during the courses.

Potential participants were approached before the start of class session 3. This was a good time because the class size enabled individual, face-to-face conversation and introduction. Recruitment protocol during larger class sizes consisted of an announcement I made to the assembled group about the research project and its inclusion criteria before the class instruction began. Interested parties were given a sign-up sheet where contact information was provided allowing me to inquire about participation at a later date. Recruitment was conducted in both the English and Spanish courses.

Table 2

Research Participants (N = 20)

	English Speaking	Spanish Speaking
With Diabetes	2	14
Without Diabetes	2	2

Table 3

Diabetes Education Program Schedule

Class 1	2 hours	Diabetes education, physiology, chronic diseases
Class 2	2 hours	Nutrition & meal planning
Class 3	2 hours	Neuropathy, eye and skin care, hygiene

Interviews

When it came time to talk with patients of CSV about their experiences of living with diabetes, I implemented a combination of unstructured and semi-structured interviewing techniques as described by H. Russell Bernard (2009). Semi-structured interviewing relies on the use of an interview schedule, questions and topics that I as the researcher, would like to discuss with each participant. Given that each individual has a unique life history and events they deem significant when sharing their story, semi-structured interviewing allowed the participant and myself the freedom to explore these open-ended avenues while maintaining ties to the general script of topics (Bernard, 2009).

Interviews were conducted at the participant's home with an average interview length of 1 hour; interviews ranged in length from 45 minutes to 2 hours. In cases where the participants being interviewed were significantly involved or related (partners, spouses, or family members), the interview was conducted with all participants (2 or 3 persons) engaging with me at once. In order to ensure full participation, I asked each participant the scheduled interview questions and recorded their responses. This technique also served to uncover some valuable topics and comments in the course of the interview which allowed me to probe for further clarification, enhancing the qualitative data being compiled.

The schedule of interview questions was compiled based on literature relating to Latinos with diabetes as well as unstructured interviews held during the observations of the health education course. According to Bernard (2009), unstructured interviewing can help researchers discover and learn about the, "...lived experience of fellow human beings" (2009, 158); it is also a great rapport building technique. As I attended the weekly health education course, informal

conversations between patients, patients and Ms. Márquez, or between myself and patients, stimulated new veins of thought and interview questioning.

Data Analysis

Interviews were transcribed using Audacity software version 2.3.1.0 and preserved in the original spoken language of the interview. Transcription was completed with the assistance of a paid assistant and with the help of a volunteer. The interview process yielded emergent themes which were confirmed during the coding and analysis process using methods of grounded theory. Grounded Theory defined by Anselm L. Strauss (2003), is the process of analyzing data “intensively” and “systematically” to produce a “well-constructed theory” (2003, 22). Strauss further comments that the emphasis of grounded theory is, “...organizing many ideas which have emerged from analysis of the data” (2003, 23).

Kathy Charmaz (2006) argues one of the positive benefits of grounded theory is the emergence of generality. By generality, Charmaz proposes that the researcher is less likely to place data forcefully into, “...favorite analytic categories”; thus effectively ‘minimizing the introduction of preconceived assumptions or biases into the analysis’ (2006, 181)). Although I did not implement strict grounded theory techniques, I did some preliminary research and reading of literature to be found on Latinos with diabetes before initiating fieldwork; I believe the analysis of data resulting from my observations and interviews did yield some unforeseen themes and ideas that will be detailed later in the results section of this thesis paper. To summarize a guiding principle applied to the research process using a grounded theory strategy detailed by Charmaz (2006), I sought to collect and describe data and apply theoretical concepts

to understand what was happening. This process is detailed in other chapters of this work, namely the literature review and results sections.

CHAPTER 4

RESULTS

In this chapter I discuss emergent themes that are the result of qualitative analysis of field notes and transcribed interviews. Selections originating from the interviews or field notes will be included when opportunity allows participants to give voice to their concerns, opinions, and experiences. Not all patients attending the courses were diabetic, however for the purposes of this paper I focus on the diabetic perspective.

Participants

Participants were approached as they attended a health education course at CSV in southwest Fresno, California. Observation started in January 2016 and concluded in May 2016. Participants included in this analysis were recruited from courses offered during the observation period. All participants self-identified as being Latino or Hispanic, had a median age of 51, and live in the Fresno area. Eighteen participants were diagnosed with diabetes and their experiences ranged from less than one year to more than 30 years of living with diabetes. Several of the female participants experienced gestational diabetes and were later diagnosed with Type 2 diabetes. Most of the interviews were conducted entirely in Spanish, since many participants were foreign-born from various states in Mexico; U.S. born participants were bilingual or predominantly spoke English and interviews were conducted in the language of their preference. What follows is an analysis of their experiences and how their identity is expressed by such experiences.

