

EXPLORING THE UNDERSTANDING OF PRE-DIABETES AND THE
POSSIBILITY OF DEVELOPING DIABETES AMONG MEXICAN AMERICANS AT
THE U.S.-MEXICO BORDER

by

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A Dissertation Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

2010

THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

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ACKNOWLEDGMENTS

I would like to thank my committee co-chairs, Dr. Joyceen Boyle and Dr. Marylyn McEwen, first of all, for sharing your incredible knowledge and wisdom. Secondly, for your enduring patience and encouragement through this doctoral process. Each of you are a gift to the art and science of caring.

I would also like to thank my dissertation committee members, Dr. Terry Badger, for promptly volunteering to form part of this committee, and for your words of encouragement through my PhD coursework, and to Dr. Sharon McGuire, a woman of wisdom and strength, a daughter of Dominic, and a preacher of the written word.

Thanks to *mi familia, especialmente mis hermanos*, Julio, Elizabeth, Francisca, y José, and each of my nieces and nephews. To Luis, for enduring patience and support. To Benny, Pius, and Xavier, who lower my blood pressure and gladden my heart. You all give love a new meaning.

Thanks to my friends and extended family at Camillus Health Center and *Clinica Santa Maria de Guadalupe*, who have safeguarded my time of study and kept me sane all this time. May we continue to be witnesses of the love of Christ in our healthcare ministry.

Thanks to the Most Reverend Bishop Jose Isidro Macias Guerrero, III Bishop of Mexicali, who took me in as a son so I can respond to God's call in the ministerial priesthood. To the Friars of the Sick Poor, especially to Br. Richard Hirbe, FSP, for his fraternal love and guidance. To the priests and seminarians of the Diocese of Mexicali, who have received me as a brother.

Thanks be to the Triune God, from whom all good things come.

DEDICATION

A MI MADRE, FRANCISCA MORALES VDA. DE VALENZUELA

A MI PADRE, + RODOLFO VALENZUELA ROMO

NISI DOMINUS FRUSTRA

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ABSTRACT

The purpose of this ethnographic study was to explore the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans at the U.S.-Mexico border. This study also explored how Mexican Americans adjust to living with pre-diabetes. While extensive research has been conducted regarding pre-diabetes, diabetes, and how individuals perceive their susceptibility to these illnesses, few studies have examined how Mexican Americans understand pre-diabetes and the possibility of developing diabetes. The increased prevalence of diabetes among this population, the divergent understandings of risk held by diverse cultural groups, and the large presence of Mexican Americans in the U.S.-Mexico border region prompted this study.

There are gaps in the literature about how Mexican Americans understand pre-diabetes and their possibility of developing diabetes. Current literature focuses on studies of causality, folk beliefs, symptoms, and treatments. Current studies do not provide a framework in which healthcare professionals can identify how Mexican Americans understand pre-diabetes and the possibility for developing diabetes or how to incorporate these lay understandings into their practice, research, and education.

An ethnographic study, guided by Freire's framework (2000) was conducted to provide insight into the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans living at the U.S.-Mexico border. An overarching theme *Living with Pre-diabetes* emerged. This theme emerged from two major themes: 1) *Awareness*; and 2) *Adjusting to Living with Pre-diabetes*.

This study revealed that Mexican Americans may not understand pre-diabetes or their possibility of developing diabetes until told of having pre-diabetes by a healthcare provider. Becoming aware of pre-diabetes may not necessarily imply understanding of what pre-diabetes is. The study also revealed that an awareness of having pre-diabetes may lead to changes in lifestyle, but may not always make these changes sustainable. The use of Freire's framework may prove useful when addressing the needs of Mexican Americans with pre-diabetes.

CHAPTER 1: INTRODUCTION

Few studies have examined how Mexican Americans understand pre-diabetes and the possibility of developing diabetes. The increased prevalence of diabetes among this population, the divergent understandings of pre-diabetes and the possibility of developing diabetes held by diverse cultural groups, and the large presence of Mexican Americans in the U.S.-Mexico border region prompted this study.

Diabetes affects Mexican Americans at a disproportionate rate. Mexican Americans are 1.7 times more likely to acquire diabetes than their White non-Hispanic counterparts (Centers for Disease Control, 2005). Lack of access to health care, cultural and linguistic barriers, poverty, familial predisposition, lifestyle behaviors, and lack of legal residency status in the U.S. are some of the reasons for the increase in the incidence of diabetes among Mexican Americans (Harris, 2001; Poss, 2006; Harris, 1999; Goldman, Smith, & Sood, 2005). In addition, pre-diabetes also affects Mexican Americans at a disproportionate rate. Pre-diabetes develops a lot earlier among Mexican Americans, usually around 20 to 30 years of age, versus 40 to 60 years of age among the non-Hispanic White U.S. population (Idrogo & Mazze, 2004).

The conceptualization of risk among racial and ethnic minorities may differ from that held by professionals, scientists, or by individuals from diverse cultural backgrounds (Jia & Libetkin, 2004; World Health Organization [WHO], 2002). Understanding an illness such as pre-diabetes or diabetes is often influenced by the socioeconomic and cultural circumstances that surround a particular group or individual, and at times, conceptualizations of risk may depend on educational level or ethnic background. For example, some studies have found that some individuals often underestimate their risk for common illnesses such as diabetes and certain types

of cancer while overestimating their risk for illnesses or risks that are rare (Lipkus, Samsa, & Rimer, 2001; Schwartz, Woloshin, Black, & Welch, 1997; Jia et al., 2004; Kahneman, Slovic, & Tversky, 1982).

To date, there have been no studies that explore how Mexican Americans in the U.S.-Mexico border understand pre-diabetes or the possibility for developing diabetes. The U.S.-Mexico border region is densely populated by Mexican Americans who have a higher incidence of diabetes than the rest of the population (Behavioral Risk Factor Surveillance System, 2005). A study by the U.S.-Mexico Border Diabetes Prevention and Control Project reported that approximately 1.2 million borderlanders have diabetes. In addition, the prevalence of pre-diabetes is 14% and over 5.3 million border residents are overweight and obese. Overweight or obese persons have 2.8 greater chances of developing diabetes. The Behavioral Risk Factor Surveillance System (2005) found that, in the targeted area of this study, Yuma County, Arizona, about 10% of adults reported having been told by a healthcare provider that they had diabetes versus 7.5% of the general U.S. population (Behavioral Risk Factor Surveillance System, 2005). The high concentration of people of Mexican descent, coupled with prevalent high rates of poverty, lack of access to health care, and undocumentedness, among other factors, make it important to investigate how Mexican Americans in the U.S.-Mexico border region understand their risk for diabetes.

The purpose of this study is to explore how Mexican Americans in the U.S.-Mexico border region understand pre-diabetes and the possibility for developing diabetes. The study will focus on Mexican Americans diagnosed with pre-diabetes. Individuals with pre-diabetes are at a much higher risk for developing diabetes than the population at large, and are also at higher risk

for cardiovascular disease when contributing factors such as hypertension, dyslipidemia, and central body obesity are present (Zimmet et al., 2001; Alberti & Zimmet, 1998). More specifically, pre-diabetes develops much earlier among Mexican Americans, usually around 20 to 30 years of age, versus 40 to 60 years of age among the general U.S. population (Idrogo & Mazze, 2004). The overall goal of this study is to generate theoretical knowledge that addresses how Mexican Americans understand pre-diabetes and the possibility for developing diabetes to create culturally appropriate interventions for this population.

Mexican Americans in the U.S.-Mexico Border Region

Mexican Americans represent the largest and fastest growing ethnic group among Hispanics in the United States (U.S. Census 2000; Garcia, 2005). There are about 27 million Mexican Americans living in the United States (U.S. Census Bureau, 2005; Therrien & Ramirez, 2001), almost 60% of them live in the four states adjacent to the U.S.-Mexico border region (U.S.-Mexico Border Health Commission [USMBHC], 2003; Bastida & Pagán, 2002). In the U.S.-Mexico border region, almost 13 million residents are of Mexican origin (USMBHC, 2003).

Historical Context

The history of the U.S.-Mexico border region is both fascinating and filled with conflict. In 1819 the Adams-Onís Treaty was signed, setting the boundaries established by Spain and the United States. The Treaty of Guadalupe Hidalgo was signed in 1848 which called for Mexico to give up the states of California, Arizona, New Mexico, Texas and part of Colorado, Nevada, and Utah. This Treaty contributed in part to the higher concentration of Mexican Americans in these states. In 1853, the Gadsden Purchase extended the U.S. border with Mexico by more than

30,000 square miles to its present configuration. It was then that cities south of the Gila River such Tucson and Yuma were annexed to the United States (Public Broadcasting Service, 2000).

Geography

The U.S.-Mexico border expands almost 2,000 miles from east to west and over 62 miles on each side of the territorial line that divides the U.S. and Mexico. This geographical region comprises four U.S. states and six Mexican states, and about 44 U.S. counties and 80 Mexican municipalities (USMBCH, 2003). There also are 25 Native American tribal nations present in the U.S.-Mexico border region. There are fourteen pairs of sister cities, or cities adjacent to each other on each side of the border. About 95% of the total U.S.-Mexico border population lives in or around these sister cities (USMBCH, 2003).

Socioeconomic Status

The number of Mexican Americans in the U.S.-Mexico border region is believed to be about 13 million. This number is expected to double by the year 2025 (USMBHC, 2003). More than one third of the U.S.-Mexico border population lives at or below the federal poverty level. Three of the ten poorest counties in the US are located in the border region. In the Southwestern states, the unemployment rate is 250-300% higher than the rest of the country and about 25-30% of the population is uninsured (USMBHC, 2005). Twenty-one economically distressed areas (EDA) are found at the U.S.-Mexico border region. EDAs are described by the Texas Water Development Board as areas where the financial resources of the community are unable to provide basic services such as potable water and sewage disposal for its residents (2007). The average annual household income in the U.S.-Mexico border region is about \$14,560 (USMBHC, 2003). About half a million people in the States of Texas and New Mexico live in

unincorporated, rural communities, also known as *colonias*, that have no access to public services such water, sewer, or electricity (USMBHC, 2003).

The 51st State

This multi-faceted region is so unique in its geographical, political, social, economic, and cultural characteristics that the U.S.-Mexico Border Counties Coalition (USMBCC) refers to it as the “51st state” (USMBCC, 1998). If the U.S.-Mexico border was in fact a state, it would rank last in access to healthcare and per capita income, fifth in deaths related to diabetes, and first in number of children who live in poverty and who are uninsured (USMBCC, 1998; USMBHC, 2003, 2005). Diabetes is the fifth cause of death among residents of the U.S.-Mexico region (Pan American Health Organization [PAHO], 2000; USMBHC, 2003).

Health Context

The rate of diabetes for Mexican Americans is 1.7 times the rate for non-Hispanic Whites (Lorenzo, Okoloise, Williams, Stern, & Haffner, 2003). Moreover, an increase in the prevalence of the metabolic syndrome (increased waist circumference, hypertriglyceridemia, low HDL cholesterol, elevated blood pressure and high fasting blood glucose) among Mexican Americans (31.9%) will likely result in a dramatic increase on the incidence of diabetes in the next ten years (Ford, Giles, & Dietz, 2002).

Diabetes causes great physical, psychological, and financial burdens for Mexican Americans. For example, a study by West, Klein, Rodriguez, Muñoz, Broman, Sanchez and Snyder (2001) demonstrated that in the state of Arizona, the prevalence of diabetes was 22% (almost double than the non-Hispanic White population), almost 50% of those with diabetes had diabetic retinopathy and over 30% had moderate to severe nonproliferative and proliferative

retinopathy. Another study concluded that the higher incidence of diabetic retinopathy among Mexican Americans is 84% higher among Mexican Americans than non-Hispanic Whites (Harris, Klein, Cowie, Rowland, & Byrd-Holt, 1998).

Mexican Americans with diabetes have a higher incidence of limb amputation than other ethnic minorities (Lavery, Ashry, Van Houtum, Pugh, Harkless, & Basu, 1996; Armstrong, Lavery, Harkless, & Van Houtum, 1997). Diabetic nephropathy, the most common cause of end-stage renal disease, is six times higher among Mexican Americans with type 2 diabetes than among non-Hispanic Whites (Arar, Hazuda, Plaetke, Sartorio, Arar, & Abboud, 2003).

Diabetes causes loss of employment, lowers productivity, and lessens the earning capabilities of Mexican American men and women (Bastida & Pagán, 2002), thus worsening the socioeconomic conditions that cause poverty and lack of insurance, two factors that contribute to the prevalence and severity of diabetes among Mexican Americans in the U.S.-Mexico border region (Treviño, Marshall, Hale, Rodriguez, Baker, & Gomez, 1999).

Statement of the Problem

Background

José is a 32 year old Mexican American working and living at a place where two worlds meet: the United States (U.S.)-Mexico border region. He considers himself to be a typical borderlander: he was born in the U.S. but raised in Mexico and frequently commutes between the two countries. His family moved permanently to the U.S. when he was a child and always maintained ties on both sides of the border. José went to elementary school in Mexico and to high school in the United States. He eventually married and had four children. José continues to

cross the border into Mexico to visit friends and family, to do business, or to seek healthcare for himself or for his family.

José was diagnosed with diabetes when he was 28 years old. He frequently jokes to his friends and family that he “inherited” diabetes from his father and maternal grandmother. José had been gaining weight since he was about 20 years old and has never participated in regular exercise. However, he was regularly reminded by family members of the increased chances of developing diabetes if he did not modify his lifestyle by losing weight and exercising more regularly. In spite of this, the diagnosis of diabetes came as a shock to him and his family.

I became interested in exploring how Mexican Americans at the U.S.-Mexico border understand pre-diabetes and the possibility for developing diabetes because of José: he is my brother. Like José, there are increasing numbers of Mexican Americans at the U.S.-Mexico border who have developed pre-diabetes or are at risk for developing diabetes. Exploring the understanding of pre-diabetes and the possibility of developing diabetes among this population has implications for nursing research, theory, and practice. Most importantly, exploring how individuals understand pre-diabetes and the possibility for developing diabetes can provide knowledge that nurses and other health professionals can use to assist Mexican Americans to adopt healthy behaviors and ultimately improve their health.

Cardiovascular Disease and Diabetes Among Mexican Americans in the U.S.-Mexico Border

Cardiovascular disease affects over 30% of Mexican American adults (Thom, Haase, Rosamond, Howard, Rumsfeld, Manolio et al., 2006). It is estimated that more than 2500 people died each year of causes related to cardiovascular disease (Thom et al., 2006). The incidence of

cardiovascular-related deaths is worse among people who have diabetes. It is estimated that over 65% of people with diabetes will die from the consequences of a heart disease or stroke (ADA, 2006). In addition, most people with diabetes have other coexisting risk factors such as high blood pressure and high cholesterol levels, which in turn increase the probability of dying from a heart attack or stroke (ADA 2006). According to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), heart disease is the leading cause of diabetes-related death (Thom et al., 2006). Mexican American adults are at a higher risk of dying from cardiovascular disease due to the high prevalence of diabetes among this population.

Mexican American adults are greatly affected by diabetes (Hunt, Valenzuela, & Pugh, 1998; Jezewski & Poss, 2002; Arcury, Skelly, Gesler, & Dougherty, 2004; Thom et al., 2006). Mexican Americans are more likely to have diabetes than their non-Hispanic White counterparts (CDC, 2003). Along the U.S.-Mexico border, over 1.2 million border residents 18 years or older have diabetes (PAHO, 2000). Diabetes is the fifth leading killer of U.S.-Mexico border residents, and an important contributor to cardiovascular disease, which is the number one killer of U.S.-Mexico border residents (PAHO, 2000; USMBHC, 2003). Healthy Border 2010 recognizes diabetes and heart disease as one of the worse problems in the U.S.-Mexico border. Nearly 4,000 residents on both sides of the U.S.-Mexico border die of diabetes-related consequences each year. Out of these, 1,500 live in one of the four bordering U.S. states, and 2,500 live in one of the six Mexican states bordering the U.S. (USMBCH, 2003).

Mexican Americans have been the focus of numerous studies related to diabetes and its prevalence among this population. Intervention studies targeting Mexican Americans with diabetes have shown that increased awareness and education leads to improved glycemic control,

knowledge (McEwen, Baird, Pasvogel, & Gallegos, 2007), and lipids levels (Corkery et al., 1997; Philis-Tsimikas, 2004). However, research about how Mexican American adults at the U.S-Mexico border understand pre-diabetes or the possibility of developing diabetes has not been documented in the literature.

Exploring how Mexican Americans understand pre-diabetes and the possibility of developing diabetes is important since various studies have shown that patients' beliefs about a disease may vary from the medical perspective. Lay beliefs about illnesses such as diabetes influence how people understand their risk for acquiring a disease, its causality, symptoms, severity, and treatment (Walter, Emery, Braithwaite, & Marteau, 2004; Hunt, Arar, & Larme, 1998; Kleinman, 1980), and at times, this lay understanding may even conflict with the healthcare professional's perspective. This conflicting view may lead to a lack of communication between provider and patient.

More specifically, exploring how Mexican Americans at the U.S-Mexico border understand pre-diabetes and the possibility for developing diabetes may help improve health outcomes (Jezewski & Poss, 2002) and may contribute to more culturally competent interventions among this population (Alcozer, 2000). Exploring how Mexican Americans at the U.S-Mexico border understand risk for diabetes may facilitate communication between providers and patients, and it may provide a foundation for healthier behaviors such as prevention of weight gain by means of lifestyle modification.

Statement of Purpose

The purpose of this study is to explore how Mexican Americans who live at the U.S.-Mexico border understand pre-diabetes and the possibility for developing diabetes. This study

will be guided by critical social theory and by Freire's (2005) conceptual framework of emancipation. This study will use a qualitative approach (e.g., critical ethnography that will elicit how Mexican Americans understand pre-diabetes and the possibility for developing diabetes). The overall goal is to develop an interpretive theory about risk among Mexican Americans in the U.S.-Mexico border region that will provide healthcare professionals with a starting point to understand risk from the client's perspective.

Research Questions

The research questions are:

1. How do Mexican American adults at the U.S.-Mexico border understand pre-diabetes?
2. How do Mexican Americans understand their possibility for developing diabetes?
3. How does being diagnosed with pre-diabetes influence the daily life of Mexican American adults in the U.S.-Mexico border region?

Significance of the Study

There are gaps in the literature about how Mexican Americans understand pre-diabetes and their possibility of developing diabetes. Current literature focuses on studies of causality, folk beliefs, symptoms, and treatments. Current studies do not provide a framework in which healthcare professionals can identify how Mexican Americans understand pre-diabetes and the possibility for developing diabetes or how to incorporate these lay understandings into their practice, research, and education. Understanding pre-diabetes and the possibility for developing diabetes and how this understanding influences the life experience of Mexican Americans in the U.S.-Mexico border region may also provide the foundation for educational programs, early

intervention, or clinical practice that encourages the adoption of healthier lifestyle behaviors (Heuer & Lausch, 2006; Kieffer, Willis, Arellano, & Guzman, 2002).

There are no studies exploring how the diagnosis of pre-diabetes influences the daily life of Mexican Americans. Exploring how Mexican Americans understand pre-diabetes and the possibility of developing diabetes may assist clinicians and researchers to provide interventions that increase the likelihood of healthcare and lifestyle changes. These interventions will in turn help delay or prevent the onset of diabetes among Mexican Americans.

This study will address the existent gaps in the literature by exploring how Mexican Americans in the U.S.-Mexico border region understand pre-diabetes and the possibility for developing diabetes. This study will explore how this understanding influences the daily experiences of Mexican Americans. The results may provide a starting point in at which health care professionals, researchers, and educators may plan interventions that consider the findings of this study.

Conceptual Orientation

Critical social theory is the guiding conceptual framework used for this study. More specifically, Freire's theory of emancipation will be used. Critical social theory emerged during the 1920s and 1930s in Frankfurt, Germany at the Institute of Social Research, also known as the Frankfurt School (Manias & Street, 2000; Boutain, 1999; Mohammed, 2006; Crotty, 1998). Critical social theory was influenced by scholars such as Horkheimer, Adorno, and Marcuse who were heavily influenced by their experiences of World War I. Their interdisciplinary writings produced a school of interdisciplinary thought that can be more properly called a "theoretical tradition" (Kincheloe & McLaren, 1994) rather than a single theory. Second and third generation

critical theorists European philosophers such as: Habermas, Foucault, and Derrida; Latin American thinkers such as: Paulo Freire; and feminist thinkers such as: Irigaray and Kristeva were greatly influenced by the critical social thought of philosophers such as Marx, Weber, Kant, and Hegel and by the members of the Frankfurt school (Kincheloe & McLaren, 1994).