Understanding Diabetes

During the health education course, patients learn that diabetes is the result of many factors. These can include being overweight or a person's hereditary; Ms. Márquez also explains that there are additional factors that place an individual at a greater risk for developing diabetes and these are associated with a person's nationality, lifestyle choices such as diet, amount of physical activity, and risk increases with age, especially for those 45 years of age or older. Since diabetes requires daily testing of blood sugar levels, Ms. Márquez also helps patients learn and interpret their readings with advice for how to manage their scores. Patients are encouraged to test their blood sugar levels first thing in the morning before consuming any breakfast. A fasting blood sugar reading is considered "normal" (80-130) and is "low" (≤ 70). Patients are also taught how to interpret their exam results when their doctor tests their HbA1c levels. Scores are categorized as follows non-diabetic (4.2 – 5.6), borderline (5.7 – 6.4), diagnosed diabetic (≥ 6.5). Once a person receives a diabetes diagnosis, the American Diabetes Association suggests that an HbA1c reading between 7 and 8 is "controlled" (Evert 2016).

For patients with a low fasting blood sugar, Ms. Márquez recommends drinking one half-cup of skim milk and waiting ten minutes before testing blood sugar levels once more. Ms. Márquez explains milk is an excellent option since it can be classified as a protein and carbohydrate; the carbohydrates increase an individual's blood sugar while the protein prevents a drastic spike in sugar level readings. On the first day, Ms. Márquez explains to patients that diabetes is not their fault, it is the person's pancreas that is not functioning properly that is to blame. She follows this with a message to her patients, 'work with your body. Work with what you have.' (Day 1 field notes, January 30, 2015).

Redefining Nutrition

Ms. Márquez recommends that diabetic patients in attendance eat six times a day; three meals and three snacks is the recommended daily diet. Even if a patient is not diabetic (borderline, or disease free), patients are highly encouraged to also follow this diet schedule to help prevent the onset of diabetes. Patients are encouraged to eat smaller portions and healthier options. According to Ms. Márquez following the prescribed diet of three meals and snacks will help patients feel satisfied throughout the day. Sugar is not entirely off limits to patients, however should be consumed minimally. Stevia, purchased in store or harvested from a plant is the recommended sugar product for diabetics to consume. When told it is best to reduce or eliminate sugar from the diet, patients are most verbally resistant to this advice. This response was fairly typical, “You’re taking away everything!”

Table 4

Food Classification Exercise

Category	Food Item
Proteins	Chicken, beef, beef jerky, turkey, turkey bacon, eggs, yogurt, mozzarella cheese, ricotta cheese, tofu, fish, nuts, tempeh, milk
Carbohydrates	Milk, flour, rice, alcohol, pastas, cereals, corn, peas, potatoes, beans, fruit, alcohol
Good Fats	Olive oil, canola oil, grape oil, avocado, nuts, safflower
Bad Fats	Lard, butter, cream, whole milk

Note: This is an exercise observed at the research site. It is performed in both English and Spanish language classes. The exercise is intended to demonstrate to patients their ability to learn new information in one, two-hour session and to help patients learn basic nutrition information. However, the American Diabetes Association guidelines regarding Nutrition Therapy supports varied eating patterns for patients managing Type 2 diabetes. *Source:* American Diabetes Association. "4. Lifestyle Management: Standards of Medical Care in Diabetes—2018." *Diabetes Care* 41, no. Supplement 1 (2018): S539-S543. <https://doi.org/10.2337/dc18-S004>. Evert, Alison B. et al., "Nutrition therapy recommendations for the management of adults with diabetes." *Diabetes care* 37, no. Supplement 1 (2014): S135. <https://doi.org/10.2337/dc14-S120>

Another important lesson learned by patients is the ability to classify food into major categories. Ms. Márquez does an excellent job of classifying foods for patients to learn on day one. Foods are classified into four basic categories: proteins, carbohydrates, good fats, and bad fats. There is a pop quiz at the end of the session where Ms. Márquez will name a food item and patients are expected to say aloud which category the food item belongs in. This end of class exercise boosts confidence and demonstrates to patients that they are capable of learning information in a short period of time.