Critical social theory is a nomenclature of ideas that has given rise to numerous theoretical frameworks, including the theory of emancipation. Some of the common ideas held by critical social theorists include, among others, the beliefs that: 1) social phenomena does not take place apart from a historical, cultural, and human context; 2) power relationships influence knowledge development and societal structures that promote inequalities; 3) language is essential in the development of meaning and the creation of knowledge; 4) cultural, socioeconomic, and political situations are created and may be transformed; and 5) research is a political activity with an emancipatory intent (Manias & Street, 2000; Boutain, 1999; Mohammed, 2006; Stevens, 1989; Kincheloe & McLaren, 1994; Thomas, 1993; Denzin & Lincoln, 1994). An exponent of critical theory is Paulo Freire, who shares the views of emancipation, critical thinking, and praxis, as proclaimed by modern critical social scholars. Freire's theory of emancipation will be the guiding framework for this study.

Freire's Contributions to Critical Social Theory

Paulo Freire was born in Recife, Brazil, on September 19, 1921. He was a professor of history and philosophy of education at the University of Recife. As such, Freire was involved in a literacy program in which he applied the philosophy of education he learned while teaching poor peasants in the slums of his native city (Crotty, 1998; Lima-Miranda & Teixeira-Barroso, 2004). He was sent to Chile in exile after a *coup d'etat*, and again declared a *persona non grata*

by the new governing militia after Chile's presidential assassination. Eventually, Freire became a professor at Harvard University and an educational consultant in Geneva and various African countries. In 1980, he returned to Brazil. Freire died May 2, 1997 (Crotty, 1998; Lima-Miranda & Teixeira-Barroso, 2004). His best known books are *Pedagogy of the Oppressed*, (1970), *Pedagogy of Hope* (1992), and *Pedagogy of Indignation* (1996). Following are some of the key concepts of Freire's pedagogy that will guide this research study.

Emancipation

Freire's emancipatory and educational underpinnings emerge from his early work among the poor of Recife in the early 1960's and from his work among the indigenous people of Chile, where he was an exile for six years (Crotty, 1998; Freire, 2000). Freire's approach to education, which he views as an instrument of emancipation, consists in first "learning the language" of the people in order to find meanings that would evoke a response. Freire asserts that emancipation is the process of becoming more human by means of liberating oneself from oppression.

Emancipation, Freire says, is the main task of human beings (Freire, 2000; Crotty, 1998).

Freire believes that human beings can be dehumanized by unjust situations provoked by exploitation, oppression, and ignorance (Freire, 2000; Crotty, 1998). Emancipation, by means of liberating education, advances humanization and is partly achieved by rejecting the "banking education" concept, which merely considers the student a passive recipient of knowledge while mirroring the oppressive patterns of society.

Emancipation is a process of continuous dialogue between the student and the teacher. This continuous interaction allows for a constant invention and reinvention of ideas that leads to critical thinking (Freire, 2000). Emancipation allows the individual to separate him/herself from

constraining ways of thinking and instead focus on ideas that lead to action and change (Thomas, 1993). In Freire's thinking of emancipation is the belief, supported by other critical theorists such as Habermas (Crotty, 1998), that human beings are co-creators of their reality by the mere fact of being conscious people. That is, people are not only in the world, but also essentially related to the world by being immersed in it (Freire, 2000; Crotty, 1998).

Problem-posing education is a process of emancipation that serves to create dialogue between the student-teacher and the teacher-student. By means of problem-posing education, people start discovering reality, as mediated by the cognizable objects present in the world (Freire, 2000). Awareness of this reality is developed by the use of critical thinking, which is also known as conscientisation, a concept closely linked to emancipation.

Conscientisation

Conscientisation, also called critical consciousness, critical perception, or critical thinking (Crotty, 1998), is the ability to perceive social, political, and economic inconsistencies in society, and to be able to take action on addressing them (Freire, 2000). Conscientisation goes beyond being conscious of a situation; it involves analysis of a situation in order to change it. Critical consciousness involves a deeper reality in which the individual becomes capable of understanding his or her relationship with the world (Freire, 2000; Estrela, 1999).

Conscientisation is a form of emancipatory learning by which people develop critical consciousness in order to challenge the ideas of a dominant group. Through the process of conscientisation, people can transform the world around them (Freire, 2000; Crotty, 1998). The process of conscientisation has as its point of departure men and women in the "here and now,"

that is, people submerged in the situation from which they must emerge and intervene. This emerging and intervening cannot happen without praxis (Freire, 2000).

Praxis

Praxis, as stated by Freire (2000), is “the action and reflection of men and women upon their world in order to transform it” (pg. 79). For Freire, praxis can never be a merely intellectual process, unless it becomes pure verbalism. It can neither involve pure action because it runs the danger of becoming “pure activism” (Freire, 2000; Crotty, 1998; Estrela, 1999). For Freire, praxis must involve a creative interaction between reflection and action that leads to conscientisation. Praxis must connect experience, understanding, and action in order to bring about social change (Thompson, 2000). In addition, reflection and action must happen simultaneously, one does not precede the other, and in this unity, “they illuminate each other” (Freire, 2000; Crotty, 1998). The action referred to by Freire is the being-in-the-world of each individual. People become the subjects, and not merely the objects of history. In becoming the subjects they become the co-creators and shapers of history, and it is this process of shaping history that leads to critical thinking and conscientisation (Crotty, 1998).

This qualitative study will use critical ethnography to answer the research questions. Critical ethnography is a scientific process that involves reflection in order to challenge current social, economical, and cultural situations. It asks, not what is, but what it could be (Thomas, 1993). In this study, critical ethnography will explore the understanding of pre-diabetes to arrive at the insider’s understanding of pre-diabetes and the possibility of developing diabetes.

Summary

Chapter one has described the purpose of this study, which is to explore how Mexican Americans at the U.S.-Mexico border understand pre-diabetes and the possibility for developing diabetes and how being diagnosed with pre-diabetes influences their lifestyle. Lastly, it will explore how being diagnosed as pre-diabetic influences the daily life experiences of Mexican Americans in the U.S.-Mexico border region. This chapter has included a brief review of diabetes among Mexican Americans, a description of the U.S.-Mexico border region, research questions, and significance of the study.

A review of critical social theory and Freire's concepts of emancipation, conscientisation, and praxis were presented as concepts that can help us understand how risk is understood among Mexican Americans. By exploring how Mexican Americans at the U.S-Mexico border understand their risk for diabetes, healthcare professionals can begin to address issues such as prevalence, compliance, and health behaviors that may delay or prevent the onset of diabetes among this population. By exploring the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans, healthcare professionals can address those sociopolitical influences that foster unhealthy lifestyles, thus effecting social change among Mexican Americans susceptible to diabetes. Chapter two will present a review of literature that is relevant for this study.

CHAPTER 2: LITERATURE REVIEW

The purpose of this study is to explore how Mexican Americans in the U.S-Mexico border region understand pre-diabetes and the possibility of developing diabetes. The aims of this study are: 1) explore how Mexican Americans conceptualize pre-diabetes and the possibility of developing diabetes, and 2) understand how being diagnosed with pre-diabetes influences the lifestyle of Mexican Americans. This chapter consists of two areas of concentration. The first section offers a background on pre-diabetes and diabetes in Mexican Americans. The second part consists of a review of the literature as it relates to risk perception and health beliefs about diabetes.

This chapter is organized into sections that focus on broad areas of research to specifically target gaps in our knowledge about how Mexican Americans understand pre-diabetes and the possibility of developing diabetes. The literature review will be followed by a discussion of the significance of this research and how the findings from this study will address gaps in the literature increasing our understanding of how Mexican American adults living at the U.S.-Mexican border conceptualize and enact their understanding of pre-diabetes and the possibility of developing diabetes.

Pre-diabetes

Pre-diabetes rates are higher among Mexican Americans than non-Hispanic Whites and non-Hispanic Blacks (Cowie, Rust, Byrd-Hold, Eberhardt, Flegal, Engelgau, Saydah, Williams, Geiss, & Gregg, 2006; Harris, Flegal, Cowie, Eberhardt, Goldstein, Little, Wiedmeyer, & Byrd-Holt, 1998). The National Health and Nutrition Examination Survey 1999-2002 found that over 30% of Mexican Americans have pre-diabetes (Cowie et al., 2006). People with pre-diabetes are

at higher risk of developing diabetes than people without pre-diabetes (Cowie et al., 2006). The Expert Committee on the Diagnosis and Classification of Diabetes Mellitus (2003) defines pre-diabetes as fasting plasma glucose (FPG) levels of 100 – 125 mg/dL or 2-hour values in the oral glucose tolerance test (OGTT) of 140 – 200 mg/dL. The American Diabetes Association (ADA) establishes an intermediate phase between normal blood glucose and diabetes known as pre-diabetes. Pre-diabetes includes impaired fasting glucose (fasting blood sugars between 110 and 126 mg/dl), determined by a single random plasma glucose test. If a 2 hour oral glucose tolerance test reveals plasma glucose levels between 140 and 200 mg/dl, the individual is then said to have impaired glucose tolerance (ADA, 2005; Hunt, Resendez, Williams, Haffner, & Stern, 2004; Alberti & Zimmet, 1998; Vaccaro, Ruffa, Imperatore, Iovino, Albarosa-Rivellese, & Riccardi, 1999). Persons with pre-diabetes are at a much higher risk for cardiovascular disease when contributing factors such as hypertension, dyslipidemia, and central body obesity are present (Winer & Sowers, 2004; Zimmet et al., 2001; Alberti & Zimmet, 1998). The Hoorn study found that 33% of people with IFG and 64.5% of persons with IGT developed diabetes over a period of 6 years (de Vegt, Dekker, Jager, Hienkens, Kostense, Stehouwer et al., 2001). Another study, conducted in the Netherlands, concluded that 15% of persons with IGT developed diabetes within 30 months (Eschwege, Charles, Simon, Thibult, & Balkau, 2001). The discrepancy in percentages may be due to the fact that some participants may have had more years with hyperglycemia and associated risk factors than others (Nichols, Hillier, & Brown, 2007).

Pre-diabetes develops much earlier among Mexican Americans and other Hispanics in general, usually around 20 to 30 years of age, versus 40 to 60 years of age among the general

U.S. population (Idrogo & Mazze, 2004). The 1999-2004 National Health and Nutrition Examination Survey (NHANES) estimated that, among Mexican Americans over 20 years of age, about 37.5% of males, and about 22.6% of females had pre-diabetes between 1999 and 2004 (AHA, 2007).

Diabetes

Diabetes is a chronic, progressive disease that is classified into two different diagnostic categories. Type 1 is characterized by a complete deficiency in the production of insulin by the pancreas. Formerly, type 1 diabetes was known as “juvenile” diabetes because of its incidence among children and young people. However, the adjective “juvenile” has become obsolete since the incidence of type 2 diabetes, formerly known as adult-onset diabetes, has increased at a rate between 8-45% in the last few years among the pediatric and adolescent populations (Kaufman, 2002). Type 2 diabetes is characterized by the defective secretion of insulin by the pancreas and/or insulin resistance in muscle, fat, or hepatic tissues (Zimmet, Alberti, & Shaw, 2001; National Diabetes Information Clearinghouse [NDIC], 2002; Skyler & Hirsch, 2001). The World Health Organization (WHO) has established criteria for the diagnosis of type 2 diabetes. It is a fasting plasma glucose level greater than 126 mg/dL and/or a 2-hour post load glucose level of greater than 200 mg/dL (Alberti & Zimmet, 1998). Obesity, decreased levels of exercise, sedentary lifestyles, and changes in dietary patterns are all risks contributing to the epidemic of type 2 diabetes among young people and adults (Hale, 2004; Kaufman, 2002; Fagot-Campagna, 2000).

Worldwide, diabetes is a pandemic expected to affect over 220 million people in 2020 (Zimmet et al., 2001). In the United States, diabetes is also on the rise (Burke et al., 1999) and

affects over 16 million Americans; about one third of those having diabetes are undiagnosed (Ismail, 1999; Brown et al., 2002; ADA, 2005), and most remain undiagnosed for an average of four to ten years (Skyler & Hirsch, 2001; Irons, Mazzolini, & Greene, 2003). The numbers of people with diabetes continue to rise at an alarming rate. Each year, over 880,000 people in the United States, or about 2,200 per day, are diagnosed with diabetes and about 182,000 people die of diabetes-related consequences each year (Skyler & Hirsch, 2001). Furthermore, it is estimated that over 56 million Americans have pre-diabetes (ADA, 2001; American Heart Association [AHA], 2007).

Diabetes can lead to premature death and an increase in the incidence of other illnesses such as cardiovascular disease, retinopathy, neuropathy, kidney disease (Winer & Sowers, 2004; Skyler & Hirsch, 2001; Brown, 2002; Burke et al., 1999). Diabetes alone is the number one cause of blindness, end-stage renal disease, and limb amputation, and an estimated 90% of all of these tragic health outcomes are preventable (Skyler & Hirsch, 2001). In addition, diabetes causes great emotional and financial cost to patients, families, and healthcare systems (Bertera, 2003; Brown, 2002). In the United States, about 98 billion dollars per year are spent on diabetes and related complications (Brown, 2002; ADA, 2001).

Diabetes disproportionately affects ethnic minorities and is closely related to socioeconomic status. For example, the 1999 Behavioral Risk Factor Surveillance System (BRFSS) found that diabetes is more prevalent among Blacks and Hispanics, and among people who are less educated and whose household income is less than \$25,000 a year (Egede & Zheng, 2002). Diabetes is also prevalent among Native Americans. The Indian Health Services (IHS) calculated that in 2003, almost 13% of all Native Americans who received care in one of its

clinics had diabetes. The total prevalence of diabetes among Native Americans aged 20 years or older is 15.1% (ADA, 2003).

Diabetes is twice as likely to affect Mexican Americans as non-Hispanic Whites older than 20 years old (CDC, 2003; Wen, Shepherd, & Parchman, 2004). The San Antonio Heart Study found that the incidence of diabetes between 1987 and 1998 almost tripled among Mexican Americans (Burke, Williams, Gaskill, Hazuda, Haffner, & Stern, 1999). Among Mexican Americans, diabetes leads to lower productivity and fewer opportunities for employment (Bastida & Pagan, 2002). Diabetes is also diagnosed at a more advanced stage for Mexican Americans and the negative health consequences are greater (e.g., greater loss of limbs, more advanced kidney disease, more advanced diabetic retinopathy), (Harris et al., 1998; Arar, Hazuda, Plaetke, Sartorio, Arar, & Abboud, 2003). The understanding of diabetes as a disease that manifests itself as sudden onset has radically changed over the years. Diabetes is now understood as the manifestation of a broad range of metabolic disorders that appear years and even decades before the diagnosis of diabetes (Brown, 2002; Burke, Williams, Gaskill, Hazuda, Haffner, & Stern, 1999). Prior to the development of diabetes, an intermediate state of hyperglycemia has been identified. These higher-than-normal blood glucose levels are known as impaired fasting glucose (IFG) and impaired glucose tolerance (IGT), or pre-diabetes.

Non-modifiable Risks for Diabetes

Non-modifiable risk factors are factors that cannot be controlled or changed. Non-modifiable risk factors for diabetes include age, gender, family history, race and ethnicity (ADA, 2003).

Age

Age is a risk factor that when coupled with obesity and physical inactivity, greatly increases the probability for acquiring diabetes. A study by Choi and Shi (2001) among Canadians showed that increased age, coupled with obesity, smoking, and decreased levels of exercise, significantly increase the incidence of diabetes. In addition, the prevalence of diabetes increases dramatically on people who are 55 years or older, especially among African Americans and Hispanics (Egede & Zheng, 2002). In addition, diabetes is increasing among children (ADA, 2003). It is estimated that over 2 million adolescents aged 12-19 have pre-diabetes (ADA, 2003). Type 1 diabetes used to be the more prevalent form of diabetes among children and adolescents. However, type 2 diabetes is being diagnosed more frequently in children and adolescents, particularly among minority youth (ADA, 2003; Trevino, Marshall, Hale, Rodriguez, Baker, & Gomez, 1999). Presently, about one third of all children and adolescents diagnosed with diabetes have type 2 diabetes (Bloomgarden, 2004; Rosenbloom, Joe, Young, & Winter, 1999).

Gender

In the United States, 10.5% of all males over 20 years of age have diabetes, versus 8.8% of women (ADA, 2007). Among Mexican Americans age 20 or older, diabetes affects 11% of the male population, and 10.9% of all women of Mexican origin (AHA, 2007).

Ethnicity and Genetics

Ethnic minorities are disproportionately affected by diabetes. One of the theories for the prevalence of diabetes among certain minority populations was originally proposed by Neel (1962). In a classical genetic study, Neel proposed that certain ethnic groups may have a genotype, the “thrifty gene,” that allows for survival during times of famine or less plentiful

seasons (1962). The increased incidence of diabetes is believed to be caused by genetic predisposition to preserve glucose during times of starvation (Lazar, 2005). Obesity and insulin resistance thus increase the chances for developing diabetes in a society that consumes overly rich foods and leads a more sedentary lifestyle (Winer & Sowers, 2004; Lazar, 2005). The theory of “thrifty phenotypes” includes the hypothesis that poor nutrition during pregnancy is associated with consequent obesity and predisposition to type 2 diabetes (Lazar, 2005; Hales & Barker, 1992).

Modifiable Risk Factors

Modifiable risks for diabetes are factors that can be changed by behaviors such as eating a healthy diet, engaging in exercise and increasing physical activities. Risk factors include being overweight or obese, sedentary lifestyle, smoking, elevated blood sugar, unhealthy cholesterol levels, and high blood pressure (ADA, 2005).

Obesity or Overweight.

Obesity is one of the main risk factors for developing diabetes (ADA, 2005). Obesity in adults is defined as a body mass index (BMI) greater than 30 kg/m². In children, obesity is defined as having a BMI above the 95th percentile. Persons with a higher BMI have a greater risk for developing diabetes and cardiovascular disease than people with lower or normal BMI (Choi & Shi, 2001; Egede & Zheng, 2002). The prevalence of obesity and overweight among adults and children in the U.S. has been on the rise for the last 40 years. However, obesity has been more prominent among racial and ethnic minorities. For example, data extrapolated from the 1999-2000 National Health and Nutrition Examination Survey (NHANES) demonstrated that the prevalence of obesity among Mexican men and women was 39.7% and 28.9% respectively

(Cossrow & Falkner, 2004). Preventing obesity and/or overweight in adults and children results in the greatest reduction of risk for developing diabetes. Among Mexican Americans, reducing weight would result in a 62% reduction of risk for acquiring diabetes (Burke et al., 1999).

Sedentary Lifestyle.

Sedentary lifestyle is a modifiable risk factor that is often targeted by researchers and clinicians because of its amenability to life style modifications. It is estimated that about 65.5% of people with diabetes do not exercise regularly (Egede & Zheng, 2002). Exercise improves weight loss and glycemic control. Empiric studies have demonstrated that lifestyle modifications targeting increased physical activities have a positive effect on the prevention of diabetes (ADA, 2003; Diabetes Prevention Program Research Group, 2000; Foreyt & Poston, 1999). These interventions have proven to be especially effective among minority populations, including Mexican Americans (Foreyt & Poston, 1999). The benefits of lifestyle modifications targeting sedentary lifestyle have been described in numerous studies. For example, increased physical activity has a positive effect on weight reduction, decreased abdominal adiposity, and increased insulin receptivity (Buemann & Tremblay, 1996). In addition, diet and exercise together help improve glycemic control better than just one of these lifestyle modifications alone (Yamanouchi, Shinozaki, Chikada, Nishikawa, Ito, Shimizu et al., 1995).

Unhealthy Cholesterol Levels.

Low levels of high-density lipoprotein (HDL) cholesterol and high triglyceride levels are contributors to diabetes (Park, Zhu, Palaniappan, Heshka, Carnethon, & Heymsfield, 2003). Together with other risk factors, such as pre-diabetes, obesity, older age, and high blood pressure, these risk factors are known collectively as syndrome X or metabolic syndrome. High

triglyceride levels (greater than 150 mg/dL) and low HDL cholesterol levels (less than 40 mg/dL for men and less than 50 mg/dL for women) are contributing factors to the onset of diabetes.

High Blood Pressure.

High blood pressure is related to an increased risk for developing diabetes. A study conducted in Europe by Conen, Ridker, Mora, Buring, and Glynn (2007) found that even in the absence of other risk factors such as obesity, high cholesterol levels and pre-diabetes, women who have high blood pressure have an increased risk for developing diabetes.

Some studies have demonstrated that interventions aimed at lifestyle modifications such as consuming a diet low in fat and increased amount of physical activity are successful in delaying or preventing the onset of pre-diabetes and diabetes (Tuomilehto, Lindstrom, Eriksson, Valle, Hamalainen, Ilanne-Parikka et al., 2001; Diabetes Prevention Program Research Group, 2002; Buchanan, 2003). However, other studies have found that lifestyle modifications are often transient and that lifestyle interventions do not appropriately address the complex life experiences of people with diabetes (Hunt et al., 1998).

Literature Review of Risk Perception

Three distinct, successive phases were implemented to search for appropriate literature. MEDLINE, CINAHL, and PsychINFO were searched to review the current literature. The first phase included a literature review on diabetes, its epidemiology, consequences and risk factors. The first phase of the review of literature included pre-diabetes. To elicit the literature about diabetes and Mexican Americans, the keyword “Mexican Americans” was added to this first phase. Secondly, articles related to understanding risk and risk perception as keywords were explored. Since risk perception literature started appearing more frequently in the 1980’s

(Skolbekken, 1995, Jacobs, 2000), the literature review included articles addressing risk perception from 1980 to the present. The MEDLINE search yielded a total of 639 entries, while a search on PsychINFO on the same dates yielded 2429 entries. CINAHL offered a total of 253 entries using risk perception as a keyword.

A total of 120 articles were reviewed, and about 60 were chosen for their relevance to contribute to this study. Many of the articles reviewed focused on cancer, HIV/AIDS, and risky health behaviors. Six empirically-based articles addressed risk perception and diabetes but none of them included Mexican Americans in the sample (Walker et al., 2003; Farmer, Levy, & Turner, 1999; Adriaanse, Snoek, Dekker, Spijkerman, Nijpels, van der Ploeg, & Heine, 2003; Pierce, Hayworth, Warburton, Keen, & Bradley, 1999; Harwell, Dettori, Flook, Priest, Williamson, Helgerson, & Gohdes, 2001; Kemple, Zlot, & Leman, 2005).

During the literature review, it became quite apparent that the concept *perception* is more often used in sociological and medical fields, while the term *understanding* is more prevalent in the nursing literature. Also, *perception* appears more often in quantitative studies, while *understanding* and *conceptualization* appear more often in qualitative research studies. Most researchers who study risk agree that perception of risk reflects beliefs such as perceived risk and perceived seriousness (Slovic, 1987; Fisher, Walker, Bostrom, Fischhoff, Haire-Joshu, & Johnson, 2002).

Defining Risk and Risk Perception

Risk

Risk is difficult to define. The difficulties of defining risk arise partially from the many dimensions that compose risk. For example, risk can be understood as the probability for an

illness, or as the consequence of an illness (Walker et al., 2003). Another difficulty in defining risk is that there is no tangible object that can be called risk (Oltedal, 2003) and the term can prove difficult to measure (Dowling & Staelin, 1994). For example, people who estimate their risk numerically, such as in percentages tend to greatly overestimate their judgment of risk (Jia, Santana, & Lubetkin, 2004; Schwartz, Woloshin, Black, & Welch, 1997).

Factors such as gender, worldviews, affiliation, emotional affect, trust, ethnicity, and the degree of knowledge, motivation, and education also affect the degree of perception of risk. In addition, perceptions of risk can be interpreted differently by various groups of people (WHO, 2002, Millstein, n.d.; Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Schoenberg, Amey, & Coward, 1998; Jia et al., 2004). Thus, the concept of risk implies many different meanings; it is used in many different contexts, and is usually subject to interpretation.

Risk is defined by the Webster's New World College Dictionary (2004) as "the chance of injury, damage or loss; dangerous chance, hazard" or to "expose to the chance of injury, damage, or loss." Risk may also be understood as the perceived probability or chance of developing a disease (Jia et al., 2004; Walker et al., 2003; Jacobs, 2000; Finucane & Holup, 2004; Aiken et al., 2001; Leventhal, Kelly & Leventhal, 1999), as something unknown to be dreaded (Slovic, 1987), or as the consequences of an illness (Jia et al., 2004). Adams (1995) defines risk as the "probability of an adverse future event multiplied by its magnitude." This tendency to view risk in terms of negative outcomes has been evolving since the 17th century from a neutral construct dealing with probabilities of losing or winning in gambling to a concept that denotes threat, or illness (Jacobs, 2000, Hayes, 1992, Slovic, 1987, Walker, 2003). For the purposes of this study, risk will be defined as the probability of developing diabetes.

Risk Perception

The term perception is defined by the Webster's World College Dictionary (2004) as the "the act of perceiving of the ability to perceive, mental grasp of objects, qualities, etc. by means of the senses; awareness, comprehension." Risk perceptions generally refer to people's judgment of risk (Slovic, 1987), or to "the extent to which individuals believe that they are subject to a health threat" (Becker, 1990). For the purpose of this study, risk perception will be defined as the "person's perceived probability of developing diabetes."

There is a paucity of literature about how much Mexican Americans (MA) understand their risk for developing diabetes. A few research studies have been conducted on perceived risk and perceived seriousness of diabetes. While it is possible to make several assumptions about how MA's might perceive risk, there is no specific literature on this important topic. How individuals conceptualize their individual risk for a particular illness or disease may have a profound influence on their health promotion behaviors, those behaviors that that persons knowingly adapt to lower their risk of developing disease.

Perceptions of Risk for Diabetes

Limited literature was found on risk perception and diabetes. Most literature on risk perception was related to cancer, HIV/AIDS, and risky behaviors (Aiken, Gerend, & Jackson, 2001; Barden-O'Fallon, deGraft-Johnson, Bisika, Sulzbach, Benson, Tsui, 2004; Connors, 1992). However, seven articles were found that addressed risk perception and diabetes. These articles focused on a wide variety of approaches of explaining risk perception: perception of risk for diabetes among siblings and children of people with diabetes (Farmer, Levy, & Turner, 1999; Pierce, Hayworth, Walburton, Keen, & Bradley, 1999), among people with one or more

predisposing risk factors (Harwell, Dettori, Flook, Priest, Williamson, Helgerson, & Gohdes, 2001), among the general population (Adriaanse, Snoek, Dekker, Spijkerman, Nijpels, van der Ploeg, & Heine, 20003), and among healthcare providers (Walker et al., 2003). One study reported results from a sample that included Hispanics but failed to report country of origin (Kemple, Zloty, & Leman, 2005), and only one other article specifically included Mexican Americans in their research samples (Kieffer, Willis, Arellano, & Guzman, 2002). These studies will now be reviewed and critiqued.

Farmer et al. (1999) carried out a quantitative study exploring the perception of risk for developing diabetes among 481 non-diabetic siblings of patients with type 2 diabetes. Perceptions of risk and perceived seriousness were assessed by one question regarding the likelihood of developing diabetes and another question dealing with seriousness of the disease. The responses to each question utilized a four-point Likert scale. The study found that less than half of siblings of persons with diabetes consider themselves at risk of acquiring the disease. In addition, while body mass index (BMI) is considered one of the strongest risk factors for developing diabetes; individuals with higher BMI's did not see themselves as being at higher risk for developing diabetes. On the other hand, having a parent with diabetes, and being a female between 35 and 54 years of age were factors that increased a person's perception of risk for diabetes.

The study by Farmer et al., (1999) was conducted in the United Kingdom and no racial or ethnic distribution was presented. The sample for this study consisted of persons who had a sibling with diabetes and we do not know if the findings can be generalized to other persons who do not have an immediate relative with diabetes. A serendipitous finding in this study suggests

that severity of diabetes in a parent may have some correlation with perception of risk for diabetes, but further research on this topic was suggested by the authors.

Persons with an immediate relative with diabetes are at higher risk for developing diabetes (ADA, 2003). However, people often underestimate their own or others' risk for developing the disease. A study by Pierce et al., (2003) explored the beliefs and concerns that people with type 2 diabetes had regarding their children's risk for developing diabetes. The study concluded that, while most parents with diabetes had some concerns about their children developing the disease, almost 70% believed that their children were not likely or very likely to get diabetes. This study involved 159 participants from four primary health care centers in the United Kingdom. A questionnaire was mailed to all participants. The survey included questions about demographic characteristics, questions about how participants view their children's risk for developing diabetes, and questions about knowledge of complications of diabetes. The questionnaire did not include any items exploring the meaning of risk or the perceived seriousness of diabetes. Only 44% of the participants thought that their children could do something to prevent diabetes, such as dietary changes and exercise. However, the participants in Pierce et al.'s study indicated that a change in diet and reducing one's consumption of sugar were the most effective ways of preventing diabetes (1999).

A study done in Montana by Harwell et al., (2001) explored the perception of risk for diabetes among a sample of 605 participants. The survey included people who were 45 years or older and excluded persons with a diagnosis of diabetes. The questions included "do you think you are at risk for diabetes?" "Do you think that you can prevent getting diabetes," and "Has a doctor or other health professional ever told you that you may be at risk for developing

diabetes?” and were asked via a telephone survey. Almost 75% of the participants did not believe themselves to be at risk of developing diabetes in spite of having one or more risk factors for developing the disease. The survey defined those at risk as persons being overweight or obese, being 45 years or older, having a family history of diabetes or having had gestational diabetes, high blood pressure, or high cholesterol levels. Women between the ages of 45 and 64 who were obese, had high blood pressure and had a family history of diabetes were more likely to consider themselves at higher risk for developing diabetes. In addition, people who had more than three risk factors (e.g. high blood pressure, high cholesterol, and a family history of diabetes), felt that they were less likely to be able to prevent diabetes. These participants were also less likely to have received medical advice from a health professional regarding risks for developing diabetes.

A quantitative study by Adriaanse et al., (2003) in the Netherlands found that almost half (43.5%) of the 7736 participants in their study were not able to estimate their risk for diabetes. The purpose for this study was to determine the perception of risk for type 2 diabetes among participants in a stepwise screening program for diabetes. This study was done among older adults (50-75 years of age), and a mostly Caucasian (99%) population in the West-Friesland region of the Netherlands. The study utilized a short, self-administered screening questionnaire that included some questions about perceived risk and seriousness. The question assessing risk perception used a Likert scale and asked participants to estimate their risk using an 11-point percentage scale (0-100%). In addition, the study asked participants to estimate their risk qualitatively, on a 6-point scale ranging from negligible to “very high.” Perceived seriousness was measured using a 4-point Likert scale by asking the following question: “I consider diabetes as...” the answers in the scale ranged from “not a serious disease” to a “very serious disease.”

Over 31% of the participants did not see themselves more at risk, in spite of being older, overweight, and having high blood pressure, the three risk factors for diabetes. Two hundred seventeen participants were subsequently diagnosed with diabetes using the WHO diagnostic criteria of fasting plasma glucose of 126 mg/dL or greater in two separate occasions or a 2-hour plasma glucose greater than 200 gm/dL. Of those diagnosed with diabetes, more than half (52.4%) were more likely to answer “I do not know” when asked to estimate their risk for developing diabetes. Only one participant diagnosed with diabetes estimated his risk to be more than 50%. In addition, 60% of the participants in the study perceived diabetes to be a very serious illness. The presence of risk factors such as higher age, obesity, and hypertension among the participants did not translate into higher perceived risk. Forty percent of the participants with an immediate blood relative with diabetes perceived themselves to be at risk for diabetes versus 20% of those without a relative with diabetes.

Risk may be perceived differently by healthcare professionals and lay persons (Slovic, 1987). At the same time, perceived risk for developing diabetes may vary among healthcare professionals. In addition, even healthcare professionals may not be fully aware of their own risk for acquiring diabetes. Walker et al. (2003) studied the perception of risk for diabetes among 535 non diabetic physicians in the United States. The study utilized the Risk Perception Survey for Developing Diabetes (RPS-DD), which consisted of four subscales measuring comparative risks, environmental risks, optimistic bias, and perceived personal control. The survey included 53 questions in a Likert scale format. The survey was administered to physicians attending continuing education conferences in the northeastern part of the United States. The majority of the participants were White (66.4%), followed by Asians (23.6%), Blacks (4.3%), and Hispanics

(2.6%). Study findings revealed that, while physicians at greater risk for developing diabetes had a greater sense of risk, almost 50% of the physicians in the study believed that they were at lower risk for developing the disease than other people their same age and sex (Walker et al., 2003). In addition, the study found varying degrees of concern among physicians according to ethnicity. For example, Asian physicians were more likely to report greater perception of risk than their White counterparts. Results for Hispanic physicians (2.6% of the sample) were not reported. The study found that the 196 physicians at higher risk tended to have a sense of less personal control, greater worry about developing diabetes, and greater perceived risk across multiple diseases. Interestingly enough, about 50% of low and high risk participants reported that they were less likely to develop diabetes when compared with someone of their same age and sex. This optimistic bias may arise from the physicians' sense of medical expertise and/or sense of personal control.

One of the strengths of Walker et al.,'s (2003) study is the inclusion of four sub-scales that measured factors related to risk perception (e.g., comparative disease risk, which measures perceived risk across other illnesses; comparative environmental risk, which measures perceived risk as compared to environmental threats; optimistic bias, which measures a person's perceived likelihood of developing diabetes). Last, the study included the personal control subscale, or the perceived personal control over developing diabetes. The study also included other possible dimensions of risk perception such as worry about developing diabetes and knowledge of risk factors. The study by Walker et al., (2003) is the most comprehensive quantitative study conducted on risk perception and diabetes. However, the sample included physicians only, and the results of Hispanic respondents were not reported separately.

A study by Kemple, Zlot and Leman (2005) included an undisclosed number of Hispanics in a quantitative random-digit-dialed household telephone survey exploring perception of risk among 1,974 residents of Oregon. The mean age of the respondents was 45 years, and the majority (84.7%) reported being non-Hispanic White. 6.8% were Hispanic and the other 7% were labeled as “other.” The country of origin of Hispanic respondents was not explored. This study found that less than a third of the respondents were concerned about developing diabetes, and less than half of total sample had been tested for diabetes in the previous year. Having a relative with diabetes was associated with perceived risk for developing diabetes, discussing the issue with a healthcare professional, and diabetes screening. Interestingly enough, Hispanics were more concerned about developing diabetes than the majority of the respondents, but were less likely to talk with a healthcare professional about diabetes or to be tested for diabetes. The authors did not disclose whether the survey was administered in Spanish to those who identified themselves as Hispanic. In addition, the survey did not include persons without telephone access, thus the generalizability of the study was limited. The findings about Hispanics in this study are interesting, but these findings cannot be generalized or be applied to Mexican Americans living at the U.S.-Mexico border.

Kieffer, Willis, Arellano and Guzman (2002) studied the perceptions of risk for diabetes of pregnant and postpartum Latina women and how this understanding influences involvement in physical activities. The purpose of the study was to explore the perceptions or risk for diabetes among postpartum Latino women, discuss the beliefs, attitudes, and practices of Latino women about physical activity, and explore the factors that influence the participation of Latino women in a regular program of exercise during and after pregnancy. This participatory research project

included a focus group that met at various intervals during the participants' pregnancy and after delivery. The study involved 13 pregnant participants during the first focus group and nine additional participants during the two postpartum focus groups for a total of 22 participants. Participants were mostly young, low-income Mexican women who primarily spoke Spanish as their first language. Most participants had less than 12 years of education, mostly in Mexico. Analysis of the data yielded five themes during the focus groups. This first group was held with women who were approximately 30 to 36 weeks pregnant. The second session was held at 4 to 12 weeks postpartum and the third session at 10 to 18 weeks postpartum. The questions of each of the focus groups built on themes identified by the participants. For example, in session 1, the participants identified the following themes related to barriers to physical activity: isolation, family responsibility, partners/spouses, community safety, lack of facilities, and health of self and baby. During session 2 of the focus group, women discussed why the elicited themes may be seen as barriers, how often they acted as barriers, and how these barriers could be addressed. In session 3, participants discussed the previous findings and discussed specific aspects of a program that could help them exercise more frequently (Kieffer et al., 2002). When asked about diabetes causes or risk factors, the participants reported that specific dietary practices, such as eating too many sweet foods or drinks or fatty foods increased the risk for developing diabetes. In addition, the participants mentioned that the experience of strong emotions such as *susto* (fear or fright) and *coraje* (anger) were precipitators of the onset of diabetes.

The findings of this study are limited to small sample of pregnant or postpartum Mexican women who were recruited via telephone and who frequently visited a local community health center. The findings of the study led to a discussion of a center-based group activity program that

included physical activities such as dancing. The authors do not mention whether the group was formed as an actual result of the participatory research study. However, the focus groups served to develop a social bond among the participants, which in turn could serve as catalyst for developing the above mentioned activity program.

Summary

Chapter 2 presented an overview of diabetes and pre-diabetes as a background for risk perception. A search of the literature failed to produce a study that dealt with the perception of risk for diabetes among Mexican American men and women. There was little research on risk perception and diabetes, either qualitative or quantitative. As a matter of fact, there is no quantitative or qualitative research that focuses on risk perception for diabetes among Mexican Americans. The literature review demonstrated that diabetes disproportionately affects minority populations, especially Mexican Americans. However, only one study included Mexican Americans, albeit only pregnant and postpartum women.

While it was acknowledged that a person's perceived risk may influence lifestyle behaviors that may prevent or delay the onset of diabetes, almost no research has been conducted on risk perception and diabetes. Seven articles addressed risk perception and diabetes, but none explored how this understanding of risk may influence lifestyle behaviors.

Risk is a subject that is not well described in the literature. Reasons for the diversity of definitions of risk may include the fact that risk is viewed differently by various cultures, and that current research has not focused on attempting to describe risk among ethnic minority populations. There was little research on how a person's cultural background may influence one's understanding of risk.

The results of some of the studies included in this review of the literature concluded that, in spite of the presence of one or more risk factors, most people were not aware of their risk. Most participants in the studies significantly underestimated their risk for developing diabetes. However, the causes for these misconceptions were not further explored by any of the research studies.

Perception of risk is defined as a person's perceived probability of developing an illness. However, this perception of risk has various dimensions (e.g., perceived seriousness). Most of the studies in the literature review did not adequately address the dimensions of risk perception (e.g., some articles explored perceived risk only, while some others included perceived seriousness, perceived control, and knowledge of risk factors).

The literature review revealed that diabetes disproportionately affects Mexican Americans, and that perception of risk may have a role in preventing or delaying the onset of diabetes. However, pre-diabetes risk perception for diabetes has not been widely studied, especially among Mexican Americans.

This study has the potential to significantly contribute to the literature on pre-diabetes and risk perception of diabetes among Mexican Americans providing researchers and healthcare professionals with information to assist in the implementation of effective programs and interventions to prevent or delay the onset of diabetes among Mexican Americans.

CHAPTER 3: METHODS

Qualitative research has its foundation in the naturalistic paradigm that emerged as a response to positivism (Lincoln & Guba, 1985; Crotty, 1998; Denzin & Lincoln, 2002). Positivism is a paradigm that is influenced largely by the search for objective knowledge by means of scientific observation, experiment, and comparison. Positivism emerged during the seventeenth century, during a time known as the *Enlightenment*, or *Age of Reason* (Crotty, 1998). Proponents of positivism rely heavily on quantitative methodologies and argue that knowledge can be measured quantitatively and knowledge that results from positivistic science is accurate, certain, verifiable, and objective. Some of the assumptions held by the positivistic paradigm include: 1) the belief that reality exists as a separate entity that can be studied objectively, can be broken down into pieces, and can be completely understood; 2) reality can be studied objectively by separating the observer from the reality in which he/she lives; 3) an assumption of “cause and effect” that allows generalization of findings to various populations if circumstances such as sampling and methods are rigorously controlled; and 4) an assumption that knowledge can be produced free of bias (Lincoln & Guba, 1985; Denzin & Lincoln, 2002). These positions have been challenged by numerous scientists. Positivistic assumptions, impossible to hold in a pluralistic world with many different realities, have given rise to a post-positivistic or naturalistic paradigm.