Benefits of the Diabetes Education Program

The most advantageous benefit to patients attending the CSV health education course is an increase in knowledge. Patients are learning basic health, anatomy and physiology, nutrition and disease management strategies while participating in health education. Strategies for physical activity, stress reduction to lower hypertension, how to navigate the CSV healthcare system, how to prepare and cook foods nutritiously, all of which translates into more confident patients prepared to manage their chronic condition.

Rapport building between Ms. Márquez and patients is certainly a surprising benefit. By scattering personal anecdotes of previous patients who succeeding in achieving health goals, reducing blood glucose levels, losing weight and maintain healthy lifestyles into the health education course, Ms. Márquez helps patients envision change in themselves. Participants are also asking questions during the class and receiving straight answers; this also qualifies when a question is asked that is beyond the realm of Ms. Márquez's role as health educator, patients are told to seek information from their doctor. The class also provides an atmosphere for patients to ask questions aloud that are perhaps not being asked in the medical exam room, questions about

which food item is better, A or B, for instance. Rapport is further strengthened when patients can observe first-hand Ms. Márquez's commitment to her job and to patients.

Community is created in the three-week cycle of participants attending health education classes. Informal conversations and information is exchanged between patients before and after class. In one particular case, a woman I eventually interviewed during the course of this research study befriended another woman whom she met in class. Although these two women live on different ends of Fresno, they check-in with each other regularly to encourage each other according to the interviewed participant.

Finally, given that patients have increased their knowledge and understanding about diabetes in the span of three weeks and have had opportunities to ask questions aloud during class or speak with Ms. Márquez individually after class, their agency has improved. Patients seem to feel more confident in their ability to manage and treat their diabetes. This improved sense of agency is also apparent in the interviews I conducted as each participant reported behavior changes that were a direct result from having attended the health education courses.

Interview Results

Understanding Diabetes

I now discuss the nuanced etiology of diabetes that should be taken into consideration when attempting to provide patient education and disease management strategies to Latino patients. To demonstrate that clinical and lay understandings of diabetes are often closely related I juxtapose what participants express as root causes for their diabetes diagnosis against public health frameworks.

Individual Responsibility

The public health approach to chronic conditions like diabetes and other co-morbidities like cardiovascular disease and obesity address the clinical and behavioral aspects of chronic expressions, however neglect to account for the entire community and circumstances that individuals find themselves in. Interventions within the public health domain target markers and avenues that are too narrow in scope to fully ameliorate the chronicity and burden of disease that afflict many disadvantaged groups. However, even considering the social determinants of health, the discipline fails to account for precious variables that are often taken for granted, time and expense. However, there do exist certain alienated groups that even though resources have been made available to them they may still lack complete understanding of how to make effective health behavior changes or may simply lack the time to partake in such healthy activities.

This is reflected in the life of someone like Magdalena, an interviewed participant whom found the daily grind too much to handle and manage her diabetes all at once. Magdalena cites a very important and all too familiar reality that she must confront daily, time. Magdalena believes that feeling rushed, overwhelmed with daily responsibilities leaves her without time to eat properly. Not having sufficient time to prepare a meal, to sit and enjoy a meal, nor having enough time to digest food is what has contributed to the development of diabetes. Magdalena explains that her feeling of control over time in her day-to-day existence is a major source of stress.

Magdalena cites that there is not sufficient time in the day or week that her current lifestyle permits her to eat or exercise properly. Time is an important factor in the daily lives that it feels like something that one does not have control over. Not having control over factors that dictate how one lives day to day coupled with the need to self-monitor and self-manage a chronic

condition that is a fluid state of complexity can seem daunting and overwhelming. I think that Magdalena points to a very important and overlooked component health care providers miss or disregard. Sometimes there are factors beyond one's control that makes it difficult to complete the tasks a person must do each day and makes it difficult for one to manage a complex chronic condition. It is not always about personal choice. There are systemic, economic forces at play that are also contributing to a person not being able to fulfill and attain a health status that they wish to achieve.

Another barrier that is very common to the families and individuals I interviewed with was the inability to purchase the quantity of food necessary to follow the recommended diet prescribed in the health education class. A healthier diet is often discussed as being instrumental in disease prevention and management. Yet, many I interviewed did not have the means to make such sweeping overhauls to their pantries and kitchens. Diana and Diego, a middle-aged couple explain during their joint interview that it is not financially possible for them to purchase fresh fruits, vegetables, and the quantity of foods necessary to prepare and eat six times each day. Patients in similar circumstances are more likely to be viewed as non-compliant, a label that will not help them as they move forward and progress into their make-shift disease management strategies.