Post-positivistic inquiry evolved as a response to positivism’s narrow view of science and reality. It relies heavily in qualitative methodologies, but does not disregard quantitative methods. The tenets of the naturalistic paradigm illuminate the fact that knowledge is never certain and not always verifiable or objective. This paradigm challenges positivistic notions and

holds that: 1) there are multiple realities that are subjective, complex, and can only be partially understood; 2) reality and observer are always constantly interacting and one can never be understood separated from the other; 3) it is not always possible to distinguish between cause and effect; and 4) research is influenced by the values held by the researcher (Lincoln & Guba, 1985; Denzin & Lincoln, 2002). The tenets held by the naturalistic paradigm influence the use of methodologies that elicit a person's feelings, beliefs, values, and behaviors. The naturalistic paradigm acknowledges that reality is holistic, complex, and varies from person to person. "Every mind is a world" seems to be the *cri de guerre* of post-positivistic researchers against those who adhere to positivistic views.

Qualitative researchers explore the participant's point of view by immersing themselves in a "natural" setting and collecting data elicited from individuals, direct observation, and written documents. Qualitative researchers acknowledge the diversity of beliefs, values, and behaviors among individuals and use this collective knowledge to describe reality. This acknowledgment of plurality and the emphasis on subjective knowledge has led me to choose a qualitative approach to the study of risk perception for diabetes among Mexican American adults.

Chapter three provides a description of the qualitative method used for this study. The chapter is divided into three sections. The first section includes a description of ethnography and ethnographic techniques. The second section offers a description of the researcher and his role in the community, a description of the community where the study will be conducted, and the selection of participants. The third section includes a description of data collection and analysis, criteria used to evaluate the rigor of the study, as well as a description of the procedures for protection of human subjects.

Ethnography

Ethnography is a qualitative approach used for describing and analyzing how human behavior is influenced by culture. As such, ethnography is both a process of description and an analysis of how individuals or groups are influenced by their culture. The processes of ethnography consist of interviewing and direct observation as well as analysis of appropriate documents (Patton, 2002; Roper & Shapira, 2000). The methods utilized in the process of ethnography attempt to grasp the individual's point of view while producing a description of the behaviors, beliefs, and values of persons belonging to a particular culture.

Ethnography originated in anthropology for the purpose of describing the way of life of cultural groups (Germain, 2001). In its most traditional sense, ethnography involves doing field work and describing the patterns of behavior of a group of people. Ethnographers share an interest in culture but utilize various styles of ethnography to study patterns of behavior in the context of culture (Fetterman, 1998).

Critical ethnography is a style for doing ethnographic work that considers the use of knowledge for social change (Thomas, 1993). Critical ethnography is used by researchers to study cultural phenomena that are often "taken for granted;" this approach enhances the researcher's ability to reflectively analyze, describe, and question the *status quo* (Shambley-Ebron & Boyle, 2006; Thomas, 1993). This critical ethnographic study is situated within the historical, socioeconomic, political, and cultural context of the U.S.-Mexico border region. Guided by critical principles, especially Freire's (2000) emancipatory theory, this ethnographic study will explore the taken-for-granted assumptions that perpetuate conditions of inequality,

lack of access to healthcare, and prevent change from happening in a particular culture, namely, Mexican Americans living at the U.S.-Mexico border.

For the purpose of this study, culture is defined as a complex reality experienced by a group of individuals that includes “informing sets of activities such as routines, rituals, action conditions, systems of intelligibility and meaning making, conventions of interpretations, system relations, and conditions both external and internal to the social actor” (Carspecken, in Denzin, & Lincoln, 2004, pg. 329). Culture is no longer believed to simply be a set of customs and beliefs that can be described as if they never change. Instead, the new concept of culture adapted by modern ethnographers reflects the ever-changing complexity of behaviors and the variety of ideas, beliefs, and knowledge used by a group of individuals in their daily lives. This complex reality is what ethnography tries to capture by the use of open-ended questions, field observations, and by the participation in people’s daily lives for a period of time (Hammersley, & Atkinson, 2003; Germain, 2001).

This qualitative study uses a critical approach to focus on perception of risk for diabetes among Mexican Americans living at the U.S.-Mexico border. Ethnography was chosen for this study for various reasons. First, this design allows for the study of risk for diabetes among a particular subculture, namely, Mexican American adults living along the U.S.-Mexico border in Yuma County, Arizona, at a given period of time. Secondly, the research design allows for the description and critical analysis of health behaviors and beliefs as well as about risk perception for diabetes among Mexican American adults who live along the U.S.-Mexico border.

The Researcher

This section offers a description of the researcher and his role in the community as well as a description of the setting and the participants. The criteria for participant recruitment are also included.

I am a nurse practitioner with a private practice in San Luis, Arizona, a community that is 30 miles south of Yuma, Arizona, the city where this study will be conducted. I have access to various potential community outreach services and healthcare agencies in Yuma. As a Mexican American and a native of this area, I am supposed to know the culture and its inhabitants well. However, I left this area when I was about 20 years old. I lived in various cities of the United States and eventually graduated from college. After almost 20 years of being away from this area, I returned home, a native, but at the same time a stranger. I am a native because I was born in this area; I am familiar with the language, the local customs, and the people of Yuma County and the U.S.-Mexico border. However, I am at the same time a stranger; I left when I was young, and returned a grown man who had experienced other cultures, places and received an education that molded who I am now. I have lived in other places longer than I have lived here. I am also a religious, a member of a religious congregation in the Catholic Church. As such, some people may recognize me as a religious leader in the community, but most likely, people will not recognize me as such since I do not proselytize religion. In addition, I have been a nurse and a nurse practitioner in Yuma and San Luis for about 10 years. While the participants in the study will not be my own patients, some of them may be familiar with my role as a primary care provider in this area.

Cultural Assumptions and Bias

Some of the disadvantages of being a researcher from the same cultural background as the participants may include an assumed familiarity with the culture that may promote cultural assumptions and prevent the researcher from noticing the obvious as well as nuances in the culture. A researcher from the same cultural background may assume that he/she understands a particular phenomenon when indeed that is not the case. Also, the researcher may have pre-existing bias about the definition of risk and perception of risk for diabetes among the population; this is a disadvantage that is acknowledged and will be controlled for early in the research process. An experienced qualitative researcher, the chair of my dissertation committee, will read all transcripts and discuss interviewing techniques and participants responses. She will review coding and analysis of data, providing guidance throughout the research and writing processes to guard against biases that may inadvertently occur.

Setting

The setting for this study was Yuma, Arizona, a border city located in the Southwestern part of the state of Arizona. Yuma is about 22 miles north of the U.S.-Mexico border. Yuma is located in the border region, politically defined as the area that comprises the 62 miles on each side of the territorial line that divides the U.S. and Mexico. The City of Yuma has 96,120 residents, of which 53% are Hispanic, mostly of Mexican origin. (U.S. Census Bureau, 2006). Some parts of the city and the county are considered a Health Professional Shortage Area (HPSA) and an Arizona Medically Underserved Area (AzMUA) by the Arizona Department of Health Services (2006).

The incidence of diabetes among Arizona residents has more than double since 1990 (Behavioral Risk Factor Surveillance System (BRFSS), 2008), and continues to steadily rise. Yuma County has a higher incident of diabetes (10%) than the rest of Arizona (8.5%). The incidence of diabetes among Hispanic residents in Yuma County has remained the same when compared with other races (Pierce, 2008).

Description of the Participants in the Study

In qualitative research, the word “participant” is used to denote the principal unit of study; human beings. It is also used to mark a departure from a positivistic tendency that tends to see human beings as measurable, predictable, unchanging units of meaning. By utilizing the word “participant” rather than “subject” qualitative researchers declare that 1) human beings are constantly reinterpreting reality; 2) are immersed in a reality that is socially constructed; and 3) creatively participate in the construction and interpretation of meaning (Crotty, 1998).

Ten participants were recruited from a local physician office who had agreed to serve as site for participant recruitment. Criteria for selection of participants in this study included persons who:

1. Identified themselves as Mexican or Mexican Americans who spoke English or Spanish.
2. Lived along the U.S.-Mexico border region in Yuma, Arizona.
3. A patient of a physician who agreed to serve as a site for recruitment of participants in Yuma, Arizona.
4. Diagnosed as having pre-diabetes by a qualified healthcare provider within the past year. Pre-diabetes is defined as fasting blood sugars between 110 and 126 mg/dl, or a

- 2 hour oral glucose tolerance test with plasma glucose levels between 140 and 200 mg/dl, (ADA, 2005).
5. Mexican American adults between 21 and 46 years of age of either sex.
 6. Reflect thoughtfully and be able to answer interview questions.
 7. Willing to participate in the study.
 8. Able to read/write in English or Spanish.

Participant Recruitment

The recruitment of participants was conducted by purposive sampling. Purposive sampling is commonly used in qualitative research to select participants that are able to provide the most information-rich data that will enlighten and answer the research questions. Purposive sampling allows for identifying cases that meet predetermined criteria useful for the purpose of the study (Patton, 2002). For the purpose of this study, participants who met the aforementioned criteria for participation in the study were recruited.

Participants were recruited from a physician's office with high volume of Mexican American adult patients and who agreed to participate as recruitment site for the study. The physician or nurse practitioner at the healthcare clinic approached possible participants by identifying those patients who have been diagnosed with pre-diabetes in the last year or by identifying the potential participants when the diagnosis was made. These potential participants were then approached initially by the healthcare provider for possible participation in a study that explored the understanding of pre-diabetes and the possibility of developing diabetes. The participants were introduced to the study by means of a Participant Recruitment Script (Appendix A), handed out to them or read aloud by the staff member in the language of their

preference. If the participant agreed to participate, he/she filled in the contact information section of the Participant Recruitment Script. The healthcare provider then returned the forms to the researcher, who will in turn, contacted the participant. The researcher contacted the participant after the initial approach was made by the healthcare provider and made an appointment for the first interview. The time and location of the interviews were selected by the participants and the Informed Consent Form (Appendix B) were given to the participant to read and sign prior to beginning the interview process.

Procedures for Informed Consent

The Informed Consent Form used for this study was adapted from the forms provided by the Institutional Review Board (IRB) at the University of Arizona. The researcher made minor adaptations for the purposes of this study. The Informed Consent Form explained the purpose, procedures, risks, benefits, permission to audiotape the interviews, confidentiality, right to withdraw from the study, contact information, and the time needed for participation in the study.

The Informed Consent Form was written at a sixth grade reading level to facilitate reading among participants. Assistance was provided by the PI if the participant requested help with understanding or reading the Informed Consent Form.

Protection of Human Subjects

Participants were asked to voluntarily sign the Informed Consent Form (Appendix B) prior to the first interview. The informed Consent Form explained the study, its benefits and possible risks, the potential time involvement needed for the study, and a statement about the participant's right to withdraw from the study at any time. The Informed Consent Form also informed the participant that their healthcare at the clinic would not be affected in anyway

should he/she had decided to withdraw from the study. The informed consent forms were provided to participants in English according to each of the participant's preference. The study was approved by the Institutional Review Board at the University of Arizona prior to beginning the study.

Ethical Considerations

Ethical considerations included respect for persons, beneficence, and justice (Munhall, 2001). Issues regarding privacy and confidentiality were considered throughout the study. Privacy is defined by the Office of Human Research Protections (OHRP) as: "having control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others" (Levin-Penslar, & Porter, 1993). Privacy was achieved by offering the participant a time and place of their choice for the interviews, and by considering their time constraints.

Confidentiality refers to the management of information obtained from an individual with an understanding that such information will not be shared with others in ways that were not intended initially (Levin-Penslar and Porter, 1993). Processes such deleting names and places in the transcripts and field notes were put in place to ensure that participants had their confidentiality protected throughout the study. The data were kept in a locked file cabinet at the researcher's office. Audio taped interviews were destroyed after transcription and analysis of the data.

Anonymity of the participants and confidentiality of the data were protected by asking the participants not to state their names during the interview, and instead, they were given the opportunity to choose a fictitious name, namely, a favorite name of theirs. If the participant

happened to state his/her name during the interview, the name and any other identifying information were omitted in the transcription of the audio taped interviews. Field notes did not contain identifying information. The researcher deleted all references to names and places that identified the participant in the transcribed interviews to ensure anonymity. Data collected during the study were accessed only by the researcher and the dissertation committee members to enhance confidentiality.

Data Collection

The data collection procedures for this study included a demographic questionnaire, one semi-structured, in-depth interviews, and observation participation documented in field notes. Following is a description of each of the data collection procedures.

Demographic Questionnaire

The demographic questionnaire (Appendix C) consisted of a series of questions that were developed by the researcher in order to describe the sample. The demographic questionnaire was administered to the participants for completion at the beginning of the each interview.

The demographic questionnaire (Appendix C) included questions about age, gender, number of years living in the United States, number of years being diagnosed with pre-diabetes, place of birth and residence, English and Spanish proficiency, and family history of pre-diabetes. These demographic questions assisted the researcher in describing the sample.

Interviews

For the purposes of this study, a semi-structured, in-depth interview with open-ended questions was conducted with 10 participants, until theoretical saturation was achieved. Theoretical saturation refers to the repetition of information and confirmation of previously

collected data (Streubert & Carpenter, 1999; Morse, 1991). Semi-structured interviews allow for some flexibility while providing a set of questions that keep the interview focused on the subject of interest, and at the same time, permits for in-depth exploration of the issue at hand and the emergence of unexpected data (Munhall, 2001; Patton, 2002).

An interview with a grand tour question, open-ended questions and probing questions (Appendix D) was used with each of the participants. The grand tour question elicited the participants' knowledge and understanding of their views about pre-diabetes and diabetes, as well as their conceptualization of what pre-diabetes meant in relation to their own health. All participants were asked similar questions during the interviews. Probe questions and new questions were asked as the interview progressed with each of the participants. Open-ended questions allowed for the participant to express their opinions without being influenced by the interviewer's point of view (Patton, 2002). The interview elicited information about knowledge and understanding of pre-diabetes. This interview also elicited feelings and thoughts about the possibility of developing diabetes and a description of ways in which having pre-diabetes changed or not changed the participant's life.

The interviews were conducted by the researcher in English, which was the language of preference for all participants.

Interviews were audio-taped, names and places were not included in the taped interviews to enhance anonymity. The researcher transcribed all of the audio-taped interviews using a transcriber program. Once the transcription of the tapes was completed, the researcher reviewed the tapes against the written transcripts for accuracy of transcription. The transcribed interviews were password protected in the researcher's personal home computer. Pseudonyms were used

instead of personal names to protect anonymity. A form containing the participants' name and corresponding pseudonyms was kept in a locked drawer for the duration of the study and destroyed after the study had concluded.

Observation Participation

Observation participation is an ethnographic technique by which the ethnographer collects information in order to describe the setting, activities, meaning, and people in a study (Patton, 2002). Observation participation is an ethnographic activity by which the ethnographer relies more extensively in observational techniques than full participation in the lives of the participants. Observation participation allows for the ethnographer to be able to better observe the phenomena at hand and to rely less on preconceived assumptions. Observation participation occurred during the interviews, at the participants' homes and offices, and during informal situations such as interactions with other family members that happened to be present during the interviews. Data collected were recorded in field notes.

Field notes are written records that provided richness and context to the study and offered a description of behaviors and actions of participants throughout the duration of the study (Roper and Shapira, 2000). In addition, field notes contained the feelings and reactions of the ethnographer, and insights and interpretations of the analysis (Patton, 2002).

There are various forms of field notes. Wilson (1989) suggests a system for recording field notes that creates a paper or electronic trail to facilitate data collection and analysis as well as the feelings, reactions and hunches of the researcher. The four categories of field notes include: 1) observational notes (ONs) describe events and experiences obtained through watching and listening. These notes contain as full-as-possible description of the event and as

little interpretation as possible. ONs were taken during the interviews at the participants' homes; 2) theoretical notes (TNs) attempt to elicit meaning from the observational notes. The ethnographer attempts to interpret, understand, and hypothesize the events written in the observational notes; 3) methodological notes (MNs) are basically self-instructions to the ethnographer, evaluations of interactions between participants and researcher, and self-reminders about methodological approaches that may be helpful; and 4) personal notes (PNs) are notes about personal reactions, reflections, and experiences. These notes helped the ethnographer become self-reflective. Working field notes were done almost daily and provided a context for the study.

Semi-structured, in-depth interviews with open-ended questions were the primary source of information for data analysis. Secondary sources of information included the demographic questionnaire and observation participation.

A code book was created in Ethnograph v.5.0 to keep track of code definitions, and changes, as well as creating an audit trail that ensured consistency in coding (Siedel, 2002; Shambley-Ebron, & Boyle, 2006). Ethnograph V5.0 is a computer software program created by John V. Siedel (2000) to help manage data during analysis.

Data Analysis

Data analysis occurred concurrently with data collection (Speziale and Carpenter, 2003; Patton, 2002) and continued throughout the duration of the study. The information obtained from the demographic questionnaire was described in the text as well as shown in table 1, thus facilitating a description of the sample.

Each transcribed interview was read and re-read until the researcher became acquainted with the “raw” data. The process of transcribing each interview helped the researcher become familiar with the data. Small sections of the interview data were coded with a word or phrase that explained what each section described. Codes are words or phrases that describe units of meaning (Munhall, 2001) and served to summarize, synthesize, and sort the observations made from the data (Charmaz, 1983).

Codes were grouped into categories. Categories were levels of abstraction that result from analysis or linking together of smaller units of data, such as codes. Categories were then examined for consistency by means of “internal homogeneity,” or the extent to which data belong together in a category in a meaningful way. Categories were also checked for external “heterogeneity,” or the extent to which the various categories are different from each other (Patton, 2002). Categories that emerged from this process of examining homogeneity and heterogeneity were further grouped and classified into more abstract conceptualizations, or themes to portray the understanding of pre-diabetes and the possibility of developing diabetes among the participants. Further examination of interview transcripts, field notes, and the literature review generated an overarching theme about understanding of pre-diabetes and the possibility of developing diabetes.

Evaluation of Qualitative Methods

Evaluation criteria in qualitative research have evolved from a dependence on quantitative understandings of reliability, objectivity, and internal and external validity, to a more sophisticated, modernist understanding of a world with multiple realities. Evaluation in qualitative research focuses on the individual and the effect of research in society. Quantitative

research, in its most pure form, asks: *have we arrived at the truth through an infallible, systematically reproducible method that controls all variables?* On the other hand, qualitative research in the critical-constructivist tradition asks: *has our research been a catalyst for action?*

The evaluation method for this study on understanding of pre-diabetes and the possibility of developing diabetes among Mexican American adults included critical and constructivist criteria for evaluation of research. The researcher believes that the results of the study should help clarify the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans and eventually lead to a better understanding of health behaviors that prevent or delay the onset of diabetes among this group.

Earlier writings of Guba and Lincoln (1994, in Denzin and Lincoln, 1994) argued for a form of validity that compares, and at the same time, extends beyond the classical positivistic understandings of reliability (dependability), objectivity (confirmability), internal validity (credibility), and external validity (transferability). In that earlier edition, Guba and Lincoln (1994) state that the criteria for judging the goodness of quality of a study should include critical principles such as historical situatedness, ability to erode ignorance and misapprehensions, and ability to provide stimulus for action. Later, Guba and Lincoln (2005, in Denzin and Lincoln, 2005) continue their argument for criteria more in tune with constructivist science: validity as authenticity. The criteria for validity as authenticity are rooted in constructivist inquiry, rather than relying solely in concepts borrowed from quantitative paradigms of evaluation. The authenticity criteria include: 1) fairness, or the inclusion of views, perspectives, claims, and concerns of all the participants; 2) ontological and educational authenticities, as indicated by the raised level of awareness and moral critique among participants and among those whom they

come in contact with; and 3) catalytic and tactical authenticities, or the ability of a given study to promote action on the part of the participants and the ability of the researcher to train participants in specific forms of social and political action.