Literacy

Literacy is one of the hardest challenges patients face. Based on her experience, Ms. Márquez is aware that some of her English and Spanish speaking patients do not understand how to read prescription bottle directions (how to take, what time, how often) nor do they fully comprehend doctor's orders and instructions. Attending the course requires that the patient, or an

accompanying acquaintance, is literate enough to write notes, listen to the information given, and comprehend the information that is being discussed. A lot of distillation is required on the part of the patient to abstract the information most pertinent to their situation and health condition. Patients also need to be in possession of basic nutrition label literacy, and this is part of the training. Patients seem to be in possession of much greater knowledge of food labels once the three courses are completed.

Coffman and associates examined these topics in their publication, “Diabetes Symptoms, Health Literacy, and Health Care Use in Adult Latinos with Diabetes Risk Factors” (2012).

In addition to lacking health education materials in Spanish, access to health care proves to be a barrier and generates overuse of emergency services and low-utilization of ambulatory or primary medical services which could control diabetes health outcomes much more effectively. These further the illusion of non-compliance among diabetes patients who do not have adequate or consistent access to health care providers. Based on the conversations I have had with the interviewees some of what Coffman and her colleagues observed seem to apply in Fresno County as well.

“Noncompliance” and the Clinical Encounter

Drawing on experiences as a diabetes clinician, medical doctor, sociologist and as an individual with Type 1 Diabetes, Claudia Chaufan presents a powerful critique of the structural violence afflicted upon diabetes patients. Chaufan’s critique focuses on four types of structural violence: 1) disenfranchisement 2) medicalizations 3) scapegoating via genetics 4) social noncompliance. Disenfranchised diabetes patients have been victims of medicalization, the scapegoats of genetic predisposition and social noncompliance. Chaufan denounces medical

literature for inconsistent and victim-blaming evidence for genetic markers and predispositions that have yet to be identified in medical science. These are highly pertinent to the populations I studied. For example, according to Chaufan's critique, the medical field characterizes diabetes as an experience of the individual. Patients are responsible taking action to make 'informed' choices regarding their care and treatment plans by becoming physically active and altering diet habits. However, as evidenced by patient interviews this is not as simple as believed.

Diabetes patients have been polarized into noncompliant categories by health policies and biomedicine. Rather than emphasizing the effects that political-economic and hegemonic forces have contributed to the epidemic, health care policies and treatment options have ignored the structural violence imposed on patients meant to receive care. Chaufan notes that it would be difficult for minority populations, who are at increased risk of diabetes compared to their non-Hispanic, white counterparts to receive adequate care when access poses a barrier. Socioeconomic disparities experienced by a significant proportion of diabetes patients are further exacerbated by policy informed by health research that fails to account for these barriers and impediments experienced by patients.

Following Chaufan's reasoning, I argue that "non-compliance" should not be interpreted as disregard for one's personal health or as an act of defiance against the medical professional. Consideration of factors outside the patient's control must be accounted for like income or lack of health insurance that prevents them from seeking health interventions or taking prescribed medications. This was the case for Diana and Diego, mentioned earlier, who sought medical treatment that was provided free of charge, irregularly at a Fresno homeless shelter, the Poverello House, when they found themselves without insurance. This led to inconsistent access to

required medications for their diabetes and inconsistent medical care from volunteer medical doctors available to them at these free health workshops.

Diabetes Etiology

When interviewing patients about diabetes, one of the first questions asked participants to explain what they believed caused diabetes and what led to their own diabetes diagnosis. Many of the responses I heard from participants echoed the information that was discussed in the health education course. Etiology was most often attributed to lack of proper nutrition and physical exercise. The conversation became interesting when participants explained what was happening in their lives leading up to their diabetes diagnosis. In the section that follows I further expand these discussions.

Folk Etiology

Participants were very open when discussing their experiences of the past and present.

While all participants agreed and stated that diet and lack of physical activity were risk factors for the development of diabetes; the stories related to various episodes of stress were much more descriptive into the underlying beliefs the participants engaging in this research study held about their condition. Tales of *susto*, *disgusto*, *coraje*, and *gusto*, emotions experienced by anyone and everyone are some of the etiologic sources for the manifestation of diabetes.

For example, Beatriz, a woman in her 40s and newly diagnosed (less than 1 year) with diabetes was one of my interviewees. She attributes her maternal worry for giving rise to many strong emotions like anger (*coraje*) and worry about her children, living in a new country as contributing to her newly diagnosed diabetes.