The criteria for validity suggested by Denzin and Lincoln (2005) fitted the philosophical perspective of this study, taken from emancipatory (Freire, 2002), and participatory action research stance. The researcher allowed the participants to express their views about their understanding of pre-diabetes and the possibility of developing diabetes freely, without imposing pre-conceived ideas or feelings. To ensure authenticity, the researcher confirmed rich thick descriptions to the point of data saturation. Following in the critical tradition, the researcher asked the participants to reflect on their understanding of pre-diabetes and explore ways in which that understanding influenced their daily lives. The analysis of personal situations that may contribute to understandings of pre-diabetes, and the resulting actions that may contribute to healthier lifestyles is called *conscientisation* (Freire, 2000). *Conscientisation* is a form of emancipatory learning by which people develop critical consciousness in order to challenge the *status quo*. Through the process of *conscientisation*, people can transform the world around them (Thompson, 2000; Freire, 2000; Crotty, 1998). Conscientisation enhanced authenticity by promoting healthier actions among the participants, and by allowing them to reflect about their understanding of pre-diabetes and the possibility of developing diabetes in the future.

Trustworthiness

Trustworthiness in qualitative research is compared to *rigor* in quantitative research. In qualitative research, trustworthiness means to accurately represent the participants' experiences (Speziale & Carpenter, 2003). Trustworthiness was enhanced by accurately representing the

participants' experiences and by asking the participants if the collected data and data analysis accurately reflected their experiences. Research processes that contribute to the enhancement of trustworthiness include dependability, confirmability, credibility, and transferability (Denzin & Lincoln, 1994; Speziale & Carpenter, 2003).

Dependability

Dependability is the process by which research findings are found to be dependable. Dependability relies in the consistency of data sources and the methods of data collection. In this study, dependability was enhanced by asking the same or similar questions of the participants and by repeated observations through observation participation experiences. Also, the responses to new questions that were generated from the on-going data analysis contributed to the dependability of the study as informational adequacy was ensured by the completeness and the amount of information. In addition, data and the processes of data analysis were shared and discussed with the dissertation chair who is an experienced qualitative researcher.

Confirmability

Confirmability refers to the standards of the process of data analysis. How does someone else confirm the findings of the study? This was done by verbatim transcription of interviews and by keeping of field notes made during observation participation. In addition, sharing data analysis as it developed with the participants enhanced confirmability. As the study was coming to a close, a confirmability audit was done by the researcher. A confirmability audit served to examine the data, findings, and interpretations, and demonstrated that such findings and interpretations were supported by the data collected (Lincoln & Guba, 1985).

Credibility

Credibility was enhanced by the continuous involvement of the researcher in the study. Careful selection of participants, recording of interviews, and accurate portrayal of the understanding of pre-diabetes and the possibility of developing diabetes among Mexican American adults enhanced credibility. Confirming findings with participants to see if the findings were true to their experiences was another technique to enhance credibility of data analysis (Speziale and Carpenter, 2003). In addition, continuous dialogue with dissertation chair about the data collected and the process of data analysis contributed to credibility.

Transferability

Transferability refers to the generalization of findings to another similar situation while preserving the same general meanings and interpretations (Speziale & Carpenter, 2003). Transferability was enhanced by providing thick descriptions of the phenomena under study for other researchers and by maintaining a clear audit trail.

Summary

Chapter three provided a description of the research methods that was used to explore the understanding of pre-diabetes and the possibility of developing diabetes among Mexican American adults. The first section included a description of ethnography and ethnographic techniques. The second section offered a description of the researcher and his role in the community, a description of Yuma, Arizona, the community where the study was conducted, and the selection of participants. The third section included a description of techniques used for data collection and analysis, criteria used to evaluate the rigor of the study, and a description of the procedures for protection of human subjects.

CHAPTER 4: DESCRIPTION OF PARTICIPANTS

Chapter four provides the sample characteristics, a brief description of the setting of the study, the demographic data provided by the participants during the initial interview, and a descriptive vignette of each of the participants.

Sample Characteristics

Potential participants in the study had to meet the following criteria in order to be considered for this study: a) Mexican or Mexican American; b) speak Spanish or English; c) live in Yuma County, Arizona; d) diagnosed with pre-diabetes by their healthcare provider in the previous year; e) between 21 and 46 years of age; f) able to reflect thoughtfully and be able to answer interview questions; g) willing to participate in the study; and h) able to read/write in English or Spanish. A total of ten participants were recruited this study. The formal data collection started on November, 2008 with the approval of The University of Arizona Institutional Review Board (IRB) and ended on November 11, 2009. A total of 16 potential participants were contacted initially for this study by their healthcare provider by means of a Participant Recruitment Form (Appendix A). These potential participants were recruited from a privately-owned physician office in Yuma, Arizona. Six of the potential participants declined to participate in the study after the first phone call. The reason most often provided was lack of time, or, in one case, the participant did not believe he had pre-diabetes, despite his provider's diagnosis. Another stated that he did not want to reveal personal information. Interviews were conducted with five participants, primarily in offices that provided privacy. Four interviews were conducted at the participant's homes, and one interview was conducted at a local restaurant that provided privacy for the tape recorded interview. The interviews were conducted at a time

convenient for each of the participants. All ten participants agreed to participate after a brief explanation of the study during the initial phone conversation. One had to re-schedule multiple times due to conflicts with her job. The names of the participants have been replaced with pseudonyms to protect their privacy and any personal identifying information deleted.

Setting of the Study

The setting of the study was the city of Yuma, Arizona. Participants in this study were all residents of the city of Yuma, and were recruited from a local physician's office. Yuma is the county seat of Yuma Arizona, which borders the state of Sonora, Mexico. Yuma, with a population of roughly 100,000, increases its population to almost 200,000 during the winter months due the influx of winter visitors and field workers migrating seasonally from the northern states of Mexico and the U.S. Hispanic or Latinos residents, mostly of Mexican origin make up almost 46% of the population. Almost 20% of Hispanic residents live in below poverty level (Arizona Department of Commerce, 2006).

Demographic Data

The demographic data were obtained from the demographic questionnaire (Appendix C). The demographic questionnaire was basically divided into two sections: background information and health history regarding pre-diabetes and diabetes. The background information contained questions about acculturation that include age, gender, place of birth, language preference, number of years living in the United States, and language preferences (Table 1). The second section included information about family history of pre-diabetes and diabetes, and the length of time that the participant has known to have pre-diabetes. During the interviews, the PI collected physical data that included self-reported height and weight to help determine the body mass

index (BMI) for each participant. Body mass index is an important determinant of risk for pre-diabetes and diabetes (ADA, 2006). The BMI is an indirect measure of body composition and is correlated highly with body fat (ADA, 2006). The BMI was calculated using the participant's self-reported height and weight.

The data collected from the demographic questionnaire were calculated quantitatively to determine ranges, means, and percentages to help establish the homogeneity of the sample as well as to recognize the differences among the participants (Table 1).

Age and Gender

Data about the age of the participants indicated a median age of 39 years. Participants ranged in age from 25 to 46 years. Three men and seven women participated in this research study.

Employment and Education

Nine of the participants are employed full time and one works part-time. One participant had elementary school education only, five attended and/or finished high school, and four were college graduates or had some college education.

Marital Status and Income Information

Five participants are married, 2 are divorced or separated, and three have never been married. The participants' annual income ranged from \$20,000 to \$80,000 a year.

Place of Birth and Length of Residence

Six of the participants were born in Yuma, Arizona, two in Mexico, and two in other areas of the United States. They were all residents of the city of Yuma, Arizona, and all of them have lived in the United States for more than 20 years.

Language

Four stated that English was the primary language spoken at home, four preferred Spanish, but decided to have the interview in English, and two spoke both languages at home. Eight participants indicated that they spoke and read English very well; two stated they spoke and read English less than well. Seven participants stated they spoke and read Spanish very well and three participants stated that they spoke and read Spanish less than well.

Family History and Length of Diagnosis

Nine participants had a first or second degree relative with diabetes and four knew someone with pre-diabetes. All participants had been diagnosed with pre-diabetes within a year prior to participation in the study.

The Participants

Ten self-identified Mexican American men and women participated in this research study. To protect their privacy, each participant has chosen a pseudonym and all identifying information has been altered.

P1- Sofia

Sofia is a 46 years old Mexican American woman who is self-employed in the health insurance business. She lives with her husband of 20 years, and has two teenage children, ages 18 and 15, who also live at home. Sofia was born in Yuma, Arizona, and attended high school and college there. She took some college courses, but did not graduate. Sofia describes herself as a high-achiever and a person who is single minded on every task she sets out to complete. Sofia's parents and siblings also live in Yuma, and she has a close relationship with them. Her mother, father, maternal grandmother and her older brother and sister have diabetes. She does not know

anyone with pre-diabetes. She was diagnosed with pre-diabetes by her healthcare provider about 14 months before the initial interview.

P2 - Stephanie

Stephanie is a 42 years old licensed practical nurse who works as a school nurse at a local high school. She is married and has two children. She was born in Mexico, but has lived in Yuma for over 35 years. Stephanie attended a community college and graduated as a practical nurse about ten years ago. Her mother and one sister have diabetes. She does not know anyone with pre-diabetes. Stephanie was diagnosed with pre-diabetes in March, 2009.

P3 - Mateo

Mateo is a 30 year old firefighter, single, with no children. Mateo was born in Yuma, and recently has moved out of his parents' home into his new house. He states that he is currently adapting to living alone, does not cook, instead he prefers to go to his parent's home for his meals. He has some college education, and currently takes classes to complete his bachelor's degree in addition to his full-time job at the fire department. His father has diabetes, and Mateo does not know anyone who has pre-diabetes. However, Mateo believes that his brother may develop diabetes due to his weight and eating habits. He was diagnosed with pre-diabetes by his provider about 6 months prior to the interview.

P4 - John

John is a 43 year old Mexican American who is separated and currently single, separated from his last girlfriend, who is Mexican, and cooks "unhealthy." He believes that his high stress level is due to conflicts with his former girlfriend. He was born in Yuma and has lived in Yuma all his life. He is a mechanic working at the local military base. He finished high school and took

some college classes. Spirituality and religion are very important to him and he is a practicing Christian. He was diagnosed with pre-diabetes by his healthcare provider in June, 2009. He does not follow a regular diet or exercise program and states that he drinks about 3 to 4 beers on a daily basis. His brother and mother have diabetes. His father died of diabetes-related complications; in addition, John has multiple relatives with diabetes. He had never heard of anyone having pre-diabetes. He was diagnosed with pre-diabetes about 3 months prior to interview.

P5 - Ana

Ana is a 45 years old Mexican American woman who was born in Yuma, Arizona, and has lived here all of her life. She has worked as a bank teller in the past but currently takes care of her grandchildren. She retired from her banking job due to “health problems.” She has two aunts who have diabetes. She was told by her healthcare provider that she was at risk for developing diabetes due to “high blood sugar” and has not heard of pre-diabetes prior to the interview. She was diagnosed with pre-diabetes about 1 year prior to the interview.

P6 - Diana

Diana is a 42 year old Mexican American who was born in San Jose, California, but lived as a child in Mexico, and then moved to Yuma, Arizona when she married. She has two children and works the graveyard shift at a local skilled nursing facility. She commutes frequently to Mexico, since her mother and siblings live there. She relies heavily in the Mexican healthcare system for her own health needs, but does have a physician in the United States, who almost a year ago diagnosed her “at risk” for diabetes. Diana thinks she already has diabetes, but has not gone back to the doctor to confirm her belief. Diana manifests symptoms of hypoglycemia and

hyperglycemia such as excessive thirst and hunger, night sweats, and shakiness. Diana checks her blood sugar frequently at work but is afraid of being diagnosed with diabetes, hence her unwillingness to go back to her medical provider for definite diagnosis. Diana does not have any family members with diabetes, but knows about diabetes through her work taking care of residents at a skilled nursing facility. She had heard about pre-diabetes through a co-worker.

P7 - Maribel

Maribel is a 38 year old Mexican American, born in California, but has lived in Yuma for over 20 years. Maribel has three children and works as a teacher's assistant at a local elementary school. Maribel was diagnosed with pre-diabetes by her local healthcare provider eight months prior to the interview. Maribel has one sister who has diabetes and had heard of pre-diabetes by way of some of her friends who have diabetes. Maribel states she has difficulty maintaining her weight at a normal level, and in fact, has gained some more weight in spite of dieting. She does not exercise, mostly due to lack of time.

P8 - Pedro

Pedro is a 40 year old Mexican American who was born in Mexico and moved to Yuma when he was about 12 years old. He works a case manager for a local mental health agency. He has never been married. He is currently finishing a degree in social work. Pedro states that he is spiritual, but not religious. Pedro's mother died of diabetes-related causes. His father is healthy, but one sister has diabetes. He was diagnosed with pre-diabetes about 6 months prior to interview. Pedro never heard about pre-diabetes prior to his diagnosis.

P9 - Camilla

Camilla is a 36 year old Mexican American who was born in Yuma, Arizona and works as a cashier at a local supermarket. Camilla's father has diabetes, as well as one sister. Camilla is married, has one child, and currently is pregnant with her second child. She lives with her husband, daughter, and also takes care of her mother, who lives at home with her. Camilla's life revolves around her daughter and family. She does not currently exercise and has failed many attempts at losing weight. Her many attempts are concentrated on temporary diets that have failed to obtain permanent weight loss. Camilla states she is knowledgeable about diabetes because she has been responsible for taking care of her father and believes she is aware of the consequences of diabetes. She had heard about borderline diabetes through a friend.

P10 - Andrea

Andrea is a 25 year old single Mexican American, who is a bookkeeper at a local accounting office. Andrea lives with her parents, her father has diabetes. She states she has a long acquaintance with diabetes since both of her grandmothers had diabetes and died of diabetes-related causes. She has failed many times at her attempts to lose weight, mostly by temporary diets. Andrea has never exercised regularly and states that she has been overweight ever since she can remember. Most of her family members are also overweight. She knew about pre-diabetes because she had been told by her healthcare provider that she was "at risk" for diabetes when she was a teenager.

Summary

Chapter four presented a summary of the sample characteristics, a brief description of the setting of the study, the demographic data provided by the participants during the initial

interview, and a synopsis of each of the participants. All but one of the participants had family members with diabetes, but only four have heard about pre-diabetes prior to their diagnosis.

Table 1 presents a summary of the demographic data. Chapter five will present the findings of the study.

TABLE 1. Participant Demographic Data

Gender	
Male	3
Female	7
Mean Age	39
Age Range	25-46
Employment	
Full Time	9
Part Time	1
Education	
Elementary School	1
High School	5
College	4
Marital Status	
Married	5
Divorced or Separated	2
Never been married	3
Place of Birth	
Yuma	6
Mexico	2
Other – U.S.	2
Language Preference	
English	4
Spanish	4
Either	2
Relative with Diabetes	9
Knows someone with pre-diabetes	4

CHAPTER 5: FINDINGS

Chapter five presents the findings of the data analysis from ten interviews with Mexican Americans who live at the U.S.-Mexico border and who have been diagnosed with pre-diabetes.

The overall goal of this study was to explore how Mexican Americans at the U.S.-Mexico border understand pre-diabetes and their possibility of developing diabetes. The specific research questions were:

1. How do Mexican American adults at the U.S-Mexico border understand pre-diabetes?
2. How do Mexican Americans understand their possibility for developing diabetes?
3. How does being diagnosed with pre-diabetes influence the daily life of Mexican American adults in the U.S.-Mexico border region?

The analysis of the data is derived from a single interview conducted with ten Mexican Americans adults living in Yuma, Arizona. Field notes were taken during each interview and used to help contextualize the interview data. Demographic data were collected on the sample participants and were presented to describe the individuals who agreed to participate in this study.

Two major themes emerged from the data: 1) *Awareness*, and 2) *Adjusting to pre-diabetes*. These two themes were abstracted into an overarching cultural theme: *Living with pre-diabetes*. This overarching cultural theme represents the two themes inducted analytically from the data and describes how the sample participants understand their pre-diabetes and how they interpret the possibility of developing diabetes (Figure 1).

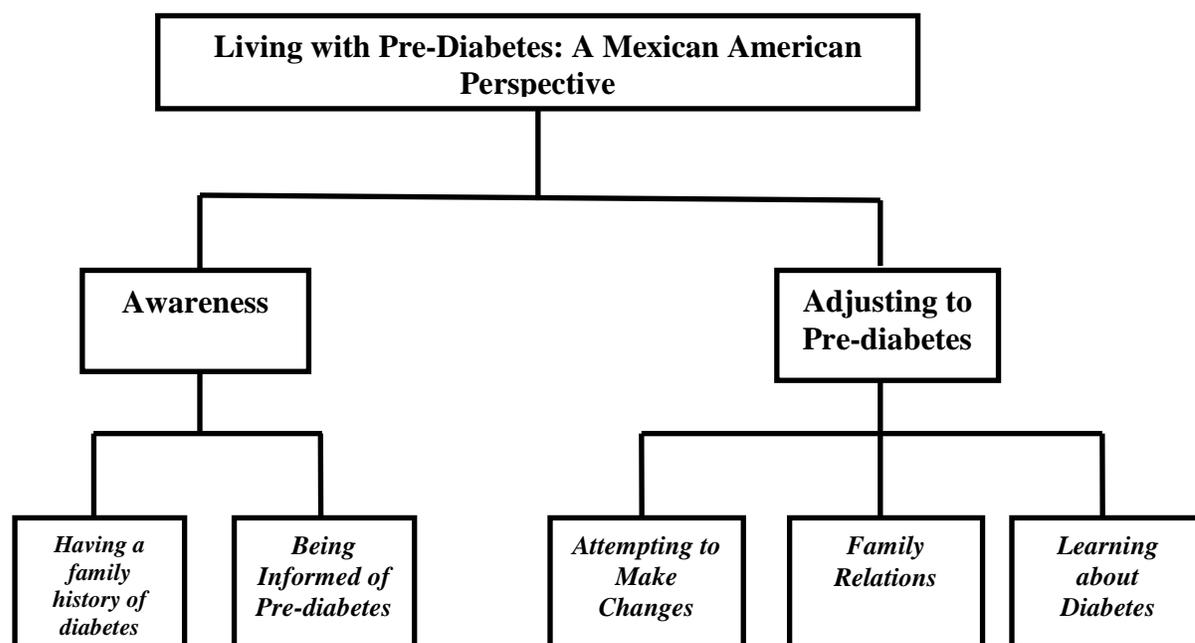


FIGURE 1. Conceptual Schema: Living with Pre-Diabetes: A Mexican American Perspective

Theme 1: Awareness

Awareness is the process of becoming conscious of something, a situation, an object, or a feeling. This ability to perceive an event or an object may be validated consciously by an individual, but this acknowledgment may not necessarily involve understanding of that event, object, or feeling. In this study, *awareness* represents the awakening to the reality of pre-diabetes, an awakening that may have started when the participant first heard of diabetes or when a family member was first diagnosed. *Awareness* continues to develop when the participant is told that he or she has pre-diabetes. This theme represents the initial state of consciousness immediately after the diagnosis of pre-diabetes. This altered state of health—pre-diabetes-- may not be initially understood by individuals. One participant described being told by her healthcare provider that she was pre-diabetic, but she did not really understand what it was. She said, referring to her diagnosis of pre-diabetes, “I don’t understand anything.”

This ability to perceive, or be conscious of pre-diabetes without really understanding the diagnosis was described succinctly by another of the participants:

“You know, I am embarrassed, because I really don’t know what pre-diabetes is. I really don’t know, in fact when Dr. Smith’s office called me, Mary from Dr. Smith’s office, called me, and told me you were doing this (study). She said: He is interviewing some people that are pre-diabetic.” I was kind of taken back because I said, “So I fall into the pre-diabetic category?” And Mary said: “Yes”. And I said, “So that means I am not diabetic yet?” (Laugh) And she said, “Yes”. And I said, “Okay”. I was really like; it was a bad word to me, pre-diabetic. I was like, “Oh my gosh! She called me *pre-diabetic!*” Like it was a bad word, you know. A bad name that she had called me. And I really don’t understand the medical concept of what pre-diabetic is.”

Awareness reflects the process by which participants became aware that they had pre-diabetes. The theme *awareness* was abstracted conceptually from two categories of meaning represented by 1) *Having a Family History*, and 2) *Being Informed of Pre-diabetes*.

Having a Family History of Diabetes

In this study, all but one of the ten participants had a first degree relative with diabetes, yet only four of them had heard of pre-diabetes prior to their diagnosis. Some participants had considerable experience with diabetes because of the significant numbers of family members who had diabetes. One participant said:

“I really did not think much of being diagnosed as having pre-diabetes because, like I said, knowing that my dad was diabetic, I have my dad, my mom, my brother and sister. We are a total of six kids, 3 boys and 3 girls, mom and dad. And like I said, it is mom and

dad and a brother and sister that are diabetic already. So I did not really think much of it at the moment, but what I felt is ‘Oh man, I need to work out and I need to lose weight.’”

Another participant said:

“It scared me, because I have family members on both sides of my family that have died with diabetes and I did not think that I would ever get it. I have uncles and aunts on my dad’s side and my mom’s side that have already died from diabetes. They are older. They were in their 70s and 80s and they have passed away already and I said, ‘Oh no, I don’t want to have diabetes.’”

Most participants had first-hand experience and knowledge about diabetes because of having a family member with diabetes. However, not all participants were consciously aware of their susceptibility to developing diabetes until they were directly told by their healthcare provider. One participant said:

“I know that diabetes has been in my family. My grandmother passed away from that. I believe my mom has diabetes and I have an older brother that just told me recently when I told him what I found out through my doctor, that he also is pre-diabetic because it runs in our family, supposedly. That’s what he my brother said. And so, it wasn’t until I started seeing Dr. Smith that she informed me that I was pre-diabetic, at risk.”

Another participant said, “Well, I think I have a big risk of developing diabetes because I already have my family history.” Some participants knew of their family history of diabetes, and had some awareness of their increased susceptibility to developing diabetes. Another participant described being aware of pre-diabetes but her response also reflected the uncertainty or lack of definitive knowledge about her condition. She said:

“The way I understand pre-diabetes is because of the history I have with my parents. My sugar is not low in the brackets, I guess it is a little bit high-- not considered high, but a little bit on the high side. Because, like I said, the history of my parents having diabetes and because I am a little bit overweight, and my age. So I think that is where it is going to begin. That is what I feel pre-diabetes is.”

One participant related she was aware of her risk for developing diabetes by knowing that her mother was diabetic. She said:

“Well, my mom has it, so I think I am going to get it, and it looks like I am going to get it based on what the doctor told me. So it seems like I am going to have diabetes sometime.”

Some participants were made aware at an early age of their susceptibility for developing diabetes due to their family history. One participant said:

“I think I was 17 or 18 years old, my first physical with the doctor, and they took blood. Of course, my fasting glucose was just higher than usual and then they asked me if anybody in my family has diabetes, and of course my mother does. And all my life, my mom has told me to be careful because we have diabetes in the family and hypertension.”

Being Informed of Pre-diabetes

Being Informed of Pre-diabetes is the second category that contributed to the theme *Awareness*. *Being informed of Pre-diabetes* refers to being told by a health care provider that one has pre-diabetes, borderline diabetes, or is at risk for developing diabetes. This information was frequently given at the healthcare provider’s office, and usually consisted of the provider’s comments based on a physical assessment and health history; as well as the presence of

abnormally elevated fasting plasma glucose levels. With this diagnostic information and after an initial consultation with the healthcare provider, participants were informed that they had pre-diabetes, had borderline diabetes, or were at risk for developing diabetes. One participant describes this moment:

“Oh, well when I went to see Dr. Smith and she ran blood work on me, she noticed that my glucose was elevated. And I didn’t know what glucose was, so she told me I was pre-diabetic. I went to see her because I have a thyroid condition. So she did lab work for my thyroid and I told her that I also thought I had high cholesterol and my potassium tends to get low. So she decided to check everything and when that paper came back she noticed that my glucose was elevated, about 113, I think. She told me I was borderline diabetic.”

Another participant was told by her healthcare provider that her plasma glucose level was abnormally high said:

“Well, I was going to the doctor for just a regular yearly physical because I hadn’t taken one for awhile. I decided I was going to take a physical. So I went to the doctor and since it was my first visit, she said ‘Anytime that I have a new patient, we do a whole physical.’ So she had me do some analysis and blood work. When I went back, she told me that because of the history of my mom being diabetic and my dad being diabetic, and because of my blood sugar level, she was going to classify me as a pre-diabetic patient.”

Another participant described the moment when he was told by his physician that he had an abnormally high fasting plasma glucose level: “Well I had an appointment with Dr. Smith and I think she did some kind of test on me and she called me back to tell me what came out on the test. She told me that my number on diabetes was 115, something.” This information, given by

the healthcare provider, was often enough for most participants to be become aware of their diagnosis. *Being informed of Pre-diabetes* prompted most participants to develop a sense of awareness that they had pre-diabetes or at least were at risk for developing diabetes. One participant, after being informed of her diagnosis, said, “I am going to have diabetes. I already know that because of lab work. It is not lying. The results are not going to lie. You know you have something.” Another participant described a similar state of affairs by saying, “Oh well, when I went to see Dr. Smith and she ran blood work on me, and she noticed that my glucose was elevated. And I didn’t know what glucose was so she told me that I was pre-diabetic.”

Awareness is an abstract theme that provides insight about how the participants in this study understood pre-diabetes and the risk for developing diabetes. Having a family history of diabetes is the first part of the process of *Awareness*. The second step is *Being Informed of Pre-diabetes*, an event in which participants were told about their diagnosis of pre-diabetes by a healthcare provider. *Awareness* is a conscious state in which the participant may be aware of pre-diabetes, but may not completely understand this altered health status and its consequences.

Theme 2: Adjusting to Pre-diabetes

The second theme generated from the data, *Adjusting to Pre-diabetes*, was developed from three mutually exclusive categories: 1) *attempting to make changes*; 2) *family relations*; and 3) *learning about diabetes*. *Adjusting to Pre-diabetes* illustrates the process of dealing with pre-diabetes. This theme describes the process of moving away from unhealthy habits that have contributed to pre-diabetes and trying to overcome difficulties encountered when trying to establish healthier behaviors. This process is often cyclic and implies a sense of determination, involvement of family members and learning about diabetes and trying over and over. *Adjusting*

to Pre-diabetes illustrates how participants attempt to engage in healthier patterns of behavior such as changing eating habits and increasing the amount and quality of exercise. Some participants were successful, but some had difficulty continuing new behaviors and some participants just returned to former patterns of behavior. This theme implies that changing behaviors to improve one's health is a process of incremental success sustained by the participant's determination to make changes that lead to healthier lifestyles. This theme also implies that changing one's behavior is not necessarily a permanent situation as some people regress to old habits after attempting to make changes in their lifestyle.

Attempting to Make Changes

Attempting to Make Changes describes the actions taken by the participants once they became aware of having pre-diabetes. This category is best defined as those attitudes and actions taken to help them improve their health behaviors. *Attempting to Make Changes* is understood as a process in which being determined, taking control, and making positive changes assisted the participants in changing old behavioral patterns.

Upon learning that they had pre-diabetes, most participants decided to make changes in their lifestyles to improve their health. One participant spoke about the changes she had made since visiting her doctor. She said:

“So I got pretty serious about making changes and I have made some really serious changes in my life since my meeting with the doctor... I really, really focused on changing my diet and losing weight. And I have almost become a little bit crazy about it.”

Another participant spoke of her sense of self determination by asking her son to exercise with her when her husband was no longer able to continue exercising with her. She was

exercising lightly with her husband, but after her diagnosis, she decided to start walking on a regular basis and more arduously by walking with her son. She said:

“Before they told me I had pre-diabetes, I was doing the walking with my husband, but he didn’t like to walk fast and now that I am doing the walking, I am doing it with my son. My husband is not coming with me. The doctor told me that I need to sweat when I am walking. The doctor said, “You need to come home after exercising and said “I am exhausted, I am tired, I worked hard.” The doctor said to me: “You need to feel it.” So I have been doing it. My son, who is 21 years old--he is also exercising-- so he runs one mile and walks with me another mile.”

Some participants expressed a desire to break their cycle of unhealthy behaviors not only to avoid developing diabetes, but because of the benefits of changing to healthier patterns of behavior. One participant said, “Exercise is now more important because it is more important for me to be healthy. Walk to be healthy, not just to look nice and thin.” Participants also broke with old eating habits by changing their diet once they were told about their pre-diabetes. One participant joined Weight Watchers, and drastically changed her diet. She said:

“Once I made the shift to get serious about my pre-diabetes I actually joined Weight Watchers, which was I think a good thing because they don’t make you feel like you are dieting. I always feel like it really was a change in my lifestyle. Now I have tons more vegetables and greens and just really avoid starches, breads and sweets.”

Other participants spoke about their change in exercise habits. This move to more regular exercise, coupled with a reduction in food intake, resulted in a better self-perception and improved lifestyle changes. One participant said:

“Well, I was doing some exercise before, but it was pretty sporadic, it was more of a stress reliever for me and I was really just walking. Then I was diagnosed with pre-diabetes and that was really when I changed my diet and started exercising. I realized then, wow, how much calories exercise burns and how much difference it makes to exercise. And now I have increased my exercise hmmm, oh, probably about 60% from what I was doing.”

Another participant spoke of taking control of her pre-diabetes by making changes in her lifestyle. She said:

“Being diagnosed as having pre-diabetes has changed my life and that’s why I have started and tried to stay on an exercise program, starting out with walking so that it has changed my mentality concerning this. And sure, if there is something that I can do to prevent diabetes, then I am going to do it.”

Other participants also spoke of taking control, and how making changes in their lifestyle included learning to say no to unhealthy foods. The participants relied on self-control to make changes that helped them improve behaviors that were counterproductive to their health. One participant said, “I am more focused now and I recognize why I am saying no to that burrito and that is a good thing to say no to that burrito.” Another participant, speaking of her dietary habits and being more in control of what she eats, said, “I am watching what I am eating, being more careful and exercising and leaving the stress. I think I can control what I eat. I think the control is on me, I have the power to control what I eat. So I am working on it.”

Some participants engaged in healthy behaviors after being diagnosed with pre-diabetes. One participant became an avid food label reader after knowing that she had pre-diabetes, she said:

“I never really knew until I started reading labels, and honest to God, I didn’t read labels on food until after I had this diagnosis, that there are some that are really okay to eat, like if you have pudding or light puddings or different kinds, which are much better than if you have, you know, this cookie. I eat an apple and that is really good. Now I know that. I did not know that before my diagnosis, honestly. I guess I knew it, I mean I knew that fruit was good for you, but I really didn’t like fruit that much. I didn’t go, “oh I am craving a piece of fruit.” Now I know it is really good to have an apple or an orange or even two apples, you know, is better than having a Danish.”

Another participant spoke of previous food choices, and how she made some drastic changes in her food intake. She said:

“I stopped drinking regular soda and regular candies. I eat only unsweetened teas, and sodas, and I stopped eating a lot of candies. I don’t eat candy. I am overweight because I eat food. I already know what food is bad: fast food. That’s what I changed in my life. No chocolate. I love chocolate. I don’t drink milk with chocolate. No banana split. Ice cream I buy unsweetened. I buy diet sodas and unsweetened teas.”

Some participants talked about making small changes towards a healthier diet, but not being ready to give it all up. One participant described making food changes and eating less. He said:

“I am trying to eat a little less and she bought these, more corn tortillas instead of the flour tortillas. We usually eat a lot of bread, sandwiches and eggs and a lot of meat, butter and mayonnaise. But I am trying to eat less bread. So yes, it is just that I am eating a little bit less but the truth is I haven’t made the big changes.”

Another participant, talking about making small, but positive dietary changes, said:

“Some of the changes that I have done, I do want to say that I have tried to eat a little bit more healthy. For example, I don’t drink soda but every once in awhile but not like before where every meal I had a soda. At work we have a soda machine, so I would sit down and watch TV and go buy a soda. I have avoided all that. Now, I go to eat at fast food restaurants but instead of getting the french fries, I get a side salad with my hamburger.”

Attempting to Make Changes did not come easily, and some participants had difficulty keeping up with new exercise regimens and diet modifications. While some participants promptly addressed unhealthy behaviors by modifying eating habits or starting an exercise program after being diagnosed with pre-diabetes, others had difficulty breaking their old habits and found it difficult to change behaviors. One participant who had difficulty changing her diet put it succinctly:

“I am not going to be able to make changes because I like bread a lot. I like to eat a lot of sweets, a lot of buns, a lot of tortillas. So I go on a diet often but I do not keep it. You know I will go for 2-3 days and then I will break it. And I know when my sugar goes high because I start getting headaches, and I feel lazy, and I know that I am not doing very well.”

Some participants were determined to make changes but battled against cravings and indulging behaviors. One participant said, “I don’t know what happened, after being diagnosed with pre-diabetes, I don’t know what happened, but I suddenly got the craving for sweets and for breads.” Other participants, despite wanting to make changes in their lifestyle, struggled with behaviors that involved food and alcohol. One participant said:

“Sure, if there is something that I can do to prevent diabetes, then I am going to do it. But I find myself not doing it 100%. Why? Because like I said, I have lived here enough years already and so whenever our Lord wants to take us, He can take us. So why not enjoy and indulge in the foods or drinks that I have been accustomed to, so to speak.”

Some participants also spoke of just thinking about changing, without making any effort to put their thoughts into action. One participant said:

“I think that I have tried to make some life changes, and one of the things is that I am 30 now, and I feel that I can lose the weight and I feel that I can do it. The funny thing is that I have not started. But I feel that in my future, I don’t know, I see myself losing the weight.”

Other participants attempted to make changes, but were not able to keep up with the intended plan, or became easily discouraged. One participant said:

“So I bought a cardio video and like I said, I will put it on and I will exercise for like a week or 2-3 days. I bought myself a bike and I will go and ride for a week and then I will stop, and I don’t know if I lose interest or what, I just stop doing it. And then I am thinking you know what, I need to start doing it again. And then I will go start the routine

again. But I will do it for a week and then like stop for two weeks and then do another week.”

In summary, *Attempting to Make Changes* illustrates how some participants make a conscious decision to break old habits and opt for healthier lifestyles. Some participants were able to make small changes in dietary habits, such as cutting down on carbohydrates and fats. Others increased the frequency of exercise after learning they had pre-diabetes. Other participants also made the decision to make changes in their lifestyles, but were not able to maintain the desired changes.

Family Relations

Family Relations describe the personal interactions that participants had with their family members once they were diagnosed with pre-diabetes. *Family Relations* were for the most part strengthened as participants disclosed their diagnosis to family members and friends. The response by family members often consisted of support and encouragement. Some participants, on the other hand, felt a sense of responsibility towards family members that prompted a desire to make changes in order to remain healthy so they could take care of their family members.

Some participants were prompted to change their dietary and exercise habits by their family members who were more physically fit or who knew about healthier food choices. Family members often reminded participants of the need for healthier changes in diet. One participant was regularly reminded by her daughters to avoid unhealthy meal choices. She said:

“The girls always told me, ‘Mom, you need to watch your diet, you are getting fat,’ because I was really, really heavy. I have lost weight, but they would always tell me, ‘Don’t eat tortillas.’ Because they are thin, they go to the gym. ‘Mom, don’t eat that.’”

Another participant was advised by her sister to begin to develop healthier eating habits, she said, “My sister is the one who told me that “this is what you have to watch, don’t eat this, and eat that all the time. And she was kind of helping me with my diet.” Another participant relied on her daughters’ comments in order to begin a diet; she said, “So I told my husband and my daughters that I am a diabetic borderline, not diabetic, but borderline, and they said, “See mom? You have to watch what you eat. You are getting older and you have to watch it you know. Your brother has got it, your brother-in-law has got it” – my daughters told me that. “From now on you have to watch what you eat.”

Another participant relied on a spouse and children’s support and guidance as means of encouragement for her losing weight or engaging in an exercise program. This participant said:

“My husband tries to help me, he tells me, ‘You are supposed to change, and let’s not buy tortillas and let’s not buy bread or eat wheat bread or wheat tortillas. Buy corn tortillas.’ But it is easy for him to say because he is not doing this diet. But they help me a lot, my husband and my children.”

Another participant also spoke of her husband’s support of her efforts to lose weight. She said, “What happens is that I have a husband who cooks and we don’t go out often. In a way, I think my husband is helping me lose weight.” Support and encouragement was demonstrated by family members through the offering of advice, moral support, and demonstrations of caring. Participants were often encouraged to engage in a fitness program or improve dietary habits. Support and encouragement were important elements of family relations that assisted the participant in adjusting to pre-diabetes and making changes in lifestyle.

Family Relations contributed to breaking the cycle of unhealthy patterns of behavior by holding participants accountable and also by supporting them during the lifestyle changes that occurred after the diagnosis of pre-diabetes. Some family members not only gave advice or moral support, but enthusiastically joined the participant in making lifestyle changes. This demonstration of encouragement by family members was described by one of the participants, who related:

“I did finally confess that I had pre-diabetes to my sister. I said, ‘Okay, I went for an appointment,’ and she was the first person that I told. And she said, ‘You know, I have had the same thing.’ And she said, ‘So why don’t we start doing something about it’ and she had to really encourage me. It probably took about a little bit over a month for me to say, ‘Okay, we are making a commitment, let’s do something about it, let’s be committed together, let’s start this exercise program, let’s start a Weight Watchers program.’”

A sense of responsibility towards family members was also a significant incentive for participants to engage in healthier habits. One participant spoke about her need to be present for the long term to benefit her children. She said, “I need to change my habits, I have a family. I need to be healthy for my kids, I want to see my grandchildren, and I don’t want to leave my husband by himself and that’s why I know I need to change.”

Another participant spoke of the responsibility he has towards taking care of his aging parents. He said, “Man! I hope I do not develop full diabetes. I am the one who takes care of my dad in the way of making his appointments, taking him to the doctor. When he was put onto insulin, I am the one who taught him how to get injected, so I see the troubles that they go through.”

Family Relations play an important role when adjusting to pre-diabetes. Most participants described how family members play an important role in helping change unhealthy behaviors. Emotional solidarity, support and encouragement with meal planning and exercise programs were some of the benefits offered by family members to those diagnosed with pre-diabetes. A sense of responsibility towards family members was often a motivator for positive changes and contributed to helping the participants adjust to pre-diabetes.

Learning About Diabetes

Learning about Diabetes describes how participants learned about pre-diabetes and diabetes. Learning is described as the acquisition of knowledge about pre-diabetes or diabetes after *Being Informed* that they have pre-diabetes by a healthcare provider. This learning came about through various sources of information. Participants learned about diabetes and pre-diabetes through information provided by their healthcare provider, family members or acquaintances who had diabetes or from other sources, such as their own reading or searches on the internet. The information about pre-diabetes and diabetes varied in quality and quantity and was at times misleading because of the confusion between pre-diabetes and diabetes.

Most participants learned something about diabetes through their healthcare provider. This information helped the participants learn the basics of pre-diabetes, diabetes, diet, exercise, and weight control. However, the information provided by a healthcare provider was often limited and was not really specific. Most information given by the provider was given to the participant at the moment of the visit and did not include setting goals for amount and quality of exercise, targeting ideal body weight, or calorie intake. One participant said:

“The only thing my doctor told me is that I needed to start walking and try to lose weight and eat healthy. The health care provider said: ‘don’t eat too late during the night’ and if I start with sweating during the night or peeing a lot I need to come back to the doctor. She only said that I need to be careful. I need to start exercising. She said, ‘Don’t stop eating, whatever you eat, eat whatever you want,’ that’s what she told me. Not a lot of unhealthy food, and start walking. Walking or exercise. That’s what she told me.”

Another participant described what little information she got from her healthcare provider, she said: “Well, she told me my blood sugar was a little high and that I needed to make some changes about what I eat and that was it.” Another participant said, “Well, I really didn’t think having pre-diabetes was that serious. My doctor didn’t seem to think it was that serious. She gave me a little paper about some suggestions about what to change in my diet but that was about it, so it didn’t seem that serious to me.”

Some healthcare providers did not provide any information at all--just the diagnosis of pre-diabetes. This lack of information left most participants without knowing what to do. One participant said, “No, he didn’t explain it. He just told me that I was borderline and that if I didn’t get on a diet, then I was going to become diabetic. No, he did not say anything else; just “You are borderline.” Another participant, talked about not receiving much information from her healthcare provider. She said: “The first time, the doctor told me: “You are borderline, you need to be careful. That’s all the doctor told me.”