Yo me preocupo mucho por los hijos. Yo pienso que eso es lo que a mi me afecta. O tambien a veces corajes que uno hace con ellos, verdad? Sentia que el corjae sentia ahogarme. [I worry a lot about the kids. I think that that is what affects me. Or sometimes the anger that passes between you and the kids sometimes, right? It felt like I was drowning in the anger.]

Another participant, Diana, expressed that her partner's diabetes was in fact the result of their daughter having moved away without their blessing. This produced such strong emotions within her partner, Diego, that he was very agitated and worried, thus giving rise to his diabetes. Diego's explanation for what caused his diabetes, being overweight, is not confirmed by Diana. She says that it was concern (*un disgusto*) for his daughter that caused Diego's diabetes,

Lo que lo hizo agarrar el diabétes fue un disgusto. Entonces del mismo coraje que hizo agarro el diabetes. [What gave him diabetes was his concern. From that anger the diabetes took hold of him.]

Diabetes management often includes the use of herbal and traditional remedies that are prepared at home. Similarly, to the creation of funds of knowledge concerning diabetes, there exists within family and social networks herbal remedies that are indicated for diabetes management. Jane E. Poss, et. al examine the prevalence of diabetes management in, "Home Remedies for Type 2 Diabetes Used by Mexican Americans in El Paso, Texas" (2003). The research was informed by Kleinman's explanatory model framework and use of grounded theory was used to interpret and comprehend the data. Knowledge generated as a result of this study created a thoughtful representation of the beliefs and values that influence the use of alternative therapies for the treatment of diabetes. Curiously, the work completed by Weller (1999) reported that folk remedies were unpopular treatment regimens for diabetes. Yet, there is sufficient documented record to prove otherwise.

For those individuals whom I interviewed, these cultural beliefs about the causes of their diabetes also helped to inform use of natural remedies. Felipe told me about his complete faith in the prescription medications he was taking to help control his diabetes,

A mi lo que me da mas confianza, yo pienso, es la medicina que me estoy tomando del doctor... [What I think gives me the most confidence is the medicine I'm taking from the doctor...]

However, he also told me about seeds he had been taking that are said to help persons with diabetes and cholesterol from his native state in Mexico. Felipe searched his kitchen and showed me Moringa seeds (*semillas de Moringa*) that he claims also help people lower their cholesterol and manage their diabetes. While Felipe has complete confidence in his prescription medication to help manage his diabetes, it is in another segment of the interview that he says something that aligns with folk etiology,

Estamos llenos de enfermedades que no nos salen o no nos detectan otra cosa. [We are all filled with illnesses that do not emerge or are not detected.]

As you can see, the idea that diabetes (or any illness) is lying dormant inside the body and is drawn out of hiding by some emotional trauma is a health belief that is an undercurrent in the discussion of diabetes etiology. Even among those, like Felipe, who do not entirely subscribe to this explanatory model of diabetes, it is common held knowledge that exists within the Latinos with diabetes I interviewed. The constructs of diabetes though largely similar to the biomedical model of diabetes etiology, there were a substantial number of participants who believed that their diabetes was the result of *Susto*, defined in this piece as, "...an episode of severe fright or a terrifying emotional experience" (Poss, Jezewski, and Stuart 2003, 306).

This conceptual framework led many to believe that the use of herbal and alternative treatments to be an appropriate course of treatment. The most cited and popular alternative therapies for diabetes were the use of *nopal* (cactus) and *te* (tea) *de yerbabuena* (yerba buena is a

term for many aromatic herbs in the mint family). Discussions with participants revealed that these treatment regimens were perceived to be less harmful, addictive and natural than oral and injected medications. This binary opposition of natural and harmful is expressed in many explanatory models and beliefs with complementary and alternative medical (CAM) use. Participants also revealed that they did not discuss their use of herbal remedies during the clinical encounter, nor were clinicians aware of folk and traditional regimens used. (Poss, Jezewski, and Stuart 2003, 306).

What Do I Eat? Redefining Nutrition, Redefining Identity

During my interviews with patients of CSV, an extended conversation about nutrition and diet as it related to diabetes management was a common occurrence. As stated above, nutrition is a key component to the information disseminated in the diabetes education course. Patients are taught which foods to avoid and healthier ways of preparing foods. Persons with whom I spoke revealed that after having taken the course, they were left with their heads spinning and not knowing what to eat and what to avoid. This can be attributed to the fact that the dishes and meal preparation methods they were accustomed to, and learned growing up, and were entirely immersed in were suddenly identified as being the culprit for their current diseased state and prompt diet changes were necessary to ensure a much more healthy future. This means that the traditional Mexican dishes that the participants were familiar with growing up and reproducing in adulthood were labeled as corrupt and off limits. One participant in particular, Teresa, reflected on her first impression upon learning the diet and nutrition recommendations during the health education class, "*Does she want to turn me into a white woman?!*" (Fieldnotes, June 01, 2016).

The conversation that ensued between Teresa and her husband, Tomas, and me revealed that the message they took away from having attended the health education class is that everything they know about food is wrong. And although not so explicitly said in other interviews, the sense I got from the interviewees was that there was a sense of identity transition that needed to take place in their near future now having learned the nutrition information from the health education class. Redefining what foods are nutritious and healthy is another attack on the individual's identity. [1st attack = diabetes diagnosis, I am a person with diabetes. 2nd attack = food, what do I eat? Everything I eat is wrong]

Nancy Schoenberg (2013) addresses food and identity where, "...food preferences have become important components of rural Appalachian identities. Common uses of locally acquired ingredients and methods of preparation shared among rural Appalachians serves as an expression of belonging that not only reaffirms cultural ties to place, but also to family and community" (Schoenberg 2013, s26). Much like the Latinos CSV patients I interviewed, food and food preparation traditions are culturally inscribed with meanings of place and belonging to a community. Being advised to avoid traditional Mexican cuisine has emotional and political implications for the patients of CSV.

When Teresa reacted to the nutrition guidelines of the Diabetes Education Program with, "Does she want to turn me into a white woman?!" it is a reaction that researcher and author Jennifer Jensen Wallach would argue is not entirely unfounded. In her book, *How America Eats: A Social History of U.S. Food and Culture* (2013) Wallach describes how social, cultural, and racial identities are formed by food consumption patterns. According to Wallach, "When the English colonists arrived in the territory that is now the United States, they brought with them concrete ideas about what constituted healthful and civilized eating habits." (Wallach 2013, 11).

I argue that these “concrete ideas” still exist today. There exists a health food paradigm that is the driving force behind what is acceptable to eat if one hopes to achieve assimilation into the health culture groups of the United States. This does not need to be the reality, traditional Mexican food is not inherently “bad”, rather it is an “American style” diet that causes problems for individuals.

Furthermore, “Despite aspirations to eat a balanced diet, to some extent the luxury of humoral eating had been reserved for the gentry in Europe....diets varied along class lines. The very poor had relatively little variation...could not always afford to eat according to what they thought was best for their health...familiar with...dietary ideas of their day...aspired to follow contemporary medical advice whenever possible.” (Wallach 2013, 12). In the interviews I conducted this seem to be very true, even today. The Diabetes Education Program provides nutrition advice and recommendations that are not affordable to all patients in attendance. This then places patients at a disadvantage of knowing what foods are best for managing their diabetes, yet when they are unable to participate they return to the folk etiologies and remedies (teas and other regional remedies) to manage by making do. It is precisely managing by making do that the participants I interviewed demonstrated their resilience to difficult economic hardships, identity loss (through diabetes diagnosis) and found ways to manage their chronic disease by being resourceful.

Behavior Change

In this last and final theme, I would like to take the opportunity to summarize the previous themes and point out that despite these emotional and existential trials; the patients with whom I had the opportunity to sit down and interview reported behavior change after having

taken the health education course. While this research project and report is not intended to evaluate the efficacy of the diabetes education program available at CSV, I would like to recognize and draw attention now to the perseverance of the persons with whom I met.

Even though my research participants cited cultural references with regard to the etiology of their diabetes, all participants in this study recognize the connection between lifestyle factors and genetics as risk factors for diabetes. In the end these individuals who are participating and engaging in the health education course are taking away with them an increased level of knowledge and information that is equipping them to make small behavior changes in their lives.

For example, for many of my interviewees, the diabetes diagnosis altered their daily eating habits. For Tomas and Teresa, a married couple in their 40s with three children took to heart the advice given in the health education course. The couple decided to overhaul their kitchen and pantry and limit the foods entering the home that were unhealthy or contained added sugars, like sports drinks and desserts. The decision to overhaul the kitchen pantry and daily meals was a health decision for Tomas and Teresa. Their youngest child was diagnosed with diabetes from a young age and is also living with high cholesterol. The kids retaliated and had very strong emotional reaction to the change occurring in their household. Tomas and Teresa recall their kids' reactions with some humor: their kids were upset, in shock, angry, they didn't want to eat anything, "¡Aqui en esta casa no hay nada de comer!" ("There is nothing to eat in this house!").