Some participants, after being diagnosed with pre-diabetes, told their family members about their diagnosis as well as their concerns. The participants often received information from family members about diabetes, not pre-diabetes. The information given by family members was

often misleading, since most family members did not seem to know the difference between pre-diabetes and diabetes. Information given by family members often contradicted what the participants were told by their healthcare provider. One participant, who told her mother she had been diagnosed with pre-diabetes, said, “I told my mom and my mom said, “No, you don’t have diabetes because if you have diabetes you are going to feel this and you are going to feel that. She told me because she knows.” Another participant heard information from his acquaintances about diabetes. He said, “People have told me you don’t feel anything until you have had diabetes for a long time and you didn’t take care of yourself.” Some family members gave the participant information about being cautious with food, but gave no specific instructions. One participant said:

“I told my daughters that the doctor said I am diabetic borderline, not diabetic but borderline. They said: ‘See mom? You have to watch what you eat. You are getting older and you have to watch what you eat, you know. Your brother has got it, your brother-in-law has got it’ – my daughters told me that: ‘from now on you have to watch what you eat.’”

All participants had a family member with pre-diabetes or diabetes and so their information about diabetes also came from observing the serious consequences of advanced diabetic disease. One participant said:

“I know what can happen because I have seen it happen. I have seen my father-in-law lose part of his foot to infection. I have seen my dad where he said he couldn’t drive because everything was turning blurry, his vision was poor, you know, he has had such bad sugar levels. So I have seen all these things.”

Some other participants also received written information about pre-diabetes and diabetes from their provider, for example, one participant said, “The doctor gave me a pamphlet on some websites to go to that would help me make healthy choices about my food and some other things.”

Learning about Diabetes illustrates the various ways in which participants received information about pre-diabetes and diabetes. This information was then used to implement or attempt to implement changes in lifestyle that would lead to healthier lifestyles. Most participants received information, in various degrees of accuracy and quantity, from healthcare providers, family members, friends, or other sources. It appeared that participants did not receive much information from healthcare providers, and that the information received from family members was often inaccurate. Only two participants admitted to receiving information from other sources such as books or the internet. This information illustrates that the participants in this study received minimal or inaccurate information about pre-diabetes. In spite of this, most participants engaged in attempts to make changes to healthier lifestyles.

In summary, *Adjusting to Pre-diabetes* illustrates how dealing with diabetes is not an easy process. Some participants were able to make changes in their lifestyles, while others could not. Making changes required self-determination, family support, and a knowledge base about diabetes. Some participants were able to decide very quickly that they wanted to make changes in their behaviors to improve their health. They focused primarily on diet and exercise and were able to make positive changes. They sought and received family support and help to exercise and to make healthier choices about their diet. They asked for and actively sought information that would expand their understanding of diabetes and pre-diabetes. These were the participants that

were able to initiate and maintain positive changes. Other participants were unable to make changes in their lifestyles. Some gave up right away, acknowledging to themselves and others that they could not make changes to improve their diet and exercise.

For the participants in this study, *Adjusting to Pre-diabetes* implied a change to healthier lifestyle patterns that included more exercise and healthier diets. Most participants started an exercise or diet program only to find out how difficult it was to maintain this new set of behaviors without family support and knowledge about diabetes. Family support systems play an important role in assisting participants to make changes that promote healthier behaviors that avoid or delay the onset of diabetes. Participants also displayed various levels of knowledge about pre-diabetes and diabetes that enhanced or diminished their ability to change behaviors that were detrimental to their health.

Overall Cultural Theme: Living with Pre-diabetes

The findings from this study describe how Mexican American participants at the U.S.-Mexico border understand pre-diabetes and how they now perceive their risk for developing diabetes.

Living with Pre-diabetes is the overarching theme derived from the data. Living with pre-diabetes was a process that involved, first, the awareness of having pre-diabetes and then, adjusting to pre-diabetes. All participants had at least one family member and/or relative with diabetes or knew someone with pre-diabetes. This fact, coupled with being told by their health care provider that they had pre-diabetes, prompted lifestyle changes. While some participants were able to maintain these positive changes, others could not, for various reasons. But for all

participants, adjusting to the diagnosis of pre-diabetes implied a process of success and failure that included attempts to make changes, family support, and knowledge about diabetes.

Most participants understood pre-diabetes to be the beginning of diabetes. They also understood that diabetes could be prevented if changes in lifestyle were made before the progression of pre-diabetes to diabetes. Some of them believed that they were going to develop diabetes anyway and with this attitude, they experienced difficulties making changes to avoid developing diabetes. Many of the participants understood that if they took care of themselves, there would be a good possibility of avoiding or delaying the onset of diabetes. They understood that exercise, diet modification, and weight loss were important when attempting to reduce the possibility of developing diabetes. Therefore obesity and a lack of exercise became risk factors to them.

Being diagnosed with pre-diabetes greatly influenced the lifestyle of the participants in this study. Most of them made changes in the kinds and amount of food that they ate or in their physical activities. Most of the participants relied on family support to increase their amount of exercise and to adhere to healthier diets. For the most part, family members were supportive and wanted to help. Participants received little or inaccurate information about pre-diabetes and diabetes from healthcare providers, family members, books and internet sources. In spite of this, they used the gained knowledge to attempt to modify their lifestyles hoping to delay the onset of diabetes. *Living with Pre-diabetes* showed that Mexican Americans in this study adapted to having pre-diabetes by making changes in their lifestyle, but these changes did not come without difficulties. Some individuals were able to maintain these changes and others had given up completely or were still struggling.

Summary

Chapter five presented the results of the data analysis and a description of the major themes that portrayed how Mexican Americans understand pre-diabetes and the possibility of developing diabetes. The themes of awareness and adjusting to pre-diabetes provided a framework in which to understand how pre-diabetes influences the daily life of Mexican Americans at the U.S.-Mexico border. The themes elicited suggest that generally speaking, the participants did not have a pronounced awareness of their risk for diabetes prior to being informed that they were pre-diabetic by a health care provider. The participants of this study became aware of their risk at the time they were told of having pre-diabetes. Once they were told by their healthcare provider, then they were able to relate pre-diabetes to their family history. This awareness prompted some changes in lifestyles that were sustained by some, but not by others.

Chapter six presents a discussion of the research questions and the significance of the findings. The implications for nursing theory, research and practice, as well as the strengths and limitations of the study will also be presented.

CHAPTER 6: DISCUSSION AND CONCLUSION

This research study used Freire's critical theory to inform the research design and analysis that are described in chapters 1-3. In this chapter, Freire's framework is used as a lens to understand and describe how Mexican Americans at the U.S.-Mexico border live with pre-diabetes. Freire introduced the concepts of conscientisation, emancipation, and praxis as the guiding framework for his theory. These concepts guided this study from its inception. In addition, strengths and limitations of the study and the implications for nursing research, theory and practice will be presented.

Using Freire's Critical Theory to Inform this Study

Emancipation

The overarching cultural theme of *Living with Pre-diabetes* explains how Mexican Americans understand pre-diabetes and their own individual risk for developing diabetes. *Living with Pre-diabetes* reflects Freire's understanding of emancipation, the process of continuous interaction of an individual with his/her environment that allows for a constant exchange of ideas that leads to action and change. This understanding influences how individuals live their daily lives and how they adjust or cope with living with pre-diabetes. Pre-diabetes was a new concept for most of the participants. *Awareness* first occurred when the participants were informed by their health care provider that they had pre-diabetes. However, being aware of having pre-diabetes did not necessarily mean understanding of pre-diabetes. The second major theme, *Adjusting to Living with Pre-diabetes* represented the struggle of participants to adapt to living with pre-diabetes. These adaptations included, for the most part, changes in diet and exercise patterns. These attempts and adaptations in diet and exercise patterns represent what Freire

describes as emancipation: the initiative taken by individuals in order to liberate themselves from a given situation, in this case, having pre-diabetes.

Conscientisation

The first theme: *awareness* of having pre-diabetes did not imply understanding of pre-diabetes for most participants. Freire (2000) describes this step as conscientisation, or the ability to perceive one's situation and to be able to take action in order to address that situation. In Freire's theoretical framework, "learning the language" is one of the steps of emancipation (Freire, 2000; Crotty, 1998). For participants in this study, having a family history of diabetes and then being told by their health care provider that they had pre-diabetes was the first step towards conscientisation about pre-diabetes. Hearing the words was the first step in learning the language and helped the participants make meaning or "sense" of what was happening to them. Having a family history of diabetes placed the participants in a social and cultural context from which to attempt to understand pre-diabetes. Most participants knew of the signs and symptoms, as well as the consequences of diabetes because they had a family member with diabetes. Yet, they had not personalized this information; they did not realize that they too would be affected by diabetes. But when told about their diagnosis by their healthcare provider, they were able to use this knowledge to begin to understand pre-diabetes. Freire (2000) maintains that finding meaning evokes a response. Most participants had no personal meaning for pre-diabetes; they simply believed that such a diagnosis did not apply to them. Nor did they understand that pre-diabetes and diabetes could be prevented or at least the onset delayed when healthy lifestyles were maintained over a period of time.

“Banking education”, is a concept in which individuals are passive recipients of information that prevents them from taking action (Freire, 2000). Information given by healthcare providers to the participants was insufficient—it was not enough to help them make sense of a diagnosis of pre-diabetes. When information was not sufficient, the diagnosis of pre-diabetes was often underrated and at times altogether dismissed by some of the participants.

On the other hand, information gathered within a context of other interactions, for example, when a participant asked other family members about pre-diabetes, the information they shared seemed to have more of an impact on participants. These interactions sometimes led to a better understanding of pre-diabetes. Other times, the information given by family members or friends was inaccurate. However, this sharing of information about pre-diabetes often stimulated the participants to engage in lifestyle changes, assisted by family members. Sharing information between the one who teaches and the one who is learning is a process called “problem-posing”. Dialogue is created and in this process, individuals start to become conscious of their reality (Freire, 2000). The ways that participants shared their diagnosis of pre-diabetes with family members and the ensuing dialogue is reflective of “problem-posing” described by Freire (2000). In this study, the family members of the participants played a highly influential role in helping the participant understand the diagnosis of pre-diabetes and, even more importantly, helping the participant make healthy lifestyle changes that would be so important to health and wellness.

Awareness was the first step towards “learning the language” and this step influenced how participants understood their possibility for developing diabetes. Some participants understood pre-diabetes to be the beginning of diabetes. But not all participants understood that

diabetes was not an inevitable result of pre-diabetes. Many participants did not know that diabetes could be avoided. Freire (2000) states that individuals are not to only “reproduce” words given to them (such as pre-diabetes), but that becoming aware of reality requires that individuals create their own words in order to emancipate themselves. Without appropriating their reality, in this case living with pre-diabetes, people acquire a sort of consciousness in which they are aware of the new reality, without really understanding it, and without making any effort to change it (Freire, 2000). Participants who understood pre-diabetes, or at least began to understand it, made attempts to adjust to pre-diabetes.

Praxis

The second theme: *Adjusting to Pre-diabetes* was a response that participants experienced when they become aware of pre-diabetes. The ensuing positive changes in lifestyle contributed to the overarching theme *Living with Pre-diabetes*. In his work, *Pedagogy of the Oppressed*, Freire (2000) proposes two distinct moments on the way to emancipation. The first one is becoming aware of reality in which the individual lives; the second refers to the action taken by individuals to emancipate themselves from that reality when it becomes oppressive. Freire refers to this latter moment as praxis. Participants in this study first became aware of having pre-diabetes at the moment of being informed by the healthcare providers, and when talking to family members about what they had been told at the doctor’s office. Secondly, they attempted to establish changes in lifestyle that would help them delay or prevent the onset of diabetes. Adjusting to Pre-diabetes is congruent with the second moment in Freire’s theory, praxis, in which the individual, after becoming conscious of reality, begins to take action in order to emancipate himself from that reality. Adjusting to pre-diabetes involves taking action in order

to prevent or delay the onset of diabetes, and some participants in the study engaged in healthier habits after becoming aware of having pre-diabetes. According to Freire (2000), the individual builds his own reality from the circumstances that are encountered as part of daily life. Being told of having pre-diabetes is the new circumstance encountered by the participants in this study, who, in most cases, adjusted to having pre-diabetes by modifying food consumption or starting to exercise.

Other participants chose to not make any changes, or made changes initially but regressed to previous lifestyles after being unable to sustain the lifestyle changes. According to Freire (2000), some individuals may not take action or attempt to “emancipate” themselves from their reality. He suggests that, in order to assist the individual to emancipate himself from that reality, education be imparted in a context that is understood and analyzed by people. The role of the educator (in this case the healthcare provider) is to create the necessary conditions in which the individual arrives at a reflective state from which to understand reality and take action in order to change that reality. In order to become conscious and make changes about their reality, individuals must be able to establish a dialogue between the one who teaches and the one who learns that promotes mutual learning (Freire, 2000). Praxis must connect the individual’s experience, understanding, and action in order to bring about changes in lifestyle that would help delay or prevent the onset of diabetes.

In summary, the findings of this study reveal some limitations in current U.S. healthcare systems that are similar to the situations of oppression cited by Freire (2000) in the Brazilian educational system. An inadequate supply of healthcare providers, and time and monetary constraints prevent healthcare providers from creating the necessary conditions for a “problem-

posing” or reflective education that can lead individuals to action and behavior change. Power differences between healthcare providers and patients prevent a constructive dialogue that promotes mutual learning. “Banking education” promotes passive learning that is often not assimilated by patients when told they have pre-diabetes. These findings suggest a gap in the literature that requires further research and has significant applications for practice. Culturally-tailored pre-diabetes education, delivered by trained members of the community, such as community health workers, or *promotoras*, has previously proven useful on diabetes education (McEwen, Rentfro, & Vincent, 2009).

Strengths of the Study

One of the strengths of this study was that the voice of the participants came through in each of the interviews. Participants were willing to share their views about their understanding of pre-diabetes and diabetes. This ability to express their views freely enhanced trustworthiness of the study (Speziale and Carpenter, 2003). Denzin and Lincoln (2005) describe trustworthiness as validity or authenticity which also refers to the inclusion of views, concerns, and perspectives of all participants. Trustworthiness in this study was enhanced by allowing the participants to express their views freely, without imposing pre-conceived ideas, words, or feelings during the interactions with each of the participants. Open-ended questions allowed the participants to express their opinions without being influenced by the interviewer’s point of view (Patton, 2002).

The principal investigator (PI) is Mexican American and is familiar with the Mexican culture. This contributed to the trust placed in the PI during the interviews. Use of Spanish language in the interviews was also a strength as the PI was able to clarify and discern subtle

nuances in the language that resulted in better analysis of the data. This also enhanced trustworthiness as it enabled the PI to represent the participants' experiences regarding pre-diabetes and diabetes.

Dependability, another construct to ensure trustworthiness that refers to the consistency of data sources and the methods of data collection (Denzin and Lincoln, 2005), was maintained and enhanced by asking the same questions to all participants, and by maintaining an accurate record of code words, memos, and descriptions via the use of the Ethnograph software.

This study identified and addressed the gap in the science related to the understanding of pre-diabetes among Mexican Americans. This study represents the initial step to exploring this understanding. In addition, this study explored how Mexican Americans view the possibility and/or risk for their developing diabetes in the future as well as their experience adjusting to life with pre-diabetes. This study also identified the important role that family and friends play in clarifying pre-diabetes and strategies for making changes in lifestyle.

The data generated from the interviews provided rich, thick descriptions that contributed to achieving saturation, which in turn contributed to the transferability of the findings to other groups.

Limitations of the Study

Recruitment from one particular geographical area limited the participation of Mexican Americans from other areas in Yuma County. Initially two healthcare providers in Yuma, AZ, had agreed to assist in recruiting potential participants for this study. However, one recruitment site was not able to assist due to changes in administrative personnel. Had the recruitment been expanded to include other medical offices, there might have been a more diverse sample. This

limitation showed in the fact that most participants who participated in this study were from a middle class background. No farm workers or unemployed Mexican Americans were recruited. Therefore the final sample may not represent the views of Mexican Americans who have lower socioeconomic levels.

The study was limited by having only one interview with each participant. Time constraints prevented the principal investigator from doing a second interview which would have resulted in thicker, richer descriptions. Guba and Lincoln (2005) suggest that returning to ask the participants to expand on answers given during the first interview ensure that the participants' views are reflected on the findings, thus influencing trustworthiness.

Implications for Nursing Research and Theory

This ethnographic study utilized Freire's theory of emancipation to guide a foundational study that explored the understanding of pre-diabetes and the possibility for developing diabetes among Mexican Americans at the U.S.-Mexico border. Freire's (2000) framework is a useful theory to explore patterns of knowledge acquisition of pre-diabetes among this population. This study has also provided a new insight on how Mexican Americans adjust to living with pre-diabetes. This study demonstrated despite the warnings from their family members who had been diagnosed with diabetes, the Mexican Americans in this study did not have a prior perception of their susceptibility to diabetes until they were told by a healthcare provider that they had pre-diabetes. Pre-diabetes seems to be a medical concept not present in the consciousness of Mexican Americans in this border community, and who are therefore not able to discern the differences between pre-diabetes and diabetes. This may be also true of Mexican Americans in other geographical locations. The knowledge gained from this study will also inform future

research and theory development that focus on exploring the understanding of pre-diabetes and diabetes among Mexican Americans.

Exploration of the understanding of other disease processes among cultural and social groups would further enhance knowledge about the awareness experience of individuals susceptible to chronic illness such as diabetes. Furthermore, the learning needs and experience of individuals must be taken into consideration when considering research among vulnerable and minority populations.

Implications for Nursing Practice

Freire's theory is a valuable tool when exploring understandings of chronic illnesses among cultural groups. Learning how individuals become conscious of their reality and how they act upon it, will help nurses understand other points of view, and become sensitive to the learning needs of others. A "banking" education concept, whereas the individual is the passive recipient of knowledge, may not be the best way to teaching prevention and disease management. A problem-posing approach, as suggested by Freire (2000), may revolutionize the way in which nurses approach pre-diabetes education. In addition, nurses and other healthcare providers may utilize the findings of this research study to promote healthier lifestyles among Mexican Americans and other cultural groups by taking into consideration Freire's "problem-posing" approach to health education.

Future Research

Further exploration of the concept of *awareness* is needed. This research study has provided the basis for further studies focusing on the development of awareness among vulnerable groups and the ways in which awareness may bring about changes in lifestyle that

would help delay or avoid the onset of chronic illnesses. More research is needed about the ways in which Mexican Americans adapt to living with pre-diabetes. The ways in which individuals make behavior changes after a diagnosis of pre-diabetes or not, as well as the ways in which people sustain healthier lifestyles after a diagnosis of pre-diabetes is an area of research that needs to be further explored. The utilization of Freire's theory of emancipation and the understanding of chronic illness among cultural and ethnic groups is another area that needs to be further explored.

Summary

Chapter VI presented Freire's critical theory and how it informed the findings from this study. This study revealed how patterns of oppression may be perpetuated among Mexican Americans diagnosed with pre-diabetes in U.S. healthcare systems. Emancipation from these oppressive patterns occur when individuals have an opportunity to understand a diagnosis of pre-diabetes that allows for changes in diet and exercise patterns. Being told of having pre-diabetes may not necessary involve understanding of the diagnosis, but once the individual becomes conscious of his/her health condition, he/she becomes involved in actively making lifestyle changes. Further research is needed about the application of Freire's theory of emancipation among adults diagnosed with pre-diabetes. Strengths and limitations of the study and the implications for nursing research, theory and practice as well as plans for future research were presented.

APPENDIX A: PARTICIPANT RECRUITMENT SCRIPT

Participant Recruitment Script – English Version

Title: ‘Exploring the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans at the U.S.-Mexico border.’”

You are being invited to participate voluntarily in the above titled research study. The purpose of this study is to explore your understanding pre-diabetes and the possibility of developing diabetes. You will be asked to describe your understandings, beliefs, ideas and stories about your perceptions of risk for diabetes. The results of this study will give us a better understanding about perceptions of risk for diabetes among Mexican American adults.

Participating in this study means that you will allow the investigator, Rudy Valenzuela, a doctoral candidate at the University of Arizona, to interview you at a place of your choice. There will be two taped interviews that will last 60 – 90 minutes. You must be Mexican or Mexican American, speak Spanish or English, live in Yuma County, Arizona, be diagnosed with pre-diabetes by your provider in the last year prior to the beginning of the study, be between 21 and 46 years of age, be able to reflect thoughtfully and be able to answer interview questions, be willing to participate in the study; and be able to read/write in English or Spanish.