Reflecting on this approach, Teresa now believes she and Tomas should have been more considerate in their lifestyle change approaches. Teresa recalls one day their kids called their grandmother to complain that they were the worst parents because all of their snacks were locked away. Moving forward Teresa says changes will be less drastic,

Vamos haciendo cambios poco poquito. Porque a veces es bien drastico. Como eso de tirar la comida, fue algo que yo misma dije que no me funcionó. Porque fue muy drastico, entonces en vez de ponerlos en lugar de ponerlos en una pagina [dijieron], “No. No quiero.” [We are making changes slowly, but surely. Because at times it can be very drastic. Like throwing away food, it was something that I can admit did not work. Because it was very drastic, instead of putting them on a positive path [they said], “No. I don’t want any part of this.”)

For other women in the study, the conflict of being the caretaker of the family meant they were initially undecided about how to cook for their new diabetes diagnosis, while also satisfying their family who longed for traditional plates prepared before her diagnosis.

Magdalena describes her plight,

Yo sé que toda la familia debemos de comer bien. Pero la familia no quiere lo no come, “Yo no quiero eso” Voy a hacer para mí, y luego para ellos y como que, no esta facil, no es fácil. Tienes que empezar a comprar para acá y comprar para acá. Y por supuesto no da para tanto. [I know the whole family should eat healthy. But the family will not eat what they do not like, “I don’t want to eat that.” I’ll make something for me, and then I’ll make something for them and how do you expect...it’s not easy, it’s not easy. You have to start buying for them and buy for you. And of course, it doesn’t last long.]

The need to navigate these new diet changes and a new identity as an individual with diabetes means there is much negotiation taking place. Individuals I interviewed managed to find balance in their multiple roles, identities, and relationships. First, it was not uncommon for the interviewees to suffer from or care for a loved one with co-morbidities. This is an added emotional, financial, and at times physical demand on the individuals with whom I met with. Yet despite these setbacks, the interviewees were quite resilient and their own agents for getting through their day. Resiliency is defined here as the ability to navigate multiple personal and social roles, specifically when it comes to managing co-morbidities, navigating new family dynamics that result from a diabetes diagnosis, as well as offering and receiving emotional support.

According to Ms. Márquez, ‘humans are creatures of habit’. Thus, though it might seem as if the changes that are being discussed in the six hours of her course would be sufficient to elicit small behavior changes that come as a result of an increase in knowledge, the reality is that it is unfair to presume that a complete behavior change overhaul will result from a six-hour course. As one interviewee, Diana, stated about the topic, change is, ‘not something that happens from night to day’. What the health course offers patients is an opportunity to gain knowledge pertaining to their health condition(s); basic nutrition information; and advice for how best to navigate the healthcare system (ophthalmology, asking for tests/analysis; how to interpret those results when their doctor reveals them). Most importantly, it is my firm opinion that the information received during the health education course is aiding to redefine the patient’s self-efficacy, therefore improving the likelihood that intentions to engage in behavior change to improve personal health will increase and come to fruition.

The field of medical anthropology can provide much richer and deeper insights into the roles, expectations and experiences of individuals in their respective cultural contexts and how those are then managed in the biomedical context. Illness is the individual and community’s experience that has been shaped by historical interactions that will determine how the illness will be perceived, labeled, explained in addition to how the discomfort will be experienced and validated by the greater network of actors (family, friends, community). This rich and complex level of managing and exchanging cultural definitions of illness will influence how an actor presents initial symptoms, when and from whom the actors will seek care, the duration of care required, and finally an evaluation of efficacy of the care received (Kleinman et al. 1978). Medical anthropology enables the intricacies of this framework to come to light and show

through in the illness narratives of numerous conditions, and one that is on display in the chronicity of diabetes.

CHAPTER 5

DISCUSSION

The rate of diabetes is quickly increasing across the United States. Elderly and ethnic minorities are slated to bear the most burden of emerging diabetes incidence and to suffer greater severity of symptoms and complications (Boyle et al. 2010). The need to address this public health issue is critical to learning how diabetes is experienced, what can be done to alleviate the symptoms and outcomes as well as to ameliorate any disparities found among available therapies

The disciplines of anthropology and public health have much to offer for the benefit of diabetes research. The increasing transdisciplinary collaborations between the two disciplines provide substantial evidence for the merit each field contributes to the identification and amelioration of health issues. The presence of anthropology in public health efforts can further the advancement of health initiatives, inform policy and eradicate barriers that are currently preventing efficient allocation of funds and program directives.