If you decide to withdraw from this study, your care at your healthcare clinic will not be affected in any way. Information that you give in these interviews will remain confidential. There is no cost for participating in this study except for your time for the interviews.

If you agree to be contacted about your participation in this study, please write your contact information on the bottom of this form and return it to the staff at your clinic before you leave the clinic. Rudy Valenzuela will contact you as soon as possible to set up a meeting.

Contact Information:

Name: _____

Phone Number: _____

Address: _____

Language Preference: English: _____ Spanish: _____

Thank you for your interest on this important study about your understanding for developing diabetes.

Rudy Valenzuela, MSN, RN, FNP-C
 P.O. Box 7053
 San Luis, AZ 85349
 Phone: 928-920-4933

Participant Recruitment Script - Spanish Version

Titulo: 'Exploración del entendimiento de pre-diabetes y la posibilidad de desarrollar diabetes entre Mexico-Americanos en la frontera México-Estados Unidos.'

Por medio de la presente se le invita a participar voluntariamente en el proyecto de investigación descrito arriba. El propósito de este estudio es el explorar su entendimiento acerca de la posibilidad de desarrollar diabetes. Se le pedira que describa sus conocimientos, creencias, y anécdotas sobre la percepción de riesgo para diabetes. Los resultados de este estudio nos ayudarán a tener un mejor conocimiento acerca de la percepción de riesgo para diabetes.

Al participar en este estudio, usted va a dar su consentimiento para que el investigador principal, Rudy Valenzuela, un candidato al doctorado en la Universidad de Arizona, lo entreviste en un lugar de su preferencia. Habrá dos entrevistas que serán grabadas. Estas entrevistas durarán entre 60 y 90 minutos. Usted debe ser Mexicano o Mexico Americano, hablar español o inglés, vivir en el condado de Yuma, Arizona, haber sido diagnosticado con pre-diabetes por su proveedor en el año precedente al comienzo del estudio, tener entre 21 y 46 años de edad, poder reflexionar y contestar las preguntas de la entrevista, tener el deseo de participar en el estudio y poder leer y escribir en español o en inglés.

Si usted decide renunciar a la participación en este proyecto, su cuidado de salud en su clínica no será afectado de ninguna manera. La confidencialidad de la información que usted comparta durante las entrevistas será mantenida durante todo el proyecto. No habrá ningún costo personal, solo el de su tiempo.

Si acepta participar en este estudio, por favor anote su información de contacto en la parte inferior de esta hoja. Antes de irse de la clínica, entregue la hoja a un miembro del personal de la clínica. Rudy Valenzuela se pondrá en contacto con usted lo más pronto posible para hacer una cita.

Información de Contacto:

Nombre: _____

Número de Teléfono: _____

Dirección: _____

Lenguaje de preferencia: Inglés: _____ Español: _____

Le agradecemos de antemano su interés en este importante estudio sobre su entendimiento acerca de la posibilidad de desarrollar diabetes.

Rudy Valenzuela, MSN, RN, FNP-C
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 San Luis, AZ 85349
 Phone: 928-920-4933

APPENDIX B: INFORMED CONSENT

Informed Consent – English Version

Title: ‘Exploring the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans at the U.S.-Mexico border.’

Introduction

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?

The purpose of this study is to explore the possibility of developing diabetes among Mexican American Adults at the U.S.-Mexico border. The study is being conducted to learn more about how Mexican American Adults understand the possibility of developing diabetes. This is a step towards learning more about what people believe and understand about the possibility for developing diabetes.

Why are you being asked to participate?

You are being invited to participate in this study because a) you are Mexican or Mexican American; b) speak English or Spanish; c) live in Yuma, Arizona; d) have been diagnosed with pre-diabetes by a healthcare provider in the last year; e) are between 21 and 46 years of age; f) are able to reflect thoughtfully and are able to answer interview questions; g) are willing to participate in the study; and h) are able to read/write in English or Spanish.

How many people will be asked to participate in this study?

Approximately 10 – 12 persons will be asked to participate in this study.

What will happen during this study?

The following information describes your participation in this study which will take place at a place of your choosing. You are being asked to participate in two separate interviews that will be audio taped. Each interview will last between 60 – 90 minutes. The investigator will elicit some responses from you regarding your perception of risk for diabetes. Also, you will be asked to fill out a short demographic questionnaire at the time of the first interview. The questionnaire and interviews will be available in either English or Spanish.

How long will I be in this study?

Two interview sessions of about 60-90 minutes will be needed to complete this study.

Are there any risks to me?

The things that you will be doing have no known associated risks. Although we have tried to avoid risks, you may feel that some questions we ask you to do may be stressful or upsetting. If this occurs you can stop participating immediately. We can give you information about individuals who may be able to help you with these problems.

Are there any benefits to me?

You will not receive any benefit from taking part in this study. However, society in general may benefit from the knowledge obtained about your understanding of the possibility for developing diabetes.

Will there be any costs to me?

Aside from your time, there are no costs for taking part in the study.

Will I be paid to participate in the study?

There is no compensation given for participation in this study.

Will video or audio recordings be made of me during the study?

We will make audio recordings of both interviews during the study so that we can be certain that your responses are recorded accurately only if you check the box below:

I give my permission for audio/video recordings to be made of me during my participation in this research study.

Will the information that is obtained from me be kept confidential?

The only persons who will know that you participated in this study will be Rudy Valenzuela, MSN, RN, FNP, the principal investigator. The dissertation committee (Dr. Joyceen Boyle, PhD, RN, FAAN, Marylyn McEwen, PhD, RN, and Sharon McGuire, PhD, RN) will have access to the data without identifiers. If mentioned during the interviews, your name and any identifying information will be deleted from the tapes during transcription.

Your records will be confidential. You will not be identified in any reports or publications resulting from the study. Representatives of regulatory agencies (including The University of Arizona Human Subjects Protection Program) may access your records.

What if I am harmed by the study procedures?

There are no procedures during this study. The risks of harm from participating in this study are minimal.

May I change my mind about participating?

Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Your refusing to participate will have no effect on the healthcare you receive at your clinic. You can discontinue your participation with no effect on the healthcare you receive at your clinic. Also any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

Whom can I contact for additional information?

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator, Rudy Valenzuela, MSN, RN, FNP-C, PhD Candidate at (928) 920-4933. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the research team, or want to talk to someone other than the research team, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website: <http://www.irb.arizona.edu/contact/>

Your Signature

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

Name (Printed)

Participant's Signature

Date signed

Statement by person obtaining consent

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

Rudy Valenzuela, MSN, RN, FNP-C

Study Personnel Signature

Date signed

Informed Consent - Spanish Version

Título: ‘Exploración del entendimiento de pre-diabetes y la posibilidad de desarrollar diabetes entre Mexico-Americanos en la frontera México-Estados Unidos.’

Introducción

Se le ha invitado a tomar parte en un estudio de investigación clínica. La información que se le proporciona en este formulario es para ayudarle a decidir si quiere participar o no. El personal de este estudio estará a su disposición para contestar sus preguntas y proporcionarle más información. Si usted decide tomar parte en este estudio, se le pedirá que firme este formulario de consentimiento. A usted se le dará una copia de este formulario.

¿Cuál es el propósito de este estudio de investigación clínica?

El propósito de este estudio es el explorar su entendimiento acerca de la posibilidad que usted tiene de desarrollar diabetes. Se le pedirá que describa sus conocimientos, creencias, y anécdotas sobre la percepción de riesgo para diabetes. Los resultados de este estudio nos ayudarán a tener un mejor conocimiento acerca de la percepción de riesgo para diabetes.

¿Por qué se le ha pedido que participe?

Se le ha invitado porque usted reconoce ser Mexicano o Mexico Americano, habla español o inglés, vive en la ciudad de Yuma, Arizona, ha sido diagnosticado con pre-diabetes por su proveedor en el año precedente al comienzo del estudio, tiene entre 21 y 46 años de edad, puede y está dispuesto a reflexionar y contestar las preguntas de la entrevista, tiene el deseo de participar en el estudio y puede leer y escribir en español o en inglés.

¿A cuántas personas se les pedirá que participen en este estudio?

Aproximadamente a 10 a 12 personas se les pedirá que participen en este estudio.

¿Qué ocurrirá durante este estudio?

Se le pedirá que participe en dos entrevistas en un lugar que usted escoja. Las entrevistas serán grabadas en una grabadora. Cada entrevista durará entre 60 y 90 minutos. El investigador le hará unas preguntas acerca de su entendimiento acerca de la posibilidad de desarrollar diabetes. También le pedirá que llene una hoja con información demográfica después de la primera entrevista. Las entrevistas y el cuestionario demográfico estarán disponibles en inglés ó en español.

¿Por cuánto tiempo estará participando en este estudio?

Se necesitarán aproximadamente dos sesiones de entrevistas. Estas entrevistas durarán entre 60 y 90 minutos cada una y las dos entrevistas con usted serán necesarias para finalizar el estudio.

¿Habrá algunos riesgos para mí?

Las cosas que usted estará haciendo no tienen riesgos reconocidos. Aunque hemos tratado de evitar riesgos, es posible que usted sienta que algunas preguntas que le haremos le podrían causar

estrés o disgusto. Si esto le ocurre, usted puede dejar de participar inmediatamente. Le podemos dar información sobre personas que posiblemente puedan ayudarle a resolver estos problemas.

¿Hay algún beneficio para mí?

Usted no recibirá beneficio alguno por tomar parte en este estudio.

¿Habrá costos para mí?

Fuera del tiempo que gaste en participar no tendrá que pagar para tomar parte en este estudio.

¿Me pagarán por participar en este estudio?

No habrá compensación alguna por su participación en este estudio.

¿Se harán grabaciones de mí, en vídeo o audio, durante el estudio?

Solamente si usted marca la casilla siguiente, le haremos una grabación de audio (vídeo) durante el estudio para poder estar seguros de que hemos grabado sus respuestas con exactitud.

Doy permiso para que se hagan grabaciones de mí en audio o vídeo durante mi participación en este estudio de investigación clínica.

¿Se guardará confidencialmente la información que se obtenga de mí?

Las únicas personas que sabrán que usted participó en este estudio serán los miembros del equipo de investigación clínica. Rudy Valenzuela, MSN, RN, FNP, el investigador principal. También tendrán acceso a esta información el equipo de su disertación (Dr. Joyceen Boyle, PhD, RN, FAAN, Marylyn McEwen, PhD, RN, and Sharon McGuire, PhD, RN).

Sus expedientes serán confidenciales. Usted no será identificado/identificada en los reportes o publicaciones que resulten de este estudio. Es posible que representantes del Gobierno Federal o de algún otro grupo como el Programa de Protección a Participantes o la Mesa Directiva de Revisión Interna de la Universidad de Arizona, quiera revisar la información. Si esto ocurre, les proporcionemos una copia que no llevará su nombre, el cual será borrado de esta copia antes de hacer pública la información.

¿Qué sucede si los procedimientos del estudio me causan algún daño?

No hay procedimientos clínicos en este estudio. Los riesgos a su persona son mínimos.

¿Puedo cambiar de parecer sobre si quiero o no quiero participar?

Su participación en este estudio es voluntaria. Usted puede decidir no comenzar a participar o, después de haber comenzado, puede dejar de participar en el estudio en cualquier momento. Su rechazo de participar no tendrá efecto alguno en el cuidado que recibe en su clínica. Usted puede no seguir participando sin que esto cause efecto alguno en el cuidado que recibe en su clínica. También a usted se le proporcionará toda nueva información que se descubra sobre esta

investigación clínica. Es posible que esta información afecte su buena voluntad de continuar participando.

¿Con quién puedo comunicarme para más información?

Para obtener más información sobre la investigación clínica o para expresar sus inquietudes o presentar sus quejas sobre la investigación clínica, usted puede hablar con el Investigador Principal Rudy Valenzuela, MSN, RN, FNP-C, candidato al doctorado, al teléfono (928) 920-4933. Si usted tiene alguna pregunta sobre sus derechos como participante en investigaciones clínicas o si usted tiene preguntas, preocupaciones o quejas de carácter general o si le gustaría hacer sugerencias o comentarios sobre la investigación clínica y no puede comunicarse con los investigadores del estudio o si quiere hablar con otra persona que no sea uno de los investigadores, usted puede llamar a la oficina del programa de protección de sujetos humanos de la Universidad de Arizona (*University of Arizona Human Subjects Protection Program*) al (520) 626-6721. Si hace su llamada desde fuera del Estado de Arizona, marque el número gratis 1-866-278-1455.) Si prefiere comunicarse por correo electrónico con el *Human Subjects Protection Program*, por favor utilice esta dirección: <http://www.irb.arizona.edu/suggestions.php>.

Su firma

Al firmar este formulario de consentimiento, yo ratifico que he leído la información que contiene este formulario, que me han explicado este estudio de investigación clínica, que han contestado mis preguntas y que convengo en tomar parte en este estudio. Al firmar este documento no renuncio a mis derechos legales.

Nombre (En letra de molde)

Firma del Participante

Fecha en que fue firmado

Declaración de la persona que obtiene el consentimiento

Certifico que le explicado el estudio de investigación clínica a la persona que ha convenido en participar, y que esta persona ha sido informada sobre el propósito, los procedimientos, los posibles riesgos y los posibles beneficios relacionados con la participación en este estudio. Todas las preguntas planteadas han sido contestadas a entera satisfacción del participante.

Rudy Valenzuela, MSN, RN, FNP-C

Firma del miembro del personal del estudio

Fecha en que fue firmado

APPENDIX C: DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire
English Version

Title: 'Exploring the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans at the U.S.-Mexico border.'

Participant # _____

Date: _____

Background Information

Date of Birth: _____ Gender: Male _____ Female _____

Employment: Full-time _____ Part-time _____ Unemployed _____

Education: Elementary School (Grade) _____ High school (years) _____

College (years) _____

Marital Status: Married _____ Divorced _____ Separated _____ Single _____

Approximate annual income: _____

Place of Birth (City, State, Country): _____

Place of Residence: _____

Number of Years living in the United States: _____

Primary language spoken at home: _____

Do you speak Spanish?

Very well _____

Less than well _____

Not at all _____

Do you read Spanish?

Very well _____

Less than well _____

Not at all _____

Do you speak English?

Very well _____

Less than well _____

Not at all _____

Do you read English?

Very well _____

Less than well _____

Not at all _____

Does anyone have pre-diabetes or diabetes in your family? YES _____ NO _____

If yes, who:

Paternal grandparent _____ Maternal grandparent _____

Mother _____ Father _____

Sister _____ Brother _____

How long have you been diagnosed with pre-diabetes? _____

Demographic Questionnaire
Spanish Version

Título: 'Exploración del entendimiento de pre-diabetes y la posibilidad de desarrollar diabetes entre Mexico-Americanos en la frontera México-Estados Unidos.'

Participante # _____

Fecha: _____

Información Biográfica

Fecha de Nacimiento: _____ Sexo: Masculino _____ Femenino _____
 Empleo: Tiempo completo _____ Medio tiempo _____ Desempleado _____
 Educación: Primaria (Grado) _____ Preparatoria (años) _____ Universidad (años) _____
 Casado _____ Divorciado _____ Separado _____ Soltero _____
 Salario anual aproximado: _____

Lugar de Nacimiento (Ciudad, Estado, País): _____

Lugar de Residencia: _____

Número de años viviendo en los Estados Unidos: _____

Lenguaje usado en casa: _____

¿Qué tanto habla español?

Muy bien _____
 No muy bien _____
 No hablo español _____

¿Qué tanto escribe español?

Muy bien _____
 No muy bien _____
 No escribo español _____

¿Qué tanto habla inglés?

Muy bien _____
 No muy bien _____
 No hablo inglés _____

¿Qué tanto escribe inglés?

Muy bien _____
 No muy bien _____
 No escribo ingles _____

¿Alguien tiene pre-diabetes o diabetes en su familia? SI _____ NO _____

Si alguien tiene pre-diabetes o diabetes en su familia, ¿Quién?:

Abuelo(a) paterno _____ Abuelo(a) materna _____
 Madre _____ Padre _____
 Hermana _____ Hermano _____

¿Hace cuanto le diagnosticaron pre-diabetes? _____

APPENDIX D: GENERAL INTERVIEW GUIDE #1

General Interview Guide #1
English Version

Title: ‘Exploring the understanding of pre-diabetes and the possibility of developing diabetes among Mexican Americans at the U.S.-Mexico border.’

Thank you for allowing me to interview you. I am interested in exploring YOUR understanding of the possibility you have of developing diabetes.

1. Tell me about when you first learned you had pre-diabetes.
 - a. what happened then?
 - b. how did you feel about it—learning you had pre-diabetes?
 - c. Tell me about how your healthcare provider explained pre-diabetes to you.
 - d. What is your understanding now of pre-diabetes?
 - i. For example, tell me how your understanding of pre-diabetes has changed since your healthcare provider originally explained pre-diabetes to you.
2. Has being diagnosed with pre-diabetes changed anything about your life?
 - a. what about food?
 - b. exercise?
 - c. anything else that has changed because of pre-diabetes?
 - d. how do you manage stress? Does having pre-diabetes cause additional stress for you? Can you explain?
3. What do you think is the possibility of developing diabetes in the future?
 - a. Are you concerned about developing diabetes? Explain.

General Interview Guide #1
Spanish Version

Titulo: 'Exploración del entendimiento de pre-diabetes y la posibilidad de desarrollar diabetes entre Mexico-Americanos en la frontera México-Estados Unidos.'

Gracias por permitirme entrevistarle. Estoy interesado en aprender sobre SU entendimiento de la posibilidad de desarrolla diabetes.

1. Dígame usted acerca de cuando usted supo por primera vez que tenía pre-diabetes
 - a. ¿Qué pasó entonces?
 - b. ¿Cómo se sintió acerca de su diagnóstico? Acerca del hecho de tener pre-diabetes?
 - c. ¿Cómo es que se le explicó lo que significa esta condición?
 - d. ¿Cuál es su Entendimiento del pre-diabetes ahora?
 - i. Por ejemplo, dígame como es que su entendimiento sobre el pre-diabetes ha cambiado desde que su doctor le dijo que tenía pre-diabetes.
2. El estar diagnosticado con pre-diabetes le ha hecho cambiar algunas cosas en su vida?
 - a. ¿La comida? Explíqueme
 - b. ¿El ejercicio? ¿Cómo?
 - c. ¿Hace algún tipo de dieta o ejercicio?
 - d. ¿Cómo maneja el estrés? El tener diabetes le ha causado más estrés?
(Explíqueme)
3. ¿Cuál piensa usted que es la posibilidad de desarrollar diabetes en el futuro?
 - a. ¿Está usted preocupado de desarrollar diabetes? Explíqueme

APPENDIX E: DEMOGRAPHIC INFORMATION

Participant	Age	Height/ Weight	Place of Birth	Education	Employed	Marital Status	Primary Language at home	Speak Spanish	Speak English	Family member with Diabetes	# of Years Diagnosed with Diabetes
Sophia	46	5'5"/ 168 lbs	Yuma	College	FT	Married	English	Less than Well	Very Well	Parents, grandmother, brother and sister	> 1 year
Stephanie	42	5'4" 175	Mexico	College	FT	Married	Spanish	Less than Well	Very Well	Mother, sister	< 1 year
Mateo	30	5'10" 248	Yuma	College	FT	Divorced	English	Less than Well	Very Well	Father	< 1 year
John	43	5'11" 263	Yuma	H.S.	FT	Single	Spanish	Less than Well	Very Well	Father, mother, brother	< 1 year
Ana	45	5'3" 142	Mexico	6 th grade	PT	Married	Both	Very Well	Less than Well	Two aunts	1 year
Diana	42	5'4 226	Californi a	Associates	FT	Married	Spanish	Very Well	Less than Well	None	< 1 year
Maribel	38	5'2" 238	Californi a	H.S.	FT	Separated	Spanish	Less than Well	Very Well	One sister	< 1 year
Pedro	40	5'8" 196	Yuma	Masters	FT	Married	English	Very Well	Very Well	Mother, sister	< 1 year
Camilla	36	5'5" 318	Yuma	H.S.	FT	Single	Both	Less than Well	Very Well	Father, sister	< 1 year
Andrea	25	5'7" 205	Yuma	H.S.	FT	Single	English	Less than Well	Very Well	Father	< 1 year

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