This research sought to learn the lay health beliefs of Latino patients and how those beliefs influence the adoption of health information. When asked what causes diabetes in the general population many participants commented that the lack of healthy eating and low physical activity levels were the primary culprits. To counter the effects of diabetes, participants reported making some or drastic changes to their daily diets. However, this is not the complete story, when I spent more time with participants and allowed them to discuss what was going on in their lives leading up to their diagnosis the explanatory models pointed to life stressors. Emotional responses to daily living is a significant factor for diagnosis —anxiety or worry (financial limitations preoccupied the thoughts and actions of some) domestic woes (daughter leaving home, domestic violence) contribute to the emergence of diabetes. Taking these patient health

beliefs and explanatory models into account at the clinical encounter could aid in benefiting patient outcomes and enrich health education and health promotion efforts.

Health Education

These recommendations are intended to provide some feedback given regarding the experiences and beliefs about a select few CSV patients. From the interviews I conducted, patients overwhelmingly believed the Diabetes Education Program is a positive intervention. Patients receive six hours of education about their chronic condition they are less likely to receive in a clinical encounter. For many interviewees, this education course was the first time they received health information in a structured setting. The course enables patients to become socially connected to others experiencing similar struggles, exchange information and receive support.

This is an especially important component of the Diabetes Education Program, it allows for patients to learn health information and form new subjective norms and create intention for behavior change. Much like the funds of knowledge posited by Vélez-Ibáñez, Susan C. Weller and colleagues (1999) applied the Cultural Consensus Model to suggest that cultural beliefs about diabetes created a bank of indigenous knowledge that was circulated and handed down through family and community ties. Educational attainment appeared to be the most statistically significant predictor of diabetes knowledge. Learning the multi-facet beliefs and practices of sub-populations within the Latino community could be beneficial for public health efforts, program development and increased education efficacy among practitioners and clinicians.

Benefits of this 1999 study include awareness of explanatory models and decision-making processes in diabetic care among an immigrant Latino population. Education services,

treatment options and preferences, the use of herbal and folk remedies to treat and manage diabetes needs to be addressed and incorporated into the larger biomedical models of health to better serve and provide quality care for patients. These approaches might be of benefit for CSV to enhance the patient education experience.

Health behaviors changes were reported over the course of the interviews. Some of these changes included switching to olive oil for cooking, baking or steaming foods more frequently, and reducing portion sizes at meal times. These are victories the patients who I interviewed were very proud to report. Behavior change does not happen overnight, giving patients the tools and information to make such changes is accomplished through the CSV Diabetes Education Program.

Recommendations

There are many positive effects of the Diabetes Education Program. There are a few considerations Clinica Sierra Vista may find useful for continued success. First, in my observations of the Diabetes Education Program participants were unaware their appointment was a 2-hour education session. Patients arrive for their “appointment with the health educator” under the impression it is an individual consultation. Given that many participants are diabetic, it would be beneficial to these particular patients to come prepared with snacks. Also, I did observe families leaving before the end of the session to pick up their children from school and extra-curricular activities. It would be beneficial if patients understood their “appointment” was a three-week time commitment with each session being two hours in length.

Secondly, updated learning materials would also enhance the learning experience. Patients are arriving to their first session unprepared to take notes, handouts with the session

information could prove useful. Thirdly, food insecurity was not a topic that was pursued in-depth during the course of my study. Many participants cited an inability to obtain enough food as a barrier to abiding by the recommendations made during the health education course. Further investigations are merited to learn the food security of the patient population of CSV. Lastly, cooking demonstrations could also be beneficial for this population. It would allow for an interactive and hands-on learning experience that would re-enforce concepts and knowledge obtained in the program.

Concluding Thoughts

Managing a chronic condition like diabetes is time and labor intensive. Learning health information for better chronic disease management is daunting, yet the individuals I interviewed as part of this study have demonstrated that behavior change is possible. Chronic disease management requires adapting to an ever-changing disease state, these stories of triumph and struggle are representative of many other individuals with diabetes. Latinos with diabetes, especially those who are monolingual-Spanish have proven that their capacity to learn and apply newly acquired knowledge to improve their diabetes. Most importantly, while they discussed how their identity is shaped by many factors, they prove that every individual is first and foremost a human being trying to exist as best they can.

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